



House of Commons  
Health Committee

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# The Provision of Allergy Services

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Sixth Report of Session 2003–04

## *Volume II*

*Oral and written evidence*

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## The Health Committee

The Health Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Department of Health and its associated bodies.

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The current staff of the Committee are Dr J S Bengier (Clerk), Keith Neary (Second Clerk), Laura Hilder (Committee Specialist), Christine Kirkpatrick (Committee Specialist), Frank McShane (Committee Assistant), Darren Hackett, (Committee Assistant), and Anne Browning (Secretary).

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# Witnesses

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## Wednesday 17 June 2004

Page

**Ms Muriel Simmons**, Chief Executive, Allergy UK, **Mr David Reading**, Campaign Director, the Anaphylaxis Campaign and **Dr Shuaib Nasser**, Consultant Allergist, Addenbrooke's Hospital.

Ev 10

**Professor Stephen Holgate**, Chairman, National Allergy Strategy Group, **Professor Andrew Wardlaw**, President, British Society for Allergy and Clinical Immunology, **Professor John Warner**, Paediatric Allergist, University of Southampton and **Dr Lawrence Youlten**, Consultant Allergist, London Allergy Clinic.

Ev 60

## Thursday 1 July 2004

**Rt Hon Dr Stephen Ladyman**, a Member of the House, Parliamentary Under-Secretary of State for Health, and **Mrs Patience Wilson**, Head, Programme National Service Framework for Long-Term Conditions.

Ev 75

# List of written evidence

---

1	Allergy UK (AL77)	Ev 1
2	The Anaphylaxis Campaign (AL31)	Ev 2
3	The Anaphylaxis Campaign (AL31A)	Ev 19
4	Dr Shuaib Nasser (AL72)	Ev 27
5	National Allergy Strategy Group (AL19)	Ev 34
6	British Society for Allergy and Clinical Immunology (AL24)	Ev 51
7	Professor John Warner (AL3)	Ev 57
8	Dr Lawrence Youlten (AL58)	Ev 58
9	Department of Health (AL10)	Ev 71
10	Department of Health (AL10a)	Ev 204
11	University of Manchester (AL1)	Ev 89
12	Barts and the London NHS Trust (AL4)	Ev 90
13	South & West England & Wales Clinical Immunology Audit Group (AL5)	Ev 91
14	Dr Michael Tettenborn (AL6)	Ev 91
15	NHS Grampian (AL7)	Ev 92
16	North-West Lung Clinic (AL9)	Ev 93
17	British Association of Dermatologists (AL11)	Ev 102
18	Norfolk Allergy Diagnostic and Advisory Service (NADAAS) (AL12)	Ev 103
19	Dr Tina Dixon (AL13)	Ev 105
20	Royal Brompton and Harefield NHS Trust (AL14)	Ev 106
21	Dr Philip Doré (AL15)	Ev 107
22	Professor Tak Lee (AL16)	Ev 108

23	Dr Chris Corrigan (AL17)	Ev 110
24	North of England Clinical Immunology Audit Group (AL20)	Ev 113
25	Dr R S H Pumphrey (AL21)	Ev 116
26	Professor T J David (AL25)	Ev 118
27	Doris M Jones MSc (AL26)	Ev 120
28	Professor A B Kay (AL27)	Ev 123
29	Dr Vibha Sharma (AL28)	Ev 123
30	Maureen Jenkins (AL30)	Ev 124
31	Dr Gideon Lack (AL32)	Ev 125
32	Elizabeth Murphy (AL33)	Ev 126
33	Bedford Allergy Support Group (BASG) (AL34)	Ev 126
34	Royal College of Paediatrics and Child Health (AL2)	Ev 129
35	Queen's Medical Centre Nottingham, University Hospital NHS Trust (AL35)	Ev 132
36	Tayside University Hospitals (AL36)	Ev 133
37	Dr Edward Kaminski and Christine Symons (AL39)	Ev 141
38	Lancashire Teaching Hospitals (AL40)	Ev 142
39	Dr Nigel J N Harper and Dr Richard Pumphrey (AL41)	Ev 144
40	Alan M Edwards (AL42)	Ev 145
41	Dr Julia Clark and Professor Andrew Cant (AL43)	Ev 146
42	Mr Malcolm Stamp CBE (AL44)	Ev 149
43	Professor Anthony Frew (AL45)	Ev 152
44	Dr Paul Cullinan (AL46)	Ev 156
45	Dr Mazin Alfaham (AL47)	Ev 156
46	Dr Rita Brown FRCP (AL48)	Ev 158
47	Dr Andrew Clark (AL49)	Ev 159
48	Dr Adrian Morris (AL50)	Ev 159
49	Dr Katherine Sloper (AL51)	Ev 161
50	Asthma UK (AL52)	Ev 163
51	Dr Penny Fitzharris (AL53)	Ev 165
52	Analphylaxis Campaign and Allergy UK (AL54)	Ev 166
53	Royal College of Physicians (AL55)	Ev 168
54	Dr G Scadding (AL56)	Ev 183
55	The British Society for Allergy, Environmental and Nutritional Medicine (AL59)	Ev 184
56	Dr Amolak Bansal (AL60)	Ev 191
57	Dr Jonathan Hourihane (AL61)	Ev 191
58	Professor Aziz Sheikh (AL62)	Ev 193
59	Margaret Moss (AL64)	Ev 195
60	Dr Tim Wallington (AL65)	Ev 195
61	Dr Alaisdair Stewart MD FRCP (AL66)	Ev 197
62	Dr G P Spickett and Dr A Fay (AL68)	Ev 197
63	Dr D E Lacy, Dr J Seager and Mr A Bardsley (AL69)	Ev 199
64	Professor J Buckley (AL70)	Ev 202
65	Latex Allergy Support Group (AL71)	Ev 202
66	Mid Sussex NHS Primary Care Trust (AL77)	Ev 204

# List of unprinted written evidence

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Additional papers have been received from the following and have been reported to the House but to save printing costs they have not been printed and copies have been placed in the House of Commons library where they may be inspected by members. Other copies are in the Record Office, House of Lords and are available to the public for inspection. Requests for inspection should be addressed to the Record Office, House of Lords, London SW1. (Tel 020 7219 3074) hours of inspection are from 9:30am to 5:00pm on Mondays to Fridays.

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C Monk  
G Chegwyn  
A Clarke  
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M Oliver  
S Field  
T Ryder  
D Shilling  
C Stokoe  
M and J Armer  
J E Sandall  
C Hislop  
L Clendon  
J Gokcen  
C Sadler  
B Saul  
S McCloskey  
S C Baxter  
A Clarke  
V Dand

J Racle  
E English  
J Riches  
L Swain  
P Schmidt  
A Marshment  
J Coote  
J Martin  
P Williams  
C Wilson  
J Whelbourn  
F M Pitchford  
A Pargeter  
J Parker  
S Davies  
J E and S E Phillips  
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C George  
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H Green  
A Andrews  
D Barker  
L Thomas  
P Kissagizlas  
P S Diver  
N Le Jeune  
S Moore  
A Green  
S Scarratt  
S Lane  
C Williams  
L Smith  
L John  
N Freeman  
L Castillo  
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E Yamson  
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D M E Gordon  
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I, V and L Newman  
C Micallef and A Yenez  
W J Cleghorn  
B Huxley  
D Horn  
P M Whitaker  
P J Lomas  
A E E Russell  
C d'Aboville  
W D Sly  
A McAllister  
J K Davis  
M Dixon  
R Gibbs  
E and S Colley  
K Yule  
D M and G Kelly  
C S Leaver  
W Smith  
H Duncombe  
C and C Phipps  
S J Tomlinson  
T Kettle

J Gibbons  
J R Murray  
E E Reeves  
C Butler  
P White  
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# Oral evidence

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## Taken before the Health Committee

on Thursday 17 June 2004

Members present:

Mr David Hinchliffe, in the Chair

Mr David Amess  
John Austin  
Jim Dowd

Dr Richard Taylor  
Dr Doug Naysmith

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### Memorandum by Allergy UK (AL 77)

#### INTRODUCTION

1. Allergy UK is the operational name of The British Allergy Foundation a charity formed in 1991 to provide information, advice and support for people with allergy and their carers.

2. In response to demand, Allergy UK also provides education and information to healthcare professionals particularly aimed at Primary Care Health services. Education has been carried out through Masterclasses and from September 2004 will be conducted via an e-learning European Diploma in Allergy.

3. 80,000 people are registered supporters of Allergy UK with the majority being sufferers from non-life threatening allergies but whose lives are substantially affected on a daily basis by the impact of allergy.

4. Through its helpline, telephone and internet services over 58,000 individual requests for assistance have been dealt with during the last year and in excess of 250,000 fact sheets, leaflets and booklets issued. The number of people seeking assistance from Allergy UK has for the last three years shown an average annual growth of 21%.

5. In addition to the direct services shown above Allergy UK also provides support through its volunteer network of 208 support contacts that provide practical advice and a listening ear to people with allergy especially those trying to find suitable management techniques.

#### PROBLEMS FACED BY ALLERGIC PATIENTS

6. Allergy UK believe that people with allergy should be treated with the same level of care as every other patient within the NHS; currently this is not the case. Detailed below are reasons why people seek the services of Allergy UK:—

##### *7. Lack of knowledge and understanding of allergy by General Practitioners.*

A high percentage of people contacting us report that their General Practitioners do not understand and in a number of cases do not accept that the patient is suffering from an allergic reaction. Others report that where allergy is the diagnosis there is little understanding of the impact on the patient's life or the potential seriousness of an on-going allergy problem.

In a survey for our 2003 report "Stolen Lives" we questioned 6,000 callers to our helpline. 74.8% stated that they had never been asked by their Doctor or Nurse how their allergy affected their quality of life.

##### *8. Funding issues for testing.*

Patients frequently complain that their GP has informed them that they have insufficient funds to pay for blood testing at the local hospital for more than a limited number of allergens. Patients are then regarded as having been allergy tested when in fact given the limited knowledge of allergy at Primary Care level the cause of the problem could well have been missed.

##### *9. Inability to gain a referral to see an allergy specialist.*

A high level of calls are received seeking advice on how to gain a referral to an allergy specialist. This can on occasions be due to a lack of willingness on the part of the General Practitioner to provide a referral but more frequently is that the General Practitioner does not know where to refer the patient and advised them to contact us to obtain the necessary information.

##### *10. Lack of allergy specialist service.*

Advice is commonly sought from areas where there is no allergy service. Patients seek advice on how they can obtain NHS funding to reach the nearest specialist and how they can obtain an appointment when they are often a great distance from the nearest specialist.

11. *Inappropriate referrals.*

Patients seek information and advice on how to manage their situation when they have been inappropriately referred and have been informed by the specialist that help for their condition is not available in that clinic. This is particularly common where people with allergy are referred to organ based specialists who realise that the patient does not have a condition suitable to his speciality.

12. *Complementary and Alternative Medicine.*

An increasing number of calls are received from people seeking advice on complementary and alternative medicine. Information is generally sought on where testing and treatment can be obtained, the validity of the tests and treatments and the costs involved. The majority of callers for this type of information state that they are being forced to turn to testing and treatment outside of the NHS and established treatments as they are unable to obtain help from the NHS for their problems.

Allergy UK has a great concern regarding some of the alternative clinics who provide clinically unproven tests and treatments at considerable cost to the patient and sometimes the NHS. The costs, when met by the patient, often results in considerable emotional distress when the patient is no longer able to continue to meet the costs involved.

13. *Lack of Patient Information and Management Advice.*

A very high percentage of calls received are from people seeking an explanation of their test results and/or advice on how to manage their allergy within their daily lives. Where patients are referred by their GP to have a hospital blood test for allergy they are frequently given the results in technical terms without any explanation of what it actually means. Patients who are diagnosed with particular allergies are rarely given a management plan to help them avoid the allergen concerned and thereby reduce their symptoms.

RECOMMENDATIONS FROM ALLERGY UK

14. As a very high percentage of people with non-life threatening allergy could be diagnosed and treated at Primary Care level, education in allergy should be funded and provided for healthcare professionals at Primary Care level.

15. Allergy clinics within Primary Care should be established with the patient able to easily identify the person managing that clinic.

16. Primary Care Allergy Clinics should be equipped to use appropriate means of diagnosing and managing allergy in the local centre without regard to cost.

17. Expertise and education to provide an ongoing support and management service for people with allergy should be available at Primary Care level.

18. Specialist allergy services should be available to all patients with allergic disease and these services should be clearly defined as allergy services able to treat the whole person and should not be part of an organ based clinic.

19. Specialist allergy services should be available to patients within a reasonable travelling distance from their home.

20. People with life threatening allergy should be appropriately referred after emergency treatment to an allergy specialist as a matter of urgency.

21. On-going education on allergy for Secondary Care Health Professionals is highly recommended.

June 2004

**Memorandum by the Anaphylaxis Campaign (AL 31)**

INTRODUCTION TO THE ANAPHYLAXIS CAMPAIGN

1. The Anaphylaxis Campaign is a national patient support group representing people who are at risk from severe allergic reactions including the most extreme form, anaphylaxis.

2. During anaphylaxis the whole body is affected. Symptoms include swelling in the throat and mouth, severe asthma, a sense of impending doom, a dramatic fall in blood pressure and collapse and unconsciousness. Extreme cases can be fatal. Causes include foods such as peanuts, tree nuts, egg, milk and seafood; certain drugs; insect stings; and natural rubber (latex).

3. The Anaphylaxis Campaign is a registered charity (No 1085527) set up in 1994 to raise public awareness of severe allergic conditions, inform and educate those affected, and maintain dialogue with the Government, food industry and health professionals. Main sources of income are membership subscriptions and donations, and fundraising by volunteers.

4. There are no nationally agreed statistics for those at risk of anaphylaxis but experts have extrapolated from individual studies, and their own experiences, to reach a conservative estimate of one million people across the UK. About half of these are at risk of food-induced anaphylaxis.

## OUR SUBMISSIONS

5. We have provided three papers for consideration by the Committee, and have included nine testimonials from members of our organisation. We would like to thank the Committee for allowing us to present these papers.

6. Most of the facts, quotes and experiences highlighted in our submissions feature people whose allergy trigger is food. This is because the membership of the Anaphylaxis Campaign (7,746 people on 24 May 2004) is made up primarily of people with food allergy problems. But we acknowledge that the other causes of anaphylaxis are also important, resulting in a significant impairment of quality of life.

7. Peanuts and tree nuts figure prominently in our evidence because allergies to these foods are the ones that most commonly cause fatal and life-threatening reactions. A recent study showed that the incidence of peanut allergy has tripled in the last decade and now affects one in 70 children across the UK (ref Grundy J, Matthews S, Bateman B, Dean T, Arshad S H Rising prevalence of allergy to peanut in children: Data from two sequential cohorts. *Journal of Allergy and Clinical Immunology* Vol 110 No 5 p 784–789).

8. Our three papers are attached:

- i. Anaphylaxis: the burden of anxiety and the role of telephone helplines.
- ii. The unmet needs of patients with anaphylaxis.
- iii. Fatal and near-fatal anaphylaxis: some case studies.

## 1. ANAPHYLAXIS: THE BURDEN OF ANXIETY AND THE ROLE OF TELEPHONE HELPLINES

### *Summary*

1. This note addresses the lack of availability of effective information about anaphylaxis through the NHS. In response to this unmet need, the Anaphylaxis Campaign runs a helpline and provides information to those affected. Helpline staff report an extreme burden of anxiety among these people caused by the knowledge that anaphylaxis can kill. The message conveyed by helpline staff is that anaphylaxis is serious but manageable. With high-quality information and guidance, those affected can be empowered to manage the condition and protect themselves from harm. In our experience, this is frequently impossible because of the lack of availability of help through the NHS.

### *Background*

2. There has been a dramatic increase in allergy in recent years. The incidence of allergy has risen, and the nature of allergy has changed. Severe and potentially life-threatening allergies are common and a gulf is growing between the need people have for effective advice and the availability of professional services. There is much suffering, often affecting whole families.

### *Responding to an unmet need*

3. The Anaphylaxis Campaign receives between 16,000 and 20,000 enquiries annually—just under half of them coming via the telephone helpline and the rest via letters and email. All telephone calls are monitored and relevant details written onto a monitoring record. The vast majority of enquirers are seeking information about food allergy. Helpline staff frequently encounter deep anxiety among families affected by allergies, particularly where those allergies are potentially life-threatening. Lack of information is the cause of this distress. It is common for patients to report that they have been unable to obtain adequate help and information from the medical profession.

4. To meet this need, the Anaphylaxis Campaign sends out 140,000 leaflets and fact sheets per annum. These are provided not only to patients and their families but also to schools, education authorities, colleges, playgroups, youth groups, hospitals, doctors' surgeries and the food industry. Most are distributed free, although donations are sought. Training videos are produced for parents, schools and health professionals.

5. There is an Anaphylaxis Campaign website, which receives almost 4,000 hits per day.

6. Educational programmes are organised for allergic teenagers and for parents of allergic children.

### *Context*

7. Witnessing a person suffering anaphylaxis is a frightening experience. There may be extreme swelling in the mouth and around the eyes, severe breathing problems caused by asthma or swollen tissues in the throat, and a dramatic fall in blood pressure leading to unconsciousness. It is not surprising that when a person has suffered anaphylaxis, and is at risk of further reactions, an extreme burden is placed on the entire family. This is particularly true where food-allergic children are concerned. The question never far from the parents' minds is: Will the next meal be the fatal one?

8. There is some justification for this high level of anxiety. Every year, a minimum of 6-7 deaths from food-induced anaphylaxis are reported, as well as 4-5 caused by insect stings and 9-10 caused by drugs. The true figure is almost certainly higher because of misdiagnosis or misreporting<sup>1</sup>. Peanut allergy now affects one in 70 children in the UK<sup>2</sup> and is the commonest food allergy to cause fatal or life-threatening reactions. When tragedies or other serious incidents occur, the media reporting is frequently sensational and alarming. Such reports add to the already heavy burden carried by families who, in many cases, have seen a loved-one rushed to A&E.

9. A mother whose son suffered his first experience of anaphylaxis while on holiday wrote to the Anaphylaxis Campaign saying: "My little boy suffered a very severe allergic reaction to a slice of cake in a restaurant. The cake contained walnuts. I am terrified I will lose him. I feel we are living with a ticking timebomb."

10. Day-to-day issues such as confusing food labelling, the increasing prevalence of nut traces warnings on food packets and a low level of allergy awareness in catering establishments exacerbate people's anxiety. Parents of food allergic children use phrases like "playing Russian roulette at mealtimes." They often genuinely believe that their child will not reach adulthood. They are unaware that anaphylaxis, whilst serious, is manageable and that deaths can be prevented. Those affected can be empowered to manage their medical condition effectively and minimise risk.

11. The anxiety linked with peanut allergy was quantified by a research study showing that children with the condition are more anxious than children with insulin-dependent diabetes mellitus<sup>3</sup>. Children from both groups completed "quality of life" questionnaires and recorded with a camera how their condition affected their lives over a 24-hour period. The results were then analysed.

12. In comparing the two groups, the researchers found that children with peanut allergy were more afraid of potential hazards, more anxious about eating and felt more restricted regarding physical activities. The researchers believe this anxiety may stem from the feeling that they have little control over their lives. The team's report said this high state of anxiety among allergic children was unjustified and did not have to be permanent. With appropriate education about allergy management, children could be helped to develop self-confidence and a positive attitude.

13. Appropriate education involves basic messages about avoiding harmful allergens, recognition of symptoms, and self-treatment. It also requires a commitment to carrying prescribed medication at all times. A key word here is "empowerment." Those affected can learn to take control of their medical condition and minimise the risks in their lives.

14. Intramuscular adrenaline (epinephrine) is regarded as the most important treatment for a life-threatening allergic reaction<sup>4</sup>. Studies suggest that most fatalities occur in cases where early injectable adrenaline is not available or is given too late<sup>4</sup>. Patients can be reassured that prescribed adrenaline injections such as EpiPen or Anapen will get them out of trouble if administered appropriately and promptly. Importantly, they must receive basic guidance on how to use them. At least one study has shown that patients have a low level of understanding about their use<sup>5</sup>.

15. There is evidence that the risks are reduced if the patient receives expert advice and assessment in a specialist allergy clinic and participates in a management plan<sup>6</sup>. Where this happens, fewer patients have further reactions and when these do occur, they are mostly mild. Furthermore, the presence of asthma in a patient with allergy must be considered a significant risk factor, and the patient must be encouraged, with plenty of helpful guidance, to keep the asthma well controlled<sup>7</sup>.

16. Starved of reliable information, people affected by anaphylaxis frequently search the Internet. Unfortunately many allergy websites provide information that is either inaccurate, confusing, out of date, unnecessarily alarming, written in terms lay people cannot understand, or promoting questionable allergy tests and treatments.

#### *Deficiency in NHS allergy services*

17. In our experience, much suffering is caused by the fact that people at risk of anaphylaxis are unable to access information and advice from NHS allergy services. Not-for-profit organisations, through their helplines and other information services, fulfil an important need that should be met by the NHS. Calls to our helpline come frequently from people who have left their GP's surgery with no help at all, or have met barriers in their attempt to be referred, or have been referred but have found the service falling short of their needs.

18. It is unreasonable for the Department of Health to expect that a charity should run a comprehensive information and help service, because this depends to a very large extent on voluntary donations. Should the economic climate change then the service might terminate at short notice. Given the expertise that now rests with the Anaphylaxis Campaign, perhaps the Department of Health should consider ways in which it might finance its continuation.

19. Evidence of the deficiencies referred to above is provided in our following paper, "The needs of patients with anaphylaxis."

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## 2. THE UNMET NEEDS OF PATIENTS WITH ANAPHYLAXIS

*Summary*

1. This note has been written to give the Committee a direct sense of what people with anaphylaxis want from the health service and what they actually receive. Sadly many of the children, families and adult patients we represent are not getting adequate care from the NHS and their reasonable expectations are not being met. We are delighted that the Health Committee has decided to investigate this issue. We endorse the 2003 report of the Royal College of Physicians, "Allergy the Unmet Need", as the most direct way of building an allergy service within the health service. It is discouraging that the Department of Health and NHS leadership have so far been unable to address directly either the problem or the proposals for action set out by the College.

*Examples of unmet need*

2. The following is a selection of real-life quotes and reported experiences, taken from letters and telephone calls to the Anaphylaxis Campaign from members living in England. All have been reported during the last two years and many of them have been repeated in a similar form on many occasions.

- Letter from the mother of a child who had suffered an anaphylactic reaction to nuts: "I am going out of my mind with worry and have been told I must wait three months before I see a consultant. My GP knows very little and would rather say nothing. Please can you help me?"
- Reported quote from a GP to the family of a nut-allergic girl: "There's nothing I can do. She will just have to go away and avoid nuts."
- Reported quote from a GP who was unconfident about diagnosing a boy with suspected peanut allergy: "Try giving him some peanut butter at home and see what happens."
- Reported quote from a GP who refused to prescribe adrenaline: "It's more dangerous than the symptoms it is meant to treat." This reflects a common misunderstanding.
- Examples showing incomplete diagnosis: Two young women who died from allergic reactions to nuts had received good asthma care from their GPs, but their families report that their food allergy had never been considered.
- Example showing lack of diagnostic expertise: A GP who failed to recognise vomiting as a symptom of allergy told the child's parents, "He must have picked one of those bugs that are going round." A correct diagnosis of allergy was made by another doctor at a later date.
- Example of inadequate allergy care at secondary level: A family in North Devon spent many months of anguish and uncertainty, worried about their little girl's allergy, until finally being referred to a hospital in London, where they received excellent care.
- Example of inadequate care at secondary level: A child aged six months had a severe reaction to egg. It took ten months to see a consultant, but this was not an allergist. Subsequently the family waited a month for allergy test results. When the test results arrived, the GP was unable to understand them because they had not been explained by the consultant. Thus even in the case of a child seen in hospital by a consultant running a clinic accepting allergy cases, the advice and level of expertise was not adequate.

- Example of inadequate care at secondary level: A five-year-old boy with severe food allergy was referred to a skin specialist for his eczema and a paediatrician for his asthma. There was no referral to an allergy specialist and therefore no holistic approach that took account of the full picture, including his food allergies. This is a common experience.
- Example of a long wait to see a consultant: A severely food-allergic girl faced a six-month wait, and suffered a serious reaction requiring hospitalisation between being referred and seeing the consultant.
- Example of a long wait to see a consultant: A man who had a cardiac arrest as a result of anaphylaxis waited six months to see an allergist. The cause was immediately identified and he was shown how to protect himself, but during this wait he had been at risk of another life-threatening reaction.
- Example showing emergency care hampered by poor understanding: A teenage boy was taken to hospital by ambulance and admitted after suffering a life-threatening reaction to cashew nut. Recovering in hospital he was offered a risotto meal containing cashew nut. His mother spotted the nuts and intervened.

3. We accept that the above cases and quotes reflect the worst end of the scale, and furthermore we do not wish to criticise individual medical practitioners concerned. After all, GPs are hampered by the fact that training in allergy is virtually non-existent, and staff at secondary care level are often burdened with a heavy workload. It must be stressed, too, that good allergy care does exist. At a few centres, a thorough diagnosis is given, plenty of high-quality advice and guidance are given to the family, training in emergency care is provided for schools and anaphylaxis management plans are tailored to suit the individual patient. A woman who had her first anaphylactic reaction to almonds at the age of 47 was treated at A&E, referred to an allergy specialist, seen within a short space of time and given a full allergy diagnosis. She now avoids a range of foods that were causing symptoms and there has been a huge improvement in her health and well-being.

4. Lacking this level of care, some patients pay to go privately; others try unproven methods of diagnosis and treatment offered by commercial, alternative therapists. One mother reported: “We were able to access allergy services successfully because our entry point was via the private sector and subsequently as a result of a research programme.”

#### *What the people with anaphylaxis and their families need and want*

5. People want access to good primary care: contact at their local surgery with a doctor or nurse trained in the diagnosis and management of allergy.

6. Where symptoms are serious or complex, people want access to specialist care, and they need to be referred quickly, in their area, to a consultant allergist who provides a dedicated service and covers the full range of allergy.

7. People want continuity of care based on a personal allergy plan, which supports the day-to-day control and management of their allergy and empowers them to take control of their lives. This requires from the health service adequate time to be set aside for full and open discussion of an avoidance regime, symptoms and treatments.

8. People want good emergency care—they need to know that during and after an emergency those responsible for their care know what to do, based on approved emergency allergy management protocols. Afterwards they need referral to an allergy specialist.

9. To make this happen we want local health authorities to invest in training their primary care workforce in the management of allergy and the Government to commit to the establishment of a core of new allergy specialists to give leadership to a modern allergy service. We believe that central direction will be essential before there can be meaningful progress at a local level.

10. We have been directly involved in the work of the Royal College of Physicians, including the discussion of possible ways forward. We totally endorse the recommendations of the College’s report, *Allergy the Unmet Need\**, and are confident that these measures will begin to give the people we represent the best chance of receiving an effective and appropriate health service.

11. We recognise that improvements may take some time and it is necessary to be patient. But people have already been waiting for a long time and asking for help. And there are things that the Department of Health could do now.

12. What we cannot accept is indecision by Department of Health Ministers and attitudes that are divorced from the realities of need and care.

13. We include with this report a selection of signed testimonials from members of the Anaphylaxis Campaign who have agreed to outline the allergy care that they received under the NHS.

*\*Allergy—the unmet need: a blueprint for better patient care, published June 2003 by the Royal College of Physicians.*

### 3. FATAL AND NEAR-FATAL ANAPHYLAXIS: SOME CASE STUDIES

#### *Summary*

1. This paper provides evidence that severe allergy presents a very real risk and not a theoretical one.
2. Information about cases where severe allergic reactions have occurred comes from the following sources:
  - The Anaphylaxis Campaign's register of fatalities.
  - Reports from our files.
  - Detailed monitoring of people's allergic reactions over a six-month period.
3. We present our conclusions about how those at risk can protect themselves, and we contend that risk management depends on help from the NHS that is rarely available. A good management plan, which requires accurate diagnosis, advice on avoiding allergens and the appropriate emergency medicines, has been shown to reduce the risk. This is exactly what a specialist allergist provides. But most patients do not get this. The health service fails these people.
4. Finally the paper records examples of serious mistakes made by food companies that have put allergic consumers at risk. The intention here is to illustrate that life can be hazardous and unpredictable for people with severe allergies, strengthening the need for good allergy services so that people can treat themselves effectively when reactions occur.
5. It is important to remember that there is no cure for anaphylaxis: self-protection must depend on avoidance of allergens and treatment of symptoms when things go wrong.

#### *Deaths from food allergy*

6. As stated elsewhere, a minimum of six to seven deaths from food-induced anaphylaxis are reported annually, as well as four to five caused by insect stings and nine to 10 caused by drugs.
7. Example one: A 13-year-old girl from Buckinghamshire died after eating a small amount of curry sauce made with peanut butter. There was some mention in her doctor's notes about peanut allergy, but there had been no proper diagnosis and no prescribing of adrenaline. Her family had no idea that she was at risk of a fatal reaction.
8. Example two: A Liverpool girl collapsed and died during a formal dinner at university after she ate a dessert that—unknown to her—contained nuts. She knew she had nut allergy and had asked her GP for help. Her GP had said: "Nothing can be done—just avoid nuts." There had been no proper allergy diagnosis or advice and no prescribing of adrenaline.
9. Example three: A Hertfordshire girl died after eating a chocolate containing nuts. Her asthma had been investigated by at her local surgery, but her food allergy had not.
10. Example four: A British holidaymaker died after being stung by an insect in the Mediterranean. He knew he was allergic to wasp venom, but had not been prescribed appropriate rescue medication.
11. The number of deaths reported annually (see point 5 above) is likely to represent an incomplete picture. The true number of those who die from allergic reactions is almost certainly higher because of misdiagnosis or misreporting<sup>1</sup>.

#### *How deaths can be prevented*

12. Deaths from food-related allergic reactions generate huge media interest. Unfortunately, reporting is often inaccurate and it is difficult for the reader to reach the correct conclusion about exactly what went wrong. However, studies of deaths have been undertaken thanks to an association between the Anaphylaxis Campaign and Dr Richard Pumphrey, of the North West Region Immunology Service. Our register of fatalities draws clear conclusions about the circumstances under which people with food allergies usually die. We deduce that most deaths are preventable. We contend that good medical management and an understanding of allergen avoidance is crucial for lives to be saved. In many cases, the victim had not received adequate medical advice.
13. Fundamentally our register of deaths is designed to formulate advice to help people with food allergies to protect themselves. The aim is to save lives.
14. Dr Pumphrey obtains a large amount of information from coroners' officers. This includes details of the patient's previous medical history, the circumstances leading to the fatal reaction, any treatment given and information from the autopsy report. Increasingly pathologists work in close consultation with him. Patient confidentiality is honoured at all times.
15. Conclusions reached by this project include the following:
  - Nearly all those who died from their food allergy were asthmatic. Many had poorly controlled asthma when they had the allergic reaction that proved fatal. We conclude that good daily control of asthma is an important factor for saving lives from food allergy, a conclusion supported by

another recent UK study<sup>2</sup>. Patients with allergy must obtain guidance on good asthma control from their GP and this must be supplemented with advice and guidance relating to the patient's other allergic conditions, such as food allergy. In our experience this holistic approach to allergy is lacking from many allergy centres, where there is a tendency to specialise in one area of allergy (eg skin disorders or ENT).

- In 22 cases out of 54 that were studied in some depth and published in the medical literature, the patient had never been prescribed emergency adrenaline<sup>3</sup>. We believe this may also have been the case for others in the group, but information to confirm this is not available. In some cases, adrenaline had been prescribed but was not being carried on the day of the fatal reaction. What was lacking here was patient education. Getting young adults to “own” and manage potential risk is a challenge that can be met only by a proper diagnosis and a thorough risk assessment.
- Well over half of the 54 food-related deaths reported in the published study<sup>1</sup> involved people aged 15-30. Special efforts need to be made to target this age group.
- Three-quarters of the reported deaths occurred when food was bought in catering establishments, such as restaurants, hotels and takeaways. Education about severe food allergy should include special advice about eating out.
- In some cases where the victim had asked for a meal without nuts, the person serving (and in several cases even the caterer) had not been aware that the food contained nuts. In other cases, the request for nut-free food had either been misunderstood or forgotten. This shows that some highly-allergic patients know they need to be extremely vigilant at mealtimes, but mistakes still occur. These cases highlight the importance of prescribing rescue treatments for “at risk” allergy patients and educating them about their use.

16. Dr Pumphrey stresses the importance of an allergy management programme for each patient, including the need for extreme care and vigilance, and good control of asthma. The allergic person must always be prepared to treat reactions triggered by accidental exposures. On a few occasions the adrenaline injection was not effective. Dr Pumphrey believes there are two reasons why this may happen: the patient has not been trained how to use it; or the patient has been accustomed to over-using his or her reliever inhaler, which may dampen the beneficial effects of adrenaline.

17. The messages are clear. Patients at risk of anaphylaxis need good diagnosis, must be prescribed an appropriate rescue treatment, and must be well educated about their allergy. This education includes recognition of symptoms and training in the use of the adrenaline injection by a medical professional, such as an allergy consultant, GP, practice nurse, or school nurse. This has been shown to be effective in studies of large numbers of people with serious nut allergies over many years after they had received appropriate advice from a specialist allergist<sup>3</sup>.

#### *Potentially fatal and other serious reactions*

18. The following cases, describing near-fatal or potentially fatal allergic reactions, are taken from the files of the Anaphylaxis Campaign. This is just a small sample of the severe reactions reported to the Campaign. The intention is to show that many serious incidents take place outside the public's knowledge, unreported by the media. The risks are not simply theoretical.

19. Chris, a boy in his early teens living in Cambridge, is severely allergic to milk. He took one bite of a pre-packed apple pie and suffered anaphylaxis. An investigation by his mother revealed that the pie contained 0.006% milk protein. He was under the care of an allergist and had an emergency treatment plan, so was able to be treated effectively immediately.

20. A young man ate a chocolate bar carrying a retailer's own-label. He suffered anaphylactic shock. Tests by the public analyst showed the presence of peanut, which was the result of cross-contamination on the production line. There was no warning on the label to indicate cross-contact with peanut.

21. Rachel, a woman in her 20s, reported a severe reaction requiring hospitalisation following a meal in cafe in Guildford. Rachel told the Anaphylaxis Campaign that the dessert menu had nut logos on some dishes, and asked about the tiramisu, which did not have a logo. The staff checked and checked again and Rachel was served the tiramisu. She began to have a reaction, which became severe, and was taken to hospital. The restaurant double-checked the box and found that the tiramisu she had eaten contained hazelnut crumb.

22. Gemma, a Surrey schoolgirl, suffered a reaction in her school after touching a friend's peanut butter sandwich. A staff member administered her adrenaline injection and she recovered quickly.

23. Marc, a young man living in South London, reported a severe reaction from a meal in his local curry house, where he ate regularly. He said the staff had told him twice that his menu choice did not contain nuts. He was taken by ambulance to hospital, spent the weekend there and then a week recovering.



24. Ben, from London, suffered a severe allergic reaction to lupin flour. This case highlights the problem caused by new, unusual allergens that are emerging (including exotic fruits such as kiwi and seeds such as sesame). Until these allergens are better understood, GPs cannot be expected to know about them, let alone know how to offer advice. Management of unusual allergies requires the guidance of specialists until they are understood better.

25. The Anaphylaxis Campaign's detailed monitoring of allergic reactions looked at 109 reactions that occurred over a six-month period between October 2000 and April 2001. Reactions ranged in severity from localised nettle rash, to severe breathing difficulties, to full collapse. About a third of reactions were either to unidentified allergens or to foods not previously identified as a risk, showing that avoidance of harmful allergens is sometimes impossible. Even when adrenaline had been prescribed, some patients were reluctant to use it, pointing to inadequate guidance on usage. Reactions involving children occurred in schools, indicating a need to improve school policies. The number of reactions reported suggests that the incidence of severe allergic reactions in the UK may have been underestimated in the past. These issues can only be addressed by having an established allergy service with support and advice from primary, secondary and tertiary care.

#### *Mistakes in the food industry*

26. The Anaphylaxis Campaign deals on a daily basis with complaints about food products suspected to pose a risk for people with food allergy. Some cases are unsubstantiated or felt to carry minimal risk, but a large number of products are felt to pose a significant risk to allergic consumers. Since January 2003 a total of 34 cases have warranted an alert by mail from the Anaphylaxis Campaign to its members. These covered a wide variety of allergens including milk, peanuts, nuts, egg, soya, sesame, wheat, gluten, chicken and yeast. Trace amounts of allergenic ingredients can trigger symptoms in susceptible individuals. Recent cases include:

27. Nuts were inadvertently omitted from the ingredient list of packs of muesli sold by a major retailer.

28. An incorrect label was applied to packs of salami, sold in a major supermarket. The product contains milk, but the incorrect label made no reference to this.

29. Due to a packaging error, frozen "Jacket Wedges" containing egg and wheat did not have these two ingredients listed.

30. A customer who bought a wholemeal loaf discovered several poppy seeds, believed to have been present due to factory cross-contamination.

31. Packs labelled syrup and ginger loaf cake, sold by a major retailer, actually contained date and walnut cake.

32. A woman who is severely allergic to sesame discovered several sesame seeds embedded in the bottom of a pre-packed teacake. Her husband returned to the store and saw other packs on the shelves containing sesame seeds. Local enforcement officers were informed but the retailer concerned declined to take immediate action to protect consumers.

33. Carob ices labelled "100% dairy free" and "suitable for milk allergy sufferers" were found to contain small but significant amounts of milk protein, the result of factory cross-contamination.

34. Jars of mincemeat containing nuts were distributed with incorrect labelling, which did not include nuts in the ingredients list.

#### *Conclusion*

35. Plainly, improving the lives of people with severe allergies is a shared responsibility. The food industry needs to improve its production methods and its communication; food safety enforcement officers need to be "allergy trained" in order to be able to educate food businesses (they receive no formal education at present); and the Food Standards Agency has a responsibility to play its part in protecting consumers. Importantly, the allergic patient must also share a large portion of the responsibility. We have contended in this series of papers that anaphylaxis is serious, but patients can be taught to "own" their allergy problem and take control of their safety through careful risk management and self-treatment when things go wrong.

36. But for many, this is impossible given the present state of Britain's poor allergy services. In order for risk management to be effective people need help, information and informed support. That is what they're not getting. Substantial improvements are needed in these services and we believe strongly that the Royal College of Physicians' report, "Allergy the Unmet Need"<sup>4</sup>, offers the best hope that this will happen.

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May 2004

*Witnesses:* **Ms Muriel Simmons**, Chief Executive, Allergy UK, **Mr David Reading**, Campaign Director, the Anaphylaxis Campaign and **Dr Shuaib Nasser**, Consultant Allergist, Addenbrooke's Hospital, were examined.

**Q1 Chairman:** Good morning. May I welcome you to this session of our Committee. May I thank you for your cooperation with this inquiry. Could I ask you briefly to introduce yourselves to the Committee.

**Ms Simmons:** I am Muriel Simmons. I am Chief Executive of Allergy UK.

**Mr Reading:** I am David Reading, Founder and Director of the Anaphylaxis Campaign.

**Dr Nasser:** I am Shuaib Nasser, Consultant Allergist at Addenbrooke's Hospital in Cambridge.

**Q2 Chairman:** In this opening area of questioning could I just begin by confessing that many of us perhaps do not know a great deal about this area. One of the good things about undertaking inquiries is that obviously we learn a lot from a range of different people and one of the things that certainly impressed me in terms of the evidence and concerned me in terms of the evidence we have had is the extent of the problems—which I do not think many of us were fully aware of. Some of the evidence talks about a major epidemic of allergy, the UK being the highest in the world for asthma symptoms, 30% of the population with allergies. What are the causal factors that seem to have lead to this epidemic, as it has been termed? You could gain the impression from some of the evidence that the more cleanliness we have, the cleaner we are, particularly in terms of the treatment of young children, the more we are preparing them for a subsequent life facing different types of allergy. I wonder what your message is about why we are where we are with this incredibly difficult problem.

**Dr Nasser:** I think this is a very important question. We do not have a very good answer for this, but the best answer is probably something called the hygiene hypothesis which has been mentioned in the evidence submitted. This essentially tells us that the immune system has evolved to fight infection and in our developed world, where children no longer get infections, the immune system feels redundant. It has really very little to do, so it goes after innocuous targets. This is now increasingly seen in medical practice. You have seen the figures, you have seen the huge increase in the number of allergy cases. Forty per cent of children are now thought to have an allergy; up to 40% of the population, and 13-14

year olds especially, have hay fever; one-third of the population, as you have mentioned, has asthma. These are very high figures and are amongst the highest in the world and comparable to some other countries. But essentially the hygiene hypothesis explains this reasonably well.

**Q3 Chairman:** As an introduction, could you tell us why you feel that, despite the extent of this problem, which is very apparent from the evidence we have, we are so ill-prepared to deal with the numbers of people who are affected.

**Dr Nasser:** It has caught us by surprise. It has caught the health service by surprise. The doctors have tried to cope with this in a number of ways, but, because allergy is a multi-system disease, it affects the immune system, which means it can affect any organ. Patients will often present with food allergy but at the same time have very poorly controlled asthma, they may have eczema and severe hay fever, so it affects many different organ systems. The way that our health service works is that if you have a problem with your nose, you go to see an ENT surgeon; if you have asthma, you go to see a chest physician; but they are not prepared to treat all the other conditions at the same time so they then have to refer you on to another specialist, for example. It has caught the health service by surprise. We are ill-prepared. We do not have the specialists to deal with an allergy or a person with allergic disease that affects multiple systems, and it leads to gross inefficiency and a waste of NHS resources.

**Q4 Jim Dowd:** You say it is the way the health service works, are you sure it is not the way the medical profession works?

**Dr Nasser:** I think they are one and the same thing.

**Q5 Jim Dowd:** Do you?

**Dr Nasser:** Yes, absolutely.

**Q6 Jim Dowd:** But the health service has to work the way the medical profession works, not the other way round.

**Dr Nasser:** I think we are talking in semantics here, but essentially the health service works according to the resources at its disposal. Doctors are trained to look after separate organ systems but, having said

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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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that, we do have the ability, and many other countries have the ability, to treat allergy, and allergists can be trained to look after multi-system disorders. We are seeing here that there is a lack of allergy speciality. This is something that is available and many of the other developed countries in the world, throughout Europe, the United States, have very well developed allergists who can treat multi-system disease. In this country we need to develop education, starting from medical schools upwards. We need to train doctors to become allergists and we need to develop centres of excellence where allergy is a recognised speciality. We can then treat these patients very adequately.

**Q7 Jim Dowd:** When you say it is semantics, I think it is more substantial than that. I think it is the medical profession and doctors in particular who regard themselves as the gatekeepers of healthcare provision in this country, and the NHS has then bent to their demands. If you say we need to change the training we do—and I have to say that is a fairly common thread through just about every inquiry we have ever done: it is said that it is a lack of training in whatever field we have done—it is for the colleges and others to decide what that training is, is it not?

**Dr Nasser:** You can recommend, though. You can certainly say, “Look, this is something that is wrong to the health service, this is something that is now being increasingly recognised.” In an allergy clinic tens year ago, if we saw a patient with a fruit allergy or a latex rubber allergy, we would call everyone in the clinic round to talk to the patient. All the doctors, all the nurses would come round and we would talk with great enthusiasm with the patient because this was such a rare disorder. Now we will see these patients two or three times a week and there is nothing surprising about it. So we have to change. The health service has to evolve with the changing pattern of illness. That is what we are saying. We are seeing this new pattern of illness because of our developed lifestyle and we need now to change with it. That is what a modern, thriving health service is all about. That is what I hope you are all about.

**Q8 John Austin:** We have seen the map of the provision of allergy specialist clinics, and they are few and far between. You were saying essentially that people are referred to different specialists for different conditions and there is not a holistic approach. That is the point that the Anaphylaxis Society have made in some of the case examples they have put forward. They have pointed to one of them as being an example of inadequate care at secondary level and they quote a five-year old boy with severe food allergy being referred to a skin specialist for eczema and a paediatrician for his asthma and there was no referral to an allergy specialist. In the patient journey where does the fault lie? Should the GP who made the referral have referred to an allergy specialist? Or, given the lack of numbers of allergy specialists, was it right to get the eczema and the asthma seen to and was the secondary care then to bring in the allergist? Was this a failure of the secondary care or the primary care referral system?

**Dr Nasser:** I think the failure is actually much more basic than that. We have already talked about education. General practitioners are not educated in allergy. Medical students are not educated in allergy. They do not understand about this concept of a multi-system disorder which is becoming increasingly more severe. Patients do not just present with eczema; they often have an associated allergic disorder. Many general practitioners in this country do not know that there are allergy services and they deny their patients because they say, “Look, we do not know where we can refer you,” and locally they may not have any allergy services. They do the next best thing and, after a lot of cajoling—because they often deny the patient any referral at all—they may refer the patient to a dermatologist who may then refer them on to an ENT surgeon who may then refer them on to a chest physician or a paediatrician. This means a very tortuous journey for the patient and it is only the very determined few, the determined parents, who can navigate their way through this jungle. It really is a jungle for them. The fault does not necessarily lie with the doctors themselves; it lies in the system. We need to be able to tell patients/general practitioners that there are services out there—not yet, but hopefully as a result of this inquiry there will be services out there—and they can be treated in a much more efficient manner—a much more efficient manner.

**Q9 Mr Amess:** Our Chairman put a very direct question to Dr Nasser, who gave us an answer which certainly caught our attention. It is very interesting to notice the interest in this inquiry compared to obesity but I bet you by the time we have finished this short inquiry there will be much more widespread interest in this subject because of course people are dying as a result of these things. You only have to visit a school and ask to have a look in the medicine cupboard: It falls open with all the nebulizers the children have. We are going to have an inquiry into the pharmaceutical industry. Every summer there is a so-called new product that is going to cure hay fever, but, as we know, it does not, it gets worse and worse. You go to a supermarket and there are all these gluten-free products, and it is getting worse and worse and worse. But I just wanted you to clarify something. You are saying that the reason for all these allergies now is that we are all cleaner—which is a showstopper—and the immune system is looking round for other things to deal with; for instance, people have peanut allergies and all these things.

**Dr Nasser:** It targets innocuous targets essentially. The immune system is a vibrant organ within us. It has to have something to do. If there is no infection out there, then it targets other innocuous targets. And, not just that, but once it targets them it is actually the fall-out from the targeting that causes the symptoms. It can target pollen, sure, that is fine, but it is actually the way it targets it and the over-reaction of the immune system, the hypersensitivity that results in all the additional symptoms.

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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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**Q10 Mr Amess:** I can understand an army of people out there saying, “My, God, David, this is just a recipe for hypochondria. We will all be walking around worried about allergies,” but it is real and it is happening. With all the brains that we have in this country—and then we will get back to the agenda, Chairman—is there a group of people working on trying to get the immune system as you have described it involved in something else other than making us all allergic to these different things?

**Dr Nasser:** Absolutely. There are some real brains behind me working on this, actually. We know, for example, that we can cure some of these diseases. This might come as a surprise to you. One of the patients in my patient survey is an airline pilot who had very severe hay fever—so much so that he had recurrent sinus infections and had to take time off work. It threatened his pilot’s licence. Imagine if you were a passenger on his plane and he just could not stop sneezing as he came into land, that would certainly be a problem. We have cured him of his hay fever. His hay fever is now no longer there because we have desensitised him. It has taken us three years but we have desensitised him. He is cured. There are certain things we can cure. As time goes on, we will be able to do more of this. There is a lot of research going on worldwide to enable us to do this.

**Chairman:** Let me ask a very naïve question—because only Richard here is medically qualified, so he understands these issues in a way that probably we do not, and our scientist is not here this morning. If one of the problems is that our children’s systems are unprepared as a consequence of our hygiene, can we not introduce some harmless grime in early years? John, say what you just said.

**John Austin:** My grandmother said, “You’ve got to eat a bit of dirt before you die.”

**Q11 Chairman:** It is a serious point. Are there not the means whereby we could recreate that in a harmless way that would protect our children?

**Dr Nasser:** Absolutely. That is one of the lines of research, in fact, to introduce this at a young age, and to take out the positive aspects of the grime, as you so eloquently put it.

**Q12 Chairman:** Mrs Simmons, in respect of your work, your organisation, what are the experiences of the patients who come to you? What do they tell you about their experiences of the NHS and their attempt to get help for their problems?

**Ms Simmons:** The major problem is getting a referral. This is the whole problem. The general practitioner, because they do not have training in allergy, are either very dismissive or they will try to find out where an allergy clinic is but then it often comes down to a funding issue or a distance issue. The main thing, though, is that the average patient is abandoned, so they turn to Allergy UK, the Anaphylaxis Campaign, and we really are propping up the NHS. We provide a very wide range of fact sheets but we are not medically qualified. We try very hard to support patients and to try to get them to see an allergy specialist, but it is very often that at primary care level it is simply not taken seriously.

They can be dismissed as hypochondriacs. There is not the help there. Could I read a very short email, which is very typical of what we receive.

**Q13 Chairman:** This is from a patient, is it?

**Ms Simmons:** This is from a patient, yes. “Thank you so much for all the information. It has been hard to get someone to listen to me. My local GP surgery have no time to something as ‘minor’ as hay fever. I even struggle to get repeat prescriptions. It is a pity they do not see me when my nose bleeds, when I am sneezing so much and can’t see because my eyes have swollen so much they have closed. I have briefly looked at the link you suggested”—which is the BSACI website—“and found that Camberley (this is only 15 miles away) is extremely convenient.” This patient has been going repeatedly to the GP. Fifteen miles down the road there is a clinic that could treat and help her.

**Q14 Chairman:** They are not aware of that, presumably.

**Ms Simmons:** They are not aware of it. The caring GPs actually often will ring us and the sad thing is that very often a GP will say, “I know nothing about allergy, can I have your fact sheet.”

**Q15 Chairman:** You are saying that both your organisations are doing, in a sense, what the NHS should be doing.

**Ms Simmons:** Yes.

**Q16 Chairman:** Who funds you? Where do you get your money from?

**Ms Simmons:** The public.

**Q17 Chairman:** You are not in any way connected to the pharmaceutical industry at all.

**Ms Simmons:** No.

**Q18 Chairman:** You get donations to keep you going.

**Ms Simmons:** Yes.

**Mr Reading:** And we struggle of course. Our members are very, very committed but they have limited funds and we struggle to keep going really at times.

**Q19 Chairman:** So there is no funding from the Department of Health or local PCTs or any NHS provider.

**Ms Simmons:** No. Allergy UK does receive a section 64 grant from the Department of Health which helps us to run our support network.

**Q20 Chairman:** What help, Mr Reading, can you give to some of your people? Presumably it is the same kind of line, where a person comes on to you where they feel they have not been properly helped by their GP or wherever.

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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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**Mr Reading:** Yes.

**Q21 Chairman:** What could you do to help?

**Mr Reading:** As you know, we are at the extreme end of the spectrum. Anaphylaxis is becoming much more common and people have a whole range of problems and difficulties and questions. They will often come to our helpline; for example, the mother of a child with a peanut allergy—which puts a tremendous burden on the family. The child may have been rushed to A&E, and once the dust has settled they go to the GP, and frequently the answer from the GP will be, “Well, if the child is allergic to peanuts, don’t give them to him,” and so they come to us. They come to us with questions like, “How do we avoid peanuts?” We go into the supermarket and we see all these warning labels, “May contain nuts”. What does that mean? They want to know can they take their child safely to a restaurant without the child ending up in casualty that night. They want to know how to assess whether symptoms are mild, moderate or severe. They want to know how to treat those symptoms. Sometimes they have been prescribed an adrenalin injection pens but they have not been shown how to use them, so they say to us, “How many should I carry and when should I use it?” We say, “You must talk to your own practitioner.”

**Q22 Chairman:** Who would provide those pens? Would that be from the GP or the hospital?

**Mr Reading:** That would be prescribed commonly by a GP. I am sure it can be prescribed by the allergist as well, but if it is prescribed by a GP you can bet there is no instruction on how to use it, either there or at the pharmacy.

**Q23 John Austin:** On that point—and it bears on something which David Amess said earlier about what happens in schools, where there are cupboards full of nebulizers—presumably a child who has a severe anaphylactic reaction to peanuts or sesame oil or whatever will be carrying a pen on them.

**Mr Reading:** You would hope so, but not all the time.

**Q24 John Austin:** Hopefully. At school, who administers that and are there difficulties? When we did our children’s health inquiry there were all sorts of resistances from some of the teachers to becoming involved in the healthcare area.

**Mr Reading:** I think over time those resistances are disappearing. First of all, you need the teachers to volunteer—we would not dragoon them into doing it, so you need them to volunteer—but you do need somebody, preferably . . . well, essentially, a medical person, to go into the school to seek out the volunteers and to train them in the use of the injection. I know in good areas like Southampton and parts of London and Cambridge you will get excellent systems set up where people train to go in and train the staff, but this is patchy. Around other parts of the country teachers will understandably be very frightened at being asked to inject an adrenalin

pen. They may be willing to do it because they know that the child’s safety and wellbeing is at stake, but they have a lot of unanswered questions.

**Q25 Mr Amess:** Chairman, just coming in on that anecdotally, I had a school where a little lad had an allergy and the school was not prepared to take the responsibility initially. It went on for a long while until eventually it was sorted out. It was very, very complicated but eventually somebody was prepared to administer assistance.

**Mr Reading:** I think the essence is good communication. We come here to talk about the health service, but the parents too must play their part. There must be good communication from the start. We find quite often that a parent maybe has not received all the information that he or she might have done, is uninformed, goes into the school with a fairly scary storey, has got it all out of proportion, and will go in and frighten the staff. That is the sort of situation where the press are involved and it turns very nasty, and you can understand why school staff are very upset and confused.

**Q26 Jim Dowd:** You mentioned nut allergies in particular and I often think we should put a sign on this building saying, “Contains nuts”! Given that this can be such a potentially catastrophic condition, perhaps I have not followed these things but just as a layperson, an ordinary citizen, this appears to have appeared out of almost a completely blue sky. A little more than a decade ago, certainly two decades ago, we just never heard of this.

**Mr Reading:** Sure.

**Q27 Jim Dowd:** Is it a recognition of something that did previously exist or is it an artificial creation of societal changes and change in diet, etcetera, etcetera?

**Mr Reading:** I am sure Shuaib could add some depth to my answer, but I would say that we were set up early in 1994 as a result of four people dying from nut allergy, including my own daughter. At that time, it was pretty much unheard of: late ’93/early ’94. It has indeed been as a result of 10 years of our campaigning and Muriel’s campaigning, but also admittedly a lot of good work initially in Nicholas Soames’s department at what was then the Ministry of Agriculture, to raise the profile of this. People would then say, “Was it always there and is it just now being identified?” We think there are two things here: Yes, we think it has been around for some time and cases in the last ten years are being identified because of the new awareness, but I am sure there is a very real increase as well over the last ten years. I am sure Shuaib has something to say about that.

**Dr Nasser:** There are now some very good studies which essentially identify that this is a growing problem. A cohort of children who were born in the Isle of Wight has been studied. Every few years, they test every single child born in the Isle of Wight. The numbers have doubled over the last five or six years, so we know that this is a growing problem, and now one in 70 of that cohort is known to be sensitive on skin testing to peanuts, for example. One in 70

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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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children is the estimate for the number of children who are allergic to nuts. The number of children sensitive to nuts in, say, the United States is 7 or 8%, so if we follow them in terms of everything else that seems to be happening, we can expect that sort of number in maybe 10 or 15 years' time. The number of children allergic to nuts in developing countries is far fewer—far fewer—so it seems to reflect the growing increase in allergy in general. You do not just get one allergy, to nuts; you may get other allergies if you have the ability to develop allergic disease and you then develop multiple allergies. We know this is a growing problem and we know many different types of allergy are increasing. This is costing the health service a lot of money. For general practice budgets, in terms of looking after allergic conditions, we are talking £900 million per year. Six per cent of general practice consultations are for allergic disease, so this is an expensive problem. If we want to fund this properly, we can probably improve the efficiency of the way that this is managed, and it probably will not cost very much money, I would have thought.

**Q28 Chairman:** Coming back to Mr Reading's and Mrs Simmons' point, and the situation of managing children's problems in the school environment, do you have any views on the ability of the school health service to deal with the kind of problems David was describing? Are they involved at all in any way?

**Mr Reading:** Yes, we are involved.

**Q29 Chairman:** No, is the school nursing service involved with this kind of problem?

**Mr Reading:** Yes. Often you will find that in a part of the country where allergy services are very good, there is much more involvement, and very high quality involvement regarding the school nursing service. But of course they can only go on what they know, so often even the school nurses themselves will come to organisations like ours saying, "Look, we do not know enough about this, can you help us?"

**Q30 Chairman:** It is very variable.

**Mr Reading:** Very variable, but patchy.

**Q31 Chairman:** If there is on our map a centre near to a school, there is more of a likelihood of them being aware in that school environment of some of the issues that they need to deal with.

**Mr Reading:** Absolutely.

**Q32 Dr Taylor:** We have had some very useful written information from all of you. The figure of one in 70 has hit us from the evidence as well because that really does bring it home to us how common it is. I think Mr Reading said this figure arises from a tripling in the last decade. I want just to refer to Mrs Simmons' recommendations from Allergy UK because I think they are very realistic, in that the first four are pointing out that in general practice, with more training, a vast amount more could be done. I really wanted to ask Dr Nasser about his survey and see if he can give us guidelines of the sort of people

who could be treated by well-trained GPs and the sort of people who would still need the specialist allergy services. Does that come out from your survey?

**Dr Nasser:** I think the important thing here is that we have to say, "Who is going to train the GPs?" first. You do need a hospital base. In every region there has to be a hospital base in order to provide the training for general practitioners. That is the first point. The second is that we certainly know that the vast majority of allergic conditions can be treated in primary care and it is probably only about one in six who would need to go to see a hospital specialist. Five out of six can almost certainly be treated in primary care.

**Q33 Dr Taylor:** The one in six that you are talking about, these are the people with real anaphylaxis, and what others?

**Dr Nasser:** Patients at the most severe end of the spectrum. We are talking about patients with severe hay fever who would require desensitisation, for example. Patients with asthma, allergic asthma, which is difficult to control in primary care and may be associated with other allergic conditions. Patients with a drug allergy; for example, patients who are allergic to antibiotics that they absolutely need, need to be investigated for this, or patients who are allergic to general anaesthetics who have to be investigated. Those are the sorts of patients, patients with multi-system disease. There are quite a lot of people out there who need to be seen in secondary care, but it is important to recognise that primary care needs the support structure in place before we should expect primary care to look after all these patients.

**Q34 Dr Taylor:** Training in primary care cannot be done until there are enough specialist units to cover the whole country.

**Dr Nasser:** In order to train them.

**Q35 Dr Taylor:** I see that. The combination of food allergy and asthma, is that widely recognised now or is that something that is not recognised.

**Dr Nasser:** We know that if you have asthma, then you are more likely to die as a result of an allergic reaction to food. These are the patients who are at greatest risk. This is not well recognised and it is a message certainly that the Anaphylaxis Campaign, I am sure, has campaigned for. This is a very important message.

**Q36 Dr Taylor:** In your survey you talked about desensitisation. I have been retired quite a long time and desensitisation in my day was not always terribly effective. Is it now? Can you almost guarantee for somebody like this airline pilot that you can cure him?

**Dr Nasser:** The patients that we desensitise for hay fever, on average would say that they have at least an 80 to 90% improvement in their symptoms. I have not come across anyone who has not said that.

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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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**Q37 Dr Taylor:** Are you still having to patch test them and get the wide range of things to which they are allergic and then get the specific desensitisation agents made up?

**Dr Nasser:** You do not get them made up, you now buy them commercially and they are standardised. That is part of the reason for the improvement in the efficacy of the treatment. There are now standardised allergens to desensitise patients. You have to choose the ones you are going to desensitise and you have to pick them very carefully in order to predict who is going to improve and who is not going to improve. For hay fever this is a very effective treatment. You certainly have to skin test them first and find out what they are allergic to and desensitise them appropriately.

**Q38 Dr Taylor:** You can pick one off the shelf to match roughly their allergies.

**Dr Nasser:** In fact there are only a few standardised allergens available and very few licensed in fact. Certainly with grass pollen you can desensitise patients, but again this is on a named patient basis and this is not a licensed treatment.

**Q39 Dr Taylor:** Are there any other lessons from your survey?

**Dr Nasser:** Yes, drug allergy was a real problem. There are two or three patients in that survey. One patient almost died as a result of a very minor injury that she had. She injured her thumb, needed a general anaesthetic and almost died on the table with cardiac arrest. It was not until one year later when she was referred to us that she was then identified as having had an adverse reaction to one of the general anaesthetic drugs. She spent a year trying to find out what had happened to her and finally when she came to see us we identified one of the general anaesthetic agents to which she was allergic and she now says that she can live her life without worrying that this is going to happen to her again. In another case, a lady with a very severe type of asthma, who had been on steroid treatment, steroid tablets, for 20 years, now has managed to come off her steroids and leads a much more fulfilled life. She is 79 years of age. There are lots of cases like this. I think the person who interviewed these patients by telephone was taken by surprise as to the emotion that these patients displayed. Many of the patients were tearful and just happy to be able to talk to someone about this and they all said that they welcomed this inquiry.

**Q40 John Austin:** In terms of being able to identify the allergens which are the triggers, a lot of the written evidence we have had suggests that people have waited a very long time until they could discover what the triggers were. It has been said that apart from the extreme ends, where desensitisation is needed, risk can be reduced by avoidance of certain things if you know what you are allergic to. Is the basic skin test for identifying the allergens one which has to be carried out in the specialist allergy centre, or is it one which could be done fairly easily in primary care with appropriate training of staff?

**Dr Nasser:** Skin testing, on the whole, is fairly safe, but there are cases of very severe allergic reactions as a result of skin testing. It is important that the person who carries out the skin tests recognises this and is prepared to deal with the consequences, and is able to resuscitate the patient if required and has the facilities to do so. I think a lot of general practitioners are reluctant to do this, especially as we have a history of severe allergic reactions in primary care during desensitisation. So there is a natural reluctance to do this. A better way would be for there to be a readily accessible clinic in secondary care, that patients would have ready access to and they could just go along and be skin tested by nurses. GPs would have access to this. It is important, though, that the skin tests are appropriately interpreted because a positive skin test does not necessarily mean you are going to have an allergic reaction to something. It is important to interpret it in the light of the clinical history. So there are some more complex aspects of this. Sometimes you have to undertake higher dose skin tests, which are more technically demanding and need even greater skill in interpretation. Although in theory they could be done in primary care, a better way would be for them to be readily available in secondary care and that the general practitioners had ready access to this and ready access to someone who could interpret them.

**Q41 Chairman:** One of the issues in which we as a Committee have taken an interest is what is generally known as tele-health and e-health, where you can electronically connect, so your primary care setting with a secondary or tertiary setting. In terms of dermatology, I have seen this working quite successfully. Bearing in mind we are never going to get, certainly in most of our lifetimes, the kind of level of tertiary provision that we would want to kick on the kind of provisions that obviously are necessary, are there any possibilities within health, if you follow me, in terms of your area?

**Dr Nasser:** Do not be so pessimistic about not being able to get this. We should not start from that premise. We should say, "Look, we have really got to go for this"!

**Q42 Chairman:** I am considering myself completely ticked off!

**Dr Nasser:** I think dermatology is very different. With dermatology, you have a rash and you can recognise it. This is a challenging subject. This is multi-system. It is not just the illness itself, it is the burden of anxiety that patients talk about. They need to be able to talk to someone who understands their problems.

**Q43 Chairman:** What I am trying to say to you—and I have seen this done with psychiatric patients—is why is it not possible for a patient to go to a GP and talk on a camera to you in your hospital and you interview that patient with the GP sitting beside them about managing their care and looking at what they need to do. I take your point that if they are doing testing that could result in a reaction that needs specific medical treatment that is not available

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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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there, but are there not things that could be done to enable you to reach out to more people further afield? I am particularly conscious—as I was remarking earlier on—that, looking at the map, from Yorkshire we have to go miles to get anywhere. Yorkshire is bigger than Wales and Scotland virtually. We have no provision in the tertiary sense at all according to the map we have and our information. Is there not a potential to do something to connect you down the line to people, where we could do more than we are doing now?

**Dr Nasser:** Ultimately the patients have to be tested. Otherwise, we will remain in a situation where children are told, if they have had an allergic reaction to, say, milk from a very young age, “You are much more likely to be allergic to nuts, you are much more likely to be allergic to eggs,” and we will end up with a lot of malnourished children who are avoiding many more things than they need to. Allergy is not just about identifying what you are allergic to but identifying what you are not allergic to, to allow the child to be able to lead a much more normal life. This is something that is fraught with stigma. These children grow up with stigma.

**Q44 Chairman:** I think the answer to my question from what you say is e-health has a limited use in addressing the problems we have at the present time. I think that is what you are saying.

**Dr Nasser:** It is probably useful in the support stages. After the initial diagnosis has been made, it is probably useful there and I am sure that something could be done. But initially they need to see someone who can explain the problem to them.

**Q45 John Austin:** You have mentioned milk. What evidence is there to link the early feeding of cows’ milk to young infants with later problems in terms of allergic reactions?

**Dr Nasser:** That is a difficult question. We know that breast milk protects from allergic disease. Breast milk is good. The early feeding of any type of allergen, be it eggs or nuts or milk may be a problem during either lactation or pregnancy or in very early infancy, but we don’t fully understand this. There is probably a susceptible time when the child is likely to developing desensitisation, but we do not fully understand what that susceptible period is. That is not a question that I think anyone can easily answer.

**Q46 John Austin:** But you are saying that there is evidence of showing a very clear correlation on the reduction of risk if the child is breastfed.

**Dr Nasser:** Yes.

**Q47 Mr Amess:** When Mr Reading told us he had lost a daughter as a result of peanut allergy, I think that more than emphasised how serious the problem is. We are hoping that by having his inquiry minds will be concentrated, and we hope to draw up recommendations which will be relatively easily obtainable, given that there is not a bottomless pit of money that is available. We have already touched upon the evidence we have received from people saying that allergy is not taken seriously enough.

GPs are very busy. They are each day receiving a pile of new products from the pharmaceutical companies. How on earth can they keep on top of it? We cannot necessarily blame the GP that they get the diagnosis wrong, etcetera. Would the three of you just give us a layman’s guide of how you really think the primary care sector for the treatment of allergies could improve relatively quickly in some tangible way, because, let’s be honest about this, we cannot say, “Right, allergies on hold. No one is going to have any of these allergies for the next six months/two years.” People need help now. Is it better communication? Is there something we can do with the primary care sector?

**Ms Simmons:** We would definitely like to see more training. The ideal situation, yes, is to have centres where from those leading centres training could go out, but that is expensive and it is not going to happen quickly. We know this. There is a very real wish for education at primary care. We run training courses. I have two master classes that are happening very shortly. Both are oversubscribed, all from GPs wishing to learn more about how to help their patients in allergy. If money could be directed into educating the GPs and also increasing the funding to encourage them to deal with allergy. Unfortunately, we know at the moment the daily grind—which is really what I am concerned about. When somebody has an anaphylactic reaction, they have to be dealt with and it is all systems go. It is the people who are trying to cope every day with an illness that is downright debilitating. It affects their family life, their social life, their working life very importantly, and these are the people who are not getting the help. That is why we feel the education should be put into primary care. We have some wonderfully knowledgeable people in the world of allergy—many of them are sitting behind us. We should be providing a lot more training for primary care to enable people to be dealt with.

**Q48 Chairman:** In the work you do with GPs, do you get any impression that the younger, more recently trained GPs have any more awareness of this area than the older ones? Is there any indication that their training is reflecting the trends that we are seeing here of this hugely growing problem?

**Ms Simmons:** Yes, with all due respect to the gentleman. They are probably rather more broadminded and they are also more up to date in the latest science.

**Chairman:** Richard is very broadminded!

**Jim Dowd:** It did take him three days to work out he had broken his arm!

**Q49 John Austin:** That is because he has been desensitised!

**Ms Simmons:** Unfortunately there is still a lack of training within their main training as a doctor, and that definitely needs addressing, but we also desperately, desperately need to do something about the GPs that are out there now. They do want to learn, and that is the main thing.



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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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**Q50 Chairman:** You basically provide for this need, but do you draw from all over the country or just the immediate area where you are located?

**Ms Simmons:** No, we deliberately put our master classes in various parts of the country.

**Q51 Chairman:** So you move around.

**Ms Simmons:** Yes, we do. I would say that it is not actually right that charitable funds should be used in that way.

**Chairman:** We understand the point you are making.

**Q52 Mr Amess:** As far as the waiting times are concerned for this area, we have been given a table that indicates that in the last quarter of the year 2003/2004 only one patient waited between 21 and 25 weeks and a further one waited 26 weeks or over from receipt of the GPs written referral until first out-patient attendance. What is your feeling about the waiting times?

**Ms Simmons:** I have to say I am somewhat surprised at those. The feedback we are getting—and I hate to stress this, but I will say it again—is, number one, these are the lucky people who are getting a referral. But we are hearing on the helpline that there is a big gap between the time the doctor refers and the time the patient gets the appointment. That is what we are hearing on the helpline. Instead of it being at that end, so it is a true reflection of the time they are waiting, they are not being given the appointment very quickly. That is what we are hearing.

**Q53 Chairman:** Have you seen the Department of Health submission, the figures to which David has referred?

**Ms Simmons:** Yes, I have.

**Q54 Chairman:** You are sceptical, quite clearly, about the accuracy of those figures.

**Ms Simmons:** Yes, I am.

**Mr Reading:** I am too. Well, I cannot deny that those figures are possibly true, but we hear a different story. I must say, being at the extreme end, if a child does have a severe allergy to peanuts or kiwi fruit or sesame seeds or whatever and there is that anxiety—and Mr Amess mentioned my daughter, and a lot of other parents think they are in the same situation as I am—they are going to find any wait of, say, more than 12 weeks an absolute nightmare, if a child is believed to be at risk of a fatal reaction. Often the truth is different and it is manageable, most certainly manageable, but it is only manageable when you have that proper care and proper information and guidance. To wait probably even more than a month for some of these parents is to them an absolute nightmare. Realistically, the tales we hear are of 11 months/12 months between the time they first see the GP and when they actually get to see the consultant, and then sometimes there is a wait to get the test results back, so it can be many, many months. Whilst not denying those figures are true, it is a different story that we are hearing.

**Q55 John Austin:** You mentioned a couple of foods. I am also wondering to what extent a change in diet and an alien diet may have some influence. Kiwi fruits and sesame seeds have only been in this country within the lifetime of those of us in this room. Peanuts did not really arrive here in numbers until the '40s and the groundnut scheme. There has been a significant change in our diet and the eating of things which are not natural in this part of the world. Is there any evidence that dietary change is a contributory factor?

**Dr Nasser:** Certainly for allergy to occur you need exposure in a susceptible individual. Peanuts, for example, are very high in protein and protein is what causes an allergic reaction. Having said that, we know, for example, that people in different parts of the world eat large numbers of these. For example, the Chinese eat lots of peanuts but they do not get a lot of allergy, but when they move to this country they do. It is not just the food itself, it is to do with the environment and a genetic background. It is a mixture of a number of things. After all, egg and milk allergy occur, and we have been eating those for a long time. We are seeing increasing amounts of fruit allergy, apple allergy, and certainly those things have been eaten for many years in this country. It is not just a simple explanation of foreign proteins, no.

**Q56 Jim Dowd:** Is this mirrored across comparable societies, other parts of Europe, North America, those in similar states of development?

**Dr Nasser:** Absolutely. The increase in allergy is being seen right across the developed world. The highest incidence of allergy is probably seen in New Zealand/Australia and in this country but also in the US and certain other parts of Europe.

**Q57 Jim Dowd:** New Zealand is often held up as an idyll of healthy lifestyle.

**Dr Nasser:** Enormous numbers of them are allergic to house-dust mite.

**Q58 Mr Amess:** Why do so many people have a wheat allergy now? That is a basic part of diet. The supermarkets are producing things to help people with coeliac disease. It seems extraordinary.

**Dr Nasser:** Yes. Again, we cannot answer why we are getting increase in allergy, we can only speculate. But, again, it is the broad increase and it is a true increase. Although we are getting better at recognising it, it is a true increase. As I mentioned previously, the hygiene hypothesis is a good one. There are different types of wheat allergy. There is a type of wheat allergy that causes similar reactions to, say, nuts; there is a type of wheat allergy that only manifests after exercise; and there is a coeliac type of wheat allergy. There are so many different types of problems that you can get with wheat and it is important, again, that you go to see an allergy specialist to be able to sort out what type you have.

**Q59 Mr Amess:** You were both concerned about the waiting time figures and you will be pleased to know that in a later session the minister will be giving evidence to us and that will give us the opportunity

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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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perhaps to clarify some of these points you are concerned about. Dr Nasser, I wanted you to say something about hospital allergy services. This is not to knock you down at all but I was fascinated when you were saying, "Go along and get these desensitising tests." When I had personal experience of this process many years ago, it took a long while. I think I was given 26 tests and I was positive to everything, including eating strawberries, and I came to the conclusion life is not much worthwhile living if I am going to fiddle about with different things. It just seemed one long drawn out procedure, where we live in a climate where you just want to take a tablet hoping that will cure things, etcetera, and the hospitals are under such strain that if you say that is the only way to fix things, so be it. So I am not going to have an argument about the veracity of what you said, but how do you think we could improve the position of hospital services to treat these allergies?

**Dr Nasser:** I am sorry you had such an awful time. If you were to go to see a specialist in this field you would probably find you would have a different experience. Come and see us up in Cambridge, if you like, and I suspect we will probably change things a little bit and improve your quality of life.

**Jim Dowd:** He is allergic to Cambridge, unfortunately!

**Q60 Mr Amess:** I just feel it is hilarious really. If we concentrate our minds on hay fever, as soon as Wimbledon is on everyone gets hay fever. There is a new product being pushed and you go to the GP and whatever is there he will shove at you, they give you steroids, etcetera. In the really serious cases, you have to go obviously to the hospitals, but how can this happen fairly quickly and easily when the hospitals are being asked to do so much now and we are trying to produce a report with recommendations which we could challenge ministers to act up but to do it fairly quickly? How can it happen?

**Dr Nasser:** I think you are looking for a quick fix to something that has been creeping upon us for the last ten to 20 years. Sometimes the quick fix is not the best way forward. We have been suffering for quite a long time, the patients have been suffering for quite a long time, it is important to get it right. If you go for a quick fix, you end up with something that is not of the best quality. It is important, as some of my colleagues here have said, that we improve education. It has to start from the beginning. It is important that we have good allergy centres throughout the country. It takes five years to train a registrar in allergy. This is post-qualification. It is important that we train up a substantial number of them and then be able to tell them, "Look, we will then have consultant posts in each region of the country, to have allergy centres in each region of the country." This can happen. We should have specialist paediatric allergists who can be trained in two or three years. Once we have this network of specialist doctors in allergy, then everything else falls into place, and the education for general practitioners, for nurses will then fall into place. You

mentioned that there is not a bottomless pit. This is not expensive. This is not going to cost an enormous amount of money.

**Q61 Mr Amess:** Really?

**Dr Nasser:** Absolutely, and with the increased efficiency this may hardly cost anything at all. Seeing four or five doctors for your allergy problem is an extremely inefficient way of practising. If you have to go to see an ENT surgeon, who could be operating instead, and he then talks to you about your hay fever, that is not an efficient use of resources. He then has to refer you on to a different specialist, a dermatologist, to a chest physician, to a paediatrician. That is inefficient. It is far better to have one doctor who can sort out the majority of your problems. This is not going to cost a lot of money.

**Q62 Mr Amess:** Is it not going to cost a lot of money, administering all these drugs?

**Dr Nasser:** If you think of the economic benefit, if you think of the number of drugs that they no longer have to take once desensitised. Once a drug allergy has been properly identified the number of mishaps that are then avoided, the reduced number of emergency visits to hospitals, the reduced number of admissions to hospitals, all of this will probably be funded very easily by the improved efficiency. I have got absolutely no doubt about it.

**Q63 Dr Taylor:** Can I pick up the point about undergraduate training. We have heard that it is pretty inadequate. Is it better in places like Liverpool, Cambridge and London, where they have got allergy clinics, or are there good examples of undergraduate training elsewhere? Is that a fair question to ask?

**Dr Nasser:** It is probably not a fair question to ask me, because I only know about Cambridge. It probably is a little better in Cambridge, but it could be even better, but I cannot speak for the other centres.

**Q64 John Austin:** In your evidence you have read a number of case studies of people who have actually got to Addenbrooks in the end, but one you have highlighted, a 78-year old lady who has been erroneously on steroids for 20 years because of a bad diagnosis, or whatever . . . We recognise that. Has this paucity of provision in terms of specialist allergy services, too few services available and long waits, caused many, many people with allergies to go into the independent sector and many to try alternative and complementary therapies? I was quite surprised when I went to see my chiropractor about my spinal problems that it says that chiropractic could be successful for people with hay fever. That was not something I was aware of, but I would like to know from your point of view as a clinician and the point of view from the patient perspective how the independent sector has fared and whether you put any improvements on complementary and alternative therapies?

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17 June 2004 Ms Muriel Simmons, Mr David Reading and Dr Shuaib Nasser

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**Dr Nasser:** I think it is important that any practice that we support and administer in the National Health Service is evidence-based. I am not against alternative treatments, and I think that patients should have a choice, but they should not have a choice between nothing and alternative, complementary medicine; they should have a choice between coming to see a specialist allergist, who will give them the choice to have something that is evidence-based and, on the whole, pretty effective, and if they then do not want that, then I am perfectly happy for them to go elsewhere, but right now they do not have a choice and that is why the private sector is doing so well, and that is not the way the National Health Service should be run.

**Mrs Simmons:** We believe that people should have a choice. I agree with Dr Nasser that it is very often because people cannot get a referral to see a proper

specialist that they end up in the hands of some practices that worry us enormously. We have more than one case where people have lost their life-savings and have been told to sell their homes. That is very, very worrying. I think that the private sector has a lot that it can offer and I think it would be good if it could work hand in hand, but we have to accept that, unfortunately, the growth in allergy has been very, very good news for some bad companies' bank balances.

**Chairman:** Any further questions? Can I thank the three of you for a very interesting session; we are most grateful to you. If there are issues following this session that you feel you want to write into us about, add to any evidence or pick up some points that were raised, please feel to get back to us. If you want to remain for the rest of the session, we will be pleased to have you. Thank you very much.

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### Supplementary evidence by the Anaphylaxis campaign (AL 31A)

#### NINE LETTERS, WRITTEN BY MEMBERS OF THE ANAPHYLAXIS CAMPAIGN

##### Letter 1

Thank you for giving me the chance to tell you about our experience of trying to get treatment for my daughter through the National Health Service.

In April 2000 my then 18-month-old daughter (who already suffered from asthma and eczema) touched a piece of toast with peanut butter on. Immediately she started to rub her eyes, which I misinterpreted as her being tired. I put her down for her usual sleep, but on waking, she had massive swelling around her eyes. She later violently vomited. We took her to the emergency doctor, who gave her Piriton and suggested we visited the GP the next day.

My GP wrote to Guy's and St Thomas' Hospital in April 2000 to arrange an appointment at the allergy clinic. The appointment received was for the September, a six-month wait. I visited my GP to suggest that this was a considerably long time, but he assured me that this was the best place to go and the earliest appointment that could be made.

During that six-month period, we knew she had a peanut allergy, but had no real understanding, training or medication to deal with a reaction. Unfortunately, in August, just three weeks before her appointment, she was merely in the vicinity of other children, who had eaten nuts. As a result of this, she developed immediate swelling around her eyes and lips, followed by uncontrollable coughing. We had to call an ambulance and adrenaline was given.

This traumatic experience for her, and us as a family, could have been avoided, if we had been seen earlier.

Our appointment at Guy's and St Thomas' found her to have a strongly positive reaction to nuts (five times the histamine level). They were very helpful, but unfortunately on each visit we saw someone different, who did not know our daughter's history. Each time we had to explain her symptoms and various other allergies. There was no consistency, which I feel is very important.

We now see an Allergy Specialist privately at The Portland Hospital, which has transformed our lives!

Our daughter is now five and is coping well with her allergies under our careful and watchful eyes. She has had a few minor reactions, but nothing serious, as we are now very knowledgeable and extremely careful.

The six months that we had to wait could have been fatal. She should have been tested and prescribed Epipens immediately after her first reaction.

There needs to be far more information and specialists available to deal with this ever increasing problem. If it were not for the Anaphylaxis Campaign, I would not have anywhere near as much information as I feel I need to deal with this situation on a daily basis.

17 May 2004

## Letter 2

I appreciate the chance to comment on my experiences of allergy services in the UK.

I was diagnosed with anaphylaxis to peanuts in September 1999 at the age of 23. However, I knew I had an allergy sometime before this, and thankfully was in a fortunate position that it was only peanuts that elicited an allergenic response, and therefore, was able to avoid them to the best of my knowledge. However, as trace amounts can bring about an allergic response this was not always possible. At first my symptoms were mild, but with each exposure became more severe, and I experienced tingling of the lips and mouth, constriction of the throat and asthma. I understood the potential for these symptoms to develop into life threatening anaphylaxis.

When I visited my GP in the summer of 1999 I explained the symptoms that I experienced. My GP suggested straight away that I should seek the advice of an allergy specialist, but warned that if I were to do this on the NHS then I would have to wait at least six to 12 months. I was told that as my symptoms sounded severe I would likely need an adrenaline auto injector, but the only way I could be prescribed this was after a diagnosis from an allergy specialist. Apart from being told that my symptoms were potentially life threatening and that I would have to avoid peanuts, I was given no practical or medical advice. Due to the severity of the allergy, and the long waiting times I discussed the option of seeking a private consultation, and was told that that would be possible but I would need to find a consultant myself that would be willing to see me before a referral letter could be written.

I felt that I really had no choice: either I wait at least six to 12 months for an appointment with a specialist and hope that I did not come into contact with peanuts, or I pay for the consultation myself. Thankfully I was in a position that I could receive a diagnosis privately and received an appointment within two weeks. I was given a prescription for adrenaline and lots of advice which has been very useful, and thankfully I now lead a normal life knowing that I have something to reverse symptoms should I accidentally be exposed to peanuts.

Since my diagnosis, on occasion, I have had problems being prescribed more than one auto-injector at a time. I have been advised that I must carry two auto-injectors on my person in case one fails to operate or that one dose of adrenaline is not enough. When I explain the reason for needing at least two this is understood, but this is a concern for individuals who may not have been given the same advice as me. I have also been told that I should take anti-histamine tablets should I experience a mild reaction, but again the advice that I have received from GPs has been inconsistent. I have been told to take tablets every day in case I am exposed to an allergen, I have also been told to take them only when I experience symptoms.

As a result of the insufficient numbers of allergy specialists and clinics in the UK, and the long waiting lists to receive an appointment, I felt my only choice was to seek a private consultation. This was a costly exercise and not something that all individuals with allergy are able to do. I feel that seeking a private consultation could have been avoided had there been more and better allergy services and support available to me.

*19 May 2004*

## Letter 3

“Thank you for setting up this committee and giving me a chance to comment”.

When Kiera was first born we all felt she was different, she went through 80 nappies a week got a lot of hives and had itchy red skin. Any doctor or health visitor I spoke to felt this was normal.

At nine months she ate her first egg, immediately she started to choke, her lips and eyes swelled, she broke out in huge hives, she even dozed off for a while, (I cringe when I think of that now,) but we knew very little about allergy then. After a five-hour wait, we saw the doctor, who gave her piriton, she said Kiera had an egg allergy.

From that moment on we avoided eggs the best we could, though she did have another bad reaction when she took a piece of wedding cake, her eyes took two days to return to normal.

In February 2003 Kiera was one moment really well and healthy the next wheezing with a severe runny nose and vomiting. We rang the on-call doctor who felt she had a virus. We still felt very worried hours later so we took her in to our doctor who straightaway called 999. By the time we got to A&E Kiera was nearly unconscious and it took them some time to stabilise her, at that point she was referred to Bristol Children's Hospital where she was put on a ventilator. Doctors never found any virus or bacteria, their verdict was pneumonia.

Two weeks later we were home again hoping it would never happen again, only it did six weeks later, all the same symptoms as before, runny nose, wheezing and vomiting etc, she was put on more antibiotics for possible virus etc, they never found any! She had hives too.

At this point I asked nearly every doctor that came in the room “would they consider doing some allergy tests”? All said no, it was probably pneumonia, or that allergy tests were very expensive. They did care for her very well; I get the feeling that they were quite puzzled by her symptoms. After a good debate with her

consultant she was referred back to Bristol, where they did some allergy testing it was found she was allergic to nine out of ten things—some of which were egg, pollen, house dust mite, dogs, cats, horses, milk and she had a IgE number of 212 which I'm told was, quite high. At this point we were given an Epipen.

Only a few weeks later Kiera was ill once more, as before all the same symptoms, this time when she was in hospital she was given Steroids, Ventolin, Becotide, Antihistamines and Singular tablets. She picked up very quickly and we were home within a few days. We were given all the above drugs to use at home.

We were then referred to St Mary's—in Paddington, London, where they were extremely helpful, we found out Kiera had a strong reaction to nuts, something that we'd not known before. We were given a treatment plan which gave us a little more confidence should things go wrong.

Thankfully Kiera improved a lot, although would go down hill if we missed her antihistamine.

Last Saturday Kiera had an anaphylactic shock one moment she was eating toast, within half an hour she started to cough, her face went very red, she then began wheezing, vomiting and the whole of her top half was covered in hives, at that point she was becoming very sleepy so we gave her the Epipen which worked very well. We had already given her Ventolin and Piriton which had no effect.

When we got to hospital we were seen very quickly but we were sent home within half an hour which seems a very short amount of time considering that one in four people can have a second phase reaction. We were given another pen but I see the shelf life is only two months! The doctor didn't seem very interested about what may have caused the reaction; it's only been through our own investigation that we think it was a sunflower.

My son Cameron is also allergic to nuts, egg, milk and bananas, I also suspect he has a house dust mite and hayfever allergy, he also has asthma but I can't ever see him being referred to an allergy clinic.

My personal feeling is that had doctors had a better understanding in allergy, Kiera might not have had to have so many hospital visits. And if I had not spoken up and challenged their diagnoses would they have even thought of allergy? Would she have gone on being treated for pneumonia and given endless antibiotics? We'll never know for sure, but I'd be willing to bet there are a lot of people like Kiera that slip through the net. I do worry about people who don't have the courage to ask questions, after all the parent often has a good hunch about what is wrong with their child.

Kiera's Epipens were up for renewal a couple of weeks ago, I had to stand my ground to get more than one. Once again I was told they were expensive, but I'm not willing to penny pinch on my daughter's life! I haven't been given them on repeat prescription so I dare say next year I'll have another battle before me. Last week shows only too well how important they are. If one had misfired or had run out of date where would we have been—I hate to think.

After speaking to many people at a support group the lack of allergy care within Devon is really awful, sooner or later a life could be lost due to utter ignorance.

*May 2004*

#### Letter 4

Thank you for giving me the opportunity to express my views on the current state of allergy services within the NHS.

I shall give a brief outline of my experiences:

*August 1998*

I became aware that I was reacting to certain foods, eg crunchy nut cornflakes and peanut butter. My GP agreed that perhaps I had an allergy, so she gave me an adrenalin pen and referred me to the Allergy Clinic (North Bristol NHS Trust). No information given.

*September 2000*

Finally my appointment at the allergy clinic, I had a series of tests and was told that I was reactive to tree nuts, peanuts and sesame.

I had an adrenalin pen and two years on, I still had no idea how to use it!

The whole experience of the clinic left me confused, there was no help or guidance of any kind, not even a booklet or a sheet of paper outlining my allergy. I got the impression that I was wasting their time.

I did my own research into my allergy and was horrified to learn that I had a fatal food allergy. I felt very angry, hurt and let down, by the NHS that, not one profession or medical person could have spared five minutes to explain my allergy.

From my experiences it appears to me that there is a dire lack of funding going into allergy clinics, resulting in a lack of doctors, nurses and support staff and essential reading materials.

What is required throughout the clinics is proper training of all staff, not only in the allergy itself but in communication skills as well.

*May 2004*

#### **Letter 5**

I have a two year old son who has a life-threatening allergy to nuts and eggs. I would like to pass on my experiences for consideration in your enquiry.

When my son had his initial anaphylactic reaction in November last year, the Paediatric A&E team at our hospital closely monitored him and he was given Piriton Syrup and steroids as the symptoms were gradually clearing up. After a few hours we left hospital with more steroids and Piriton but we were not given any information at all about what to do next. We only had instructions for the next three days. We weren't told to avoid nuts, we were not given any written or spoken information, we were not told to go to the doctor for referral, we were not told about Epipens, we were not told about skin prick testing, anaphylaxis was never mentioned and no-one suggested that the raw egg in the peanut butter cookie mixture our son had eaten could also have caused the reaction. It was only through surfing the internet and finding the anaphylaxis campaign that I realized how potentially serious the situation was and what I needed to do.

I went to see my GP and asked for a private referral (we are lucky enough to have private medical care) and Epipens. Our GP questioned my initial request for an Epipen before my son had his skinprick test but when I pushed him he grudgingly gave me one Epipen (but not two). I was not shown how to use them either at the doctors or the chemist. Again I found out this information for myself via the internet.

Through skin prick testing his allergy to nuts and eggs was confirmed and he will have to carry Epipens and Piriton with him wherever he goes from now on in case of a reaction.

We were well looked after in A&E, the staff were attentive and caring and we didn't have to wait too long to be seen but their lack of knowledge about anaphylaxis and what we should be doing next was frightening and potentially life-threatening for my son. This situation needs to be addressed urgently, more information needs to be given to pharmacists, GP's, hospital staff and the general public about serious allergies and how to deal with them.

*14 May 2004*

#### **Letter 6**

As one of the many severe allergy sufferers living in the UK today, I greatly appreciate this opportunity to share with you some of my own experiences regarding anaphylaxis and the healthcare / support networks that currently exist in this country. I very much hope that this feedback will prove beneficial in assessing the impact anaphylaxis has on sufferers' daily lives, and will help determine ways to best move forward in the future.

Please note, I've included a bullet point summary at the end of this letter in case you don't have time to read everything; however, I hope you do as I feel this will give you a far greater understanding.

I first experienced an anaphylactic shock about five years ago after playing a game of squash at the local sports centre. When I went for a drink in the bar afterwards, I literally only touched my lips with the outside of a glass of orange juice and lemonade, when I immediately felt "funny" and realised I couldn't sense any feeling in my lips and face. I went to the changing rooms to check myself in the mirror and to splash some water on my face, and was horrified by what I saw. My whole face had swollen beyond recognition and I was rapidly feeling worse and worse. Despite a lack of any support from the First Aider on site I was eventually rushed to A&E where I was put on heart monitors and given adrenaline injections and antihistamines. Several hours later I was sent home, and told to contact my GP first thing the following day.

My GP explained that I had experienced a severe allergic reaction and suggested I should see an immunologist as soon as possible. Due to having private medical cover at the time, I was promptly seen and given prick tests for the same brands of orange and lemonade that had been in the glass at the Sports Centre bar. The results were inconclusive, but after the dialogue I had with the immunologist I was told I probably had oral allergy syndrome. I was given a list of foods which, based on my hay fever season, may be best to avoid (at least raw). At the same time I was prescribed an adrenaline injection (Epi Pen) by my GP.

Naturally it was frustrating to still not know what it was that had caused the reaction, or to have any offers of help in ever finding out what it might have been. However, I did at least take some comfort from knowing that I now had the necessary medicine to treat myself promptly if the problem arose again. My own investigations on the Internet taught me that the reaction could have been caused by even the slightest trace of peanuts on the outside of the glass, or that carmine dyes often used in orange drinks have also been known to induce anaphylaxis. I also discovered that exercise could bring on anaphylaxis too.

Despite finding the uncertainty disturbing, I carried on, with a definite sense of denial about the whole thing, for about three and half years without serious incident.

In the latter part of 2002, and the early part of 2003 I was having a lot of problems with eczema and general ill health. I was convinced this was due to my diet and as such had taken to avoiding certain foods including dairy produce, substituting soya products instead. At the same time I was having long running problems

with my eyesight, and after having a central serous retinopathy and allergic conjunctivitis diagnosed I was eventually referred to the Ophthalmology department at Gloucester Hospital. I was scheduled to have some analysis done of my retina taken by injecting a dye and then taking photographs of the dye's movement over a period of approximately 10 minutes or so.

On arrival at the hospital I was given some eye drops to dilate my pupils, and asked if I had any allergies they should be aware of. I explained my allergy history in great detail, and was told that although there was a slight chance of me reacting to the dye, they had been doing this for eight years and never had a problem. It was also joked at that time that there was a "crash" machine on standby so I had nothing to worry about. I was then asked to wait in the waiting room whilst the eye drops had time to take effect. When it was my turn to go in for the procedure proper I was asked if I felt ok—I complained that I felt woozey and was told that this was not uncommon. The dye was then injected into my arm, and I was put into position to have the photographs taken.

Approximately one minute into the procedure the doctor asked if I was feeling alright. I struggled to answer her and felt very heavy and weak. I could sense and hear things going on around me, but was unable to lift my head, move or communicate. My vision became tunnelled and I felt very much outside my own body. I was also finding it difficult to breathe and had to be given oxygen. I heard mention of my blood pressure dropping rapidly, at which point my mother (who had driven me to the hospital that day and was waiting outside) was asked to come into the room.

After several shots of (what I believe were) adrenaline, antihistamine and steroids I began to come round and was able to speak. I was given a cup of tea and a biscuit and told I could go home after having them. As soon as I tried to drink the tea I started shaking all over, and quickly slipped back to a state similar to how I was before. I'm not sure on the details of what happened next, but I do remember an ambulance being called and being taken to A&E where I was kept until early the following morning. Throughout being in A&E I was kept on oxygen as I continued to struggle with breathing, and my heart rate and blood pressure were also monitored.

On arriving at the men's wards I was told I would be kept in overnight and that the Immunologist would see me in the morning. The following day no one seemed to know what was happening, and I was offered food and drink without any question as to whether I was allergic to it or not. Eventually, I discovered there were no arrangements for an Immunologist to visit me whilst I was in hospital, and that this would take weeks, maybe months to be arranged. On managing to eat some food I was allowed to go home.

It was very noticeable how hard this reaction had affected me relative to the reaction I had experienced before. For nearly a week I struggled to even get out of bed, and I began to experience difficulty in breathing too.

After a few weeks had passed I went down to Cornwall to visit my sister for the day, and on the way back we stopped for some food. As I drove back onto the motorway I felt extremely ill, couldn't breathe, and it seemed to me that I was having another allergic reaction. My wife was able to confirm that my face and tongue were not swelling and fortunately we were able to make it to the next junction reasonably quickly. It now seemed apparent that I was actually having a panic attack, although at the time I struggled to realise or rationalise this fact.

Having already had inconclusive RAST test results back from my GP, I returned to ask him to expedite my seeing the immunologist as I was finding it difficult to know what I could eat based on the guidance that had been given me. He commented himself that I was losing a lot of weight, and that he could tell I was really troubled.

Months of waiting, chasing, lost letters, mis-directed messages and unbelievable admin errors followed, and still it was looking like further months of waiting and uncertainty before I would get to see the specialist. In this time I "resorted" to seeking alternative help from a local nutritionist/kinesiologist. She was amazing. As soon as I spoke to her on the phone she said she could tell I was in need of immediate help, and she agreed to meet me the next day, staying late after work especially. I was very sceptical of her methods of diagnosis, but felt immediately better being given the chance to discuss what had happened. I was even given a diagnosis (systemic candidiasis) and an explanation as to why I might suddenly be allergic to things that I had happily eaten before.

Initially I continued to be sceptical despite the diagnosis making good sense, however as the treatment began to work with astonishing speed I knew I was in good hands and should follow her advice faithfully.

Eventually an appointment came through for me to see the immunologist I was supposed to have seen whilst in hospital, so in an attempt to ensure the session went well I prepared a potted history and list of questions I felt I really needed answering. At the appointment I was told there wasn't sufficient time to go through all my paperwork as there was only a set period of time allocated, and therefore I would have to prioritise my questions until the time ran out. Several times during the meeting the immunologist left the room to see to other patients, and in the end I was told that I probably didn't have anaphylaxis and should go ahead and eat the foods I had previously been avoiding due to them coming out as positives on my RAST tests. I expressed my concern at doing this, and when I explicitly asked if he was recommending that I go ahead and eat some peanuts, he changed his mind and suggested that I should perhaps avoid those after all.

Thoroughly troubled by the appointment with the immunologist, I decided to stick with the advice I was getting from the kinesiologist instead. During this time I continued to seek answers to my questions using the Internet, and it was in doing so that I first made contact with the Anaphylaxis Campaign. Again, this was a huge benefit to my overall well being, as I now had a contact for helpful considerate people who were knowledgeable about my condition. From speaking to members of the Campaign I quickly learned that it is advisable to have 2 Epi Pens prescribed due to the importance of this medicine in the event of a severe reaction.

In April 2003 I moved house, and as such decided to take the opportunity to change my GP after numerous unsatisfactory dealings with my previous practice. I was delighted to find my new GP far more understanding, and was amazed when he suggested a double appointment to allow time to go through my history at length. Further tests were subsequently carried out, and due to my high IgE levels I was now advised to avoid all allergens where I had registered a positive result, even if these positives were not especially high individually. It was suggested that I was “prone to anaphylaxis” and therefore should consider any allergen as being a potential trigger, and this is how I now live my life and manage my condition.

The tests I have had carried out by the kinesiologist and the GP correlate very closely so I now totally avoid nuts, wheat, and soya from anything I eat.

After having skins tests carried out for my eczema I was told I was allergic (skin rash, not anaphylaxis) to “carba mix” which is used in a number of rubber products, so, out of curiosity I asked if I should be tested for any allergy to latex (common trigger for anaphylaxis) as well. The results came back positive so this was added to the allergy card and bracelet that I carry with me at all times.

Despite not being happy to eat out due the improbability of any restaurant being able to prepare food that is clear of contamination from nuts, wheat and soya, I feel I now manage my diet very well. My life, and my wife’s life, have changed significantly as a direct result of the aforementioned experiences, but without the help of my kinesiologist, the Anaphylaxis Campaign, and the information available on the internet I seriously doubt whether I would have got past the point of considerable anxiety that I was in a little over a year ago. It is imperative that more is done to educate GPs and hospital staff on the basics of severe allergy awareness, and with the number of children with severe allergies dramatically on the increase we need better education in schools as well. I also feel we need legislation ensuring labelling of ingredients in food is extended to include guidance on cross contamination including trace elements, but, above all, we need education for the general public to prevent people with severe allergies being treated like “freaks” or social outcasts.

My own efforts in addressing these needs have brought me into contact with many fellow sufferers through a small documentary that I have started to film. I have been amazed at the lack of understanding sufferers have to endure from family and friends, and almost everyone I’ve spoken to has had at least one person say to them “a little bit won’t hurt you, surely”. Several people have expressed how the biggest change they struggle with is the loss of a social life, and one lady has even experienced direct discrimination by being asked not to attend a company Christmas party due to her condition.

I hope describing my own experiences helps you to form an accurate picture of what it is like to experience severe allergic reactions to food and medicine, and I trust this will prove useful in taking the appropriate steps to improve the quality of service that can be offered by the NHS, through better awareness and other measures.

## SUMMARY

- I’ve experienced two severe allergic reactions, one of which could have been avoided if the NHS staff had taken my allergy history more seriously.
- I believe my condition may have been caused by medicines prescribed in the past.
- I have to carry two life-saving adrenaline injections with me all the time. I had to educate my GP as to why two Epi Pens are necessary. Generally GPs do not prescribe two injections, neither are they particularly good at demonstrating to the patient how to use them.
- Alternative medicine has been far more helpful and eager to understand than the NHS. It would be great if the NHS would embrace this complementary medicine, rather than seeing it as competition to be scoffed at, and dismissed, without thought.
- Food allergies are not taken seriously in the UK. This includes the food industry, the NHS, and indeed the general public.
- GPs are themselves frustrated at not understanding severe allergies better. Several have openly admitted to me that they wish they knew more than me about the condition.
- People tend to consider nut allergies as being more serious than other food allergies. They are generally not aware of “anaphylaxis” and the fact that it can be triggered by any allergen.



- Sufferers are often made to feel like social outcasts and hypochondriacs. People seem unable to comprehend that food can be life-threatening, and are typically quick to state or imply that it's a figment of the sufferer's imagination. On numerous occasions I've had people say to me "surely just a little bit won't hurt you", or they have jokingly wafted a bag of peanuts under my nose.
- There is a drastic lack of specialist immunology help in the South West.
- Having a severe food allergy makes eating out in restaurants nigh on impossible for some.

### Letter 7

I am writing to highlight my experiences of, and disappointment with, the services and support available in this country to those suffering with allergies.

It became painfully clear to me following the birth of my son six years ago, and his subsequent development of life-threatening food allergies, that there is a woeful lack of readily available information/expertise in relation to this health specialty.

I live in Berkshire which does not even have an allergy consultant since Rita Brown retired as, it would seem on a cost basis, a decision was taken not to replace her. When I was pregnant I joined the National Childbirth Trust ("NCT")—of the six mums in our group two of the babies produced have serious allergy to nuts and now have epipens, to say nothing of the asthma sufferers in the group—and I don't believe for one minute that we are not reasonably representative of the local population.

Allergy (and intolerance) has not, until very recently, even formed part of the basic training of doctors. I received some poor, and often contradictory, advice along the painful learning curve that comes with having a very allergic young man in my care. There have been a few highlights (for example the pharmacist who did take my concerns about my son seriously and gave me instruction re giving of liquid Piriton by syringe at the first sign of something serious, which more than likely saved my then six-month old son when he went into shock on his first bottle of formula). But on the whole these highlights have been too few.

I also learned along the way that "there's no evidence to suggest" can often mean "there's been inadequate research in this area"; ("we've no idea" would be more honest).

There was a short time when there I did feel that there was some more "joined up" care available ie when James was referred to Great Ormond Street Hospital ("GOSH") allergy clinic. With the support of the fantastic dietician, Chris Carter, and the clinical team under Professor Stobel, I at least felt someone was monitoring his development thoroughly and telephone support was available from Chris. At GOSH I received advice re the delayed introduction of certain highly allergenic foods (eg eggs, kiwi). I am fairly certain that this has assisted James in not developing a major problem with these foods. This type of advice is just not available generally.

You can imagine my anger and disgust when the GOSH Clinic was closed by withdrawal of funding. In fact I'm not sure my faith in the medical services in this country will ever be entirely restored.

I have also been amazed by the comparison between the advice/guidance which was made available to me (particularly prior to GOSH) and that which I have subsequently found has been made available to friends in Australia and US re allergies (eg if there are allergies in the family, guidance is given on diet during pregnancy and breastfeeding and on when to introduce potentially problem foods). In fact I don't think we need to go as far to find some uncomfortable comparisons. A friend who lived here and whose son has asthma went to live in Germany. The first thing her doctor did was ask what her son was allergic to ie what triggered his asthma so that steps could be taken to minimise reactions. Her doctor could not believe that this had not already been investigated—and immediately arranged all available tests.

To be honest it has made me feel that I was living in the third world at times. Preventative advice does not seem to be the order of the day—and once the problem is there (currently incurable and a constant feature of the affected person's life) all that is taught is avoidance (which frankly no one needs to be told).

It seems to me that there are a number of areas that need immediate attention:

- (a) better awareness of allergies amongst the medical profession and the general population (I've met a number of people who reacted adversely to things but did not realise the potential risks they were running);
- (b) prompt, accurate and readily available testing (and support/advice) for those with allergies;
- (c) research, to find more accurate ways of testing for allergies and intolerances, to better treat them and finally to understand more fully the mechanism by which they develop in the hope the development of allergies can be prevented, or ideally reversed. Drug companies clearly have a vested interest in finding drugs to treat illnesses—this country needs to spend money to find ways of avoiding or curing illness.

Allergies are a growing problem. They can have a severe, if not fatal, affect on the lives of sufferers—and at the very least they can make life pretty miserable at times (my little boy would love to go to a party and eat what the others are eating!).

It seems to me, as a lay person, and putting aside the actual direct symptoms of allergic reactions, that many major illnesses have their roots in our auto-immune responses. If we had a better grip on how and why these responses operate. I can't help but thinking we might find the key to stopping some of these things from developing.

Please make this country a better place for my little boy to grow up in. Some things have improved in the last six years—in particular the availability of “free from” type foods—but its not enough.

20 May 2004

### Letter 8

Thank you for allowing me to share with you my family's experience with allergy services.

#### EMMA'S STORY

I am from an atopic family and my husband has problems with peanuts. Neither of us has had a referral to an allergy clinic or specific advice on how to avoid allergies in our children.

Our daughter had a reaction to biological washing powder. I knew she had a high risk of other reactions so we asked if she could be tested for peanut allergy. We were told this was only possible if she had already had a reaction to nuts as the test would have to be at hospital. We were given no advice on how to test her safely ourselves. Not knowing what else to do we kept her away from nuts until she was five then rubbed a peanut on her skin. When that produced no reaction we let her eat half a nut. She said her throat felt as if it was closing over so we gave her antihistamine and left it for another couple of years. Then we felt we had to know one way or the other as she was increasingly going to other houses and tried again. It produced a similar response so we asked our doctor for a referral. As there was no rash he refused. We weren't happy but accepted our doctor should know best.

About two weeks later at Brownies our daughter was given a chocolate cake containing nuts. She had a severe reaction and we called the emergency doctor. We live in a rural area and they would have been unable to reach us for perhaps an hour but they did not advise us to call an ambulance. While they were still en route Emma vomited and began to recover. We had a very disturbed night—no-one had warned us of the possibility of a secondary reaction so we did not realise we should have again sought medical attention.

The emergency doctor had recommended an epipen but our doctor still thought it wasn't an allergic reaction and was reluctant to refer us for testing. Fortunately our practise includes a female doctor who is allergic to nuts. After I threatened legal action for negligence if my daughter had another, reaction my GP agreed to seek her advice urgently. We then had an epipen, an apology and a referral. Training in the use of the epipen consisted of our doctor reading us the leaflet enclosed with the pen.

The nut allergic doctor gave us the address of the Anaphylaxis Campaign. They provided us with a trainer pen and a video on how to use the epipen. They were also the only people to offer any emotional support. It is traumatic to discover your child has a life-threatening condition. Nut warnings on labels are easy to miss and whenever your child is away from you there is the fear that someone else will not check their food carefully enough. The death of a milk allergic baby at a nursery did not help. To make your child take sufficient care you have to tell them of the risk to their life. Recent research has shown how scared nut allergic children are—but our daughter's nightmares and night terrors had already made us well aware of that.

We waited months to see a consultant. Emma's allergy to peanuts is so severe that it is off the top of the scale. Her blood test is positive for all tree nuts. During the wait to see the consultant my daughter had no epipen at school, also at least 35 minutes from a hospital, as our doctor would not confirm the diagnosis and without a firm diagnosis the school would not accept the epipen. We discovered later, from other parents of allergic children, that our doctor had not prescribed the fastest acting antihistamine for minor reactions. Once we had a formal diagnosis I had to arrange training in the use of the epipen for staff at my daughter's school.

We are extremely strict about our daughter's food—but there is a limit to what we can achieve. She reacts to slight contamination, even to traces of peanut from a pool cue that were transferred accidentally to her mouth. She has a handicap—but without the support given to children with other handicaps. Her epipens may one day save her life, but are also vital for her social life and my sanity.

We are aware that we have been extremely lucky.

Our inexpert attempts at testing for nut allergy were not fatal.

Because we have allergies we had access to antihistamine promptly when our daughter had a severe reaction and the secondary reaction was less severe.

Emma vomited up the nuts—she might otherwise have died before the emergency doctor reached us.

We have a nut allergic doctor in our practise and hence were able to get an epipen before seeing the consultant, although her life was still at risk at school.

Thanks to an Anaphylaxis Campaign meet up we have the fastest acting anti-histamine for minor reactions.

We have been able to see an excellent consultant.

The staff at our daughter's school have been willing to be trained to use the epipen—there is no requirement that they administer this life-saving medication.

A child's life should not depend on luck!

*14 May 2004*

### Letter 9

My son Aneil was diagnosed with asthma at the age of about eight months. His attacks occurred every few months and each time he was taken into Newcross hospital and put on a nebuliser. As a result of these frequent attacks he was asked to attend Dr Ross' outpatient's clinic on a regular basis.

At the age of three Aneil was diagnosed with nut allergy. He came into contact with cashew nuts and had a severe reaction. I was told that this was a life-threatening condition and Aneil should be kept away from all nuts. We were given epipen injections for emergencies.

At one of the outpatient appointments I discussed Aneil's allergy with Dr Ross. I asked for Aneil to have a "nut challenge". I felt that he might only be allergic to cashew nuts and not all of the other types of nuts. Cashews would be easier for me to eliminate from his diet. Dr Ross agreed to do the challenges. Aneil was challenged with seven different nuts. He was severely allergic to four of them.

The service we received from the hospital was excellent. We were given a room for the day of each challenge. There was a television and videos for Aneil to watch. The nurses were very pleasant and the doctors were on hand, their approach to Aneil's condition was one of sympathy and understanding.

Aneil is now eight. He has been discharged from the outpatient's clinic. His asthma is controlled and we have learned to cope with his allergy.

*14 May 2004*

### Memorandum by Dr Shuaib Nasser (AL 72)

I am an accredited consultant allergist and respiratory physician and work full time at Addenbrooke's Hospital in Cambridge in one of only six specialist allergy clinics in the UK. This Select Committee's inquiry is timely and I welcome the opportunity to give evidence. It is important that Committee listens most closely to the patients who are in need of good quality allergy treatment that is difficult to access in the UK.

The NHS has been wrong-footed by the unexpected allergy epidemic. Current provision of allergy services are patchy and inadequate and in the main provided by doctors with only limited allergy training. Many are struggling to keep pace with the ever-increasing numbers of referrals, often to the detriment of their own services. Most do not have the facilities or experience to investigate complex multi-system disorders outside their own focussed area. For example, there are only a handful of hospitals able to investigate drug allergy. Today's NHS must acknowledge that numbers of patients with allergy are not only increasing at an alarming rate but have also become more complex with more severe and often life-threatening conditions. These inefficient practices are likely to lead to longer waiting lists for ENT operations, dermatology outpatients, chest clinic appointments etc. Furthermore, the next 5–10 years will see the advent of new and expensive bioengineered pharmaceutical agents capable of remarkable health benefits in targeted individuals with allergy. Without an extensive network of trained specialist allergists in each region with the ability to identify the subset of patients to benefit, it is likely that the NHS budget will further spiral out of control.

Many of the patients I see in clinic have been told that there aren't any allergy clinics and they have to cope with their symptoms. Others are told that there is little point in being referred as "nothing can be done anyway" or that the "tests are too dangerous". Persistent patients may eventually be referred to organ-based specialist such as ENT surgeons for rhinitis, dermatologists for eczema and urticaria and respiratory physicians if their predominant symptoms are asthma. They may be given advice on the management of one of their symptoms but it is rare for allergy tests to be carried out or an attempt made to find the underlying cause. It is not often appreciated that treatment of rhinitis in certain types of asthma is mandatory in order to improve asthma control. Children with asthma die because of an allergy to a pet but this is never discovered. A chest physician may then refer the patient on to an ENT surgeon for rhinitis or to a dermatologist if the patient has urticaria. This method of treating interrelated and often interdependent conditions is clearly inefficient but also bad medicine. It fails to recognise that one symptom may be improved by treating another and that in a particular patient all allergic symptoms may have a common cause. One often hears a sigh of relief from a patient eventually seen in an allergy clinic and their allergy disease diagnosed, explained and managed. This is not the NHS that our patients expect or deserve and is frustrating for health professionals who see well-developed allergy services in other parts of Europe.

I sincerely hope that the Health Select Committee consider recommending the following:

1. Improve training from Medical Schools upwards in order to improve allergy services especially in Primary Care.

2. Immediate central funding for substantial numbers of Specialist Registrar training posts in Allergy.
3. Guarantee to centrally fund new consultant posts in Allergy starting when the specialist registrars have completed their training.

Finally, 12 of our patients were contacted by telephone by an experienced lay colleague and selected in order to illustrate the range of disorders dealt with by an allergy clinic. On the following pages, brief summaries are presented together with a synopsis of the telephone interview and a comment at the end of each case. The overriding message is that allergic disorders affect everyday lives and must be taken seriously. Patients often spend years attending inappropriate clinics before they find a specialist allergy clinic and may then have to travel great distances. A modern, vibrant and thriving NHS cannot be seen to offer good medical care to the determined few.

3 June 2004

Annex

#### LIVING WITH ALLERGY: THE PATIENT'S EXPERIENCE. A SURVEY FROM ADDENBROOKE'S HOSPITAL ALLERGY CLINIC

Addenbrooke's Allergy Clinic sees about 5,000 patients a year, mostly referred from the East Anglia Region and the north east home counties, but a proportion travel longer distances to the clinic.

We wanted the Health Committee to be able to hear about the experience which very ill patients are having of allergy care in the contemporary NHS, what they think about it and what they consider important.

Telephone contact was made over the May bank holiday weekend and, for one contact, immediately afterwards, with 12 patients selected to demonstrate some of the problems typical of those we see in patients attending our clinic.

Those contacted were told about the Health Committee's Inquiry and asked whether they wanted to tell the Committee about their experience. All said yes; several went out of their way to welcome the Enquiry before the interviews began.

The interviews were carried out by an experienced colleague working independently from the clinic in order to capture the patient's own perspective.

It is estimated that a minimum of three million people have serious allergies in Britain. Perhaps 260,000 of these people will have found their way to a clinic with some expertise in the management of allergy; and perhaps 50,000 a year will do so each year at the moment.

We cannot comment on what happens for those that do not reach specialist allergy advice and help. Here are the stories of some that have done so. A comment has been provided for each report and a clinical summary has been added from the clinic. Names have been changed; the rest is verifiable.

#### REPORT OF INTERVIEWS

##### *Summary of Findings*

- Allergy makes its presence known in very different ways.
- A common experience is that people felt they were working on their own to manage a persistent, wearing, often unpredictable and sometimes dangerous illness.
- Many people were anxious; this was more so if a child was involved.
- In every case very substantial health gain was achievable with proper medical care.
- When care was effective, this came about through recognition of the needs of the whole person and of all aspects of the illness.
- The search for help through the NHS was all too often blocked at some point, often at several points, and sometimes for long periods of time, by a health service ill prepared to care appropriately for severe allergy.
- Considerable resolve (or luck) was often required to negotiate or find a way through the system of front line care and referral.
- Experiencing lack of understanding and help, people were frustrated and sometimes frightened by what they needed to face.
- People had to, and were prepared to, face long journeys to get the right help.
- All this when people have severe and often dangerous disease.

1. *Mrs Andrews spoke about her son, Peter, aged 13.*

*Clinical summary:* nut anaphylaxis; allergic asthma; allergic rhinitis; egg, kiwi fruit allergy.

“We moved to Cambridge when Peter was three. The GP referred him to Addenbrooke’s because he had instructions from the Department of Health that peanut allergy could be serious. From that point on it all worked well. I think now how fortunate we are. With anaphylaxis it’s outside your control, you can’t just give medication. It’s frightening and distressing. But we feel that support is there. The community paediatric team visited us and talked it through, so we feel supported. They also visited the nursery and trained them. And now they visit the school, and they visit every year as he moves through the school. We can phone the nurse whenever we need to. At school he isn’t treated differently and he’s not prevented from doing anything. Now he can manage himself; it has helped him to be more confident.

When he was aged one he was treated in London for his eczema. The consultant then said that peanuts are ‘bad news’ and when he is a teenager and goes to parties he may have to take medication. That’s all he said. Nothing about other nuts or foods. Looking back we should have followed that up.”

*Comment:* Good allergy care is not beyond reach. GPs need central guidance as well as a local context. A specialist clinic supports the patient and the family and other public services, making a network of supportive care. Even when eventual outcomes are good, allergy patients have often received inappropriate advice at an earlier stage.

2. *Mrs Baker spoke about her son, Paul, now aged 13.*

*Clinical summary:* Referred as multiple antibiotic allergy; antibiotics needed for ear infections but not known which if any could be given; diagnosis identified as not allergic and which antibiotics are safe to use.

“It began when he was 18 months old. He had recurrent ear infections and violent reactions to antibiotics. Over about seven years he had operations to help sort out his ears. But last year he had another infection while we were in Majorca. And we had to sort out his allergy. We had to wait nine months for an appointment to Addenbrooke’s. And all the testing was nerve wracking; it took the best part of a day; and there wasn’t enough room in the clinic so we got shunted around. But eventually it came out all right because now we know what forms he can use in an emergency.

At some stage we saw a paediatrician in our local hospital. He took blood samples and said we should use adrenaline.

Going to Addenbrooke’s was traumatic. We had to travel 50 miles, then 50 miles-back. It wasn’t pleasant.

But there’s a sense of relief in the end.”

*Comment:* Repeated wrong diagnosis in primary and secondary care due to lack of allergy knowledge. Clinic role is also to investigate and advise on multi system non allergic illness. And to establish drugs which are safe for the patient.

3. *Mrs Campbell aged 78.*

*Clinical summary:* Aspirin sensitive asthma, rhinitis and nasal polyps.

“I developed asthma for the first time in 1979; the doctors said it was stress related; also nasal polyps. I have been under continuous treatment since 1984. I have had two emergency admissions for asthma. I have had my sinus washed and scrapped. In 1992, after my sinuses were washed a second time, I was told that I was too impatient and I should give it time. I was upset that day. In 1997, my GP had tried everything. He asked if I would be prepared to go to Addenbrooke’s (200 miles away).

My first consultation lasted one hour and 20 minutes. What understanding. Here was somebody who knows what I am saying and what it’s like. He said he wished he had seen me 10 years before.

I had been on steroid tablets for 20 years; he took me off them; my asthma control is much better. But my polyps had to be removed. I had the operation privately in 1998. I couldn’t wait. I had a second operation in 2002. That was private too. I feared a long wait.

I still have no sense of smell; they said a box of chocolates when I got it back; no chocolates yet.

Addenbrookes is a long way to go. But where else is there that I would have had this help?”

*Comment:* Delays in diagnosis resulted in 20 unnecessary years on oral steroids. Mrs Campbell lives in a part of the country where allergy care is inadequate. Allergy advice was needed and referrals to other consultants were not an adequate substitute.

4. *Mr Diamond, aged 47.*

*Clinical summary:* Severe hay fever; desensitisation treatment; disease now controlled.

“Basically I have had hay fever for as long as I can remember, certainly from when I was at primary school. I worked abroad a lot until about 10 years ago. When I returned here to work the symptoms became much more pronounced. I am an airline pilot and we have a lot of pressure changes and this was leading to sinus infections and time off work.

Since I have had the treatment at Addenbrooke’s there has been no recurrence.

My wife suggested I try the treatment. My GP wasn’t unsympathetic; but basically wasn’t able to advise; he sent me to an ENT person, who sent me on to Addenbrooke’s. I had to find my way to the right place. The treatment is weekly injection for two months, then monthly before the season, going on for at least three years, and they only do it one morning a week. It would be convenient if it was more available; but my employer has been very good about it.”

*Comment:* Hay fever is not always trivial; disrupted family life and threatened job performance. Patients have to negotiate their own way through the system, often leading to inappropriate clinic appointments and contributing to inefficiencies in the NHS.

5. *Dr Edmonds, aged 26.*

*Clinical summary:* Aspirin sensitive asthma; treated without allergy diagnosis since a small child; now controlled for the first time.

“I wasn’t referred at all for allergy.

I had asthma from age five, which was GP and chest clinic treated. My asthma was difficult, with numerous A&E admissions. I was in an undergraduate seminar, and my asthma was bad, when a tutor said that he was working with a doctor who was interested in my type of asthma. They were in the same laboratory, so I went to the Addenbrooke’s Allergy Clinic.

I did my post-graduate in Oxford. The GP there said that there was no equivalent place in Oxford for me to be referred to, so I commuted to Cambridge for treatment.

Now I haven’t had an attack for over a year. I have to avoid fruit. But I can have chocolate and gin.”

*Comment:* Lottery of care. Poor control of asthma for many years because of failure to recognise allergic triggers and treat appropriately. Inappropriate referrals led to costs to patient and the NHS. It was luck that got this patient to an allergist.

6. *Mrs Fellows, spoke about her daughter, Anne, aged 10.*

*Clinical summary:* Peanut allergy, eczema, hay fever, allergic asthma.

“When Anne was 18 months I gave her a crumpet with peanut butter. I left the room. When I came back she was floppy in the high chair, one eye was swollen, she had a rash and had vomited. I rang the doctor; but it was lunchtime and I was told to wait. I went down anyway. They said it was a reaction to something; and said to go to the chemist and get some piriton. She vomited again and we went back to the surgery. Eventually we got the medicine down her.

I then read in a newspaper an article by the man from the Anaphylaxis Campaign. I got in touch; he said I should demand an allergy test; the doctor said no; the Anaphylaxis Campaign sent a copy of a White Paper which said I had a right to the test. They then referred me to Addenbrooke’s.

Then the full enormity of what was wrong fell on me. I thought this would go away. That’s not the case. Anne is now 11. I have been to Addenbrooke’s every year since. She has been to hospital twice. I have had run-ins with play groups, schools, especially in the early years. That is less so now. In the current school (350 children) there are three children with nut allergy, and other allergies as well. The head couldn’t be more sympathetic. But now we have got the secondary school coming up, and that’s a new ball game.

We now live in (750 miles away from Addenbrooke’s, round trip). I have just come back from a visit to the clinic. I feel safe with Addenbrooke’s. Nobody here is as involved. I can’t take a chance; it’s my daughter’s life.

There is no awareness of the seriousness of the situation. Nobody seems to be taking it seriously. It’s a tremendous worry, constantly.”

*Comment:* Need for a national network of expert care.

7. Mr Garner, aged 60.

*Clinical summary:* Angioedema of the tongue with respiratory and cardiac arrest; drug cause identified; no further attacks.

“I woke at seven in the morning. I couldn’t speak. I thought I had had a stroke or something. My wife called the doctor and we were taken to hospital. My tongue was swelling and bleeding. In the hospital they summoned all the doctors, it was an unusual case. I thought they nearly talked me to bloody death. I suffocated; and was rushed to intensive care. They couldn’t get me to breathe. They did a tracheotomy and tried to get me round. I was fighting, fighting. They gave me adrenaline to the heart. They told me they were massaging for half an hour. I was covered in blood. I had had my throat cut.

I had two days in a private ward; then they discharged me. After, I wrote to ask what happened. They said my pulse had dropped, incompatible with life, and they couldn’t get me to breathe.

They mentioned in passing that there was Addenbrooke’s. I rang them and made an appointment. I heard about a referral weeks later.

The second time it happened was worse than the first. But Addenbrooke’s had given me the preparations and I knew what to do. And I rang Addenbrooke’s again straight away.

They don’t treat this thing seriously and they don’t know what to do. You hear weeks later about a referral. At Addenbrooke’s I ring up and they say come straight in.”

*Comment:* Delay and six months wait, despite near death; inappropriate response to drug-induced allergy emergency.

8. Mr Halsey, aged 47.

*Clinical summary:* Severe hay fever; 14 years of long-acting steroid injections; 90% improvement on immunotherapy.

“I have been a hay fever sufferer for over 20 years. After I was 27 it got progressively worse; the season went on from April to November; it was terrible; attacks might last two to three days; my nose was running; I was sneezing constantly; I couldn’t sleep and finally couldn’t work.

The GP prescribed all the over-the-counter drops and sprays. They made some difference, but not enough. In the end he realised that I was not an average case; and he prescribed corticosteroid injections. In April each year, which would last until July; then again in July. The treatment was effective on the same day and was welcome.

That lasted for 11 years. In summer 1997 I had had the July injection and was playing with the children in the park. I began to limp. I didn’t take much notice. But it went on for two to three weeks and got worse. I went to the doctor in August and he said wait, it might be a muscle sprain.

When it hadn’t cleared by December we began to realise that it was the side effects of the steroid treatment. I was diagnosed with avascular necrosis. Nobody admits it. Nobody accepts. They say the dose I was getting is not big enough to cause it. But the accumulation must have been a factor.

Now I have avascular necrosis. Both my hip bones are damaged. The right is at stage 5, total collapse and needs replacement. And avascular necrosis is now present in the left hip bone.

I was referred to the orthopaedic department at a hospital in London in April 1998. I still go there. I am putting the operation off as long as possible; I don’t want to have a series of hip replacements over the years. But it’s serious discomfort and limited coping.

Then came the problem with what to do about the hay fever. They referred me to the Allergy Clinic at Addenbrooke’s. They gave me skin tests and began desensitisation. That was four years ago. It seems to work. Yesterday (30 May) I sneezed once. Today is fine. I’ve known nothing like it before.

I have friends from France. In 1992 they said that desensitisation was commonly available in France; and they were surprised that I couldn’t get treatment. I wish it had been available from day one. I have missed work and all this could have been prevented.”

*Comment:* Delayed referral for 14 years despite desperate quality of life in the summer. Serious life-long side-effects of inappropriate treatment and failure to refer to an allergy clinic. Heavy costs to the patient and to the NHS.

9. Mrs Inchcliffe, aged 33.

*Clinical summary:* Latex, fruit and nut anaphylaxis.

“I have atopic eczema and asthma. As I grew up and it got worse I tried to explain what was happening. Nothing really happened. Seven or eight years ago I was working with self seal envelopes. I didn’t then know I also have latex allergy. My eyes and lips blew out. Then they took it seriously.

I was living in (the south of England) and was referred to an allergy consultant; they were helpful to a degree; but they wanted to find respiratory problems, and they asked about wheeze; when I said no, but my lips were massive, they moved on.

Five years ago I was making satay sauce and licked the spoon. My lips blew up and the next day I had hives. I had read about Allergy UK and explained my situation to them. We had moved to Essex, and I eventually pressed to get more advice. What I had might not be full blown anaphylaxis but I didn't want to wait to find out. Recently I have discovered I am allergic to strawberries, so new things are being discovered all the time.

When I got to Addenbrooke's it was like a door opening. They knew where I was coming from. I was not working on my own anymore. When I last had a bad reaction they pinned it down. Before they had tried to knock it out; but then you end up with a tiny weenie amount of food to eat. Addenbrooke's have given me a written emergency plan. It's on the seat of the car in case of medical alert.

It's hard to live your life; I feel nervous in day to day life. The GP was very good; he helped me about what to do when things go wrong. He was the first person to take it seriously; but I guess people don't know much about allergies.

Knowing what to do helps to suppress your panic."

*Comment:* Allergy is a multi-system disease. Need to manage the whole disease, not just some of the symptoms.

10. *Mrs Johnson* spoke about her son, Andrew, aged 13.

*Clinical summary:* Dairy produce and egg anaphylaxis; allergic asthma and eczema.

"Andrew was very ill in his first few days of life. The doctor recognised his eczema as atopic by eight weeks. At three months he had a bad reaction to something in the Welcome Pack, which contained baby rice. At one point epilepsy was diagnosed (wrongly) because he was unconscious from a crumb of biscuit. At seven months he was in hospital for three days, reacting to something in a jar with milk in it. Almost immediately he had another reaction and was in hospital for 10 days. We were then fairly sure and were avoiding milk. He had another attack at about two-and-a-half when he got hold of something; we were very lucky that time.

Then we got a proper diagnosis of anaphylaxis; and everybody got a bit of a fright. Then we had three to four years living a nightmare; not knowing. The doctor (GP) was wonderful; he came round and showed us what to do. Having the pens and the protocol made the difference. If it's not clear what the problem is then it's not safe.

I myself had anxiety attacks. I still do. It changes life for the family. You have to be one step ahead and know what you can do to save them. We had got milk out of the house; but my daughter is now in puberty and she must have milk and that brings a new risk back into the house.

People don't know the difference between allergy and severe allergy. And you don't know how a reaction will develop. They know the tingling in the throat and lips; but you can't cut off all exposure and it's not clear what's going to happen next. I would say that every year we need a trip to the hospital because we are not sure.

But once you are in the system you are very supported by it. Andrew now has a relatively normal life. He is still bothered by it and has to protect himself; but he runs for the county. Accurate diagnosis and having the EpiPens and the adrenaline puffer make the difference.

Nobody should underestimate the effect this has had."

*Comment:* Patient made safe by identifying then avoiding the allergic causes and with an emergency plan to cope with reactions. Child given a nutritionally sound diet. Family anxiety reduced.

11. *Mr Kelsey*, aged 36.

*Clinical summary:* Venom anaphylaxis switched off by desensitisation (immunotherapy).

"I'm a bee keeper, with 200 hives. 90% of my income comes from this source. It's very erratic, but I might get stung three to four times a day.

Three years ago I was stung and within a minute I was out of it, unconscious and throwing up. At the hospital they let me out after three hours and lots of injections. Subsequently my GP told me that I would have to give up bee keeping.

After some aggressive discussion he said that there was this place, Addenbrooke's, and he would write if I was willing to go on the course (desensitisation or immunotherapy which switches off the allergic reaction). I got a place and was treated. I'm as chuffed as buggery. I am two years into the course and have injections every three months. There has been only one mishap when I sat down with the EpiPen, but I didn't have to use it.



My biggest trouble was with the GP who said there was no way I would get on the course because I was just a bee-keeper.”

*Comment:* Mr Kelsey is able to continue with his livelihood.

12. *Mrs Longworth*, aged 60.

*Clinical summary:* Near fatal anaphylaxis with cardiac arrest due to drugs used in general anaesthetic; one year delay before allergy diagnosis (wrong referral initially, then waiting time for allergy clinic appointment); now made safe for future general anaesthetic.

This all began on 17 April last year. I had never in my life before had an operation of any kind. But I tripped and hurt my thumb when I was out with my son and his family. The fracture clinic said I needed a small operation. They told me there was a bed and I went down for the operation at 12 o'clock the next day.

I woke up later that evening and I was hooked up to everything. People were looking down at me. I couldn't make out what they were saying. My family had been called and told I had had "EMD". Everything had stopped. My whole body had shut down. They told my son that they had got it going again and everything was stable.

Next day I was still groggy. I remember a group looking over me. They took the tube out of my neck and some things. They were gradually taking me off the machines.

I was taken to a different ward. I was still on oxygen. Then the anaesthetist came and said "you gave us a scare yesterday". Well, I'm scared now. Nobody told me they didn't know what had happened. They treated it like an everyday occurrence. Nobody came and said they didn't know.

Then I had the operation on my thumb. They took me to the same place. The same room. I was terrified.

When I was about to leave the hospital still nobody had said. I told them I was worried about what was happening. They said they would send somebody up. Then they told me to go. I was completely drained. I felt like nothing. I was dismissed.

I wrote. I wasn't complaining. I was asking to be told. I wanted them to know how I felt. They certainly got the ball rolling. Complaints and Litigation wrote explaining what had happened. They said they had explained when I came round. I was in no fit state to recognise what they were saying. They did not say that blood tests had been sent away for.

I was given tests to my heart. Three or more. A 24-hour cardiogram; a transoesophageal echo. That was November last year.

But in July the consultant anaesthetist rang to say that the National Adverse Drug Advisory Service had sent back results suggesting a reaction to the anaesthetic and saying I needed skin testing for all the drugs that had been used on that day. Nobody had said they had taken blood. Nobody said it might be something in the anaesthetic.

I was nine months before I got to Addenbrooke's. In that time I had a nice letter to carry around saying I had cardiac arrest following anaesthesia and what drugs were implicated and a bleep number.

In one way I felt relieved. All those weeks I was wondering whether I was doing something. I just felt that whatever I did could be the last time I did it. If somebody had said before and they were going to try to get it sorted out. Now, I think I could have had an accident and been on my own somewhere. And never come out of it. Why can't they find out before?

When I got to Addenbrooke's it was amazing. They did the tests; (the drug which caused the reaction) exploded on my arm. It was like a door opening. I was treated like a human being. They gave me confidence. They didn't dismiss me and showed respect. Why wasn't I allowed to get there sooner? How easy it could have been. I wouldn't have felt so alone. A year out of my life.

Now I have a bracelet with all the details. And a letter. I feel safe. And the MedicAlert people have all the details on their computer. Two drugs I am allergic to, and a list of anaesthetic drugs that it will be safe for me to have.

This will always be on my mind. If I hadn't written, what would they have done? Are there other people like me? What is happening to them? I still keep thinking things like that."

*Comment:* This person was at recognisable, but unaddressed, risk for one year.

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**Memorandum by Professor Stephen Holgate and Dr Pamela Ewan (AL 19)**

THE PROVISION OF ALLERGY SERVICE

1. We are writing to you jointly as Chairman of the recent Royal College of Physicians review committee on Allergy and of the National Allergy Strategy Group (NASG) and as President of the British Society for Allergy and Clinical Immunology (BSACI).

2. The NASG is an alliance of organisations, each of which is independent of the others, that have agreed to work together with the specific objective of seeking improvement in NHS allergy services. The alliance has existed since 2001. Its core members are BSACI, The Anaphylaxis Campaign and Allergy UK. Other organisations, such as those who provide training in allergy, lend help. Some pharmaceutical companies have provided grants which support our activities. We remain independent of all affiliations and of each other.

3. We are pleased and gratified that the Committee is holding its enquiry into the provision of allergy services; we will help the work of the Committee in any way we are able to.

4. The publication of the report of the Royal College committee (*Allergy: the Unmet Need*, June 2003) was a seminal event. The review committee met and took evidence for over a year; commissioned research; and thoroughly explored the state of allergy in Britain. The report, together with correspondence with Department of Health Ministers, will we believe, be important source documents for the Committee's work.

5. We have annexed to this letter—

- (a) a recent letter and a paper written initially for Dr Ladyman at the Department, following contacts with the Minister at the beginning of the year. The paper, which we have called "Making a Start", was written in an attempt to clear up possible misinterpretations by the Department of what was proposed by the Royal College and to set the developing situation in context. We hope that the Committee will accept correspondence as evidence and that it helps your work; and
- (b) copies of past correspondence with Department of Health Ministers and officials.

May 2004

**ADDENDUM**

**THE NATIONAL ALLERGY STRATEGY GROUP (NASG) TREAT ALLERGY SERIOUSLY**

1. The NASG exists because patients and professional organisations, and others, in the field of allergy have agreed to work together because the provision of NHS allergy services is extremely poor. There is a need to get allergy recognised as a public health problem and raise the standards of allergy care available through the NHS.

THE ISSUE

2. The context for this agreement is set by:

- (a) a current allergy epidemic: reliable estimates are that
  - an estimated 30% of the population have an allergic disease (18 million people in the UK);
  - 12 million people have active allergic symptoms in any year;
  - at least 3 million have allergic symptoms sufficiently complex and severe to require help from a specialist doctor;
  - these are among the highest rates in the world;
  - prevalence is growing, making allergy a particular problem for today's children and tomorrow's young adults;
  - allergy impacts on the lives of all groups in the population, irrespective of socio-economic class, ethnic origin or geography.
- (b) poor access and quality of care available through the NHS: a June 2003 report from the Royal College of Physicians (see 3 below) found:
  - poor understanding of allergy, a lack of relevant training and low adherence to good clinical practice within primary care, where major parts of a disease with such widespread prevalence must ultimately be managed;
  - inadequate information and comprehension among NHS commissioners, an earlier attempt to forge a way forward by identifying the disease as a subject for "specialised commissioning" in order to focus knowledge and initial responsibility about what should be done on a few selected individuals having been made and failed;

- in the hospital sector, clinics providing services for allergy patients mixed in with the management of other conditions; and doctors, who are not allergists and who have had little or no training in allergy—all in the absence of specialised alternatives—helping to manage the epidemic;
- fully fledged and comprehensive, specialised allergy services available only in six locations across the UK, including Scotland, Wales and Northern Ireland (three of these in London, with others in Southampton, Cambridge and Leicester) with no services to the standards set in these centres west of Bournemouth or north of Manchester.

3. In June 2003 a Royal College of Physicians expert committee reported—Allergy: the Unmet Need (1). The Royal College report, having documented the findings in 2 above, proposed an agenda for change and improvement based on pump priming investments to create a cohort of new, allergy specialist doctors. The Royal College recommended that teams of four (two for adult care and two for paediatric allergy) allergy consultants should be trained and deployed to augment the existing services, giving a national infrastructure of clinics, with each team serving populations of 5–7 million people. These clinics would provide services for the most complex allergy cases. They would also act as information, training and support centres for both NHS commissioners and providers, helping more widely disseminated allergy services to come into existence within the NHS.

4. The Royal College calculated that the cost to establish and train the new cohort of specialists would eventually be £8 million a year, building up as each local clinic became fully staffed to provide a comprehensive service. Costs of at least 10 times that figure will be required to provide the NHS with fully comprehensive hospital based allergy services (2). No estimates exist of the investment necessary in primary care to bring its services up to standard; but the Royal College has recommended that the sustained development of primary care cannot occur without the creation of a national infrastructure of clinical allergy experts to ensure clinical leadership and accountability.

5. The Department of Health has agreed that improvement in NHS allergy care is needed. But has said that the Royal College agenda for change is only one, and not necessarily its preferred, way forward. Health Ministers wish to rely on an approach based on local service commissioning—ignoring the absence for major parts of the country of any service infrastructure or basis of skill or information on which to base such a development. The preferred policy also underplays the extent to which centrally driven clinical priorities are currently overpowering all other possibilities for health service improvement.

#### WHAT WE ARE DOING

10. NASG members have decided that they must act responsibly in this situation. There are large numbers of people who need access to health care, which they are currently denied. First exposure to allergy can be a very frightening experience. Particularly when the allergic reaction could threaten death, constant vigilance is required, often something which envelopes the life experiences of the whole family. And the long term grind of managing chronic allergy can too often sap the energy and enthusiasm we all need to have a full life. We must balance the need for hope, and the prospects for help and relief, with “telling it as it is” about the poverty of the NHS in this area.

11. While acting responsibly, therefore, the NASG has sought to get allergy treated seriously. It has:

- (a) taken its case directly to Health Department Ministers and senior officials. A Minister has agreed there is a need for better allergy care and to discuss with his colleagues and officials the publication of a possible “action programme on allergy” which could inform local commissioners and service providers of the need to find a way forward. While less than we would hope for, we regard action by the Department in these areas as a start—particularly if it involves NASG directly;
- (b) opened ways for people with allergy to give expression to their opinions and wishes. In this respect we have initially encouraged allergy patients motivated to do so to write to their Members of Parliament asking them to take two concrete actions: to ask Health Ministers to pay attention to the issue and to ask their local health services what they are proposing to do about allergy care [attached example of the patient card]. Patient opinions are currently reaching Parliamentary representatives; and monitored responses so far have been mixed. While some MPs have asked questions, as we asked, and others have offered meetings—others have responded by formula. Further Parliamentary and local campaigning is planned for later in the year;
- (c) begun work towards establishing an All Party Parliamentary Group on Allergy.

12. NASG members are as follows:

- A core group comprises: the patients organisations working in allergy (Allergy UK, the Anaphylaxis Campaign and a representative of the Allergy Alliance) and the professional allergy organisation in the UK—the British Society for Allergy and Clinical Immunology.
- A wider group of supporters comprising: training organisations and corporate organisations with interests in allergy and the NHS Alliance.

## REFERENCES

1. Allergy: the unmet need. A blueprint for better patient care. Royal College of Physicians, London, 2003.
2. Allergy, in Consultant Physicians working for patients: the duties, responsibilities and practice of physicians. 2nd edn. London; RCP, 2001:45-53
- 3 March 2004

## Annex A

## AN NHS PLAN FOR ALLERGY—MAKING A START

1. This paper sets out the options available to the Department of Health on how to modernise NHS allergy services. A summary is given in paragraphs 2 to 5 below.
2. Central Government initiatives are required to give an effective start to the improvement in NHS allergy care. The initiatives need only be small scale. They would be the precursor, not an alternative, to close to patient developments which can be the main driver for change once allergy services have become part of the NHS mainstream. Central intervention to begin change will give direction and leadership, will make it possible to address the most serious gaps in service first, and will help to make the overall process more effective and more efficient.
3. Mixing (supportive) central initiatives with (mainstream) local developments would be the right way to develop services for allergy. It need not create difficult policy precedents for the Government, given its desire to make service development a local health authority responsibility.
4. The initiatives which are needed would help to create a core NHS allergy service where currently none exists. This would eventually cost an additional £5.6 million pa for the English NHS, building up over a number of years. Some of the costs will be offset by necessary interventions to prevent an imminent deterioration in allergy care. And—although this cannot be quantified, given the information which is currently available on the NHS—reduced calls on other parts of the NHS would also result as provision for allergy becomes consolidated around the new core.

*The Analysis—Four Parts*

5. Four aspects to the analysis are presented, as follows:

*A: Growing need and inadequate services:* There is a current epidemic of allergy in Britain. An estimated 30% of the population now have allergic disease; the proportions for children are ten percentage points higher still; the numbers with complex, severe or life threatening illness are growing disproportionately. Faced with the unprecedented levels of need which result, but with no effective service base from which to grow, the allergy service of the NHS needs to be transformed if it is to provide 21st century care. A start must be made on doing this.

*B: Achieving Change—the right response:* The core issue is how to create a health service capable of meeting the needs of the  $\frac{1}{3}$  of the population who have allergy—given the current, effective absence of any national, clinical or commissioning infrastructure for such a service within the NHS.

- While recognising there is a problem, the Department of Health has said that it does not see any need for central intervention. Additional general flows of funds into the health service, combined with close to patient decision taking within a devolved NHS, will—Ministers have said—be sufficient to address any significant problems the service may face from the epidemic.
- A consensus of clinical and patient opinion, however—including the Department's own expert advisers on the management of the NHS medical workforce—have concluded that some central action will be required to respond to the situation which is developing. Well managed, what has become necessary could be the start of an effective change process resulting in the creation of new services for people with allergy within the NHS.
- That said, the choices facing the Health Department are not—as they have been presented—between centralised or devolved decision taking. The advice being offered to the Department—principally by the Royal College of Physicians—is that strategic central investment in medical manpower will support and complement, not cut across, locally driven change.

*C: The NHS allergy workforce:* The NHS currently offers a vestigial allergy service across all sectors of care.

- The small group of specialist, consultant allergists is forecast to become even smaller in the coming decade because not enough doctors are being trained to replace those who will retire. This is an exceptional situation across virtually all medical disciplines in the NHS.

- In consequence the Department's expert advisers on the medical workforce are proposing that the balance should be redressed. If their advice is accepted, the resulting increase in centrally funded, specialist training would begin a process of improvement in the way recommended by the Royal College.
- For paediatric allergy, where successive birth cohorts of children are driving the epidemic, allergy doctors face a very serious and growing imbalance.
- Ensuring the medical workforce is appropriately trained—given the national information requirements for planning, the very high premium on getting workforce numbers right and the timescales and costs of delivery—is anyway a responsibility of central government.
- Using a workforce intervention to initiate change need not, therefore, be seen as cutting across the preference for allowing local health decision taking to drive change wherever possible.

*D: Ends and Means:* Government's plans for the NHS promise a service which is there when its patients need it, access which is timely and convenient to arrange and which offers the best in modern medicine. Wide ranging change will be needed if an NHS allergy service is to become part of the mainstream NHS, delivering on this promise. With commitment and imagination most of what is required can be developed within a devolved service; but creation of the initial core group of allergy doctors cannot. For this group to be recruited, trained and located, Government must act using resources it controls centrally. Doing this opens the way for other changes which can be driven locally and within the medical profession.

#### A BREAKDOWN OF THE PROBLEM AND A WAY FORWARD

##### *The allergy epidemic and current services*

6. In June 2003 a Royal College of Physicians' expert committee<sup>(1)</sup> reported, having studied the emerging allergy epidemic in Britain. The report contained new clinical and epidemiological estimates of allergy prevalence—the latter based on official data—an appraisal of the current state of allergy services in the NHS and recommendations for improvement.

7. On allergy prevalence, the Royal College found reliable evidence of an allergy epidemic in the UK.
  - (a) an estimated 30% of the population have an allergic disease (15 million people in England); 10 million people have active allergic symptoms in any year;
  - (b) at least 2.5 million people (one in six of those with allergy) have sufficiently severe symptoms to require tertiary level clinical help. A further group of people need more specialist help than can be provided in primary care; it is difficult to estimate the size of this group;
  - (c) these prevalence rates are among the highest in the world;
  - (d) 40% of children have allergy—each birth cohort increases the numbers of people needing help; the epidemic continues to grow, making allergy a particular problem for today's children, and their families, and for tomorrow's young adults;
  - (e) there are no socio-economic class, ethnic origin or geographic variations in the disease.

8. On NHS allergy service provision, the College found widespread poor standards. There is insufficient understanding, training and adherence to good clinical practice within primary care, where major parts of a disease with such widespread prevalence must ultimately be managed. NHS Commissioners have inadequate information about allergy; and few of them seem to have thought about the illness or the requirements for an allergy service. In the hospital sector, the College found clinics providing services for allergy patients mixed in with the management of other conditions. And, in the absence of specialised alternatives, doctors who are not allergists, some of whom have had little or no training in allergy, are working to help to manage the epidemic, as an add-on to their main role. It follows that patients are not receiving adequate standards of care; children may be particularly badly served.

9. As far as the specialised allergy services are concerned, the College found gross under resourcing and an inequitable geographic distribution. However, in six locations across the country (three of these in London, with others in Southampton, Cambridge and Leicester) the College found a significant concentration of allergy expertise, and service and training capacity. For the most part—although not exclusively—this national expertise on allergy had been developed by doctors funded primarily in their capacity as clinical academics and researchers.

10. Therefore, major improvements in the hospital based services, combined with a significant "reskilling" programme in primary care, are required to enable the NHS clinical workforce to meet the challenges of the allergy epidemic.

11. An independent assessment of one aspect of what will eventually be needed is available from the Royal College of Physicians' report on NHS specialist workforce requirements across all medical disciplines (2). Using a methodology common to all specialities to take account of emerging need, the latest Royal College assessment is that 520 additional consultant allergist posts in England and Wales are needed in order to provide a competent, reputable and fully fledged specialist allergy service within the NHS. This is just one measure of how far commissioning will need to drive the service once its basic infrastructure is in place.

12. The patient's organisations, quite reasonably, are asking for:
  - convenient and timely access to the health service; and appropriate and accurate diagnosis of allergy;
  - treatment or referral; convenient and timely access to a clinic in the case of referral;
  - for evidence based information to be provided to individual patients on how to manage their allergy;
  - continuity of care to be available; and
  - for emergencies both to be well managed by clinical staff who know about allergy and for the emergency to be used as an event triggering an appropriate medical review.
13. Meeting these aspirations for allergy patients from today's virtual standing start will require:
  - the introduction into primary care, more or less de novo, of competence to diagnose and manage allergy (as opposed to the drug treatment of specific allergy driven diseases, such as asthma);
  - the parallel introduction into most teaching hospitals of an allergy service, providing convenient local access for people with more complex allergy;
  - and the development of a regional or tertiary level service which can manage the most complex cases and provide overall leadership during a time when, however fast the service grows, a serious imbalance between needs and capacity will exist.
14. We have estimated the service gap which exists. Estimation is inevitably imprecise because the NHS has virtually no clinical information available on allergy. The most complex cases will be appearing throughout the service classified and managed as other, specific illness. We can make no estimate of the gap in the case of primary care. But we have concluded as follows for specialist services, for the UK as a whole
 

“The numbers of children with allergy in need of specialist help are estimated to be increasing by over 40,000 each year across the UK. An estimated minimum of 2.7 million people currently need specialist diagnosis and treatment for their allergy. NHS allergy clinics are able to cope with a maximum of 50,000 new cases a year—less than 2% of estimated unmet need assuming no annual increase in need. All current clinics, working as they are, would take 50 years to clear the backlog, if there were to be no new cases of severe or complex allergy”. See the annex to this paper for more detail.

### *Achieving Change*

15. Department of Health Ministers have agreed—in debates in the House, in answer to Parliamentary Questions and in correspondence—that there is a need for improvement. But they have also said that decisions on how great a need, and on what priority should be given to this in relation to other areas of need for service, are the responsibility of local health authorities and trusts in partnership with other local stakeholders—not of central government.

16. For allergy, this approach is bound to result in inaction. The reasons for this are common to all clinical areas not currently identified as a centrally determined, national priority—even with the increases in health finance currently in evidence, local priorities are being squeezed out by the pressing urgency to deliver results on centrally driven targets.

17. And in the case of allergy there are additional considerations, namely
  - (a) clinical knowledge of allergy is poor across all sectors. A primary care led approach, for instance, would not be appropriate at this point for this reason<sup>1,3</sup>. This does not rule out investment in a better prepared primary care workforce—indeed the reverse—but expectations of what can be achieved through such an investment must be constrained until there is an infrastructure of clinical expertise within which it could be fully utilised. And local clinical leadership is precisely what is lacking.
  - (b) the NHS does not know, in any regular and reliable way, where its allergy cases are, how many there are and who is managing them. It needs to rely on estimates of the kind provided through the Royal College, and in the annex to this statement, in the absence (until recently<sup>4</sup>) of a recognised way of coding allergy work within the NHS. Even then, because allergy care is suffused across a wide range of NHS and private health care, it will remain difficult to build a true picture of the clinical workload for the foreseeable future. In this situation local commissioners have, and will have, effectively no robust, local clinical information base to work from.
  - (c) the seriousness of the developing workforce situation explained in paragraphs 24–30 below, and local awareness of the national picture, is a case in point. We are aware of no Department of Health instructions, advice or information which has been given to local service commissioners on how to decide or predict local specialist workforce capacity or requirements. And local commissioners seem unaware or at best unclear about the appropriate investment levels for the future clinical workforce. And in the circumstances, when juggling to meet cost pressures from existing services,

they can hardly be expected to take a new situation seriously, and develop new services, unless told to do so or unless local pressures build up in an unavoidable way. It is then, of course, too late for long term investment into having the right workforce in place to manage the new situation.

- (d) not surprisingly, local commissioners are paying little or no attention to the population's allergy need. To give one example: in January 2004 Department of Health Ministers and officials provided the names and contact details of NHS officials in lead PCTs in England responsible for commissioning allergy services. Thirty contact names and addresses were provided. All were immediately contacted to ask what they had done with respect to allergy services and what priority they attached to the area. Five months later seven have replied. One has said they attach importance to allergy. One has refused to answer the questions. The others do not commission allergy services, so do not appear to think allergy is important. The response from the authority saying allergy is important in their area is difficult to interpret as it is in a part of the country which relies on "block contracting". Under this arrangement those who provide a range of services receive a general guarantee and are trusted to determine the mix they provide across clinical services. It is difficult to see any scope for commissioner driven change in this situation. And elsewhere commissioners clearly have other things on their minds.

18. How, then, to start the changes required beginning from this situation? It has been said that if allergy patients were to become more vocal, and to make their voices heard by local health authorities, then the prospects for change would improve. Certainly patient's organisations in allergy are contacted by very large numbers of people seeking help; the Royal College Report documents the contact levels. But it would be perverse if the only way to achieve change in a health service professing to be sensitive to patient need was by turning patient's requests for help into campaigns for service improvement.

19. There must be a better way. The Royal College of Physicians have proposed a way. Other growth strategies, it was thought, would demand substantially larger investment to get them off the ground and, without clinical leadership, the results across the country would be at best uncertain.

20. The College has, therefore, proposed an initial concentration on tertiary allergy care for those in the most need to give the earliest and most direct possible impact on the provision of high quality allergy services across the NHS. It has proposed that

- (a) a core initial infrastructure of regional allergy centres could be created, a minimum of one for each population of five-seven million people and providing for both adult and paediatric allergy;
- (b) the centres might be centrally sited within their local populations, or dispersed across the region—depending on local service configuration;
- (c) they would deal directly with the most complex clinical cases; in doing so they would be addressing the most serious need and would help to reduce service pressures, making more effective the clinical management of the most complex cases;
- (d) they would also be an educational and information resource for their areas—providing training and clinical assistant opportunities, and path finding the clinical management of emerging, complex allergy; and they would network with others contributing to allergy care;
- (e) in these wider roles they would support the development of regional and local expertise among both service commissioners and other providing units;
- (f) and they would become the allergy champions making locally driven service development a reality.

The wider roles would therefore be at least as important as that of direct service provision.

21. The College judgement is that, with this core in place, the essential initial impetus would exist for more local developments to drive change. Implementation of such a way forward requires training to be provided for an additional 32 specialist allergy consultant posts, covering adult and paediatric allergy—four posts, two for adult allergy consultants and two for paediatric allergists in each regional centre (numbers of posts are calculated as whole time equivalents for clinical care). The consultant posts themselves would not need to be resourced until consultant training for them had been completed. But prior commitment to create these would be needed to attract good young doctors into the new core service structure for allergy. The costs would build up to an additional £5.6 million pa when all the trained consultants were in post.

22. Capacity exists to provide this amount of additional training for specialist allergy. But new ways of networking will need to be developed so that the new allergy doctors have access to both specialised supervision and to patients in parts of the country where new specialist services must be located. While other parts of the country have allergy services run by doctors from other specialities, and it is important that these are recognised, there are currently no specialist allergy services in England west of Bournemouth and north of Manchester. The current specialist allergy centres will, therefore, need to find ways of networking with clinics located in the north, west midlands and west of the country.

23. It is perhaps relevant to set the additional costs in context. Academics from three British universities have very recently published estimates of the current cost of allergy to the NHS<sup>5</sup>. They have estimated £1 billion across the UK; and they have concluded that "the more serious systemic disorders . . . are rapidly increasing". This will prove to be an underestimate. It is based on historic NHS data; and, as the authors say, the epidemic is escalating and the rates of serious and complex allergy are growing disproportionately. Reality may well now have outstripped this assessment. It is also relevant that

- (a) expensive medical emergencies for allergy are increasing. There was an eight fold increase in community prescriptions for allergic emergencies in the decade to 2001<sup>6</sup>. Since the 1990s, hospital admissions for anaphylaxis increased seven fold and more than doubled for other systemic allergic conditions (6).
- (b) adverse drug reactions account of 5% of all hospital admissions and 15% of inpatients have a hospital stay prolonged as a result of drug allergy<sup>7</sup>.
- (c) Service pressures resulting from the allergy epidemic which are currently experienced across the NHS would be relieved if a dedicated allergy service were to be developed. See annex—we have assumed a ten year period to clear the current care backlog. In that scenario, and not taking account of new cases, between 10% and 12% of clinic care provided for allergy patients could be delivered by doctors with other specialities providing allergy cover. These valuable services would need to remain in place, working as they are. But pressures on them would be correspondingly less.

### *Workforce Issues*

24. There are currently only 26.5 whole time equivalent specialist allergy consultant posts in the English NHS, with a higher proportion than in other specialities being filled by individuals supported by academic funding (42%) and/or working part time for the NHS.

25. Tertiary services, once established, will be required to provide training and education to undergraduates; primary and secondary care education and support in establishing allergy clinics; and very importantly, research and development to inform clinical practice. Consultants in these centres will have to deliver a mix of academic and service provision. The number of consultants proposed (see 21.) is calculated on the basis of whole time equivalent NHS funded service posts.

26. In total five NHS funded training posts currently exist in allergy. Recently an additional training post became available for 2004, in future making a total of six (five of which are centrally funded) training posts.

27. With the extra post included, the most recent forecast of the expert group set up by the Department to advise on medical workforce planning (the Workforce Review Team<sup>9</sup>) is that by 2012 the NHS specialist allergy consultant workforce will have declined by 3%, taking into account predicted retirements, the academic and service mix of the discipline and all current and planned training. The advice, therefore, is that allergy will soon fail to maintain even its current specialist service contribution to the NHS. It will be one of only two medical disciplines which will decline in size across the medical workforce planning horizon. The allergy services available to patients will deteriorate in consequence, from a mixture of increased need and reduction in the size of the workforce.

28. The situation is considerably more serious in respect of paediatric allergy. There are only six consultants in paediatric allergy, four of whom receive academic funding. Four of the six have been appointed in the last three years; so, the paediatric allergy workforce is likely to decline slightly in size in the next decade; but it is of course totally, inadequately small. None of the six, because they have academic responsibilities or are part-time, spend time equivalent to a full-time NHS consultant on clinical care for children with allergy.

29. The Department's medical workforce advisers are therefore saying that centrally supported training provision in adult allergy should be increased by an additional 10 posts for 2005–06, with a further 10 for 2006–07<sup>10</sup>. If implemented as part of a national plan for allergy, this would both make up the impending shortfall due to retirements and fully implement the proposals of the Royal College as far as services for adults with allergy are concerned. Initial training costs would be met from the medical manpower training programme; and they would be contained overall within the total cost estimates provided in the Royal College Report. A Government decision is awaited on this latest advice.

30. A way forward for paediatrics is different because the training arrangements for doctors who work with children are specific to that discipline. Regional Committees work with training quotas for paediatricians from all the disciplines within their region and may assign training numbers for sub specialities. It is possible therefore to assign to paediatric allergy some proportion of each region's general paediatric training quota. A training programme for paediatric allergy but combined with two other specialisms has just been developed, and one national grid post created. However, a separate sub-speciality training programme for paediatric allergy is needed; and the whole arrangement is exposed to the catch 22 discussed in this paper. Without experts and advocates for allergy within the planning and allocation arrangements, the need for change cannot be registered effectively. As elsewhere, the approach of the Regional Committees would change if the Department of Health were to say that it is important to develop the service.

### *Ends and Means*

31. Allergy commonly affects many organ systems and it is common practice in the UK for such patients to end up attending separate clinics for different problems, which are often not recognised as allergic in origin. The burden of disease in allergy patients is therefore unrecognised as well as unmet, and current management is wasteful of NHS resources. A comprehensive allergy service will not only improve the



holistic care of patients and remove this enormous burden on their quality of life, but also has the potential to reduce costs and relieve the load on other disciplines currently picking up these patients. An improved allergy service would thus be cost efficient.

32. This paper has discussed the rationale, context and options for making a start on the improvement of allergy services in the NHS. Its key recommendation is straightforward and is in line with the recommendations of the Royal College of Physicians. There needs to be an initial, central investment to create a core workforce of allergy specialists. The investment would be through the medical training programme in the first instance. As such, it would not be in open conflict with a general desire to devolve decisions into the NHS wherever possible. It would need to be followed up by commitments to finance subsequent new consultant posts in allergy.

33. By taking this step, and by saying it is important to do so, and why, a way would become open to move forward discussion on other issues—like the training of primary care doctors in allergy, within the structures being created; and like improving the paediatric allergy training curriculum. While these are not direct Government responsibilities, acting on those issues which are its responsibility would help to create an environment where other work can be orchestrated and progressed. Subsequent developments, having created the new core for an allergy service, could be locally and professionally driven.

34. The Department is being asked to bring allergy care into the mainstream of the NHS and to let it be known that this is the intention. To achieve this end a national plan for allergy will ideally be needed, with both central and local aspects.

At the start, a core specialist service is required. For this, commitment by the Department to the following essentials is needed.

- Intervention to provide for 20 additional specialist training posts in adult allergy (CCST Allergy) by 2007; and 18 additional adult and 18 additional paediatric allergy consultant posts for trainees to move into;
- Support for the creation of a separate paediatric allergy sub speciality and allocation of training posts in this by 2007;
- Support for discussion with RCGP on making allergy a more central part of training of tomorrow's GPs;
- Development and distribution of an action plan which would make clear who, within the devolved NHS, is accountable for the allergy service locally and which would provide the information and other means for the accountability to be discharged.

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## ESTIMATES OF SPECIALIST ALLERGY CLINIC CAPACITY AND POPULATION NEED

## SUMMARY

1. The numbers of children with allergy in need of specialist help are estimated to be increasing by over 40,000 each year across the UK. An estimated minimum of 2.7 million people currently need specialist diagnosis and treatment for their allergy. NHS allergy clinics are able to cope with a maximum of 50,000 new cases a year—less than 2% of estimated unmet need, assuming no annual increase in need. All current clinics, working as they are, would take over 50 years to clear the backlog, if there were to be no new cases of severe or complex allergy.

## APPROACH

2. We thought it useful to form estimates of allergy clinic capacity in relation to estimated population need.

3. In the time and with the data available the estimating process is inevitably imprecise. Estimates are provided for the UK taken as whole.

4. In the calculations below an indication is given, at each step, as to whether an aggregate under or over estimate is likely to result.

## CLINIC CAPACITY

5. *Clinics*

The BSACI data base of NHS allergy clinics, published on the BSACI website (bsaci.org) was used for the estimate. Other clinics in the country may offer an allergy service. True capacity may therefore be somewhat higher than these estimates. But we have no reliable data on the additional services on offer. And it was judged that the BSACI members' clinics comprise the core of the current national, evidence based allergy service.

6. *Doctor Sessions*

The numbers of self defined, half day doctor sessions available for each clinic in the data base were used as the measure of clinical capacity. These show:

- (a) Dedicated clinics led by an allergy specialist have 123.5 half day sessions available per week.
- (b) Other clinics offer 184.5 half day allergy sessions (since patients with other illnesses may also be treated in these clinics, this may be an over estimate of true capacity). Most do not offer a comprehensive service. These clinics are run by consultants in other specialties.
- (c) Total tertiary and secondary care for allergy is therefore estimated at 308 half day doctor sessions a week.

7. *New Patients per session*

It was assumed that a doctor might diagnose and treat four new and four repeat cases at each clinic session. This is a broad approximation; the true figure will vary with the case mix being managed in the clinic. Many clinics are trying to see patients only once (increasing throughput); this means that they see patients only once, but for longer.

8. *The working year*

The Royal College of Physicians working year protocol for manpower forecasting was used—a 42 week clinic year. On this basis the existing clinics can diagnose and treat new cases as follows:

- (a) Specialist clinics ( $123.5 \times 4 \times 42$ ) = c 20,748 patients a year
- (b) Other clinics ( $184.5 \times 4 \times 42$ ) = c 30,996 patients a year
- (c) Total capacity ( $308 \times 4 \times 42$ ) = c 51,744 new cases a year.

9. *Numbers already treated*

In order to form an estimate how many people who require specialist help may already have received it, we assumed that all current clinics offering an allergy service have operated for the last five years and have discounted from the equation the number of new cases they might be assumed to have treated. (This could result in either under or over estimates. Clinics have closed over the period; and the number of doctors working in the existing clinics have increased. On balance, given the need to decide a broad estimate based on the most robust available data, we have assumed equivalent capacity exists over the five year period.)

10. The results indicate that, of the need estimate—see paragraphs 11 to 15 below—( $51,744 \times 5$ ) = 260,000 of the people needing specialist help may already have received it.

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## POPULATION NEED

11. The allergy population estimates published in *Allergy : the Unmet Need* were principally used for this.

### 12. *Aggregate need*

30% of the total population (18 million UK; and 15 million in England) have allergy. 40% of children have allergy

### 13. *Specialist care for adults*

One in six people of those who have allergy are estimated to have sufficiently severe symptoms to require tertiary level, specialist help—three million people. It was recognised by the Royal College that a further group of patients required more specialist care than could be provided in primary care; but no estimates could be made of the size of this additional population.

### 14. *Outstanding potential case load*

The total of outstanding allergy cases in need of specialist help is in consequence estimated at a minimum of (3,000,000—260,000) = a minimum of 2,740,000 across the UK.

### 15. *Specialist care for children—new cases each year*

With a UK current birth cohort of 650,000 and using the same assumption as in the paragraphs above for children, an estimated minimum of 43,000 new cases of paediatric allergy requiring specialist advice can be expected to present each year. This discounts all new cases of adult onset allergy.

## NEEDS AND CURRENT CAPACITY

### 16. *Conclusion*

Estimation with the information available can give at best order of magnitude results. As services develop, more robust data must be created to support service planning. Taken as a whole the results show:

#### (a) *Current Need*

- An estimated minimum of 2,740,000 people need specialist help with their allergy. They have not received it.
- The available specialist allergy clinics are able to diagnose and treat 20,748 patients a year—around 0.8% of estimated current need.
- All clinics offering some type of allergy service, with any capacity to diagnose and treat allergy above primary care level, are able to manage 51,744 patients a year—less than 2.0% of estimated current need.
- To put this another way. All current clinics, working as they are, would take more than 50 years to clear the allergy backlog, if nothing changed.
- To put this another way again. Concentrating growth in service capacity into the development of a specialist allergy service within the NHS (as recommended by the Royal College) would still need to be supported by other clinical services. But pressure on these services would be relieved. Assuming a 10 year clear up rate for the estimated needs backlog, and also assuming no new need emerging, the other clinics would be able to contribute 10–12% of clinic care over the period, working as they are.

#### (b) *Developing need*

- An estimated minimum of 43,000 new cases of paediatric allergy in need of specialist help are occurring year on year.
- Therefore, new severe, paediatric allergy need requiring specialist advice, year on year, is estimated to be more than twice the size of the capacity of current specialist allergy clinics (adult and paediatric taken together); and 80% of total clinic capacity.

#### (c) *The total picture*

These estimates take no account of imbalances which exist in primary care. Insufficient data exists to make any such estimates.

## CORRESPONDENCE WITH DEPARTMENT OF HEALTH MINISTERS AND OFFICIALS

## 1. DR STEPHEN LADYMAN

## AN ALLERGY PLAN FOR THE NHS: MAKING A START

*Treat Allergy Seriously*

At the beginning of the year you kindly met with some of our colleagues to discuss how to improve NHS allergy services. You and your fellow Ministers had agreed that there needs to be improvement—that allergy patients are not receiving an adequate standard of care. The meeting discussed how progress might be made.

You agreed at the meeting to consider what might be done to improve the level of investment in training the allergy, clinical workforce and you said you would ask the CMO about drafting a possible “action plan” to support and guide local NHS work on allergy service development. Subsequently Pam Ewan wrote to you, on behalf of all of us, offering our help and saying that we would write to you again.

Since then, as you will be aware, interest has grown within Parliament about the need for something to be done to improve allergy services.

However, in correspondence which we have seen and in answer to questions in Parliament, you have maintained a line that only change driven by the local health service can be contemplated and that a sustained, general increase in health expenditure will be all that is required from the centre to begin to affect the availability and quality of allergy services.

We thought that we should write in a rather different way from that contemplated immediately after the January meeting; and we attach a paper. We have particularly wanted to ensure that the advice in the June 2003 Royal College Report, and an assessment of its merits given the framework of Government health policy, was fully explained.

You may know that academics from three British universities have very recently published estimates of the current cost of allergy to the NHS (*Clinical and Experimental Allergy*, volume 34, number 4, April 2004). They have estimated £1 billion across the UK; and they have concluded that “the more serious systemic disorders . . . are rapidly increasing”. For that reason, and for other reasons outlined in the attached paper, £1 billion will prove to be an underestimate. And the allergy care that is delivered as a result will be neither as effective nor as efficient as it should be because there is currently no proper infrastructure for its delivery (the paper describes the care that is available for allergy patients currently as being “suffused” across a wide range of services and arrangements; what is lacking is a clinical focus).

So, the challenge that the allergy epidemic presents is how to create service arrangements capable of meeting the needs of the  $\frac{1}{3}$  of the population who have allergy, with an increasing proportion having severe and complex allergy, when the NHS currently lacks any national, clinical or commissioning infrastructure for such a service? How is progress to be made from this base?

Following the advice to you of the Royal College of Physicians, our answer is to invest first in the creation of the base.

The allergy epidemic, although it has been developing in scale for over a decade, is presenting the NHS with new challenges (these are ones not foreseen when Government built a consensus around its current 10 year NHS Plan for the NHS; certainly one with dimensions not fully understood until the work of the Royal College Committee; and possibly one requiring some flexibility in the evolution of clinical priorities for the NHS going forward). If the delivery of allergy care through the NHS is to realise its potential in the face of the current epidemic, wide ranging changes will be required. The attached paper explains these.

But our immediate concerns are with making a start; and we strongly urge you to do the following.

First, create an initial, national clinical structure for allergy services based on tertiary regional centres. This is the most cost effective immediate action which can be taken. It involves central commitment to the creation of 32 new specialist consultant posts across the English NHS. It will cost £5.6 million per annum in England, building up over a number of years as adult and paediatric allergy doctors are trained to the appropriate standard. It will deliver both a service for those most in need of help and clinical leadership for other developments which must follow.

Two further points about this first step. Something needs to be done to stop the situation getting worse. Not enough doctors are being trained in allergy to replace those who will soon retire—your own specialist advisers are telling you this—so training levels need to be increased. Also, given both the scale of investment to train doctors, and the timescales, this must be considered a central Government responsibility even in a devolved NHS. Initial central investment in the development of an allergy service through a training route could therefore take place, if you wished it, without major disruption to the general thrust of the policy to rely on the initiative of local health services.

Second, help and support local allergy service planning. Only six of the 30 officials specifically responsible for commissioning allergy services whose names you gave us in January have found the time to reply to our contact with them. Only one has said they attach any importance to allergy; and, for reasons spelt out in the paper, we find this reply incredible. By themselves these figures can easily be dismissed; and we refer to them only because they illustrate the indifference to the needs of people with allergy which exists, comprehensively, across many parts of the NHS. If serious service development is to take place, focused help will need to be provided. We hope that meaningful “action planning” can come about following your discussions with the CMO.

Lastly, if any aspirations for change are to be acted on, Health Ministers need to say that it is important that the NHS responds to the allergy epidemic by building appropriate allergy services, and by indicating how this is to be done. Unless you add your voice and authority, messages to the NHS about allergy care will not be heard or taken seriously.

*17 May 2004*

## 2. DR STEPHEN LADYMAN MP

### DEVELOPING ALLERGY SERVICES

Thank you for agreeing to meet with us on 28 January. It was encouraging for us to be able to put our case on the need for improved allergy services directly to a Health Department Minister.

You explained to us the nature of the relationships, under the NHS Plan, between central government and the devolved health service, and the ways in which these constrain the types of central initiative which can be taken.

Equally, we explained—and you agreed—that the current allergy epidemic faces the service with significant and new challenges and, as matters stand, the service response has not been adequate. Across the country there are serious inequalities in access; for much of the country the services available are vestigial; and in only a few centres are we up to the standards routinely achieved for the treatment of allergy in comparable health care systems.

We discussed the prospects for sustained improvement in allergy services led by PCTs and Strategic Health Authorities. We put it to you that, without informed local leadership in allergy, with no one to make bids for allergy services, without an identifiable information base, with many other pressures on time and resources, the prospects are not good. This applies to the majority of the country.

As so much depends on the local capacity to deliver change—for allergy as for so much else—we shall now do all we can to help local commissioning.

However, we see little prospect for improvement without direction from the centre to take allergy seriously and to plan for services appropriate to need. We hope that you remain open to further discussion of what is being achieved, and what is needed, therefore.

Two points for action from the Department of Health were identified in our discussion. You offered to write to the CMO to ask whether he would be prepared to produce an Action Plan for the development of allergy services which could be used to inform and guide local service change. You also said that you would look yourself at the quotas that operate around the central funding of specialist doctor training posts. (Specifically, more centrally funded SpR posts in allergy are essential for service development; and this has not been addressed despite powerful arguments being put to the Medical Workforce Review Team and the Workforce Numbers Advisory Board over several years.)

We see the two possible areas of work to be linked—as the Royal College Report on allergy spelt out, putting specialist clinical leadership in place is the most cost effective way of getting local change under way.

We should like to offer our help in taking both action points forward. We can contribute knowledge and skill and, if it were needed, some secretarial services to put together a first draft an Action Plan. Would that be helpful?

In the first instance, you might care to see some costed analysis on the specialist training situation in allergy. We shall aim to send you a note on this for the end of February.

Thank you again for your time. We look forward to hearing from you.

*3 February 2004*

## 3. RT HON JOHN HUTTON MP

We are writing to you as chairs respectively of the recent Royal College of Physicians committee on allergy in Britain and of the National Allergy Strategy Group (NASG)—an alliance of health organisations working together to support the development of effective NHS based allergy care. We are writing with the active support of our colleagues on NASG: Professor Andrew Wardlaw, President of the British Society for Allergy and Clinical Immunology, as well as those from Allergy UK and the Anaphylaxis Campaign, the principal patients’ organisations in the allergy field.

The Royal College committee produced a report in June this year entitled *Allergy: the unmet need*. The report documented the significant public health problems being faced from the epidemic in allergy which has arisen; and it provided a blue print for how to respond to the epidemic, one which the committee concluded was the most cost effective approach available.

The information your Department is using to respond to enquiries from Members of Parliament and the public about Government's response to the Royal College report contains factual errors, and gives a misleading impression about what is happening and what is possible for the care of people with allergy. We write to begin to set the record straight.

Your 21 August letter to Michael Ancram (copy attached) contains paragraphs being used in other letters. We shall refer to the Ancram reply below.

A number of facts are wrong. The correct information is detailed below.

(i) ALLERGY AND IMMUNOLOGY ARE DIFFERENT CLINICAL SPECIALTIES

Your letters combine information on these two differing areas of medicine. In fact they are different specialties, with very different training and skill requirements. Immunology is predominantly a laboratory based discipline, whereas allergy is totally bedded into the clinical management of patients.

Some immunologists provide care for people with allergy, and this is to be welcomed as the alternative would be no NHS service for many more people. However, their expertise is in another branch of medicine; specifically they are not specialist allergy doctors. In consequence, the service they provide is limited leaving people with other allergy symptoms, which they are not able to provide for, to find help where they can elsewhere.

Combining data about the numbers of doctors working in the NHS from the two disciplines is therefore misleading and gives people the wrong information about what is happening.

(ii) THE NHS HAS FAR FEWER ALLERGISTS THAN YOU IMPLY, AND MANY AREAS OF THE COUNTRY ARE DEPRIVED OF A SPECIALIST SERVICE

Your letters say there were 80 consultants in "immunology (including allergy)" in 2002.

In fact—using data from the Medical Workforce Review Team Reports, which we take to be your source—there are 26 whole time equivalent NHS allergy posts (and not all of these are NHS funded) across the whole United Kingdom.

There is no specialist service west of Bournemouth or north of Manchester; and no service in the whole of Scotland, or Wales or Northern Ireland.

We believe this exposes people with allergy to the unacceptable consequences of post code lottery in access to care.

(iii) THERE HAS BEEN LITTLE GROWTH IN THE SERVICE FOR ALLERGY SINCE 1999

Your letters say there has been an increase of up to 58 posts or 264% since 1999, taking allergy and immunology together.

Of these only six have been in allergy, two of which were part time posts.

This is offset by the fact that earlier two allergy consultant posts vacated by retirements were not replaced.

(iv) CENTRAL FUNDS FOR FUTURE GROWTH IN SPECIALIST TRAINING CONTINUE TO OMIT ALLERGY

Your allocation of funds for 400 additional specialist doctor training posts from 2003–04 allow for one additional immunology post but none for allergy.

The additional immunology training post will add to the seven training posts in this discipline which are currently unfilled.

There are at least seven allergy centres prepared to take responsibility for a new trainee should funds be made available.

The letter contains misleading information. The correct position is shown below.

(v) GENERAL WAITING TIMES INFORMATION DOES NOT REVEAL WHAT IS HAPPENING FOR ALLERGY

Your general statements about success in reducing waiting times, implying a specific benefit for allergy from the general improvement, do not take account of the following.

- For very large areas of the country there is no specialist allergy service at all—for anybody to be referred to. A survey of GPs carried out by the Royal College committee revealed that 80% of GPs thought that NHS services were poor in respect both in access and in quality. The situation is especially serious in paediatric allergy, where there are only three specialist centres and a total of five clinicians for the whole country.
- Where there are specialist clinics, the gap between potential use and available capacity, given the imperative to meet waiting time targets, faces clinicians with choices which we believe patients should know more about.

- Some clinics have so far remained open to all allergy referrals. The result has meant “efficiency improvement” of the kind intended by the waiting times initiative. But our colleagues are increasingly concerned at the risks to patient safety as we see patients less often and for shorter periods in order to keep up with an increased throughput. It should be emphasised that the allergies being managed in these clinics are not trivial; some patients have serious or life threatening conditions.
- Other clinics are restricting access by narrowing the range of allergic symptoms they will admit. A clinic might only accept referrals from local PCTs—increasing the disparity between those fortunate enough to live near an appropriate quality service and those who do not. Alternatively, a clinic might only admit certain cases of confirmed allergy. GPs might be informed about the restricted criteria being used. A patient referred with allergy outside the restricted list will not be contacted.
- Requiring confirmation of allergy in primary care before accepting a referral, of course, presumes competence in primary care to make the diagnosis. Our committee found that the overwhelming majority of GPs have no training whatsoever in the management of allergy; less than one in four have any knowledge of a clinical guideline for the management of allergy; and you will find there is a general reluctance among untrained GPs to test for allergy and make a clinical diagnosis in the first place.

We believe these observations begin to expose further dimensions to the pressures building up over access to allergy care. The situation is sufficiently serious to warrant more investigation.

(vi) THE NHS IS UNPREPARED TO BENEFIT FROM CURRENT RESEARCH AND DEVELOPMENT

Your letters point to the contribution being made by British research towards the international R&D effort in allergy.

The problem this exposes is that the state of clinical services in this country is so far behind what is considered acceptable standards elsewhere that we are unprepared to benefit from new allergy treatments which will become service opportunities over the next decade.

New treatments are going to be effective and expensive. They will rely on an accurate diagnosis and good clinical management. People with allergy receive this only exceptionally from the NHS now. We see no sign of a commitment to improve matters.

(vii) LEAVING ALLERGY SERVICES TO “FIND THEIR LEVEL” WITHIN A PATTERN OF GENERAL IMPROVEMENT ACROSS THE NHS IS NOT, BY ITSELF, AN APPROPRIATE RESPONSE TO THE ALLERGY EPIDEMIC

Your letters say that there are “a wide range of services to which people with allergies have access”, that allergy patients can be seen “within a wide range of hospital specialities”, and that it is for Strategic Health Authorities (SHAs) and Primary Care Trusts (PCTs) to decide what services are appropriate for “people in their care”.

We are unsure of the status of the statement in your letter that this duty of care “would also include any increase in the number of speciality clinics”.

Given the known distribution across the country of these clinics, and the inequality in access to care which results, are you saying “it’s totally up to them”, the SHAs and PCTs?

Or does your statement that they are close to the people they serve and best placed to respond “sensitively” to need, imply any judgement about consequences of failures in duty of care? Is there to be no other body for patients to resort to if no specialist service is available locally?

We should perhaps point out that in a visit to your officials in March 2003 we said there was uncertainty about precisely who was responsible for specialist commissioning and for leading PCT work in this area. An action point was recorded to find out and let us know who was accountable. We still do not know.

Melanie Johnson said in the House of Commons on 14 October that NHS allergy services are starting from a low base, that the Government takes the need for improvement “very seriously indeed” and that the need to improve the numbers of consultant allergists in the NHS was a specific issue. While falling far short of recognising the need for any kind of national priority for allergy, this statement leaves open the possibility for dialogue. The standard letter currently in use offers no such prospect.

We look forward to your response, especially to learning how you intend to inform the public of the true situation about allergy services in the UK.

## 4. DR JOHN REID MP

## THE STATE OF ALLERGY SERVICES IN THE NHS

I am writing to you as chairman respectively of the recent Royal College of Physicians committee on allergy in Britain and of the National Allergy Strategy Group (NASG)—an alliance of health organisations working together to support the development of effective NHS based allergy care. I am writing with the active support of my colleagues on NASG: Dr Pamela Ewan, its co-chair, and Professor Andrew Wardlaw, President of the British Society for Allergy and Clinical Immunology, as well as of Allergy UK and the Anaphylaxis Campaign, the principal patients' organisations in the allergy field.

The Royal College committee produced a report in June this year entitled *Allergy: the unmet need*. I attach with this letter a copy of the Executive summary of the report.

Following publication, there has been correspondence between people with allergy, and their representatives, and your Ministers and officials. And there has been a debate in Westminster. Our purpose in writing is to let you know what we have done to help to ensure a correct public understanding of the facts on allergy and to ask you to look personally at the central issues to be faced.

First what is being said. The Department is answering enquiries about allergy services in the NHS through the use of a general letter which contains factual errors, and which we believe gives a misleading impression about what is happening. We have written to John Hutton about this. We attach correspondence.

In the debate on paediatric allergy in Westminster Hall on 14 October Melanie Johnson outlined the Government's policy on allergy services. She accepted that current levels of NHS provision are not adequate and are working from a low base. She emphasised that the Government was taking this "very seriously indeed". She referred to the Royal College of Physicians' report, *Allergy: the unmet need*. And she said that general improvements in funding levels and in the delivery of patient sensitive services across the NHS would raise general levels, bringing benefits to allergy services.

She nevertheless recognised a "specific issue" in respect of the need to improve the numbers of allergy consultants at work within the service—currently 26 whole time equivalents across the whole UK, and none west of Bournemouth or north of Manchester; and none at all in Scotland, Wales or Northern Ireland.

Government's recognition of the problems being faced by people who experience allergy is an important step forward. And Melanie Johnson's offer in the Westminster debate of a meeting with Stephen Ladyman is welcomed. But it is quite unclear to us how general health improvements by themselves will benefit allergy; and we shall need to be convinced.

We believe there is a central issue which Ministers as a whole must take into account. Might we ask that, as Secretary of State, you consider this. If we can be of any help, we are at your service.

The issue is that the current devolved approach to service improvement, outside the overriding national clinical priorities, cannot succeed in an area like allergy. For most parts of the country there are insufficient people with adequate knowledge about what is required to commission or provide effective services, and no local champions. Without central help, allergy simply has an inadequate service infrastructure to build on. Something therefore needs to be done to put in place enough grass roots leadership to allow local service planning and priority setting to work.

The recommendations of our Royal College working party were designed to achieve precisely that—at a full eventual cost in England, covering adult and paediatric services, of £5.8 million, building up over a number of years. Service improvements will offset some of these costs. For example, 5% of hospital admissions result from adverse drug reactions; avoiding drug-induced allergy would make a big dent in these largely avoidable consequences of inappropriate care. Multiple referrals of an allergy patient to non-experts and continued use of NHS resources because illness has not been prevented would be reduced.

Some details follow:

*In primary care*

With one in three of the population suffering from allergy; and one in five receiving treatment in any year, primary care ought to be in the front line of an allergy service. Yet the overwhelming majority of GPs have received no training in allergy; and we found less than one in four have any knowledge of a clinical guideline for the treatment of allergy. With less than eight in 100 of the GPs surveyed for our committee believing they had access to a fully comprehensive allergy service, we might expect service improvements currently in place to be addressing the need for change. Yet there is no reference to allergy in the new GP contract. And we are not aware of any plans coming forward from within primary care for the introduction of GPs with a special interest in allergy into the service.



*Specialist care*

A central finding from the Royal College work was that allergy has become more challenging clinically over recent decades. It is now more often severe, expresses itself in complex ways and involves multiple organ systems. Specialist allergy care is needed for these cases. Particularly if we want to help people to manage their allergy as well as possible, we need to help them to identify and isolate the causes of any allergic response and not just respond to presenting symptoms.

Yet the specialist services are, if anything, in a worse state than primary care. There are serious and dramatic variations in access to appropriate services. Large parts of the country have no specialist allergy service. People have to travel long distances to find a specialist allergist able to treat their, or their child's, illness. Often the nearest allergy service is provided, because no alternative is available, in a chest or eczema clinic or because an immunologist has developed an interest in allergy. But these are not specialist and clinically comprehensive services. While welcome because the alternative is no service at all, limited care provided by experts in other clinical disciplines cannot be the right basis for a modern and reliable health service.

*Starting change*

Our proposed solution is to commit to fund 32 consultant posts across the country, covering paediatric and adult allergy, and to gear training to secure the eventual supply of sufficient specialist allergy doctors to do this. The dual commitment to training now and to an adequate number of posts over time, as qualified allergists become available, is necessary to attract good quality young doctors into the discipline. While they are training the young doctors will begin to enhance the service. The new posts, when added to what already exists, will give an infrastructure for devolved leadership, allowing the service then to grow through its own momentum.

Yet recently, when your Department funded 400 extra training posts, none were made available for allergy. And when we raised this with CMO, Sir Liam thought that “we may not be able to do anything directly at the moment given the majority of the NHS funds are allocated for the next five years”. If we may say so, five years seems a long time for one third of the population to have to wait for service improvement to even begin to get underway.

We put it to you Secretary of State, and ask for your help. Ministers have accepted a need for something to be done. But relying on local priority setting will not be an adequate response to the challenge posed by the current allergy epidemic. And waiting until well into the next Parliament before any new approach can be considered is indefensible.

*What's needed and what could be done*

The country is facing a significant public health problem from the epidemic in allergy. The evidence for this is in the Royal College report and international medical literature. Distinctively in the UK, our service response has been delayed.

We believe that what is ideally needed is to make allergy a national priority for the NHS and to direct resources to build an appropriate service infrastructure to tackle it. We think that we must continue to call for this, and we shall do so.

However, there are some pragmatic steps which could be taken, with your help and support, which would not challenge the whole thrust of your policies and priorities for the NHS—but which would help to get important work on allergy underway.

*First: primary care*

We need to introduce primary care to allergy in a meaningful way. We are planning through the NASG to mount a series of “road shows” aimed both at executive and management and clinical staff—to show what is involved in delivering a good quality allergy service in primary care. These will provide material for publication and discussion with the other Royal Colleges whose help will be needed to change overall responses to the epidemic—general practice, paediatrics, pathology and so on.

Viability depends on money and on attracting the attention of primary care leaders to the initiative; we have the expertise. Would you consider helping us to get “on the road”? Would you consider a Ministerial involvement in the road shows, to give them authority and a sign that the Government is seriously interested in a build up of capacity to manage allergy within primary care?

*Second: commissioning*

Government has already agreed and published a protocol for specialist commissioning of allergy. There are two problems we face:

- (a) we simply do not know who the specialist commissioners or lead PCTs on allergy actually are. We do not know, across the whole country, who is specifically responsible.
- (b) PCTs do not understand the need to commission allergy services. It is likely that in the large parts of the country where there is no allergist, PCTs have ignored this speciality. This would be helped by government support for the road shows (above).

*Third: funded training and consultant posts in allergy*

No progress can be made without an increase in funded SpR posts for allergy training. Current funding arrangements contain “slack”. A central commitment of funds for a training post may take several years before the finance is actually used, as no doctor or training location may be forthcoming. Across all disciplines there are currently workforce resources not actively deployed for their intended purpose—so called unfilled posts. Within such a system it must be possible to find funds centrally for a handful of allergy training posts. Allergy is able to provide training locations if the finance were to be released.

More consultant posts in Allergy are also needed.

The Royal College committee has identified a moderate and pragmatic way forward. This letter sketches out some moderate steps which could begin to move along that path. We hope and trust you and your Ministerial team are able to respond to the challenge in like terms.

6 November 2003

5. SIR LIAM DONALDSON, CHIEF MEDICAL ADVISER DEPARTMENT OF HEALTH

## ALLERGY SERVICES

Thank you for finding time to meet me and Andy Wardlaw to take forward the Royal College Report on allergy.

It was encouraging to know that you support the analysis in the report. Growth in the incidence, complexity and severity of allergy over the past two decades, together with the emergence of new disorders, have caused a significant public health problem—made all the more serious by a general failure to recognise what has been happening. Within the NHS, poor management of allergy is leading to unnecessary suffering and health service costs and to many patients seeking help outside the service, often through resort to unproven therapies. And we have an inappropriate service base from which to exploit the allergy therapies which are in development.

The situation is unsatisfactory; and a key step towards turning it round—as the Royal College report says in its primary recommendation—is to set in place a core group of allergists who could themselves take the more complex cases and who would orchestrate the work of others who are prepared to help. This requires the development of at least one specialist centre, allergist-led, for each region. We shall need to encompass the work of immunology and other organ specialist colleagues who are prepared to use their clinics to support the management of allergy cases and to provide local clinical leadership to growing a capacity within primary care. We need to cover both paediatric and adult allergy.

The Royal College committee was unanimous that this is the most appropriate and least costly way forward (the committee costed its proposal for the establishment of regional centres with paediatric and adult allergy consultants at £350,000 per annum per centre for an adult allergy service (£2.8 million for England) and less than double this to include paediatric allergy. The cost is low for a valuable service to five million population served per centre; costs would be phased in; and would be off set by cost savings in other parts of the NHS, now dealing inadequately with the problem. The challenge before us is to turn these sound principles into a practical programme of service development.

*Specialist Commissioning*

We need to set up capacity for specialist allergy leadership in those parts of the country where none exists currently and sustain it in those areas where NHS support is fragile. Encouragement to implement the agreed plans for specialist commissioning (produced by the Department of Health in 2001) would support this and we discussed whether you could highlight this to Strategic Health Authorities and lead PCTs, or in other ways. Allergy is simply not on the agenda of commissioners in large areas of England. It needs to be.

*Allergy doctors*

In parallel we need to offer good young doctors a secure career pathway if they embark on a career in allergy as an NHS speciality. Their leadership can then become the driver for local service development and the dynamic they set in train can become self sustaining. To do this we need to establish a small number of NHS funded consultant posts, in paediatric and adult allergy. Additional funded SpR training posts are also essential to support the programme.

As we discussed, however, it is exceptionally difficult to see how any of this can be achieved in the current, devolved NHS, and it may be impossible to do so, without central leadership of some kind. The problem is simply that devolved developments require the pre-existence of local capacity with the knowledge base and authority to be the local champion. In large parts of the country that precondition is not met for allergy. We nevertheless plan among other things to spend the remainder of the year trying to stimulate local activity in selected areas and to encourage local commissioners to resource new consultant posts for allergy if we may, we shall let you know how we get on.

Patient's organisations active in allergy are working closely with us to establish a case for action behind the Royal College recommendations. But central and local pressure of the kind which patient's organisations can put on the service merely add to the pressures which colleagues are anyway under—unless a practical way forward can be found.

You kindly suggested some things which you might do to help. You said that you would talk with your colleagues to see whether there is anything which can be done from the Department at this stage about the provision of central funds for consultant posts. Central funding of consultant posts would of course be the most straightforward way of resolving the dilemmas faced by the allergy services.

You said you will see whether some funded SpR allergy posts could be obtained to increase our allocation in the current round from zero towards the needed figure of an additional seven (by creating additional posts or by re-badging those not used). I append the relevant contact details of those I deal with for Allergy on the Workforce Review Team and WNAB.

You suggested that it might be possible to add allergy into SHO training schemes, which could be used to provide primary care doctors with exposure to allergy. This would be a helpful supplementary development; but it needs proper infrastructure to relate it to and it could only happen in the few major centres that can provide training.

You said that you would be very happy to see a chapter on allergy in CMO's Annual Report. We welcome this and—both as individuals and as from the BSACI—will give any help needed in writing the chapter.

The main need, however, is to recognise the importance which allergy now has to the health of the society and to give it the appropriate priority in NHS ratings, both locally and centrally.

If you are able to identify any help that can be given centrally we would be delighted to hear from you. We are proposing to write to the Secretary of State later in the year; perhaps we might copy you into that correspondence.

Before then it would be most helpful if we could talk to you again to review developments.

21 July 2003

### **Memorandum by British Society of Allergy and Clinical Immunology (AL 24)**

#### **BACKGROUND TO THE BSACI'S EVIDENCE**

The BSACI was established in 1947 as a professional society to represent NHS based practitioners with an interest in diseases of the immune system and in particular those multi-system diseases seen by allergists and specialists in related disciplines.

The society currently has about 500 members. These include:

- Consultant allergists (treating both adults and children).
- Consultants in other specialities with an interest in allergic disease (these include clinical immunologists, respiratory physicians, dermatologists and ENT surgeons).
- Specialist registrars training in allergy and allergy related disciplines.
- Scientists working on mechanisms of allergic disease.
- Specialist nurses with an interest in allergic disease.

The central aim of the BSACI is to enhance the care of patients with allergic disease by improving NHS allergy services. It seeks to do this by:

- Providing general support for the membership.
- Lobbying for more capacity for the NHS to diagnose and treat patients with allergic disease in the UK.

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- Setting standards of care for people with allergic disease by establishing and disseminating guidelines for management of common allergic conditions.
  - Providing education in the form of an annual scientific meeting and support for regional and local educational meetings aimed at continuing professional development.
  - Having editorial responsibility for the leading allergy journal Clinical Experimental Allergy.
  - Managing a database of allergy clinics in the UK which is published on its website. This is the only source of detailed and accurate information of which we are aware that gives information on the capacity of the NHS for seeing patients with allergic disease. This provides the BSACI with an accurate picture of the current state of NHS based allergy services in England.

For the purposes of this evidence the BSACI regards allergy as covering the following conditions:

- Asthma.
- Rhinitis.
- Food allergy and intolerance, (including nut allergies).
- Anaphylaxis (including reactions to insect stings).
- Urticaria and angioedema.
- Atopic eczema.
- Drug allergy.
- Latex allergy.
- The allergist may also be involved in the management of patients with migraine and irritable bowel syndrome as well as patients with diseases such as chronic fatigue syndrome where it is necessary to exclude allergy as a cause.

#### BSACI's EVIDENCE

Unless stated this evidence applies to both adult and paediatric allergy services.

#### SECTION 1: AVAILABILITY OF ALLERGY SERVICES (INCLUDING ISSUES SUCH AS GEOGRAPHICAL DISTRIBUTION, ACCESS TIMES AND PATIENT CHOICE) AND SPECIALIST SERVICES FOR SEVERE ALLERGIES

##### *Allergic diseases are very common. (The allergy epidemic)*

It has been estimated that up to 15 million adults and children in England will suffer from allergic disease at some time in their lives with 10 million being symptomatic at any one time<sup>1</sup>. Many of these people will have mild disease that they will either self-manage or can be satisfactorily managed at a primary care level. However, a major problem with management in primary care is that because of the low profile of allergic disease in secondary care GPs have virtually no exposure to the diagnosis or management of allergic disease in either their undergraduate or postgraduate training. This problem begins in medical school as the lack of allergy consultants means most students get no exposure to allergy clinical practice. The overall skill level in primary care is therefore low resulting in at best a patchy quality of care for patients with allergic disease<sup>2</sup>. An urgent priority is to develop undergraduate and postgraduate training programmes with a co-ordinated approach to continuing professional development in allergy aimed at primary care. However, this can be only be undertaken if specialist allergy services are expanded to provide the leadership, capacity and organisation for such a training initiative.

##### *Referral Rates to Secondary Care are not a good measure of demand for allergy services*

It is sometimes suggested that if there were a great demand for allergy services in secondary care, this would be reflected in high rates of hospital referral and lobbying by GPs through their PCTs for better services. However, rates of referral in areas where there is an inadequate service (which is virtually everywhere) are not a good guide to patient demand for the following reasons:

- The skill level in primary care will be lowest in areas where there is a paucity of secondary care services. This means that the GP may not be aware that a specialist opinion could benefit their patient and, even if they did recognise this, there would be no one to refer them to.
- The capacity for seeing new patients is so low that allergy practitioners limit their practice by not advertising the service or by limiting the types of patients seen to the specialist area in which they practise so that a comprehensive service is not provided even though an allergy clinic is stated as being present.
- Hospital managers under pressure from waiting list targets discourage practitioners from taking on more new referrals than they can see in the time available. In extreme situations this approach can involve closure of the service. Several clinics have closed in recent years including those in Reading, the Isle of Wight and Liverpool where full time allergists who retired were not replaced.

Where a comprehensive service with the necessary capacity is available the new patient referrals approximate to what would be expected from the estimated number of patients with severe allergy. For example, in Leicestershire (population one million) 2,000 new patient referrals a year with a current waiting time of 13 weeks. In contrast a single part-time allergy clinic such as the one that serves the South West (population five million) would have a capacity of approximately 250 new patients a year and yet have a similar waiting time. Referral rates and waiting times for new patient appointment do not therefore relate to need but to the level of service provided. A clear example of this is the allergy service in Cambridge which had approximately 500 referrals in 1993 and 5,000 in 2003. This 10-fold increase was due almost entirely to increased awareness of the service by local GPs.

*There is a large unmet demand for specialist allergy services*

It has been estimated that up to 2.5 million people (5% of the population) suffer from allergic disease of sufficient severity to justify referral to secondary care for a specialist opinion.<sup>1,3</sup> Reasons for referral will include:

- Confirmation of the diagnosis, (including exclusion of allergy as a cause of symptoms).
- Definition of the allergic triggers of the disease, including situations where there is an occupational element where identification and avoidance of the trigger is an essential part of management.
- Patients requiring special investigations such as challenge testing.
- Patients with unusual allergies.
- Patients whose disease is not controlled on standard medication.
- Patients who require hospital based treatments such as immunotherapy.

*The current provision of NHS allergy services in England is very poor<sup>1</sup>*

The Royal College of Physicians have estimated in their review of NHS specialist requirements across all disciplines that 520 consultant allergy posts are required to provide a high quality service. There are currently 26.5 whole time equivalent (wte) posts in the UK (compared to approximately 500 for example in respiratory medicine). The NHS allergy service in the UK (figures are not separately available for England) consists of just 15 clinics run by specialists whose main interest is allergy and 86 clinics run by specialists from other disciplines who see patients with allergic disease alongside patients with other diseases in their speciality. Of the 15 clinics with a consultant allergist only six approach an optimal level of service as defined by the Royal College of Physicians<sup>4</sup>, five of which are in the South East of England. Four of these clinics are staffed predominantly by academic physicians employed by the university with a limited clinical commitment. In the non-specialist clinics a comprehensive service is often not provided with consultants only seeing patients with disease relevant to their main discipline (eg ENT surgeons seeing patients with allergic rhinitis), sometimes as part of their general clinics. Such clinics, which comprise the majority of UK allergy clinics, also have limited capacity running perhaps one out patient session a week, (approximately four new patients whereas a comprehensive service would expect to see at least 30 new patients a week). We have estimated that, at best the current capacity is 50,000 new patients a year which would mean it would take 50 years to see all the patients who currently should be seen by a specialist.

*What is happening to those people?*

What is happening to those adults and children with allergic disease who are denied the opportunity of consulting an allergy specialist? There is no firm data on this, however from the patient support groups it is clear that many are simply not receiving any adequate NHS based medical intervention. A patient with allergic disease will be faced with a number of unsatisfactory health care options:

- *Self-management*: This is obviously unsatisfactory where a diagnosis has not been made. Even when the diagnosis is secure it is only appropriate for patients with mild self-limiting disease such as mild seasonal rhinitis. The person may rely on advice from a pharmacist who is unlikely to have had any training in allergy. The allergy sufferer is also vulnerable to the largely unregulated and ineffective products advertised in the non-pharmacy retail sector.
- *Private practice with an orthodox practitioner*: This can offer high quality but expensive care which in any case is severely limited in capacity.
- *Private practice with an alternative practitioner*: This is unsatisfactory for the reasons set out below, (section three).
- *Under NHS secondary care but allergy not diagnosed as causing the problem*: This occurs in cases of anaphylaxis, drug allergy and severe asthma.

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- *Referral to an organ based specialist without an interest in allergy (eg dermatologist, respiratory physician, ENT surgeon, gastroenterologist):* The allergic basis of the disease will not be addressed leading to sub-optimal management. Just as importantly the organ-based specialist rarely addresses the other conditions that the patient often suffers from allergy being a multi-system disease.

Indeed the BSACI would like to stress that one of the great strengths of a comprehensive, dedicated allergy service is that the consultants are trained and equipped to deal with all the organ specific conditions associated with allergy in a holistic manner. This is both more cost effective than visits to multiple organ based practitioners and improves patient management.

Apart from consultant allergists the two main specialities seeing patients with allergic disease in about equal numbers are clinical immunologists and respiratory physicians. The BSACI recognises the important contribution that these specialities make to the provision of allergy services. Both specialities include the management of allergic disease as part of their training (to a greater extent with clinical immunology than respiratory medicine). Indeed, several clinical immunologists regard patients with allergic disease as their main interest. However, the majority of clinical immunologists and respiratory physicians have a considerable workload caring for patients with diseases relevant to their main interest (managing the immunology laboratory and immunodeficiency in the case of clinical immunologists and chest disease for respiratory physicians) and do not have the time or often the inclination to develop allergy services. The BSACI believes that allergy services should be provided by a cadre of consultant allergists fully trained in that speciality who can lead the service in their area working in concert with other relevant specialities in a multi-disciplinary manner.

In summary therefore, despite allergy being one of the commonest causes of ill health in England, the current NHS allergy service is vestigial with a very poor level of knowledge in primary care and derisory capacity in secondary care, which in any case is being provided in large part by specialists in other disciplines.

## SECTION 2: PRIORITIES FOR IMPROVING SERVICES

The major priority is to create a high quality, comprehensive specialist allergy service in the secondary care sector across the whole of England. The BSACI therefore fully supports the strategy outlined in Allergy the Unmet Need<sup>1</sup> and further elaborated in the NASG document Making a Start<sup>3</sup> for the establishment of a core of regionally based allergy centres that will lead the service in each area.

As a minimum this requires the creation of 32 specialist wte allergy consultant posts covering adult and paediatric allergy (two FTE of each for each centre). This in turn requires the establishment of sufficient specialist registrar training posts. There are currently five allergy trainees, all in the southeast. A new centrally funded post has just been awarded to Leicester in 2004. The Department of Health's medical workforce advisors have recommended that 10 centrally funded posts are required for 2005–06 and a further 10 for 2006–07 to provide trainees for expansion and replacement posts. Although not all the consultant posts are required immediately, they need to be guaranteed so that the trainees can plan for their future.

Obtaining centrally funded training posts is essential. One frustration for the BSACI has been that over the last few years the workforce planning process has recommended that allergy be awarded several centrally funded training numbers each year only for the Department of Health not to award any. For example in 2003 it was recommended that allergy be given seven centrally funded posts and yet none were awarded. No reasons for this lack of support were given. The post awarded in 2004 was the first that was centrally funded in the last three years and only the second in recent years. None of the five unfunded numbers that are currently available have been taken up, once again emphasising the difficulty in persuading local providers to make allergy a priority.

Implementation of this plan requires central support from the Department of Health. If it is left up to local commissioning there will be no expansion. Indeed a further contraction of the service is predicted with retirements and may be further reduced because of pressure on academics to do less clinical work. Local commissioning will not suffice because allergy is currently a low priority for PCTs. The evidence for this is as follows:

- The Department of Health provided a list of 30 PCT leads who were responsible for allergy services in their strategic health authority. We contacted the named individuals in January. At the time of writing only seven have responded. Of these only one said that allergy was a priority and in this case commissioning was based on a block contract so that the PCT had no influence.
- Of 29 MPs who contacted their PCT's to enquire about allergy services 17 have had no reply. The 12 PCTs that did reply were complacent about their service. One, astonishingly, considered allergy to be rare and another was satisfied with an adult service run by a GP with a special interest (there is no training programme for GPwSI in allergy). Other PCTs regarded allergy as the responsibility of organ based specialities such as dermatology and ENT and others expressed satisfaction with the service based on the fact that waiting time targets were being met.

- Without local champions services are not developed. The competition for resources for the development of new services at a local level is intense especially where there is no national framework for development. In this climate a speciality such as allergy which lacks lead clinicians in secondary care to lobby for enhancement of the service will never become a priority. This is a major factor behind the present underdeveloped status of the NHS allergy service.
- Even with local champions it has been difficult to persuade local commissioners to provide resources to support allergy services. Members of the BSACI in the North West invested a considerable amount of effort in developing a strategy for the development of allergy services in their region and produced a document (NICWAS) which has been submitted as evidence to the committee, which was agreed by all parties including the North West Specialised Commissioning Group. However 15 months later there have been no resources set aside by local commissioners to implement it with no prospect of them doing so.

In summary the key priority is to develop NHS secondary care based services for allergy by central support to create new consultant and training posts. This will allow the establishment of regional centres to provide a core service which can provide a high quality level of care for patients with more severe and complex disease and lead further development of the service in primary care and other secondary care centres.

#### *Governance and regulation of independent sector providers and links between the NHS and independent sector*

The independent sector consists of orthodox and unorthodox approaches to the practice of allergy. By orthodox we mean practitioners whose practice is based on scientific evidence and by unorthodox (alternative or complementary) we mean practitioners whose approach is not limited by adherence to such precepts.

#### Orthodox

- *Medically qualified private practitioners practising orthodox medicine:* This sector is small not least because there are so few consultant allergists. The BSACI supports NHS based practitioners undertaking private practice as long as it is within the terms of their contract and appropriate measures are in place to ensure good clinical governance.

#### Unorthodox

- *The retail sector:* This includes pharmacies (not including regulated medicines), health food shops and life style magazines. The sector is almost wholly unregulated offering treatments and tests which for the most part are ineffective. The BSACI has no data on the size of this sector but would imagine in financial terms it is considerable. We also have no hard information on the range of products available or their potential for doing harm. We would welcome an enquiry into this sector to determine if it requires better regulation.
- *Medically qualified private practitioners following alternative practices:* Doctors in this sector almost invariably do not have any formal training in allergy or related disciplines.
- *Non-medically qualified private practitioners following alternative practices.*

The BSACI fully subscribes to the concept that the practice of medicine including the management of allergic disease, should be based on scientific evidence with diagnostic tests and treatment subjected to rigorous evaluation in well conducted studies preferably using randomized double-blind placebo-controlled study designs. Where such evidence is not available research should be encouraged and in the meantime practice should be based on consensus opinion. The BSACI's main concern regarding the independent sector is with practitioners of alternative approaches to management of allergic disease and the remainder of the BSACI's submission refers to this type of provision.

Alternative allergy is a multi-million pound industry that includes a wide range of practices. These include retailers selling herbal and other remedies to tests undertaken by mail order to clinics in which a variety of investigative and management approaches are undertaken. Some alternative allergy practitioners also make new diagnoses. This includes "multiple chemical sensitivity" which the great majority of doctors do not believe exists. These approaches were described in a detailed report by the Royal College of Physicians in 1992<sup>5</sup>, and a review article in the leading international allergy journal<sup>6</sup>. It is outside the scope of this evidence to describe each alternative approach in detail and only passing reference will be made.

A major reason why alternative approaches to the treatment of allergy are so popular with patients is that for the reasons described above, they receive such a poor quality of care from the NHS. The negative effects of seeking advice and treatment from the alternative sector are both financial in that consultations and remedies are often expensive, especially when ineffective, and medical in that wrong diagnoses can cause unnecessary concern and lead to inappropriate treatments including potentially injurious diets.

There are a large variety of alternative approaches to the management of allergic disease. Many of these, for example iridology and VEGA testing, have no basis in any accepted view of science or medical practice. Others such as the leucocytotoxic test have a pseudoscientific veneer that implies a rational basis which is in reality non-existent: others eg acupuncture, are based on eastern medical practice and are more widely accepted while yet others such as testing for specific IgG to food allergens have a potentially rational scientific basis but are of unproven benefit. Unorthodox practices include:

#### *Alternative Diagnoses*

- Multiple chemical sensitivity.
- Allergy to *Candida albicans*.

#### *Investigations*

- VEGA testing.
- Iridology.
- Applied kinesiology.
- Catatonic food testing.
- Hair analysis.
- Pulse test.
- Measurement of food specific IgG.

#### *Treatments*

- Reflexology.
- Provocation-neutralisation.
- Homoeopathy.
- Herbalism.
- Acupuncture.
- Osteopathy and Chiropractice.

The view of the BSACI, after studying the available literature, is that the great majority of alternative approaches to the management of allergic disease have little if anything to add over and above orthodox approaches. At best they are harmless, except for the financial cost, but ineffective, and at worst they can cause harm. We do not believe the NHS should be paying for services from the alternative sector unless the practise is supported by good evidence that it is effective and safe. The BSACI recognises that patients will often gain some clinical benefit from seeing an alternative practitioner as a result of a placebo effect. We also recognise that views of what is the “correct and orthodox way” to manage a condition can change, often radically, in the light of new evidence. We therefore fully support further research into alternative practices as long as there is some rational basis for believing that the approach may bring benefit. Where new evidence comes to light the BSACI is absolutely willing to change its views. We also recognise the patient’s right to seek alternative approaches to management of their disease especially where orthodox medicine has let them down either because of sub-optimal management or the lack of understanding of a disease. We would contend that patients with allergic disease are constantly being let down by the NHS because of the paucity of NHS allergy services. We believe the best way to protect patients from unscrupulous or misguided practitioners of unorthodox allergy services is to improve NHS based services.

May 2004

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### Memorandum by Professor John Warner (AL 3)

#### 1. INTRODUCTION

I am most grateful for the opportunity to make a submission to the Inquiry. I am the Professor of Child Health in the University of Southampton based at Southampton General Hospital. My principal clinical and academic interest is in allergic diseases of childhood. As such, I have been involved with allergy research for the last 30 years. I am currently Editor-in-Chief of an international medical journal, *Paediatric Allergy & Immunology*. I am a Trustee of the Anaphylaxis Campaign and a member of a number of national and international allergy societies. My current research programme focuses on the early life origins of allergic disease in order to identify targets for future prevention strategies.

#### 2. ALLERGY SERVICES

Southampton General Hospital is one of the few Hospital Trusts in the country which is able to boast a fully comprehensive allergy service for both adults and children. However, it is entirely staffed by University employees. As such, there is no guarantee of continuity in event of any one academic leaving. Furthermore, the service has evolved without a proper business case and is, therefore, not adequately funded. There is no dietetic or specialist nurse input. This is also provided entirely from soft money acquired by individual University clinical academics. Thus the paediatric allergy clinic is supported by a research dietitian and research nurses, myself as Professor of Child Health and a senior lecturer, Dr Jonathan Hourihane. The adult allergy service is provided by Professor Tony Frew and a reader in medicine, Dr Peter Howarth, together with their research teams. If the University's research agenda changes, this whole service would disappear overnight. Furthermore, enormous waiting lists have developed over the years because of the paucity of services. The only way this has been controlled is by either the academics doing additional clinics or the employment of past clinical allergy fellows to return for limited periods. This is a wholly unsatisfactory way to run a clinical service.

#### 3. PRIORITIES FOR IMPROVING SERVICES

Notwithstanding the problems itemised above in running a clinical allergy service exclusively with University appointed academic clinicians, I believe that the structure we have established is a working example which could be used throughout the country. Because Southampton currently has a large research programme in allergy, there are sufficient numbers of clinicians and scientists to run a postgraduate training programme in this discipline. This extends to a full MSc which has been running for the last two years and has allowed us to train a cadre of doctors, nurses and dietitians who I hope will form the core of those who might be able to establish allergy clinics in their own localities.

We have also established an allergy network for our health region. We have regular meetings with our colleagues from surrounding District General Hospitals. A website has been set up, though only with input from a pharmaceutical company grant, and protocols for management of specific disorders and for care pathways are being formulated and agreed. However, our District General Hospital colleagues are constrained by their Hospital Trusts and are unable to establish appropriately staffed allergy clinics themselves. Furthermore, they have found that once it becomes known that they have an allergy interest, their own waiting lists for new appointments very rapidly exceeds acceptable limits. We are now also involving primary care within the network and hope that appropriately trained general practitioners might be able to handle more cases, thereby reducing the load on hospital services. However such is the very high prevalence of allergic disorders and the paucity of expertise in handling them, it will be many years before adequate services will be in place.

I and my colleagues believe that the establishment of allergy networks involving primary, secondary and tertiary care with clinicians, nurses, dietitians and immunologists is the way forward to improve services.

However, this can only be achieved if it is resourced from within the Health budget. It cannot be sustained by academics alone. Adequate resourcing of our service in Southampton through the Hospital Trust would allow us to devote more time to training, research and development and to supporting the evolution of services in surrounding health districts.

#### 4. GOVERNANCE & REGULATION

I also have a role as the allergy expert on the Advisory Committee for Novel Foods & Processes at the Food Standards Agency. As such, it has become very clear to me that there is a desperate need for a post-marketing early warning programme to be established, to review evolving allergies to new foods. This will only be possible if there is an adequate network of properly constituted allergy clinics around the country that could act as the sentinels reporting new cases as they arise, following a similar programme to the yellow

card system for adverse reactions to drugs. Currently the only agency providing any early warning system to patients is the charity, The Anaphylaxis Campaign. Without this organisation, many patients with acute severe and life threatening allergies would be left undiagnosed, unsupported and uninformed with the inevitable occasional disaster of severe acute reactions which are increasing in prevalence, presenting to hospitals and still tragically sometimes the cause of death.

We have recently completed a survey of attitudes to allergic aspects of asthma amongst patients, families and health professionals. This highlighted that patients and their families are well aware that allergy contributes to their problems and are desperate to obtain appropriate advice. Approximately one quarter of the patients had had allergy tests. However, only 2% had been organised by their general practitioners. The remainder had come through the independent sector where there is no regulation or governance. Many of the tests performed have been proven to be of no value whatsoever and much exists within the so-called complementary medicine sector. Sadly the response of the health profession has been wholly inadequate to patient and families' expectations. At primary care level, allergy avoidance advice is given without doing any tests which, of course, is totally inappropriate. At secondary and tertiary care level, there is a great reluctance to do allergy tests at all. In my view, the inevitable consequence of this is loss of confidence in the health profession, reduced compliance with therapeutic recommendations and, therefore, poor outcomes. This requires urgent attention, and will only be addressed by establishing allergy services staffed by appropriately trained staff uniformly across the country and eventually in all District General Hospitals. The pattern of service in our Region of a "hub and spoke" arrangement with the tertiary centre providing the leadership, training and support is likely to be the most effective arrangement.

## 5. RESEARCH & DEVELOPMENT

Research and development must be an integral component of the clinical service. Allergic diseases are currently not curable, though they are imminently controllable. While clinical services for allergy are rudimentary in the United Kingdom, this country has provided a disproportionate number of the world's leading allergy researchers. Dwindling resource is beginning to take its toll. It is imperative that the expertise in allergy research is sustained by ensuring adequate resourcing. It does seem rather remarkable to me that the largest amount of funding to support allergy research in the United Kingdom comes from the Food Standards Agency. Why is the Department of Health not involved in supporting such research, given the enormous prevalence and health economic burden of allergic conditions?

*June 2004*

### **Memorandum by Dr Lawrence Youlten (AL 74)**

#### 1. AUTHOR'S BACKGROUND

From 1977 to 2002 I was a consultant in the Department of Allergy at Guy's Hospital. During part of this time I also provided the allergy service to University Hospital Lewisham, in the context of a district general hospital chest clinic. Since retiring from Guy's, I have continued working in the NHS as visiting consultant in allergy at Addenbrooke's Hospital Cambridge. I have served on the Council of the British Society for Allergy and Clinical Immunology, including spells as Assistant Secretary and Secretary for three years each in the 1980s. Since 1982 I have been a consultant and director of the London Allergy Clinic, a private allergy clinic in the West End of London.

#### 2. INTRODUCTION

I would like to address particularly the questions relating to the Independent Sector of provision of allergy services. I am speaking from my personal experience, and do not purport to represent the private sector as a whole. The London Allergy Clinic was founded, and continues to operate, as a co-operative endeavour, in which all the consultants have NHS hospital consultant appointments. We share premises and resources but only rarely meet each other. Consultants attending the clinic include paediatricians, a chest physician, a general allergy specialist (myself) and, in the past but not currently, a dermatologist. In the early years of this enterprise, a significant proportion of patients from overseas were seen, but nowadays the majority of patients are resident in England, predominantly in the London and south-east England area, and have sought private treatment for reasons of convenience, or because they have insurance arrangements financed by their employers which allow them to seek private medical treatment. The great majority of cases seen at the London Allergy Clinic are referred by a primary care doctor, either NHS or private, and a significant minority come from other specialists, particularly in the context of drug allergy referrals.

### 3. ALLERGY SERVICES IN THE INDEPENDENT SECTOR AND THE NHS

Having worked for many years in parallel in both NHS and private allergy clinics, I do not find any significant difference in the case mix which presents to the two different types of clinic. In both types of clinic, patients have often experienced considerable difficulties in arranging an appropriate referral. In some cases this is due to lack of a local allergy service, in others demand leads to long waiting times for appointments, and there is an overall shortage of specialists qualified and willing to give advice about difficult problems such as drug allergies. Some patients have only managed to find an appropriate clinic with the help of patient support groups. A certain amount of mismatching of expectation occurs in both directions, some patients with significant allergic problems, such as potentially dangerous drug, food or venom allergies, or asthma with a strong allergic component, finding it hard to persuade their general practitioners that any useful purpose will be served by an allergy referral. On the other hand, lack of understanding of the scope of conventional allergy services, such as are provided at the London Allergy Clinic or NHS allergy clinics, sometimes leads to referrals where patients' expectations may be disappointed. Some patients have to travel considerable distances to the clinic, often because access to local services, either private or NHS, is restricted.

### 4. GOVERNANCE AND REGULATION

Most of the issues of governance can be covered by the fact that all the consultants at the London Allergy Clinic have an NHS hospital appointment, and the arrangements in place for appraisal, validation etc operating in their hospitals are also relevant to their work at the private clinic. For most, work at the private clinic only occupies a small fraction of the working week. Some of the major health insurance providers will only approve reimbursement of fees for private treatment if the consultant treating the patient has a current NHS consultant post.

### 5. LINKS BETWEEN THE NHS AND PRIVATE SECTOR

In recent years the London Allergy Clinic has attracted a significant number of adult and paediatric referrals in batches from a London teaching hospital NHS allergy clinic, unable to cope with service demand without exceeding patient waiting time guidelines since they have lost an experienced allergy specialist. I have not discussed the financial implications to the Hospital of this arrangement, but the fact that they have repeatedly submitted further batches of patients from their waiting list to be seen at a private clinic suggests that the cost to the hospital trust is considered reasonable. My own approach to the testing and treatment of patients with allergies is exactly the same in the context of the private clinic as it is in my NHS work, and I believe that my colleagues at the London Allergy Clinic bring the same approach as myself to this question. Although past retiring age, I am working close to full capacity, doing two notional half days a week in the NHS and four in the private clinic, this amounting to six clinics per week. I am not aware of any significant "slack" in the private sector which could be used to support the clinical activities of NHS clinics to any further degree.

### 6. OTHER ASPECTS OF THE INDEPENDENT SECTOR

Because of the dearth of medical expertise and advice available to patients who wish to explore the possibility that allergies and intolerances, particularly of a dietary nature, may account for their symptoms, such patients have often paid for food allergy tests as promoted in the lay press, in health food shops or directly advertised. Some of these tests are of very questionable validity, and the advice provided to patients who have arranged such tests, often at considerable personal expense, is sometimes deficient, and in some cases actually detrimental to the patient's health. There are many situations in which reliable tests are not available. There is widespread exploitation for commercial profit in this area of the general lack of understanding by both patients and non-specialist doctors of the availability, scope and limitations of the various forms of allergy testing.

*June 2004*

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*Witnesses:* **Professor Stephen Holgate**, Chairman, Royal College of Physicians Committee and National Allergy Strategy Group, **Professor Andrew Wardlaw**, President, British Society for Allergy and Clinical Immunology, **Professor John Warner**, Paediatric Allergist, University of Southampton and **Dr Lawrence Youlten**, London Allergy Clinic, were examined.

**Q65 Chairman:** Can I welcome our second group of witnesses and express the Committee's thanks for your help with this inquiry and for the submissions that we have received. Could I ask you to briefly introduce yourselves to the Committee so we know who you all are?

**Dr Youlten:** I am Lawrence Youlten, and I have been involved as a consultant physician in the clinical treatment of allergy patients since 1977, for a large amount of that time both in the private sector and the NHS.

**Professor Warner:** I am John Warner. I am the Professor of Child Health in the University of Southampton. My main clinical and research interest is in children's allergies.

**Professor Holgate:** My name is Stephen Holgate and I am a Medical Research Council Clinical Professor at the University of Southampton. I chaired the Royal College of Physicians working party on Allergy Services and am currently Chairman of the National Allergy Strategy Group.

**Professor Wardlaw:** Professor Andrew Wardlaw, I am Professor of respiratory medicine and allergy in Leicester and am currently the President of the British Society for Allergy and Clinical Immunology.

**Q66 Chairman:** Can I begin by asking a similar question to that which I asked at the start of the previous session, which I think you heard, about your views on causal factors and why we suddenly have this apparent epidemic that has crept up on us. Do you concur with the evidence that was given in the previous session or do you have different thoughts?

**Professor Holgate:** Professor Warner and I have just come back from the European Academy of Allergy and Clinical Immunology in Amsterdam where there in Amsterdam where an update of this topic was presented, so we can give you a fairly up to date view on it. There seemed to be four major factors involved here. As we have already heard, one is linked, to diminished early life exposure to bacterial fungal and viral products and the remarkable protection that children experience from allergy when they are brought up on livestock farms. The second relates to diet. There has been a major change to our diet over the last three decades and, in particular, the diet that alters the micro-flora in the intestine on infants and young children. This is crucial during the first three years of life because this is the period when the immune system becomes programmed to be able to defend the child against infections. The third area relates to new allergens. There is little doubt that our 'tight' housing and the introduction of chemicals and other foreign substances, such as natural proteins into our environment, has produced increased sensitisation: kiwi fruit, avocados, latex and so on, are good examples. Finally, there is an interesting debate at the moment whether or not giving antibiotics early in life to treat infections

might be a factor that is contributing to altering the bacterial flora and therefore damaging the ability of the immune response to mature during early childhood. If there is a strong debate, it is over the role of air-pollution and other environmental factors, which we can touch on that later if you find that valuable. But I think that has now been pushed largely to one side.

**Q67 Chairman:** Can you expand a little bit on what you mean by changes in our feeding arrangements? I cannot think immediately of any obvious changes.

**Professor Warner:** It is not just about the foods that generate the allergic responses themselves, but our diet will have an impact on the way the immune system responds. For instance, there is increasing evidence that altering the fats that we have in our diet will change immune responses, and there are one or two trials now looking at supplementation of diet during pregnancy in very early life to reduce the chances of allergy developing by, for instance, using fish oils. There are issues about fresh fruit and vegetable and whether having less in the diet affects the way in which the immune system responds so that it generates more inflammation than it should.

**Q68 Chairman:** Are you implying that we are eating too much fresh vegetable?

**Professor Warner:** No, the opposite—not enough.

**Q69 Chairman:** At least that is consistent with our obesity inquiry!

**Professor Warner:** It is absolutely consistent. It seems that similar factors that may well be contributing to increasing obesity may well also contribute to increasing allergy. Indeed, there are even studies that have suggested an association between obesity and asthma. It is not because obesity causes asthma but because factors that contribute to causing obesity also contribute to causing asthma.

**Q70 Chairman:** Do any of you want to add to that?

**Dr Youlten:** Perhaps I could just add one point. One of the striking epidemiological features of allergy is the increased susceptibility of the oldest child in the family. This has been put down to the fact that they are more likely to have been spared infections early in life and therefore this hygiene hypothesis early kick-starting of the immune system is less likely to happen in the oldest child. Because of the change in family structure I think the whole of Western Europe and North America has seen over the last generation a decrease in family size so that there are more children who are the oldest, or only, child in the family and that may have some impact.

**Professor Wardlaw:** The point I would make is that the reasons are very complex and it is very closely related to Western lifestyle. It is very unlikely that we are going to be able to influence it in any major way,

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner  
and Dr Lawrence Youlten

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certainly in the next ten or twenty years, so the current epidemic is with us, is here to stay, for many years.

**Q71 Chairman:** What I do not understand is quite why we seem to be leading Europe on a number of fronts according to the views of the European conference. What is the reason for that?

**Professor Holgate:** You notice that it is Australia, New Zealand, Canada and North America that are the next ones in the pecking order. If you remember, a few years ago there were mass immigrations from the United Kingdoms into these countries. In Southampton, and other places, we have been doing a lot on the genetics of allergic disease and we found some major candidate genes that increase the susceptibility of particular populations to the effects of allergens as well as to other environmental factors are also changing. So we must not forget the genetic stock, but we cannot account for the rise on allergy worldwide purely on the basis of genetics; it has to be the environment acting on a susceptible genotype. As presented at the Amsterdam meeting of the European Academy of Allergy and Clinical Immunology countries that had previously had a very low prevalence of allergic disease such as Latvia, Lithuania, Estonia, as well as African and Asian populations are witnessing a marked rise in these allergic conditions at an alarming rate.

**Q72 Dr Taylor:** Professor Holgate, you described the publication of "Allergy: The Unmet Need" as a seminal event, and you took evidence for a year; it was a huge work. Could you tell us a little bit about it? Could you summarise the report's findings? Is that possible in a few moments?

**Professor Holgate:** I will not, I think, make any comment about the allergy epidemic itself which is dealt with in the Royal Colleges of Physicians report. But I would like to draw attention to allergy epidemiology in the UK, funded by the British Society of Allergy and BSACI. In this report, we identified a tremendous mismatch between the provision of clinical services and the clinical need. We identified that there were only six full-time allergy centres operating in the UK, and that was a real problem. The remaining allergy clinics were run by part-time consultants who were obviously organ-based, respiratory physicians and ENT surgeons, etc. The second thing we found was this tremendous geographical poor distribution, and inequality of allergy service provision across the UK. In Northern Ireland, Wales and Scotland, where there are hardly any specialist allergy services at all, and this is obviously very difficult for the patients living there. A third finding we identified was the fact that the low level of knowledge about allergy by organ-based specialists. This came as a bit of a surprise to us, but in some respects, looking back on it, it is not a surprise because organ-based specialists concentrate on their organ, and the incentives for them to educate themselves in allergy are probably not as powerful as they should have been and they have slipped behind. Finally, among the most important

finding was that general practitioners, across the country, were very poorly informed about allergy and generally they just reached for anti-histamines or steroids to treat patients instead of establishing a diagnosis, which all doctors really should do as a primary move. Those were the four main findings of our survey. What the RCP working party recommended was the need a specialist-led service. We cannot expect primary care physicians, nurses and pharmacists to start this on their own, it really does need guidance from the top. If there is one take-home message that the report came home with it was this. We examined a range of alternative service models, including one led by primary care. Because of the low level of knowledge about allergy in primary care. But we also think that we do need secondary care and tertiary care doctors to first take a real interest in this. We need to move this forward on two fronts, on the one hand, to generate allergy specialists geographically spread evenly across the country; and, secondly, to use that force to create knowledge about allergy in primary care—and by "primary care" I do not mean only GPs here, but nurses and pharmacists as well—as well as connecting with the schools, which we have already discussed this morning. For this we would need to start with 20 adult allergy specialist posts and 18 pediatric allergy posts along with laboratory back to get us going. However, the issue, of course, is that there are no trainees. You will have had evidence that we have been promised an increase in the numbers of trainees for the last three to four years, but each time it comes to the cut we have been brought down to zero and only last year we managed to fight for one extra trainee. What we need is more trainees, more young people, who are willing to go into this discipline. There is no shortage in enthusiasm by young doctors for this subject. A lot of young people are keen to do this, but there just are not the training slots available. To offer this training we need regional allergy services, and by "regional" I mean the general geographic spread of the old health regions (eight within England, say, Scotland and Northern Ireland) making 10 in all. We recommended two allergists looking after adult allergy, two looking after paediatric allergy; the right laboratory support structure there in the pathology laboratory; appropriate dietician pharmacy and nursing support. If we had this, they would act as a hub and spoke model to spread good allergy practice across the region, as has proven so successful in Cambridge and Southampton. The issue at the moment is that 80% of the full-time allergy practitioners are paid from academic and research salaries and that they are using a significant part of their research time to deliver a clinical service. This is totally unacceptable. The simple answer would be to say that we should not do this, we should walk away from it, but we feel the problems are so severe that we, for the sake of the patients, really cannot do that. We need the NHS to come behind this; we need better resource; and we are really only talking about £5.6 million to be able to do this, to get these first allergy consultants in

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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place, so we are not asking for a huge sum of money. Working closely with the primary care sector, we should be able to lift up the whole service provision of allergy, as has happened in every single other country in Europe.

**Q73 Chairman:** What are the historical reasons for the location of the current specialist centres which are, as we have remarked already, geographically uneven?

**Professor Holgate:** This is a very good question. It is all about where allergy research takes place in the UK. I hope you will forgive me for saying this, but the UK leads the world in research in this field, with a publication and citation record being almost top of the league and is very competitive with that of the United States. So it is led by latent enthusiasm and interest in the science, and, as a consequence of that, we have provided as best we can clinical service in the NHS. But it is secondary to the provision of research in the academic centres. So in Leicester we have got Professor Wardlaw, in London, Professors Kay and Lee in Manchester, and so on.

**Q74 Dr Taylor:** Can I go back to undergraduate training for the moment? As the Royal College, are you able to have an overview on the standard of undergraduate training, because you are asking for—I know it is only £5.6 million, but everybody else in the different specialties is also asking for things, so if we could get undergraduate training a bit better it might have some difference. Have you any views on the standards?

**Professor Holgate:** Absolutely. That is an area where we have got to focus effort, but one needs champions within the medical schools to be able to do the allergy teaching. What usually happens is that this subject gets taught as immunology during the first or second year before the students have had much clinical contact. Because there are so few clinically interested allergists, the whole field never gets taught in a clinical context and as a consequence gets forgotten about. If we had clinical allergists, like we have in these various cities where there are these clinics, then you will find that the medical schools have, in fact, picked this up and the students that they are producing are better trained in the area.

**Q75 Dr Taylor:** Where does it come in the curriculum at Southampton?

**Professor Holgate:** John Warner and myself—John runs paediatrics, I run adult medicine—when we do our ward rounds and our clinical teaching during the third and fourth year, we deal with it then. Our students also do what is called a “study in depth” during their fourth year, where they do a research or evidence-based project, and a high proportion of these in our medical school are in this field.

**Professor Wardlaw:** The problem is, as Stephen has said, there are not the people out there to do the teaching so it is totally ad hoc and fragmented, and if you have an enthusiast a student might be exposed to some allergy, but there is no real planning within the curriculum for allergy, I would say, in the UK. It

would just depend on the interests of an individual in any one place. There is no structured place for allergy within the curriculum. It comes under immunology, and that is not where allergy gets taught.

**Dr Youlten:** I think it is worth pointing out that to say that we ought to be doing more training either at undergraduate or post-graduate level has quite large resource implications for the existing staff, because there is no doubt that allergy, being very much a history-based specialty where taking a proper history is an absolute core activity in an allergy clinic, to do that with a student and then explain to the student all the implications, does mean that you take longer to see the patient, and therefore you need more staff. I do not know what the answer is.

**Professor Warner:** We started from such a low common denominator. There are so few people who are fully trained and able to apply the training for others. This is why the college report has had to try to be practical, and focus and say, “How are you going to be able to develop the discipline, allow it to cascade out to the point where we have general practitioners who have the knowledge and are able to take on a lot of the load?” But it just does not exist at the moment, and we have to start somewhere if we are to deal with what the patient needs.

**Q76 Dr Taylor:** Can you explain to us university research funding, because I think Professor Holgate said that you are in allergy purely because of your research interest which allows you to spill out into the clinical field, and the risk if the university’s agenda changes you might all be out of work?

**Professor Warner:** I am the professor of child health, so I am responsible for all paediatrics, not just for allergy immunology. There is no guarantee, when I retire, that I will be replaced by someone with an interest in allergy immunology; it could be an endocrinologist or a cardiologist, anything, because, as far as the university is concerned, they are interested in having somebody who has academic credibility and is able to do research and teach, and if there is nobody around in allergy they will go for somebody in another discipline, and that means the whole of the paediatric allergy service in Southampton disappears over night.

**Q77 Dr Taylor:** How does allergy rate on the star system for grading research at universities?

**Professor Warner:** It depends entirely on what research moneys we are getting and where we are publishing our papers, but in Southampton it rates very highly because Professor Holgate is probably the most well-known international expert in allergy and his papers are published in all the best journals; so he is five star rated as a consequence.

**Professor Holgate:** Well, this is something!

**Q78 Dr Taylor:** I have been called narrow-minded today. Now he has been given five stars, so that is brilliant.

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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**Professor Wardlaw:** Going back to what John is saying, in Brompton, one of the six centres, I think I am right in saying the only HEFC funded Department Chair of Allergy in the UK who has just retired, his post is being replaced by a geneticist, and that post is therefore lost. So that is a typical example of how priorities change in the university and therefore precious allergists disappear.

**Dr Taylor:** Thank you. That is very clear and very alarming.

**Q79 Mr Amess:** Professor Wardlaw, I wonder if you would say something about how the various allergy clinics around the country are staffed and resourced?

**Professor Wardlaw:** Yes. The BSACI runs a website which captures most of the allergy clinics running in the UK, and, as Professor Holgate has said, there are only six centres which could be regarded as providing anything like a comprehensive service in allergy with a committed, fully trained full-time allergist who runs and leads that service. There are then about 15 clinics across the country where there is a part-time service, an allergist who has a part-time commitment, and then there are the rest of the clinics. About 80 clinics are run by organ-based specialists where allergy is not their speciality, so in many cases it is a bit of a hobby in which they take a passing interest, and, of course, that provides a very fragmented—service. These clinics are vital, actually, providing an allergy service, I am not denigrating it in any way, but it clearly is not an optimal service. The six centres that do provide an optimal service, as we have heard, they are very strongly reliant on the university sector and the academic sector, there are only, I think, one or two which have NHS funding to any degree. It is very difficult for them, we will perhaps hear later, but from Southampton and the Brompton and Cambridge there have been years of pressurising the NHS to try and support the service and they have refused to do so. It needs strong lobbying from champions in that area, never mind areas where there are not any champions. So, quite honestly, for a disease which is one of the commonest diseases in the UK, which, as you have heard, causes so much morbidity and a certain amount of mortality, the service is utterly derisory, and if you compare it, there are something like 26 full-time allergists in the UK, and really we should be able to have the same as chest physicians and dermatologists, where there are 500. Quite honestly, I think it is a disgrace.

**Q80 Mr Amess:** You describe the service as “utterly derisory” and a “disgrace”. That is pretty graphic. We understand how fed up you feel about the situation. Why do you think this has come about, because we heard from one of our previous witnesses that this epidemic has taken everyone by surprise? Why do you think you are so clearly the Cinderella service?

**Professor Wardlaw:** I think for complex reasons. I think allergy as a whole is complex and not well taught at medical school, so there is not a lot of exposure to it for doctors coming up. We had an

interesting debate earlier on about how you get new consultants and how services develop in an area, and certainly ten, 20 years ago it was very much consultant led. The medical profession has not ever given allergy a particularly high profile, mainly because I do not think they understand it, and also, because the NHS in the UK is so organ-based, it has a very organ-based view. What used to happen, and does still happen to a certain extent, is that a chest physician would want another chest physician, a dermatologist would want another dermatologist and the multi-disciplinary specialities, such as Allergy, have always lost out. Now the situation is changing and the commissioning process is a lot more complex, in that while consultants or the medical profession still has a role to play, there is now much more emphasis on PCTs as commissioners, and also we have Department of Health targets with the Cancer plan and the emphasis on cardiovascular sciences. So what you tend to get is you have a pot of money and there is a lot of horse-trading going on, a lot of emphasis on waiting list targets and that sort of thing. The target culture has had a big influence on this, and you get this horse-trading where you need strong champions locally to try and press for service development, and again allergy has suffered because there are not any local champions. Also at primary care level in the PCTs—I am going to come on to this because I think it is a crucial point—the PCTs do not see allergy as a priority for all the reasons that are talked about really.

**Q81 Mr Amess:** It is strange though, is it not, because you think it would be patient driven? With all these people presenting themselves with symptoms, you would have thought a real head of steam would have been driven up: all the GPs discussing it and saying, “For goodness sake, what is going on”?

**Professor Wardlaw:** But local commissioning, whatever it is, is not patient driven.

**Q82 Chairman:** Can I come in on the commissioning question. Do you think that the devolution of the commissioning to PCTs has lost any expertise in commissioning the kind of services that you provide?

**Professor Warner:** My perspective is that the problem is that they are deluged with recommendations for commissioning. The Department of Health have produced, for instance, new specialist definitions for specialist referral, but there are such an enormous number of them they cannot cope with the model, and in the end are only going to respond to those where there is an imperative that comes from the Department of Health. So it is going to be cancer and cardiovascular disease, now obesity, I suppose, but unless there is some directive they are not going to take any notice. We have fought—I have been in Southampton for 14 years, Stephen for a great deal longer—to try and get allergy recognised as part of specialist commissioning, and it is not, it is on the

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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general tariff. So from the hospital's perspective, they perceive that we are losing them money, because they get the lowest common denominator payment per patient who is referred, and it is below what the hospital is paying out in terms of investigation costs and the service provided. There has been a serious risk of our services being closed down by the hospital. If I may I will read you a brief email dated 26 May 2004. I sent an email to our services manager saying that there were now new potentials for coding allergy referrals that would allow us to identify the numbers and therefore begin to understand our service better, and the response was as follows: "We have discussed this in setting up allergy speciality codes. This will automatically send a message that we are delivering a fully supported service. If we are to develop this it must be done in the correct manner as a concept paper and then a business case, for which there is currently no financial resource available." So we cannot even generate the data to show what we are doing, because we are not being allowed to because people do not want to ask to be recognised as running an allergy service. That is in Southampton where we are providing a service.

**Q83 Chairman:** Can you give us a bit more information on that coding? Was that in the written evidence? I cannot recall it.

**Professor Warner:** No, it was not. I only received this—

**Q84 Chairman:** This is very recent?

**Professor Warner:** Yes.

**Q85 Chairman:** Can you come back to us with that? I am very interested in that example.

**Professor Warner:** This is something that Pamela Ewan sent round to all her colleagues within the British Society of Allergy and Clinical Immunology, that there was now an opportunity to be able to code patients who were referred to hospital with problems as having an allergy rather than having asthma or other codes, and all I was doing was asking that we coded our referrals appropriately and that was the response I got.

**Chairman:** We are going to invite the Department of Health to give evidence and we will be asking detailed questions on the referral figures that we have got, and that information might be very helpful.

**Q86 John Austin:** Given the map that we have got with these big areas of virtually no provision, we were talking about PCTs not necessarily having either the resources or having it as a priority in their set of guidelines, is there a role of ensuring a reasonable spread of services, a role for the strategic health authorities, and what discussions do you have with the SHAs?

**Professor Warner:** We do have discussions with them, but at the moment their influence over what happens with an individual hospital trust is very much less than it might be. The trusts have to

manage their own affairs now and they are pinned down by the health authorities to make sure they stick within their budgets.

**Professor Wardlaw:** I think this is a hugely important point, because we have had lots of meetings with the Department of Health and they have said, "Yes, there is a problem", and, "Yes, there is a need, but it is all down to the local commissioning service and, if patients really want it, it should be a priority", but it simply does not work like that. We were given the names by the Department of Health of the 30 PCT leads who are responsible for allergy commissioning and we wrote to all of them some time ago and of the 30 only seven replied, and of those seven, allergy was not a priority for any of them. Also, through your colleagues writing to local PCTs, it is quite clear that they are either ignorant about allergy or have no interest in it. So we are absolutely convinced that we are not going to get anywhere unless there is central direction and central funding from the Department of Health along the lines of the cancer plan, although probably costing a 100th or a 1000th of what that is costing.

**Q87 Dr Taylor:** Can I try and tie you down to what we need, not quite in an ideal world, but in a realistic world? The recommendations we have had are the establishment of a minimum of one full-time fully resourced allergy clinic in each of the eight NHS regions, plus one each in Scotland, Wales and Northern Ireland. Is that the sort of thing we should be aiming for?

**Professor Holgate:** That is the basic minimum. To keep things level would require 20 additional adult and 18 paediatric allergy specialist training posts that would enable these consultant positions to be filled.

**Q88 Dr Taylor:** These are 20 new adult and 18 periodic NTNs, as they are called?

**Professor Holgate:** Yes.

**Q89 Dr Taylor:** How many SPRs are there already in allergy?

**Professor Warner:** In allergy?

**Q90 Dr Taylor:** Yes.

**Professor Holgate:** One new one. We have got five previously, now six.

**Q91 Dr Taylor:** Five now six?

**Professor Holgate:** For the whole of the UK.

**Q92 Dr Taylor:** We were told that 20 had been recommended and the quota was reduced from seven to nil?

**Professor Holgate:** That is right.

**Q93 Dr Taylor:** Then you fought back and got one?

**Professor Holgate:** Yes, that is true. We gained one extra post last year.



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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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**Q94 Dr Taylor:** So six SPRs in the whole country?  
**Professor Holgate:** Yes.

**Q95 Dr Taylor:** We have got terrible difficulties, obviously. Is there any sort of short mid-term solution? It has been suggested that obviously one can train more dieticians, more nurses, more GPs, but we have already been told that the people to do the training do not exist?

**Professor Wardlaw:** I do not think there is a short-term fix. As Stephen Holgate has pointed out, there is not anything that can be done because there is not the critical mass there. You have to accept that to get a decent allergy service it is going to take five years to train the people, even if we put those posts in place now; but, in the scale of things, we should be doing things properly. I think that the RCP report is a very realistic minimum but very effective way forward.

**Professor Warner:** I think there is a sort of intermediate quick effect in that a number of specialist registrars have gone through our units over the last 10 years, most of who have gone out to general posts because there are not any allergy posts for them to apply for. There are a number of general paediatricians working around Southampton who have worked with me for variable periods of time, including one person who did a PhD in allergy and is now a general paediatrician on Guernsey because there are not any posts. If you create the posts there may well be some of those people who would be interested in moving into them, and they are there and trained. I think if the posts are created some of them will be filled pretty rapidly, but we still need to have a cadre of younger people that we are training. For paediatrics and specialist registrar, there normally do two years of general paediatric training first and then it is three years of allergy training. So there are a lot of people keen to do it, if they could see there was an outlet for them, with appointments. We could be training new consultants in paediatric allergy by three years.

**Professor Holgate:** There is no shortage of people wanting to come and work with us. Academically we lead the world in this field. We can find top class people, but where do they go to? That is the issue.

**Q96 Dr Taylor:** Are your feelings the same as the first group of witnesses about the allergy clinics in pale grey on our map?

**Professor Holgate:** Yes.

**Q97 Dr Taylor:** As there is no short-term fix, we have got to aim in the medium to long term. Can I go on to the next question of waiting lists, because the first lot of our witnesses very definitely did not really believe the claims that the Government makes. I certainly have discovered many ways that trusts can get round waiting list targets, not least that you do not open the referral letter: because the time does not start until you have opened the referral letter. What are your feelings about the interpretation of waiting list targets?

**Professor Holgate:** Could I say something about this? Because there are so few allergy clinics, patients are not going to be referred at all. That is one point. So these are very artificial. It total they probably represent five to 7% of the total allergic population. So you can hardly call them representative. Secondly, they have mixed the subjects of allergy and clinical immunology together. We know that there are Clinical Immunologists in the United Kingdom, who have responsibilities for managing immunodeficiency and rheumatoid arthritis and these other immune diseases. I understand they outnumber us by about five to one or six to one, so these figures are much more likely to reflect clinical immunology rather than allergy referrals. Finally, one of the biggest problems is the one that you have just recognised namely that many of these letters do not get opened and are returned, because the waiting list is too high and they are just returned.

**Q98 Jim Dowd:** Can I come back to you. A moment or two ago you used the figure 5 to 7% of the real figure?

**Professor Holgate:** Yes.

**Q99 Jim Dowd:** If we put that to the Minister he may come back and says, "How do you come up with that conclusion?" How do you come to that conclusion?

**Professor Holgate:** Because if you look at the provision of the allergy services around the United Kingdom and look at the referral patterns within the places where there are services provided at least reasonably adequately and then extrapolate to the rest of the country, you end up between 5 and 7%. That is probably being on the up rather than the down side.

**Q100 Jim Dowd:** You are making the assumption that the level of need is the same geographically across the country where there is no provision?

**Professor Holgate:** We have no evidence from our survey that we did for the CPC that the BSACI supported that there is any geographic variation in the UK in this area.

**Professor Warner:** There has been a very large countrywide survey of the prevalence of allergy in children which has shown pretty uniform distribution across the country. I think it is marginally higher in non-Metropolitan areas and in Scotland than England, but the differences are very small.

**Q101 Dr Taylor:** One other thing. Is the sort of confusion between clinical immunology and allergy international?

**Professor Holgate:** The Clinical Immunologist has a very wide remit. It is a laboratory-based specialty, so they run laboratories for diagnosis of complex immune conditions, and as a consequence their clinical work is quite restricted to immunodeficiency or complex immune problems where they develop these auto-immune disorders. Allergy is very, very patchy. So you will have some clinical

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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immunologists who take an interest in allergy, just as a chest doctor would or an ENT doctor, and maybe undertake one clinic a week in that area, and you will get others across the country doing none whatsoever. So again, we could really, with the clinical immunologists, park them with the organ-based specialties in that regard because they have their own remit to look after, which are complex immune conditions.

**Professor Warner:** Can I answer something more about waiting lists? There is a lot of referral shunting occurring as well, which produces a false impression. For instance, in Southampton because we are the only paediatric allergy clinic on the south coast and we are taking referrals from a vast area, we were asked by our Trust to try and address this huge waiting list by looking to see whether it was possible to suggest that referrals were made back to the local hospitals; and to a certain extent that was possible because some of our trainees were now working in those hospitals. So we asked them would they be willing to see these cases, so the letters are sent out to them with a letter to the GP saying, "We have transferred your referral back because this person can see patients", and then the Local District General Hospitals were saying, "I am sorry, this is not a funded allergy service", and the letter goes back to the GP, "Sorry, we cannot provide this." Then the GP writes another letter back to us saying, "This is not happening. You have got to see them", and that reduces the waiting time whilst the letter shunts backwards and forwards.

**Q102 Dr Taylor:** We picked that up from your written evidence.

**Professor Wardlaw:** It is important to emphasise, because the targets are no longer any measure of demand at all really. For instance, Tina Dickson in Liverpool: because of the waiting list problem, she was told she could only see emergency referrals and she could not see any of the other routine referrals. So they are managed very aggressively now, of course. The other point to say about those figures, really questioning the accuracy on it, I would estimate that just Cambridge and Leicester alone would see 2,000 new patient referrals in the first quarter. So I really do not know where those figures come from.

**Q103 Chairman:** I am conscious, Dr Youlten, that we have not brought you in at this stage, but I think Jim Dowd might change that picture.

**Q104 Jim Dowd:** There appears to be a paradox. You say that we lead the world, or that we are as good as any in the world in research terms. The rest of the picture you describe though is a very scant and in many places non-existent practising base. So if you do not have that practising base, where do the researchers come from?

**Professor Holgate:** The practising base has grown around the researchers; hence the academic specialists to be found at the Brompton Hospital, Southampton, Manchester, because it is these

centres that have actually serviced the clinics there through our university money, and, in my case, through the Medical Research Council money, but there is no NHS support whatsoever for it. So in a way you could say that we have propagated and kept allergy alive these last two decades purely on the basis of our interest in wanting to move the discipline forward. Why we have not been successful is not because we have not tried. We have had endless meetings with the Department of Health since 1997 and then, for the last three or four years, all sorts of people we have met with, and at all levels, we have been told that this is going to be passed down, and so eventually we formed the National Allergy Strategy Group—that is why we formed it following the report—because we were making absolutely no progress at all by operating through official channels.

**Chairman:** I would like now to bring in Doug Naysmith?

**Q105 Dr Naysmith:** I am very interested in this discussion. I must apologise, first of all, for being unavoidably late in arriving. This is probably the evidence session that I would least like to have missed if I had to miss a session. You are discussing the situation where if you are a patient with an allergy of some sort you can get treatment at a special allergy centre, or you can go to a clinical immunology service, or you can be seen by a chest physician, or someone else who does some allergy work now and again. Are there any really good figures to suggest that going to the special allergy clinic means that you have better outcomes?

**Professor Holgate:** There are extremely good figures. In fact Cambridge and Southampton have done tight audits of their referrals and I suspect the same is true of the other centres, though I am not certain about that.

**Q106 Dr Naysmith:** This is published, is it?

**Professor Holgate:** This is part of the reports. I do not know whether it is published. It has been submitted to the Department of Health as part of our original evidence to try and get action.

**Professor Warner:** There are data published from Cambridge. We have some data on . . . We have looked at quality of life issues in relation to referrals again from Southampton, which is published.

**Dr Naysmith:** But compared with other places as well, that might be very useful?

**Q107 Jim Dowd:** Dr Youlten, following on from what we were saying earlier, the paucity of NHS provision in this area means that people in disproportionate numbers are turning to the private sector because of the absence of services. I wonder if you would care to say a word about the general provision of allergy services in the private sector and to describe why patients are having to take this course and what are the consequences of lack of provision?

**Dr Youlten:** I do not know whether my written submission was circulated?

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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**Q108 Chairman:** Yes.

**Dr Youlten:** I would like to make a clear distinction between the private and the alternative part of the private sector. My own experience, and the only part of it that I can speak on with any authority, is in the private sector, reflecting what goes on in the National Health Service, and I worked for many years, and still do, in parallel in both sectors, so the service I offer and the standards I apply are just the same and the case mix I see is very similar in both parts of my activity. What I think is of great interest is the other part of the private sector, that is the fringe sector of both testing and treatment. I think, on the subject of testing, the availability of unvalidated tests which people can go straight to without any referral, through their health food shop, or their hairdresser, or whoever it may be, they are paying large amounts of money for tests which are quite unvalidated. I think that has been something that has damaged patient care and it has also damaged the reputation of allergy overall: because the general feeling is either, "We know that there are good allergy tests, so if you cannot get them from your hospital you might as well go and pay for them privately", is one aspect of it. The other aspect is, "We know allergy tests are complete rubbish and so I am not sending you to a hospital to be given tests there." Consequently, one way or another, people are getting a very bad service. I think some of the consequences of people relying on some of these fringe laboratory tests like hair testing, VEGA testing, and so on and so forth, particularly in relation to the advice they are given to modify their diets, can be very damaging. We expect a new drug, or even a new surgical procedure, to go through some process of validation and clinical trials before it is widely acceptable and introduced. People do not understand at all that tests should go through a validation procedure too. They should be correlated with clinical conditions; there should be some estimate made of their utility in relation to patient care. What is happening is that people are being given lists of foods that they are advised to avoid, and sometimes they are getting into serious problems over this. I recall a vivid picture of a patient at Guys, a lady, something under five feet in height, very anxious because she had had a relative who died of anaphylaxis who had herself developed some problem with urticaria, which I do not think had anything to do with food allergy, she just had a rash, but she had gone to a fringe practitioner who had given her a list of foods that she should avoid. When I saw her she was tottering along the corridor holding a baby that she was breastfeeding, which was almost as big as she was, and she had been told that she should avoid milk and eggs and all the things you would encourage a nursing mother to take. That is an example of the sort of bad advice, to the detriment of patients' health, that is coming about through fringe testing. Equally, because of the bad reputation of that sort of testing, I believe that patients who really could benefit from proper testing, skin prick testing and IGE tests, and so on,

are being denied access to that and being discouraged from having what is a very reasonable approach.

**Q109 Chairman:** Would it be your contention then, or would you agree with my assertion, that because overall NHS provision is so poor in this area we are exposing people far more readily to quacks and charlatans and any kind of passing fad than in any other area?

**Dr Youlten:** I do believe that strongly.

**Q110 Chairman:** The Heath Care Commission, of course, is supposed to have a responsibility for regulating and inspecting the private and voluntary health care sector from April this year. Do you think they are impelled and are capable of protecting the best interests of patients in this field, particularly with regard to complementary and alternative treatment?

**Dr Youlten:** I do not really know.

**Q111 Chairman:** I have seen other animated movements along the bench.

**Professor Holgate:** If they take allergy seriously as part of their broader remit then they could make a major and important contribution. It is a lot of work to have to do. It is a large sector out there. The HCC are not empowered to look at laboratory diagnostic practice, only treatment practice, so that would have to be a change in their remit if they were going to examine this: because one of the big issues about alternative practitioners is their erroneous diagnoses using these various bits of kit that they have, or their hair analysis, but if they took it seriously and did this we would welcome this. This would be an excellent way of helping move the field forward, but it would be an awful lot of work for them.

**Q112 Chairman:** Practically you do not think they have got the resources to do it?

**Professor Holgate:** They have so many other things they have to deal with at the moment. I was involved with a House of Lords Select Committee report on complementary or alternative medicine. One of the recommendations that Lord Walton made on that occasion was that greater regulation should be introduced into this sector; and now, as you are aware, into acupuncture and herbal therapy. So the sector is now responding in a responsible way and I think it will improve over time with allergy being captured in that general regulation. There are one or two other areas where there are totally untested methods which are used which are, frankly, dangerous. I was part of a Royal College of Physicians visiting team to a hospital in England that undertook a range of diagnostic and therapeutic procedures in allergy to inspect it, being asked to visit by the Chief Medical Officer. This hospital had seen 12,000 patients over a period of six years had used very wide range of diagnostic and therapeutic procedures, of which had been validated. Not only that, they were seeing children and there was not a single practitioner there

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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qualified in child health, they were using treatments that had never been properly tested using established procedures and, in fact, the whole activity they were engaged in very alarming and worrying.

**Q113 Chairman:** Did they not, as clinical practitioners, themselves have a view on this while they were doing it?

**Professor Holgate:** We put it to them, and, of course, as you might imagine, the practitioners at the Centre have had training that is non-conventional and more based on the basis of patient satisfaction than efficiency as the criteria upon which they were judging therapeutic effectiveness. These are private clinics. Huge sums of money are involved here and the NHS authorities are being asked to pay for it, and so our recommendations were not terribly glowing.

**Professor Warner:** The key problem is that it is on the diagnostic side that the greatest difficulties occur within complementary medicine. I do not think we are quibbling so much with some of the treatments, at least some of them are now undergoing proper evaluation, but on the diagnostic side there nothing; and it is, frankly, dangerous. We have an enormous number of anecdotes of people who have been given false allergy diagnoses, put on nutritionally unsound diets, children really severely malnourished, under weight, not growing, really suffering severely; on the other hand, even patients being told that they were not allergic when they were allergic and relaxing their avoidance and having life threatening reactions. So this is the area that requires the most scrutiny. It is the area that at the moment is not covered.

**Professor Holgate:** Alternative allergy practise is now Tesco's or Boots, for example. The first thing you will see as you walk into the pharmacy area is a whole array of complementary therapies for allergic and related diseases, and this is a great concern.

**Dr Youlten:** I think it is a very sad reflection of the way people have been served by the allergy services in the NHS, but I can remember several patients being referred to Guys when I was working there who actually said "The reason I have come to the NHS is that I have run out of money. I can no longer afford the fringe tests and treatment", and, of course, when you got down to it, what they needed was not the alternative route, it was conventional testing and advice.

**Q114 Chairman:** In your written evidence you have talked about the lack of provision in paediatric services, specialist allergy services?

**Professor Warner:** Yes.

**Q115 Chairman:** Could you expand on what can be done to address that problem?

**Professor Warner:** Yes, I think it is very much like in the adult services, that we have to go back to setting up the tertiary centres that are going to provide the training that should be in each health district to paediatric allergists working with two adult allergists, with the back-up of the specialist nurses

and dieticians that can service both sides, with the laboratory back-up that is required with that, who would then be able to train the next cadre of paediatricians. There will be some paediatric registrars who will go through a more general programme and maybe have a one-year exposure to allergy and then have an allergy interest, who will go into district general hospitals as general paediatricians and will be able to set up a secondary referral allergy clinic to see the more straightforward allergy patients. Obviously, we then also would be able to train GPs to do some of the allergy diagnostic work and treatment in primary care; and the tertiary service would then be there to deal with what we estimate is about a sixth of the total number of cases that require special attention. That is still an enormous number. In childhood now 40% of all children have some allergy. Of those, about a sixth require specialist referral, and that means we are talking, based on the current birth rates, about 40-45,000 new cases a year for specialist referral.

**Q116 Chairman:** Could you say something about what happens when children transfer from paediatric services to the adult allergy services? Is there any lack of continuity?

**Professor Warner:** In the best run system, there is a graded transfer. If there is a good allergy service being provided paediatrically and in the adult, then there is a seamless transfer because it will be within the same system. We sometimes run joint clinics for adolescents to gradually transfer them over, but that is a very precious commodity that does not exist in many places. That is only where the paediatric and adults allergists are working together, and, as we have said, there are only six centres that are doing that at the moment.

**Q117 Chairman:** So, until the numbers change, there is likely to be little means of improvement?

**Professor Warner:** Yes. I think the other thing to say is that when we say there are 40% of children with allergy problems and only 30% of adults, in another 10 or 15 years that will be 40% of adults as well, because we are talking about a cohort effect here where we are seeing an increase occurring first in the children, but as they grow up they are taking their allergy with them.

**Q118 Jim Dowd:** That is assuming you cannot effect a treatment?

**Professor Warner:** Yes. Obviously my objective is to put all my adult colleagues out of business by preventing the disease in the first place or curing it as soon as it arises, but I have to be realistic and say that my Nobel Prize is on hold at the moment!

**Chairman:** We will look out for it with interest. David.

**Q119 Mr Amess:** Much as we have said about funding already, it does appear that many of the problems experienced have been caused by a switch to funding towards PCTs and towards district hospitals, and already we have heard about the lack

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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of willingness, seemingly, of the Department to fund centrally, and we have talked about the Cancer plan and other issues. Do you consider that the establishment of full-time allergy clinics should be centrally funded, and would you like to expand on that if you answer in the affirmative?

**Professor Holgate:** It is quite clear from the evidence that has been presented to you, in written and in oral form, that the current Department of Health policy in providing allergy services is failing, and we have persistently tried to persuade the Government to take on specialist allergy commissioning as a way through all this, recognising that developing responsibility to the PCT is not delivering an adequate allergy service all for patients. So far we have not had any success in being able to raise the profile of allergy amongst the NHS Specialist Commissioners. You will have heard earlier today that we have tried to contact a number of them and received negative responses and frequently no response at all. So it is up to the Department of Health now to decide how they are going to respond to this, recognising that further devolvement down PCTs is not a formula that is likely to work in the current climate of the NHS; and the only way that the National Allergy Strategy Group, can see a way through all this is to get specialist allergy commissioning in place so that there is some central guidance to help drive the medical practise on the periphery to create change, as has been so tremendously successful for implementing the Cancer initiative. Just as they have been successful, we would like to follow their model, and our report from the Royal College is a blue-print of that particular way of delivering a service which is above any single organ specialist. If, in the case of allergy, we were dealing with single organ disease then we would not have this problem; it is because we are not that we are falling between the cracks of all the different ways of trying to generate priorities within the NHS.

**Q120 Mr Amess:** I think you have answered my second point, but I will still ask it, and, you will be pleased to know, gentlemen, when it comes to the evidence session with a minister or ministers, we will be able to put those points directly to test the robustness or otherwise. Primary care trusts are really still in an embryonic state and they are being asked to do a great deal, but it does seem to be the case that there is not enough understanding or knowledge of allergies generally. The Cancer plan, introduced into the NHS to meet national improvements in cancer care, has been funded centrally. What are your comments on that?

**Professor Holgate:** Yes, and it is very successful. We are looking for a much smaller version of that. Allergy is a discipline that would lend itself very nicely to the GPSI system and specialists within groups of general practices that could concentrate effort and involve some nurses working in primary care, but, as we keep saying, we need to train these people. As a speciality we would very much like to train these people and we are doing our best to do it

but, at the moment, GPSIs and allergy are not a priority. We have GPSIs in diabetes, and in other areas. So one step government could take is to recognise this as an area that they might be able to support allergy specialists in the secondary care sector.

**Professor Warner:** If I may say, there is no lack of interest from GPs in this. We now run a full allergy MSc in Southampton, and the highest number of people who are applying to go on that MSc are GPs. So there is enormous enthusiasm there. They recognise that there is a need to improve their skills; the problem is when they go back to their PCTs again there is no priority for allergy, and they just have to attend to doing the general work and cannot necessarily even indulge in the extra skills that they have gained from doing an MSc.

**Q121 Mr Amess:** So Members of Parliament need to ask their primary care trusts what they are doing on this particular issue?

**Professor Warner:** Yes.

**Professor Wardlaw:** We have asked them, and the answer is they are doing nothing.

**Q122 Mr Amess:** What did you say, seven out of 20; is that right?

**Professor Wardlaw:** I think 30 MPs have written and I think twelve got replies, and all twelve had a variety of responses—it is in my evidence—but they are either complacent or ignorant.

**Mr Amess:** There are 659 of us, not 30! This is a tiny sample. I was not one of the 30 asked!

**Q123 Chairman:** I suspect that the patient groups that were here earlier giving evidence will be writing to their 659 MPs! Professor Holgate, you have referred to some of the things which need to be done which are in the Royal College of Physicians' recommendations. A number of recommendations have been made to the Department. We, of course, will be seeing the Minister. Perhaps you could tell us what response you have had from the Department to those recommendations?

**Professor Holgate:** We sent a letter to Dr Ladyman which outlined our plan, which was really a recapitulation of what is in the RCP Allergy: the unmet need report, but translates it into what we can do over the next year or so, as opposed to trying to look at the longer term. As yet, we have not received a reply from that. You have a copy of the letter we wrote as evidence, I think, there.

**Q124 Dr Taylor:** Is that the one of 17 May?

**Professor Holgate:** Correct. We are awaiting a reply that gives our view of making a start over the next twelve to eighteen months.

**Q125 Chairman:** Perhaps we may be get a reply before you do when we see the Minister. I wonder if any of my colleagues have any other questions or whether there is anything you would like to add?

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17 June 2004 Professor Stephen Holgate, Professor Andrew Wardlaw, Professor John Warner and Dr Lawrence Youlten

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**Professor Warner:** There were some questions you asked earlier on about schools and issues that relate to that. Clearly, there should be a sort of networking which involves all the agencies that are caring for individuals, whether that be adults or children, and if there is a clinic established, an allergy clinic established, then it is possible to train school nurses, to provide the training for the schools to be able to handle the problems effectively. We do it in Southampton. We have a special group that regularly trains all the school nurses and gives them the materials to go and cascade the information around schools, and it has been very successful. In fact, we have even done a research programme to look at the outcomes in relation to asthma, and it really has been effective in improving care considerably, and the papers are about to be published on that. So it is possible that you have to have the core of the service there to start off with to deliver it. There is some recommendation coming out within the national service framework for children and the medicines component of that. I sort of insinuated myself onto that group in order to make sure that there was some recommendation about the way in which medications for allergic disease were handled in schools. So that will be included in the recommendations.

**Q126 Chairman:** At the end of the day, it is going to be teachers, classroom assistants and others who will be in the front line?

**Professor Warner:** Yes; but there is a problem of indemnity for those people, and also their job descriptions; and there are many teachers who are recommended by their unions not to take responsibility because they are not covered.

**Q127 Chairman:** The reason for my question earlier on is that it is six or seven years ago now that we did our report on children's health but that there was a real problem there?

**Professor Warner:** There is still one. There is no lack of willingness, again, but they need to have some kind of structure that allows them to be able to do it. The concept within the medicines group of the children's NSF is that newly appointed staff should be offered contracts which include a component of delivering medications, for instance. Obviously, those people would have to have appropriate training, but it would be a perfectly reasonable way of ensuring that that was effectively delivered in schools.

**Chairman:** Could I thank all of our witnesses, both yourselves and the earlier group, for attending.

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**Thursday 1 July 2004**

Members present:

Mr David Hinchliffe, in the Chair

Mr David Amess  
John Austin  
Mr Keith Bradley  
Mr Simon Burns

Mr Paul Burstow  
Siobhain McDonagh  
Dr Doug Naysmith  
Dr Richard Taylor

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### **Memorandum by the Department of Health (AL 10)**

#### **INTRODUCTION**

1. The Government welcomes this opportunity to set out the existing position on the care and treatment of allergies.

2. This memorandum describes existing NHS allergy services and how the relationship with the private sector is regulated.

3. The term allergy covers a wide array of symptoms that can cause a range of conditions or reactions in an individual, from a mild flush to a serious debilitating or life threatening condition. This is reflected in the provision of care and treatment services for allergy, where actions to meet the needs of individuals who suffer from an allergy are required to be comprehensive and can be internally complex within NHS care. It is an important aspect of developments across the NHS to ensure that this complexity does not hinder the individual patient getting the right care and treatment at the right time.

#### **THE GROWING INCIDENCE OF ALLERGIES**

4. This enquiry does not address the incidence of allergies, but as incidence is an important driver for development of NHS care and treatment it may be helpful to discuss this briefly. This sets the context within which different services need to be made available and informs the need for the overall mix and availability of information and care across the public, private and voluntary sectors.

5. There have been a number of estimates of the increasing incidence of allergies. The Royal College of Physicians' helpful report, *Allergy: the unmet need—a blueprint for better patient care* (RCP June 2003), detailed the estimates and evidence of a three-fold increase in allergies, now affecting a third of the UK population, some 18 million people. Within this increased incidence there is evidence that there is increased severity and complexity, some of the more severe and potentially life threatening disorders are becoming more common and patients more often have disorders affecting several systems in the body.

6. Among 13 to 14 year-old children, 32% report symptoms of asthma, 9% are reported to have eczema and 40% allergic rhinitis. Across the population, increasing trends are apparent in nut allergy, anaphylaxis and occupational allergy (eg to latex), and allergic reactions to drugs.

7. Anaphylaxis occurs in one in 3,500 of the population each year. Incidence of peanut allergy, the most common food allergy to cause fatal or near-fatal reactions, is estimated to have trebled over four years and now affects around one in 70 children in the UK. Only 10 years ago this was deemed a rare disorder.

8. It should be noted, though, that the majority of people with an allergy experience mild or moderate symptoms. Most self medicate or can be successfully cared for and treated with conventional pharmacotherapy without the need for confirmation of an allergic mechanism or identification of specific allergic triggers.

#### **PREVENTION MEASURES**

##### *Food allergies*

9. The Food Standards Agency (FSA) strategy on food allergy has three main components:

- improving understanding of this issue amongst consumers, all sectors of the food industry including caterers, and Local Authority Enforcement Officers;
- funding research to investigate the causes and mechanisms of food allergy; and
- encouraging informative labelling of foods.

10. Most food allergy deaths occur when eating away from the home environment. To respond to this, the FSA published in May 2004 advice for caterers on food allergy and intolerance and will work to introduce food allergy and intolerance concerns into training for the catering and Local Authority enforcement sectors.

11. Even after clinical diagnosis, a high proportion of food allergic patients go on to have further adverse reactions, some of which can be life-threatening. The FSA provides detailed information about food allergy and food intolerance on its website to help and support consumers affected by such conditions, so that they can make informed decisions about the foods they need to avoid. The FSA is also currently working to provide practical information for people affected by food allergy and food intolerance and their families through specialist allergy clinics and GP surgeries.

12. Improved food labelling, scheduled to come into force in the UK in November 2004, will require food labels to indicate the presence of the most common allergenic food ingredients, regardless of the amount present, thereby making it easier for consumers allergic to such ingredients to avoid them.

#### *Environmental—air pollution*

13. Asthma has a variety of causes: these certainly include a genetic predisposition to develop allergic reactions to allergenic substances such as house dust mites and pollen. It is considered unlikely that air pollution has anything to do with this underlying predisposition. However, there is evidence to suggest that air pollutants increase the likelihood of developing an allergic response to, for example, house dust mites. Some experts believe that air pollution is playing a supplementary role but whether this is an important factor in the UK remains unknown. The Committee on the Medical Effects of Air pollutants (COMEAP) are currently working on a new report looking at air pollution and the causation of asthma. This will be published in 2005.

#### NHS CARE AND TREATMENT

14. The NHS offers a range of care and treatment services, developed locally to meet the varying needs of the population served and provides for:

- General information for the public
- Information and treatment through primary care
- Referral for diagnosis and identification of allergic triggers
- Treatment and care through specialist clinics.

#### *Information*

Access to information on allergy, and web-based links to the main voluntary organisations are offered through NHS direct online. NHS Direct also offers general advice as well as specific clinical advice for individuals.

#### ALLERGY SERVICES

15. When patients present with allergies, they may follow different pathways of care depending on the type and severity of the problem:

- Most patients with simple allergic disease will be dealt with in general practice.
- Some patients will be seen by organ-based specialists with an interest in allergy—eg in local hospitals.
- More complex cases should be seen in specialist allergy centres. Consultants in specialist centres have important links with organ-based specialists and GPs providing allergy care. Allergy care is best provided as a network, co-ordinated by specialist allergy centres.

#### *Primary Care—information/treatment/referral*

16. GP practices play a central role in treating people with allergy and in referring for diagnosis and specialist treatment.

17. The new general medical services (GMS) contract launched by the Department of Health in February 2003 was accepted by the profession on 20 June 2003. The contract includes a specific quality indicator for the treatment and care of people with asthma.

18. The new contract significantly benefits patients by improving the quality of care and widening the range of services available at GP surgeries. It provides an unprecedented level of investment into primary care to improve services to patients and revitalise general practice. UK expenditure on primary care will rise from £6.1 billion in 2002–03 to £8 billion by 2005–06, an increase of 33%.



### Allergy clinics

19. There are currently around 100 clinics providing services in allergy, mainly run by organ-based physicians, paediatricians and immunologists in response to patient demand.

### Specialist Allergy Centres

20. There are currently six specialist centres in England run by allergists providing a full-time service and a further nine centres offering a part-time service. These services are commissioned through the special collaborative commissioning arrangements covered by Specialised Services National Definitions (see paragraphs 28 and 29 below).

21. Specialised services for allergy include

- specific disorders; and
- allergic disease (including asthma, rhino-conjunctivitis, urticaria, angioedema and eczema) where this is severe, multi-system, not controlled or where an allergic aetiology is suspected.

This includes the more complex cases and those requiring special facilities for investigation and management that are only available in specialist centres, for example facilities required for challenge testing and immunotherapy. Conditions addressed in particular include severe multi-system allergic disease, anaphylaxis, and food, drug and venom allergies.

### Waiting times

22. Information on waiting times for clinical immunology and allergy treatment are collated together. Latest figures are shown below:

#### SPECIALITY FUNCTION—IMMUNOLOGY AND ALLERGY

GP WRITTEN REFERRALS ONLY									
Number of referral requests for first outpatient appointments		Effective length of wait from receipt of GP written referral request to first outpatient attendance (weeks)						Not yet seen at the end of quarter who have been waiting (weeks)	
GP Written	Other	0 to <4	4 to <13	13 to 17	17 to <21	21 to <26	26 and over	13 to <17	17 to <21
1,976	571	352	806	559	73	1	1	37	—

Waiting Times for 1st Outpatient appointments (England)—Quarter 4, 2003/04

23. Government action to reduce maximum waiting times will benefit people with allergies, particularly those who require referral to specialists for assessment and treatment. As part of the NHS Plan, inpatient waiting times will fall from nine months to six months by 2005. The maximum waiting time for a first outpatient appointment will also fall from four months (17 weeks) to three months (13 weeks) by 2005. The Government's eventual objective is to reduce the maximum wait for any stage of treatment to three months by the end of 2008.

### Workforce issues—numbers

24. Access to services will also be improved by increases in the workforce. Consultant numbers in immunology, which includes allergy, have increased by 28.5% from 63 consultants in September 1997 to 81 in December 2003. Numbers of consultants in allergy remain very low, but are increasing. The Department of Health has ongoing discussions with the British Society for Allergy and Clinical Immunology with the aim of improving the provision of consultant allergists.

25. The Department of Health is distributing central funding for the implementation of 400 more Specialist Registrar training opportunities in 2003–04 and giving NHS Trusts scope to create additional Specialist Registrar opportunities. For 2003–04, Trusts have the opportunity to create up to five locally funded Specialist Registrar training opportunities in allergy. In 2004–05, allergy was been allocated a centrally funded post, a further post has been allocated for 2005–06, and Trusts continue to have the option to locally fund additional posts.

### Workforce—Training

26. Responsibility for the content, standards, management and delivery of medical education is shared between regulatory bodies (eg the General Medical Council and the Specialist Training Authority), professional bodies (notably the medical Royal Colleges), universities, the Department and the NHS, where postgraduate deans have a pivotal role. While allergy is a growing issue of some importance, is not however practicable, possible or desirable for the Government to prescribe the exact training that any individual doctor will receive.

27. Training for general practitioners begins during their undergraduate degree and continues throughout the entirety of the doctor's career, through specific training posts and effective Continuing Professional Development and Continuing Medical Education. GPs are expected to keep their professional skills up-to-date.

## SERVICE DEVELOPMENT

### *Specialist Commissioning*

28. The development of allergy services has been, and continues to be, undertaken within the context of Shifting the Balance of Power and Improvement, Expansion and Reform, the priority and planning framework 2003–06. This provides new freedoms and responsibilities for the commissioning and prioritisation of health care to local health bodies.

29. Whilst primary care trusts (PCTs) are the primary commissioners of health care services for their local populations, there are collaborative arrangements for commissioning some specialised services, including specialist allergy services. Guidance on Commissioning for Specialist Services was issued in March 2003. This requires PCTs to work together in specialised services commissioning groups to plan, procure and monitor those services that are provided to large populations across many PCTs. Strategic Health Authorities (SHAs) are responsible for ensuring that their PCTs adopt effective collaborative arrangements for commissioning specialised services to ensure that:

- the right patient (clear patient selection criteria and referral guidelines) is offered
- the right treatment (evidence based, clinically and cost effective interventions) by;
- the right provider (agreed monitored, service/clinical quality standards) in
- the right place (optimising geographical access but avoiding unnecessary duplication of provision).

### *Local initiatives*

30. Within the context of specialist commission and improving services local health communities can encourage bottom-up improvements in allergy services. If they deem it necessary and appropriate, Primary Care Trusts can set local targets and performance manage progress locally. These may linking with or develop from patient feedback, both informal and formal (eg patient surveys), that can provide a local means of identifying shortfalls and the involvement and discussion with Patients' Forums.

## PRIVATE SECTOR/VOLUNTARY SECTOR REGULATION

31. Some allergy services—particularly allergy testing—are provided within the private and voluntary sector. In April 2004, the Healthcare Commission took over responsibility for regulating and inspecting the private and voluntary healthcare sector, which was previously the responsibility of the National Care Standards Commission (NCSC). The duty to regulate and inspect private and voluntary healthcare is laid out in the Health and Social Care (Community Health and Standards) Act 2003 (the 2003 Act).

32. During the statutory annual inspection an overview of the whole service provided would be completed, checking the establishment's compliance against The National Minimum Standards, issued by the Department of Health in 2002. Allergy is not a service which has its own category under the legislation, and therefore would not be specified on the establishments licence (certificate). Not all allergy screening services would come under the regulatory arm of the Healthcare Commission, as only those providing medical treatment are registerable. Therefore all those allergy screening centres that screen and treat will be registerable. No significant reported problems with the private sector have been brought to the attention of the Healthcare Commission. Where clinics manufacture injectable treatment vaccines on site under a Manufacturing Licence from the Medicines and Healthcare products Regulatory Agency (MHRA). This means that these clinics are then also subject to regulation by the MHRA.

33. Allergy tests are also offered by a variety of commercial outlets, including some health food shops and on internet sites. Before purchasing or using a test recommended by such an organisation, we would advise potential customers to ensure that the person advising them holds a professional qualification that is clearly relevant to the treatment of allergies.

## COMPLEMENTARY AND ALTERNATIVE MEDICINES

34. Several complementary and alternative medicines (CAM) claim to treat allergies. In the first instance, practitioners of a diet-based therapy such as naturopathy or nutritional therapy may test for a food allergy. Treatment often takes the form of fasting, dietary changes and supplements. We advise the public to check that any practitioner they approach is registered with one of the major professional organisations for that therapy, is covered by indemnity insurance, and subscribes to a common code of ethics.

*Witnesses:* **Rt Hon Dr Stephen Ladyman**, a Member of the House, Parliamentary Under-Secretary of State for Health, and **Mrs Patience Wilson**, Head, Programme National Service Framework for Long-Term Conditions, were examined.

**Q128 Chairman:** Can I welcome you to this session of the Committee and welcome our witnesses. Minister and Mrs Wilson, we are very pleased to see you. Could you introduce yourselves to the Committee members?

**Dr Ladyman:** I am Stephen Ladyman, the Minister for Community, and in my brief are Long-Term Conditions, which include allergies.

**Mrs Wilson:** I am Patience Wilson and I the Programme Manager at the Department of Health for Long-Term Conditions.

**Q129 Chairman:** Can I thank you for your cooperation and the very helpful evidence that you have given. Perhaps I could begin with a brief opener? Obviously we are not focusing on causal factors, as you made the point in your evidence, but one of the interesting things has been witnesses' thoughts on why we have this significant problem. The Royal College's document talks about an "allergy epidemic" in the UK. What are your thoughts on why we have this major problem? One of the issues, interestingly, is the suggestion that it is because we are now much more hygienic, in the sense that children do not have the experience of fighting off the bugs very early on. Do you have any general thoughts about that?

**Dr Ladyman:** Clearly I am not a scientist that focuses on these issues, so I am not in a position to give you any definitive statement. Genetics has to be a factor. The fact that it is the UK and the Anglo-Saxon world, which seems to have more of a problem than the rest of the world, would indicate that there is a genetic susceptibility. I have read some of the things that your witnesses have told you about the hygiene hypothesis, and clearly that is one possibility. Environmental factors must be another one that we look into. My guess is that at the end of the day this will be narrowed down to a range of factors rather than one single, simple factor.

**Q130 Dr Taylor:** Minister, we have a basic difficulty in that the NHS has a plan to work according to diseases of a system—cardiology, gastroenterology, whatever—and with allergy you have something that goes right across all the fields. We have heard from the real allergy specialists that there are disadvantages of the clinics that have just grown up on the back of a respiratory sort of clinic that copes with asthma, and that they can miss out on the food allergies. How did this state of affairs occur, where you have the very few highly specialised allergy clinics that can cope with allergy right across, and far more of the ones where they have grown into it from their other interests?

**Dr Ladyman:** How did it happen historically? I suspect that it happened like that because that is the way these things have always happened—people have identified conditions and have reacted to those conditions. What I would counsel you about is that I think there was an implication from some of your earlier witnesses that there was a consensus view about the benefit of specialist centres. I do not

believe that there is that consensus view; I believe, for example—and I think you have had written evidence to this effect from some of the other specialist areas—that dermatologists take the view that if you have a skin condition or eczema you should start off with a dermatology specialist rather than going to a multiple allergy centre. Dieticians take the view that you would be better off seeing a dietician first. There are some specialists in respiratory diseases who think that if you have asthma you ought to start off with lung specialists and respiratory specialist. The impression I got from some of your earlier witnesses was that what they would like to see was a direct referral of people from their GP to their allergy specialists, and I think that is probably appropriate where there is clear evidence that the person is suffering from multiple allergies, but it is not necessarily the best thing to do is if it is clear that the allergy they are suffering from is more specific than that.

**Q131 Chairman:** Are you suggesting that we could be manipulated by certain professional specialists, in their own interests, to come up with certain conclusions that are not necessarily accurate?

**Dr Ladyman:** I would not put it as harshly as that.

**Q132 Chairman:** Were you implying that?

**Dr Ladyman:** I would say that they have a clear view of what is necessary from their experience and, from their experience, because they are dealing mostly with people with multiple allergies, they can see the merit in people with multiple allergies coming straight to them rather than through a half-way house of another specialist. All I am saying is that that is not necessarily the only view of the way the world ought to work, and I think if you look in the written evidence that you have received, as I am sure you have, you will see that there are other specialities who are actually saying that to you.

**Q133 Dr Taylor:** I have become very used to members of the profession in minority specialities desperately trying to push their speciality, and I honestly do not think that is the case here; I think we have figures to show that very severe allergy is incredibly common and is increasing. I cannot quote any figures from memory, but we have lots of them in the evidence. It is very, very worrying. All that these true specialists in multiple allergy are asking for is a spread across the country of really only a few more clinics than there are at present, because they are necessary for their basic training when we want to expand GPs to do much more of the work. The argument from them would be that the people working in, for example, asthma clinics are not actually trained in allergy—they are trained in asthma but not actually in allergy—and this is the huge gap because they miss out the other allergies that are going on.

**Dr Ladyman:** I understand their view. What I am saying to you is that it is not necessarily the view of everybody that that is the best way to handle these

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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things. You started off by saying, how did these services emerge in the way that they did? They have emerged in the way that they have because people have been responding to the situation as they saw it, and to the view that very often you are better treated by a generalist rather than a specialist. Sometimes, when it is believed that you do not have a multiple allergy, you have a single allergy, there may be a specialist that you ought to see before you go to a multiple allergy centre. I think it is a legitimate view for them to say that in their belief the world is changing and the pattern of services therefore needs to change to reflect that. What I am saying is that that is a debate that we all need to be in and they need to be convincing the people who commission services locally because, remember, we are again in this cleft stick, which I frequently am when I come before you, where I have to say to you that these are decisions that we have now pushed out to the field to commission services locally. So I think it is perfectly feasible for them to make these arguments to central government and to the Health Select Committee, and those messages will no doubt get down to the commissioners; but it will be ultimately for the commissioners to decide that they need to create new specialist centres in their areas, if the consensus of view in their area is that there is a need.

**Q134 Dr Taylor:** That is the whole point of this inquiry, that we are opening up this debate on this very question.

**Dr Ladyman:** Exactly, and that is why I welcome the inquiry.

**Q135 Dr Taylor:** It is not really realistic to say that PCTs should commission when they do not even know what it is that they should be commissioning, and there is nothing specialist in their area to commission.

**Dr Ladyman:** That is why it was so helpful that the Royal College of Physicians produced their study which set out their view of this increasing problem, and their statement about the models that might be used to address it, and I think that will prove to be a very helpful and supportive document for PCTs who need to commission services. They are all starting this summer to write their next three-year Local Delivery Plans, and one of the pieces of advice that I have given, both to the Allergy Lobby and to the Royal College, is that this is a very important time for them to be getting those messages to commissioners, to say, "Here is something that is changing, it is increasing; you need to be thinking about it in your next three-year plan, and here are our models as to how you can address it."

**Q136 Dr Taylor:** So our report will continue this discussion and hopefully transmit to PCTs the importance of it.

**Dr Ladyman:** Absolutely, if that is the conclusion that you come to, yes.

**Q137 Mr Burns:** Just on this point, I fully accept what you are saying, if you are going to have a devolved provision service in decision making, and

you mentioned PCTs to Dr Taylor. But do you not think that there is also a role for Strategic Health Authorities and, if so, what is that role?

**Dr Ladyman:** I think the role of Strategic Health Authorities here would be to look—because if one decides to set up a specialist service it is clearly going to have to deal with patients from far more than one PCT—at the standards that government is setting centrally, to look at the sort of reports that the Health Select Committee and the Royal College produce, and to say to their PCTs, "Do we not think that we have a problem here and we need to be thinking of a way to address it?" Whether they decide to take the lead, or whether they would consider it to be more appropriate that they appoint a lead PCT team within their Health Authority to take the lead and to go into this in more detail, would be a matter for them. Certainly I think that is a valid suggestion.

**Q138 Mr Amess:** I have real concerns about the way the Department is dealing with this whole question of allergies. I feel passionately that it is a very, very serious problem, and I believe it is only being dealt with at the margins, and it is one of these occasions where I really wish that witnesses were here together with the Department so that we could have some real exchange as to where they are with this particular issue. There is certainly a complete contradiction in terms of where the funding is coming from. We heard from the clinician witnesses that much of the funding of the initiative for the provision of new full-time allergy clinics come from academic sources. The Department completely contradict that. You cannot both be right; someone is being economical with the truth, spinning the situation. What really is the case in terms of funding of these allergy clinics?

**Dr Ladyman:** First of all, let me say that I am as passionate about this as you. I notice from the earlier evidence that you suffer from allergies; I have experienced anaphylaxis, my allergy is so severe. So, believe me, there are not many areas of my ministerial portfolio that I can claim expertise in, but this is one in which I can claim expertise! Secondly, although it would be nice if all the witnesses sat round together with the Health Select Committee and thrashed these things out, I have met most of the groups that have given evidence to you anyway. I would also say to you that if you really wanted to get to the bottom of this you would have to have some of the groups from whom you have not taken oral evidence, because in your written evidence that you have received there are some divergent views about the way forward. Do I think that this is serious? Of course, I think it is serious. Do I think that the numbers are increasing? Certainly I do. Do I think that there is clear evidence though of unmet need in the system? There, I think the evidence is less clear and, in my view, and looking at the waiting list figures and the referrals—given that we can have a debate over whether referral patterns are correct or not—I believe that the NHS has absorbed the increase and has coped with it reasonably well. It could always do better, of course it could always do better, but I think it has absorbed the increase pretty

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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well. Do I think it is right that services are tagged on the back of academic services? I was a bit surprised that one of your witnesses—I may be doing him an injustice, I think it was Professor Holgate, who is at Southampton—was pointing out that he was funded by the Medical Research Council rather than the National Health Service. He had a concern about that, and I can understand that concern, but, equally, is it not valid that with a rapidly changing field—and bear in mind this is rapidly changing, as you have acknowledged as a Committee this is something that has taken you by surprise, this increase has taken the clinical world by surprise, and the difference between the level of the problem in this country and the level of the problems in other countries. We do not have a clear idea of what is causing it, as all of your witnesses have said, and as we established right at the start. So is it not a good idea that some of the clinical delivery mechanisms are actually on the back of the academic environment because we have that marriage then between the leading research and clinical practice. As one of your witnesses has said, quite correctly, the UK is actually at the forefront of research on this subject.

**Q139 Mr Burns:** You say you felt that the NHS was absorbing the increase in the problem and that you had looked at the waiting list figures. What are the figures?

**Dr Ladyman:** The waiting list figures for allergy we cannot give you because they are not collected in that way. The waiting list figures for dermatology we can give you, and for referrals to respiratory disease specialists we can give you, and we have given you those figures. We can also give you the general figures for total waiting list referrals. What we cannot do, because we do not collect the figure separately, is give you specific figures for referral for multiple allergies, and we cannot separate out immunology and allergy figures. Maybe one of the things that we all need to reflect on is whether we should do some more analysis and collect those figures, but the downside of that of course is that it means a further demand on the Health Service to provide that data.

**Q140 Chairman:** More bureaucrats?

**Dr Ladyman:** I resist the temptation to call people who are doing absolutely valuable and essential work bureaucrats. There are others around this table who demean them like that. Certainly it would mean more people to gather the paperwork and do the figures.

**Q141 Mr Burns:** Can you give us the waiting list figures that you were specifically referring to in your answer to Mr Amess, which you have seen, as you told us in your answer? Can you share them with us now to help us move forward?

**Dr Ladyman:** I thought we had shared those figures with you in our written evidence.

**Q142 Mr Burns:** Given that you said you had seen them, I assumed you would be able to tell us now what they are.

**Dr Ladyman:** I can certainly pull them out of my paperwork. I think there is 1% over 20 weeks for referral to a specialist, but those were figures based on figures earlier this year, so even those figures are a lot less now.

**Q143 Mr Amess:** I would like to develop one or two points because I listened carefully to what you have said about the role of the academics, and none of that I would dispute. But would you agree with me that their priorities are not always consistent, so that makes it a very variable situation, whereas the Department is there. I am not delighted that you are a sufferer, and it was not a personal attack upon you because it has gone on for a long while and I do not think it has been taken seriously enough, but could you give the Committee a little more detail as to the evidence that the NHS has absorbed this situation pretty well? How tangibly can we see that this has been taken seriously?

**Dr Ladyman:** First of all, let me explain again. If there is an academic institution in an area that is providing a clinical service, which they would presumably be doing because they regard that to be mutually beneficial, the fact that they are provided with clinical service helps their research and helps keep them current, and the fact that they are so current in the situation means that they can provide an optimal clinical service. If that exists in a particular area it seems to me perfectly rational that, while it exists, the local Health Services that commission services take advantage of it. Were they to stop existing then Health Services in the area would have to commission a new service to replace that. So in the situation, which I think Professor Holgate describes, when he retires and the Medical Research Council or the University, whoever it was, decide to appoint a different specialist, and therefore the multiple allergy service he provides ceases to exist, the unspoken implication of that in his evidence was that there would be a valuable service that would disappear for ever and would not be replaced. That is the bit I disagree with because it would be the responsibility of the local Primary Care Trusts working within the framework of the Strategic Health Authority in that area then to say, "If that is not going to be there in the future we need to find another service and commission service, so we will recruit another allergy specialist and we will set up another service to replace that."

**Q144 Mr Amess:** That does not seem to be happening at the moment.

**Dr Ladyman:** I disagree and that is where we come back to the waiting times for the referrals. Mr Burns has asked for the figures and they are given at paragraph 22 in the written evidence that we gave to the Committee.

**Q145 Mr Amess:** What is your advice to the three million or so sufferers, where do they go for help at the moment?

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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**Dr Ladyman:** They go to a variety of places. What we have here is a triangle, I guess. First of all, there will be a huge body of people who will be self-medicating, who will use the advice of pharmacists, NHS Direct, and will be perfectly happy controlling their allergy through self-medication processes. Then there will be those who go to their GP and the GP will feel competent to deal with their issues. Then there will be a smaller number where the GP feels that it is necessary to make a referral and the GP will make a decision as to whether that person should be seen by a generalist or by a specialist in a particular type of physical function, or by sending them to a multiple allergy specialist. In a much smaller number of cases the people will end up with a multiple allergy specialist. What we need to do is constantly look, as best we can, at how long it is taking people to get to those multiple allergy specialists, if that is where they need to be, and that is a matter for local commissioners, to decide on how long it is taking people to see those specialists and to commission more services if they need them.

**Q146 Mr Amess:** Thank you for explaining the situation, but would you accept that the evidence we have had from patients and the profession is a little bit different?

**Dr Ladyman:** No, I would not say that. What I kept reading in the evidence was people saying things like, "I am sure those figures are true, but it is not what I have heard." I am sorry, but these are the figures and we have not fiddled them, we have not made them up and we have not plucked them out of the air. Maybe they are not as perfect as they ought to be because we cannot tease out all the different types of specialism, but they are the figures. The fact that somebody has telephoned the help line and said, "I am having difficulty to get to see a multiple specialist," that is a specific problem that needs to be dealt with. But I do not think that you can extrapolate from that anecdotal experience and say that somehow the figures are all wrong.

**Q147 Dr Taylor:** Can we take it from what you have said, that if a professor retires and is replaced by somebody else, the NHS would step in and keep that clinic going?

**Dr Ladyman:** No, you cannot say that. What I have said is that the NHS would review the availability of services locally and make sure that they had a resource that patients could continue to be referred to. Whether it was that clinic or another clinic or some other sort of arrangement that they made with another area would be a matter for them, having looked at their local position. So I am not going to give you a blanket reassurance that if Professor Holgate retires, as he postulated in his evidence, that the clinic would immediately continue with somebody else in it, but that might be a choice that the local Health Authority decides to take.

**Q148 Dr Taylor:** Is it fair to ask you, would you know what happened at the Brompton when the Professor of Allergy did retire and was replaced by a geneticist?

**Dr Ladyman:** I do not have evidence on that but I am happy to find out and write to you, if that would be helpful.

**Q149 Dr Taylor:** Because it seems as though we risk losing these few specialist clinics on several occasions in the future.

**Dr Ladyman:** I do not want to belabour the point but the local commissioners of service would be responsible for deciding what was the best way to replace that service. One of the things they would do in the case of a clinic, which was offered on the back of an academic institution, is to have discussions with that academic institution and decide whether they were intending to replace the academic with another similar academic, and therefore to continue service on the back of that academic institution. If then the decision were taken that that person will not be replaced with a similar academic, then they would have to say, "What are we going to do because we still have a need to provide this service?" They will then look to other academic institutions; they will look to appointing specialists based in hospitals that are going to provide a totally clinical service.

**Q150 Dr Taylor:** "They" would be the Strategic Health Authority and the local PCT?

**Dr Ladyman:** They would be the local PCTs working within that framework, yes.

**Q151 John Austin:** Can I come back to this issue of waiting times? I appreciate that the evidence which we received, both written and oral, has not been uniform and there have been conflicting views. When we had our first evidence session our witnesses specifically challenged the Department's figures on waiting times and argued that the figures produced are not credible because they largely relate to immunology as well as allergy.

**Dr Ladyman:** Yes, exactly.

**Q152 John Austin:** Also because many of the allergy sufferers are not in there because they are on other waiting lists.

**Dr Ladyman:** Yes, and I have acknowledged that and accept that.

**Q153 John Austin:** You accept that they are fairly meaningless in that sense to assess the extent of allergy?

**Dr Ladyman:** I accept that many people being referred for allergies will be being referred, for example, to dermatologists, dieticians or to other people, and therefore their figures are in the waiting lists for those specialities. I accept entirely that we cannot tease apart allergy and immunology figures. What I do not accept is that you can conclude from that that there are huge waits for people who need to see allergy specialists, because we have the overall figures for waiting times. What I do think might well be a case which leads people to believe that they are not getting their referral quickly enough is the one that was highlighted by your first evidence session, where people are first of all referred to a generalist or perhaps to a dermatologist and then, after having

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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gone through that process, it is determined that they have a multiple allergy and need to be referred on again to the specialist centre, and therefore you have two periods of referral in an individual's case. That is clearly not something that you would want to see happening, and maybe that is the reason why they have this anecdotal evidence that it takes a long time to get from GP to multiple allergy specialist.

**Q154 John Austin:** Would it be sensible to separate allergy and immunology figures?

**Dr Ladyman:** As I have said, that is something that we would need to reflect upon, but we need to look at the downside of that as well, and the downside of that is that somebody has to go and collect those figures and somebody has to start filling in separate forms with that data, and I then have to answer questions next Tuesday at oral questions from our colleagues on my left here, saying, "Why are you appointing more managers and why are you overloading the National Health Service with red tape?" There are costs associated with collecting that data and we have to balance the gains with the costs.

**Q155 Dr Naysmith:** We have had quite a muddled discussion since we started, partly because it is a muddled area and partly because there is some controversy. Could I clarify exactly what it is that the Department and you believe in terms of the model for looking at the care for allergic diseases? There seems to be a fair measure of agreement about this increase and prevalence, although there is a lot of argument about what is causing it, and there are different theories and, as you have rightly said, in my view, there is still a lot to be found out in that area. Nobody disputes that most allergies are a primary care responsibility?

**Dr Ladyman:** Yes.

**Q156 Dr Naysmith:** You go and see your GP first, or you may be carted off to hospital. There seems to be a very worryingly large increase in severe and complex allergies on top of this, which needs specialist treatment and care. You said in a written Parliamentary answer in May 2003 that severe diseases are now common.

**Dr Ladyman:** Before you finish that question could I just pick up something that you said in it? I do not think that we should confuse severe with complex. I have severe allergy but it is caused by one thing—it is caused by rats. It is not a multiple allergy.

**Q157 Dr Naysmith:** We are coming to the whole point of this question. So you are saying that some severe allergies are perfectly reasonably treated by GPs?

**Dr Ladyman:** No. If you had a very severe allergy, such as a food allergy, then it might be appropriate that it is dealt with by a specialist in food allergy or a dietician; it might not be appropriate or necessary for you to go to a multiple allergy specialist centre.

**Q158 Dr Naysmith:** When you talk of multiple allergy specialist centres, do you mean an individual who has a multiple allergy or a place where you go to if you have all sorts of different things?

**Dr Ladyman:** I am saying that it could be either of those things; it could be an individual who has a multiple allergy, or it could be somebody where it is not clear what is causing their allergy and who therefore needs to go to somebody who can tease out exactly what it is that is causing their allergy. In some cases it can be perfectly clear. If it is a peanut allergy and you get it when you eat a peanut then maybe there are local specialists who can help you with that, without the necessity to refer to the specialist centres that you are talking about. I am just saying that that is a reasonable route for the National Health Service to help you, and it is the route that some of the other specialities say is necessary. As I said, the dermatologists, for example, in the written evidence that you have received, certainly seem to be implying, if not stating directly, that they believe, for example, that people with eczema should go to a dermatologist first.

**Q159 Dr Naysmith:** So basically you are saying that it is not necessary for people to be referred on to a specialist centre for allergies?

**Dr Ladyman:** Exactly, and in fact for many people the first place you would need to be dealt with would be a generalist; for other people it may be a different type of specialist because it is clear what is causing your allergy; then for some people, who either have multiple allergies or allergies that they do not know what it is caused by, to go to a specialist centre.

**Q160 Dr Naysmith:** Since you have read the evidence that was given to the Committee previously, you know that there are people who disagree with that?

**Dr Ladyman:** Absolutely, and that is what I have said; I started off by saying that there is not a consensus on this.

**Q161 Dr Naysmith:** You are not accepting that model?

**Dr Ladyman:** No. The only point I was trying to make to you as a Committee was that the people who you see are part of a consensus, but they are not part of a wider consensus, and some of the people who have given you written evidence have given contrary viewpoints, and they are possibly equally valid.

**Q162 Dr Naysmith:** Can we agree on roughly three million? I know we have been arguing about figures for about 20 minutes or so, but three million is a rough estimate of severe allergy?

**Dr Ladyman:** Yes. I am happy to accept the figures that are in the Royal College's report as probably the best.

**Q163 Dr Naysmith:** So they need specialist care of one sort or another, whether it is in a clinical allergy centre or not?

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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**Dr Ladyman:** Yes.

**Q164 Dr Naysmith:** At this point I want to read out two or three statements that were made in the Westminster Hall. Melanie Johnson said in October 2003, “We agree NHS allergy services need improvement,” and that the Department had taken the provision of these services very seriously indeed; that they were starting from a low base and had some way to go. That was in October, recognising that there was a problem. So what has happened since? There was recognition there was a problem, and has anything been done to improve that?

**Dr Ladyman:** I think what she was suggesting was that clearly this is a growing problem; it has, as has been identified, become increasingly severe and the NHS needs to keep pace with both the change in medical knowledge and the change in prevalence of the condition, and that is what we are attempting to do. The sorts of things that we are doing, for example, we are talking to the National Institute for Clinical Excellence as to whether there are any pieces of work that they ought to be doing to help us, and one of the things we need to be chatting to them about is the possibility that they may provide a guide about anaphylaxis, for example. So we are talking to them about what needs to be done. We are talking to the Food Standards Agency about the work that they can help us with. We have the National Health Service Improvement Agency working on these issues. We have the Health Care Commission starting to inspect. We have the new Standards for Healthcare, which are being published—the Core Standards are going to be published shortly. We have the National Service Framework for Long-Term Conditions, which comes out at the end of the year, which focuses on neurological conditions, but is being written in such a way as to provide a lot of help for people with other chronic conditions. We have the announcements that the Secretary of State has made recently about chronic disease management. We are moving forward on all those areas. We have the Expert Patient Programme, where we are moving forward to try and help people self-manage the condition. So we are working forward on a whole raft of areas.

**Q165 Dr Naysmith:** I have to put this question to you: that there is a lot of talking going on, there is no doubt, from what you have said, and much discussion, but is there any action taking place in setting things up?

**Dr Ladyman:** It is easy to say that there is a lot of talking going on, but all of these things emerge in action. When we produce the New Core Standards, for example, then commissioners have to work with them and commission services accordingly. The Royal College’s blueprint document itself has stimulated commissioners to look at the commissioning of local services; that is why they wrote it, that is why we welcomed it. The work that you are doing will stimulate commissioners to commission new services and to check that they are actually meeting their waiting times and that they

are meeting the need that has been identified. I think there is a lot going on on the ground. I do not know if Mrs Wilson would like to add anything specific?

**Mrs Wilson:** I think there is quite a lot set out in the NHS Improvement Plan, which is putting a new emphasis on moving away from focusing on acute conditions and tackling acute conditions to actually making real changes for people who live with conditions that can affect them their whole lives. That includes allergies, obviously, as well as eczema, as well as some of the other conditions like the muscular-skeletal disorders.

**Q166 Dr Naysmith:** We have been told that there are some treatments that can, if not cure, make life very much more bearable for people, so they do not necessarily have to go on chronically, for the rest of their lives, seeing a specialist.

**Mrs Wilson:** Is this about desensitisation?

**Q167 Dr Naysmith:** No, drug treatments that are helpful. I am attacking a little you categorising them as chronic diseases.

**Dr Ladyman:** Drug regimes we make available to people, once it is identified that a drug can help. I think it is £100 million a year we spend on drugs for people with allergies.

**Mrs Wilson:** And we have done a number of technology assessments around drugs in this area.

**Q168 Dr Naysmith:** I was not attacking what you were saying, but perhaps pigeon holing chronic disease sufferers for the rest of their lives.

**Dr Ladyman:** Where the disease is treatable it will be treated.

**Q169 Dr Naysmith:** They are almost curable, some of them.

**Dr Ladyman:** One would hope so.

**Q170 Dr Naysmith:** I am not a great one for desensitisation therapy, personally.

**Dr Ladyman:** I decided not to go through it, as well!

**Q171 Dr Naysmith:** One last question in this area. You have suggested that you do not accept this idea of referring people on to clinical allergy centres for everyone, and yet this is something that has been a successful model in the National Health Service, and is recommended for cancer services.

**Dr Ladyman:** What I am saying is that care for individuals needs to be tailored for the needs of that individual, and for some people it will be the right solution to send them to such a specialist, and we certainly need a number of such specialists and specialist centres to deal with this increasing problem. All I am saying is that there are alternative routes and it is for clinicians to make decisions about which is the most appropriate route for their patient.

**Q172 Dr Naysmith:** What I am saying to you is that there was a time, not very long ago, when the results in treating a number of cancers was not very good—below the European average—and we deliberately set up cancer Tsars and all sorts of things, and the



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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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results are improving dramatically. There is a need which has been established for allergy services. Could we help that problem by having something similar?

**Dr Ladyman:** I accept that entirely, but the reason that by concentrating cancer treatment in specialist centres they managed to improve outcomes was because they created centres of excellence, where the doctors were able to share information and were thereby able to remain at the forefront of technology and the subject, and therefore guarantee people the best sort of treatment. Some of the specialist centres in allergy are doing exactly that, and that is why they are tying on the back of academic institutions, because that is a very important place for them to be in order to stay at the forefront. That does not mean to say that the only place that you can be treated for cancer is in the local centre of excellence. If I could pluck the example out of my own area, the centre of excellence is in Maidstone, but many of my constituents who have treatment will be treated in the local hospital in Margate, even though the expertise is being delivered from Maidstone. So it is no different from the solution that you are talking about.

**Q173 Dr Naysmith:** There are still places where the GPs have more specialists to whom they are going to refer their patients, either Maidstone or Margate.

**Dr Ladyman:** That is the responsibility then of commissioners in that area to ask themselves whether that is acceptable and how they are going to commission that specialist service in that area. I note the very clear indication in the Royal College's blueprint that many of the specialist services are in the south and southeast of England, and there is limited geographical variation of them.

**Q174 Chairman:** Not in Yorkshire. A population bigger than Wales and not one.

**Dr Ladyman:** Exactly, and that must be something that local commissioners in those areas take seriously.

**Q175 Mr Amess:** There seems to be enormous disparity with the figures that have been submitted in such a way, frankly, that it seems to make the whole situation incredible. For instance, the number of referrals in the Department's submission appeared to be very low. We are told over 2,000 written GP referrals in the quarter, so that is 8,000 a year. Yet one large allergy clinic alone might be receiving 2,000 to 3,000 referrals a year. Analysis of the BSACI website indicates that altogether something like 50,000 cases a year can be dealt with at the clinics. These are huge disparities. So, Minister, are you confident that the Department is serving you well with these figures? I am not seeking to embarrass you but these are extraordinary disparities.

**Dr Ladyman:** As I said, in order to get the total figure for people being referred as a result of allergy we would have to do an analysis of the referrals to dermatology clinics; we would have to do an analysis of the referrals to respiratory lung disease specialists;

we would have to do an analysis of referrals to dieticians; as well as doing further analysis on the immunology and allergy figures that we have given you. We would then have to add up all of those numbers and then we would be able to come to you and say, "Here is the totality of people who have a specialist referral for allergy and here is how long they have to wait." We simply do not have those figures. What we have are the aggregated figures that show the aggregated waiting times in those specialities, and we have the figures that we have given you, which are the joint figures between immunology and allergy. I will wait with interest as to what your report says, and if you come to the conclusion that we need to do more analysis of this data I will reflect on that, and if I decide to do more analysis of this data I shall pray in aid your report when I am standing at oral questions and you object to the fact that I am collecting the data.

**Q176 Mr Amess:** Do you feel at the moment that a more accurate collection of data is a waste of valuable resources?

**Dr Ladyman:** I think that is certainly something that we have to take very seriously.

**Q177 Mr Amess:** It does slightly cast doubt on the method of recording these elements. I am a little puzzled and, frankly, slightly worried about it all.

**Dr Ladyman:** I think you have hit on an alternative route to getting this information that we may need to reflect upon, that, maybe, without adding to the total amount of data collected, there is a way in the future, given this increasing problem, that we can clarify the existing collection of data to be a bit more specific in this area, and therefore not add to the total amount, but I am not in a position to give you those figures now. It would not be a quick process, nor would it give you figures in the future.

**Q178 Mr Amess:** It is something you might look at?

**Dr Ladyman:** Absolutely, I am happy to look at it, yes.

**Q179 John Austin:** I accept the answer you have given to David and the very clear response you gave to my question earlier, but the National Allergy Strategy Group wrote to the Department in November of last year and have not had a response. Perhaps you could find out why.

**Dr Ladyman:** Perhaps they should have written to me!

**Q180 Dr Taylor:** I am quite puzzled how to get at this because you said fairly early on that the case for unmet need was less clear. We have to somehow get at the unmet need, if it is there, but it is difficult because if there is not a service to refer somebody to then you do not record the cases that have not been referred. You have mentioned yourself, and I do not want to dwell on that, but is there not a record in GP practices of the numbers of patients with anaphylaxis—the really most severe end of it? Is there not a relatively simple way of getting at this sort of gap?

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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**Dr Ladyman:** I do not know whether we collect figures on anaphylaxis. I do not know if Mrs Wilson knows?

**Mrs Wilson:** Each GP's records will record very clearly which of their patients have anaphylaxis. Whether each GP practice could then easily give that figure, I would find less competent. We can take that away and check.

**Dr Ladyman:** There is the new contract a measure which allows us to record whether GPs have in their practice the means to treat anaphylaxis—it is one of the quality measures. What I do not know—and I will find out for you and write to you—is whether simply all that will do is record how many GPs are capable of dealing with anaphylaxis, or whether it will also go on to give us data about how many people with anaphylaxis those GPs are dealing with. I am happy to try to tease that out and to write to you if I can find that out.

**Q181 Dr Taylor:** It must be possible to find out the number of self-injection adrenalin kits that are given to people, self-adrenalin inhalers. Would there be any future in investigating the amount of use of those?

**Dr Ladyman:** It may well be that we could find that information and I will certainly see if we have that and then let you have it.

**Mrs Wilson:** We should be able to get that detail.

**Q182 Dr Taylor:** Certainly the impression—and I am afraid at the moment it is only an impression—is that if you are a practising physician somewhere and you get somebody with a difficult multiple allergy, to find the nearest place to send them to—and we have a map—there are only a very small number of multiple allergy clinics. It is relatively easy to send somebody to a respiratory physician, but they may not pick up the multiple allergy. It is something like 60% of people with an allergy have a multiple allergy.

**Dr Ladyman:** I accept that. As we started off, there is not a consensus about whether a referral should be made straight to a multiple allergy specialist. There is the view of the dermatologist, for example, that if it is a dermatological condition it should start with a specialist dermatologist. So the GP is not necessarily always looking immediately for a multiple allergy specialist.

**Q183 Dr Taylor:** I absolutely agree. The vast amount can be coped with by the GP; it is only the very occasional one that needs a specialist service, and that is what is then so difficult to find. I am desperately trying to get at the unmet need for that highly specialist service.

**Dr Ladyman:** Where I would agree with you is that it would seem logical to me that, given the state of our knowledge, we cannot know how many times a GP would prefer to send somebody to a multiple allergy specialist but then settles for second best because he does not know where the multiple allergy specialist is. How could we ever collect that data? How could we collect that in any speciality in any condition?

**Q184 Dr Taylor:** Terribly difficult, yes. Can I make a comment with a question about NSF because it seems more and more that this Long-Term Condition NSF, is almost becoming a dustbin to pile everything into? It started with neurological conditions and, as one of our other members said, really with allergy it should not be a chronic disease. You do not have a chronic disease, you cope with it, so it is not appropriate.

**Dr Ladyman:** The only point I was making about the NSF Long-Term Conditions is that it is focused on neurological conditions but it is being drafted in a way to give guidance about the creation of systems for people who are managing other chronic conditions as well. So there will be generic guidance in it as well as neurologically specific guidance in it. So for those people for whom their allergy is a chronic condition, such as asthma, they may well find that there are things being set as standards in the NSF for their local National Health Service to implement that are of benefit to them. That is the only point I was making. Certainly I was not suggesting that the only route that people should look for further improvements is through the Long-Term Conditions NSF. Clearly that is not the case.

**Q185 Dr Taylor:** Can I move on to targets? On several of our inquiries in various different specialities we have always got the message from Primary Care Trusts that they are lent on by Strategic Health Authorities to meet targets, and if there is not a specific target then that gets rather pushed under the carpet. How does one cope with that because allergy is one of the things that seem to be pushed under the carpet?

**Dr Ladyman:** You would not expect me to completely agree with that analysis of the pressure that they are under.

**Q186 Dr Taylor:** It is a thing that comes across to us time and again from PCTs.

**Dr Ladyman:** What PCTs are expected to do, in drafting their Local Delivery Plans, is to take account of nationally set priorities, set down, for example, through the National Service Framework and the Care Standards that we are about to publish, and then look at the needs of their local population and produce their Local Delivery Plan. That Local Delivery Plan then will be the basis for further action for the period of the plan—so the three-year period. Clearly, one of the things that they do when they are working out their Local Delivery Plan, it would be natural for them to start off with any targets that have to be met. So, for example, if there is to be a target on reducing waiting times at the local Accident and Emergency Centre, then they have to make sure that there is sufficient money passed on to the Acute Trust and the Accident and Emergency that they can meet that target. That seems to me to be both a statement of the obvious and a perfectly reasonable position.

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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**Q187 Dr Taylor:** But if Local Delivery Plans do not fit in with a particular target is there any hope that PCTs will be less lambasted for not meeting that particular target?

**Dr Ladyman:** Local Delivery Plans have to take account of targets; that is what they are, they take account of all the targets and all the nationally set standards and then they take account of local need and they marry up all those things and they say, "This is how we are going to deliver on all these things over the next three years."

**Q188 Dr Naysmith:** Could I just chip in there with something that I think is very relevant? We have had evidence from lots of people that commissioners commission so much to specialists services in this area, and obviously if there is no more money they do not get any more, yet GPs sometimes continue, in different parts of the country, to refer people for whom there is no money, there is no commission service. How can that happen under the system you have outlined?

**Dr Ladyman:** I am not sure that I entirely understand what you mean.

**Q189 Dr Naysmith:** GPs provide patients by referring them on to the specialist centre. We were given evidence that quite often it happens is that there is no service or the service is grossly oversubscribed and the GPs keep on referring the patients.

**Dr Ladyman:** Under those circumstances it is the responsibility of the GP to talk to their Primary Care Trust about the need to change their commissioning practice and to commission extra service. That is why we based healthcare and healthcare planning around primary care.

**Q190 Dr Naysmith:** People who gave evidence seemed to suggest that this was something that happened regularly.

**Dr Ladyman:** The key targets that the PCTs are given when they write their Local Delivery Plans, before all others, are to take account of the health needs of their local community. It is difficult to say somehow that there is a conflict in the targets that allow the Primary Care Trust to ignore some health need in their local community; that because there is not a target that says you have to do such and such on allergy that they can ignore allergy. What I do think is probably reasonable criticism is to say that perhaps there was not the genuine recognition of the needs of allergy sufferers when the last round of Local Delivery Plans were written, but since then we have had the Royal College Report, we are having your report, we are having generally a greater recognition of this problem in the community, and I would be very surprised, therefore, if Primary Care Trusts around the country this summer, when they start sitting down to write their Local Delivery Plans, were not thinking, "We need to do a bit better for allergy."

**Q191 Dr Taylor:** Do you think public health specialists on Primary Care Trusts have enough input because allergy is primarily something that one ought to be able to prevent with adequate services? Do you think the public health specialists are pushing it?

**Dr Ladyman:** I really cannot tell you. I do not know if Mrs Wilson can.

**Q192 Dr Taylor:** Should they be?

**Dr Ladyman:** Of course they should, and that is why public health specialists are part of primary care and will be having input into the writing of Local Delivery Plans. If you have read any of my speeches on the area of my portfolio which impact on the NHS and other areas of care you will have heard me say that we need to move generally to a more proactive service, and in the National Improvement Plan there is a very specific commitment by the Secretary of State that the Health Service will move from its traditional role as a sickness service to being a genuine Health Service, and the White Paper that comes out later this year will be stating very firmly the need to look at public health issues and proactive activity. So I 100% agree with you and I am not going to sit here and tell you that I think it has been happening in the past—but it needs to happen in the future.

**Q193 Dr Taylor:** Prevention is very important?

**Dr Ladyman:** Absolutely. It is a lot cheaper than cure.

**Q194 John Austin:** Can I go back to the data point? Sorry to be a bore because I was quite happy with the answer you gave until I looked at the evidence we had last week from Professor Warner. He told us that the department did actually introduce a coding system for recording allergy care in April 2004 so that the volume of work could be measured but it has not been introduced because the NHS managers say that the service is not there. Is there a new service?

**Dr Ladyman:** I will find out whether a figure was put forward like that. What is not the case is that if it was not introduced the reason for it was that it might show up some unmet need because that just is not the way things work. What might have happened, and I am speculating but I will try and find out, is that the mechanism we have which prevents ministers and people at the centre from overloading the management of the administration of the National Health Service is called Gateway. If I want information from the National Health Service, if I want to write to them and set them tasks of any sort, Gateway review that process and they either say, "No, you cannot do that because it is going to increase the workload and we cannot cope with that", or sometimes they say, "We cannot do it now but we will combine that information with a lot of other information requests and we will do it all together at some time in the future". It may be that Gateway has taken a view that that information should not be collected. I can investigate that for you and let you know. I totally refute the idea that any

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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collection of data has been stopped on the basis that it might show a problem. That is why we collect data—to show up a problem.

**Q195 John Austin:** I have just been advised that there is a new Department of Health coding system which came in on 1 April.

**Dr Ladyman:** So is that witness going to retract that slur on our integrity?

**Q196 John Austin:** For the record, so that you or your department might be able to respond later, I will say so that it is on record what Professor Warner said. He said that he sent a note to his services manager saying that there were now new possibilities for coding allergy referrals which would allow people to identify the numbers and therefore be able to understand his service better. The response, which he quoted, was: “We have discussed this in setting up allergy specialist codes. This will automatically send a message that we are delivering a fully supported service. If we are to develop this it must be done in the correct manner as a concept paper and then a business case, for which there is currently no financial resource available.”

**Dr Ladyman:** I accept that they had that correspondence but, to be frank with you, it was unfair of Professor Warner to introduce an e-mail into evidence. We all know that when people are responding to e-mails we do not necessarily proofread it three times and think of every nuance of how it can be extrapolated and misinterpreted. The whole point of e-mail is that it is supposed to be an informal communication system. The fact that a manager has said something that could be interpreted in such a negative way—I think it was Professor Warner’s responsibility, if he was concerned about that, to go back to his manager and discuss it, it was his responsibility to have a formal exchange of letters if he disagreed with it, and then it might have been rational to bring it to the Health Committee. I think that is a rather unfair thing to do, to be frank with you. What the manager may well have been saying was that if we are going to change services we have to work out how we are going to pay for them. Therefore there has to be a business case and we have to compare that with the other priorities we have got. That is a perfectly rational thing for people to do locally. That is why we have given them the power to do this.

**Chairman:** David Amess has a parliamentary question listed for a few minutes’ time so we are going to jump the agenda and bring him in slightly out of turn.

**Q197 Mr Amess:** These are questions about the workforce because it seems to us from the evidence we have been given that trainees are absolutely crucial to trying to crack this problem. Without getting too bogged down, we were told that the allergy specialist workforce is about to decline absolutely in size and that an increase in funded training numbers of ten for next year and ten for the year after was a minimum necessary to establish a credible workforce. We have seen that the

allocations for 2005–06 and we note the proposal to fund only one extra training place for next year when we thought there were going to be ten, and we also understand that a large number of the allocated training posts are actually not filled by trainees. What is your response, Minister, to the expert panel’s advice?

**Dr Ladyman:** I think it was one centrally funded new training number. We will reflect on this in the next few moments but my understanding was that it was possible for another five or six locally recruited training numbers as well to be available. I do not think the situation is quite as bleak as you say. Clearly I am happy to take that away and look at it and write to you just to clarify the situation.

**Q198 Mr Amess:** It seemed pretty dire if it was only one here. I do not know if you are able to answer this now, but how many of last year’s allocation of centrally funded posts remain vacant?

**Mrs Wilson:** We could find out and write to you.

**Q199 Mr Amess:** Where are the “ongoing discussions” with the British Society for Allergy and Clinical Immunology relating to improving the provision of consultant allergists leading to?

**Dr Ladyman:** I am not involved in those discussions at the moment but we can find out.

**Q200 Mr Amess:** Could we have an update on where these discussions are going and has anything been firmed up? I understand that in January this year you saw a delegation led by your colleague, Jon Cruddas, who was very keen to have improved allergy services. I am not trying to trip you up, but I understand that you promised to look at the need to do something about improving training for allergy. Have you had the opportunity to come to a decision yet?

**Dr Ladyman:** We have not come to a decision but I did give that undertaking and I am continuing to look at that. Of course, we have to remember that not all of this is in the power of the Department of Health, of course, because the training standards and other curricular issues are matters for the Royal College rather than for us.

**Q201 Mr Amess:** If I can generally say what slightly concerns me, you had a meeting in January with your colleague. Five months on we are nearly into the summer recess. We all know what happens then. It is going to be the end of the year before we have the opportunity perhaps to come back to you and say, “What is happening with these training places?”, and all the expert advice says, whatever the ambitions are for the department to defeat allergies which we feel are curable, it is not going to happen without the trainees being in place sooner rather than later.

**Dr Ladyman:** I accept that entirely and I will be happy to write to you and give you an update on the position in time for you to write your report.

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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**Q202 Chairman:** We have already had reference to the debate that took place in Westminster Hall last October initiated by Jon Cruddas who has just been referred to. He specifically made some comparisons of four paediatric allergists in the NHS in the UK, and in Sweden 96, and in Germany 500. There were lots of comparisons which left us behind. In the light of the choice issue and the way in which the government has in other specialities allowed people to travel abroad for treatment, is it considered appropriate for referrals to be made from this country for specialist needs of this nature to some other European countries?

**Dr Ladyman:** We have a responsibility to commission the services that people need. If there are individuals who we cannot support in this country—

**Q203 Chairman:** There is nothing to stop it, basically?

**Dr Ladyman:** —and there is capacity in other countries that can support them, we have taken that decision before that we have referred them abroad and we would do it again. I have got no evidence that there is anybody that we have not been able to support in this country.

**Q204 Chairman:** Can I go back to your point about tertiary provision and, as Richard and others have pointed out, it is very uneven and I chipped in saying that in Yorkshire there is not any at all? Is there another way of dealing with that? I have no reason to take a position either way on this because I have no evidence locally of a particular problem. Is there a view that the lack of tertiary provision might mean that alternative approaches are being taken that are possibly effective in certain circumstances lower down the scale, shall we say, even by primary care?

**Dr Ladyman:** Do you mean people might be referred to non-conventional forms of treatment?

**Q205 Chairman:** That is a possibility and we may be getting into that later on. Do you have any evidence in areas not like my own, where there is not tertiary provision but where alternative approaches are being taken, that that could be in some instances effective?

**Dr Ladyman:** I come back to the point I was making at the start, that there is not a consensus that it is always the best thing to go to an allergy specialist service. In those areas maybe they have taken the view that they are dealing very happily and very effectively with the problem by using generalists or by having people refer to, say, dermatology clinics or respiratory clinics or to dieticians. It is for them in their area to decide whether, having done all of that, there is a need they cannot meet locally. They will have to come to a view. If it is two people in the whole of Yorkshire that they cannot deal with like that then they may well take the decision that what they want to do is to buy some service from a more remote specialist service down in the south. If it is a lot more than two clearly there comes a point where it becomes cost effective for them to create a specialist service in their area.

**Q206 Chairman:** We have no solid evidence that the lack of a tertiary provider in areas like Yorkshire is driving forward alternative effective approaches. It could be the case but it may not be the case. We are not sure.

**Dr Ladyman:** That is the case, but equally we have tried very hard in preparing for this appearance today to find evidence of unmet need and clear evidence that there are deficiencies. I am loath to say this because it always opens you to the challenge of complacency, but we have not found that evidence. The message that we are getting back from the areas is that either they are happy with the arrangements they have got and they feel that they are coping or they have started to come to the view that things are changing and they now need to commission some new service but they are processing that through the normal channels and will ultimately commission some new service to deal with that need.

**Q207 Dr Naysmith:** We have already dealt with this issue before. You have made it clear that the department does not accept the need to have specialist clinics for complex allergic diseases—

**Dr Ladyman:** No, I did not say that.

**Q208 Dr Naysmith:** —as the only model that can work clinically. What I want to put to you is a different piece of evidence. Does having such clinics, as a one-stop shop perhaps for patients, aside from whether it is possible to get the clinical expertise available in different units without the complex teaching, make a big difference to patients if they are being referred to different specialists with different expertise on their disease?

**Dr Ladyman:** I accept that that was a view that was put to you but equally, in your written evidence, you have had alternative views put to you. What matters is patient outcomes, whether patients get better or not. It looks to me from the written evidence that you have received that the dermatologists would say that that would not be so good for outcomes of people with skin conditions, particularly eczema, and people who deal with asthma are saying to you that that would not be so good for the people with asthma.

**Dr Naysmith:** I have not got to the question yet.

**Chairman:** You have got the answer.

**Q209 Dr Naysmith:** It was the answer to a different question. If there is this controversy or difference of opinion going on whose business is it to assess the evidence and decide which is right or do we just let it go on because it has always gone on that way? Does the department accept any responsibility for evaluating the evidence and giving some guidance as to which is the best model?

**Dr Ladyman:** Ultimately these things I suppose get resolved. If there is no growing consensus on the way forward then these things do get resolved by national guidance, like national service frameworks being produced in order to say, “Here is the model that we think is the best evidence-based way forward”. How these things normally get resolved is through processes like the one we are undertaking today, the

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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publication of the Royal Society's documents and a review of services by local commissioners and discussions with clinical specialists in order eventually to come to something that approaches the consensus of the best way forward. I know that does not sound terribly clean but the alternative is something which I think would be less effective. Maybe it has been the traditional way that we have been doing it and that is for me to sit in my office in Whitehall and make these decisions for you all. Frankly, keen as I am to see support for people with anaphylaxis and desperate as I am to improve services, I do not consider myself to be the fount of all wisdom on this subject and I do not consider myself to be in a position to make those central decisions. It is not a clean process. It is a process of evolution, of academic discussion, clinical discussion, commissioning processes, and if all of those fail to resolve it then yes, ultimately we end up pulling a working party together and writing an NSF on the subject, but one hopes that we can do it without that.

**Q210 Dr Naysmith:** We had some evidence this morning that specialist centres such as we are talking about now do not exist for large chunks of the country. Specialist commissioners are simply not accepting a full share of the responsibility for setting these centres up. Would you say that is true?

**Dr Ladyman:** There are some tertiary services that get commissioned centrally because they cannot be resolved any other way. Are commissioners locally shirking their responsibility? If their patients are referred out of town as it were they have to pay the bill. Ultimately, if they have to pay enough bills they will commission a service locally because it is more cost effective to do it that way. It is not as if commissioners can simply say, "Right: nobody in Yorkshire is getting allergy treatment any more". If the services in Yorkshire ultimately require the advice of a multiple allergy specialist centre then PCTs there will have to refer someone to a centre and will have to pay the bill.

**Q211 Dr Naysmith:** Our evidence is that hardly any PCTs commission a service in allergy.

**Dr Ladyman:** They do commission a service in allergy but they may not commission a service in allergy through a multiple allergy specialist centre. They may leave that to referrals on a paid-for basis because the number of people in their area that have to have that sort of treatment are within the scope of those centres, but they are commissioning these services because they are commissioning the local dermatology service. I bet there are not many that are not commissioning dermatology. I bet there are not many that are not commissioning respiratory clinics. I bet there are not many that are not commissioning dieticians. Allergy is being dealt with through all of those things, so it is not very sensible to say that they are not commissioning an allergy service. They are just not commissioning allergy services directly through a specialist centre.

**Q212 Dr Naysmith:** So do you think that the process is working reasonably well, including the process of specialist commissioning in the case of allergy?

**Dr Ladyman:** When you look at these things forensically you can always say that it could be done better.

**Q213 Dr Naysmith:** So what do you think could be done better?

**Dr Ladyman:** The reality is that on the evidence we have the service is coping, is absorbing the increase, people are getting the treatment they need within a reasonable period of time. Would I like to see them getting that service much more quickly? Of course I would. There is a 17-week waiting list to see a consultant. Do I think 17 weeks is acceptable? I would love it to be seven weeks. I would love it to be seven minutes. We could always drive down those waiting times. That is a matter of investment, as was pointed out in the questions from Mr Amess. It is a matter of training people. It is a matter of the different priorities in the people that we train. These are things that do not happen overnight. They take a long time to resolve but yes, I think the system is working reasonably well. Could it be done better? Of course it could, but it is not working badly.

**Q214 Dr Taylor:** The overwhelming evidence that I have read that has been given to us is exactly contrary to that, that it is not coping.

**Dr Ladyman:** You have read the wrong bits.

**Q215 Dr Taylor:** I am going to go back and look at everything else and see if we have got evidence to say that it is coping, or have we been asking all the wrong people? If we went to the people who are running general allergy clinics as part of dermatology and respiratory diseases would they say that things are coping? These are all things we have to think about. I was very interested when you said, talking about trainees, that there was one centrally funded and five or six are going to be locally funded. I think you have promised to come back to us with details on that and I think that is absolutely crucial because again the impression we have got is that the PCTs just do not have the money for those sorts of posts. That is very interesting. My question is a very general one. Who reviews whether the NHS is making the right strategic choices? Is it ministers? Should it be auditors? Should it even be the Healthcare Commission?

**Dr Ladyman:** Ultimately it will be the Healthcare Commission which inspects the delivery of health care services. Could I come back to your first question? You might want to look at the evidence from the Joint Speciality Committee for Dermatology. You might want to look at the evidence from the British Association of Dermatologists. I do not have specific organisations representing the views of respiratory and chest physicians and dieticians, unfortunately, but certainly those groups of people would argue that certain conditions are best treated by their specialists. However, none of them is arguing that you should not have access to a multiple allergy

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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specialist centre if that is necessary. They are simply saying, “For certain conditions you are better off coming to us first”.

**Q216 Dr Taylor:** Oh, yes. I do not think there is any argument on that. General practice can cope with the vast majority. Dermatologists can cope with a lot. There is just this extra bit of the really serious allergies that we are trying to get at. I am interested in what you say that it is going to be the Healthcare Commission because one views that very much as something that is just inspecting local services but it has a much wider remit and it could examine the way the Health Service is going strategically, could it?

**Dr Ladyman:** Yes. One of their roles is to look at local delivery plans, to ensure they are properly written and are taking proper account of the needs of their local communities. They are also going to be looking at government targets and the national standards and seeing whether services locally match those targets and standards. As well as the specific role of inspecting services to see that those services are quality, they have a role to ensure that strategic decisions have been taken.

**Q217 Dr Taylor:** They can come back to you and say, “That target is wrong and we should be doing this target”?

**Dr Ladyman:** Yes, they can provide me with that feedback. The reason I am hesitating is that of course we reserve the right to set targets at the centre and to justify them ourselves. Some people will sometimes come back with feedback and say, “Those are wrong targets”, but we may feel we have a bigger picture that we are dealing with.

**Q218 Dr Taylor:** But you would be receptive to the Healthcare Commission’s arguments?

**Dr Ladyman:** Absolutely. It would be madness not to be. That is true also of national minimum standards and the Commission for Social Care Inspection would offer the same feedback. Ultimately there is some material which we have said we will produce at the centre to set a national standard. Of course, we will constantly take feedback in that way but at the end of the day that is the bit which the government gets elected to do, to set that standard, and so the government of the day will always presumably reserve that to itself.

**Q219 Chairman:** You know we were talking about areas like mine and where people could go if there were no specialist tertiary clinics and you suggested alternative therapies as a possibility. Of course, the independent sector is a possibility as well. I wonder what your thoughts are of concerns that have been expressed to the committee that sometimes the independent sector can be expensive for patients, occasionally patients are misdiagnosed by unregulated practitioners and, of course, in the area of complementary and alternative approaches there is a concern—and I am not knocking this at all; I stress that—that some of the approaches are

completely unproven. Do you have any thoughts yourself about what is the government’s view of how you approach this area of the independent sector?

**Dr Ladyman:** It is an area which does concern me very much. First of all, let me add to the answer I have just given. The Healthcare Commission is also responsible for inspecting the independent sector. Clearly I would expect them to be looking at anybody who is making claims to be providing clinical treatment and inspecting whether what they are doing is safe and of high quality. Secondly, the government believes that people should have the choice to use alternative medicine if that is what they wish to do but nobody should be allowed to make claims that they do not have evidence for or to mislead people into using those services, so there is a raft of work we can do to try and make sure that people are not making unfair claims and that we draw a distinction between people who are claiming pharmacological properties for what they want to sell therefore to go through a very rigorous process of testing and safety measurements before they can sell what then becomes a licensed medicine, and people who are selling a food additive who we take a very strict view should not be allowed to claim pharmacological properties for food additives. If a food additive is capable of a pharmacological response then it should go through the medicines approval process. Having said that there are methods for getting overt misinformation and dangerous practices out of a system, it is of concern to me—and you might say, “Well, he would say that, wouldn’t he?”, meaning being of a scientific background and somebody who used to work for the pharmaceutical industry—that many people do turn to procedures which are not evidence based and which it is suggested to them will be efficacious on the basis of word of mouth rather than through formal processes that the government can check up on and are misled sometimes into spending at best their money, sometimes a lot of money, on things that will not work, and at worst are putting their health at risk. One of the things I am looking forward to reading your report on is to see what your advice is on how we should be tackling that.

**Q220 Chairman:** You mentioned the Healthcare Commission taking over responsibility for the inspecting the private and voluntary sector in April, and you have mentioned that they have a role here in respect of treatment in the independent sector. Am I right in believing that those providing only diagnosis are not covered by this inspection regime, so you could end up with a situation where a person is diagnosed and persuaded, perhaps as a consequence, to enter some form of very expensive treatment which is a complete nonsense because the diagnosis in the first place was wrong and the treatment was therefore wrong?

**Dr Ladyman:** Yes.

**Q221 Chairman:** What about the issue of inspecting the agencies involved in diagnosis?

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1 July 2004 Rt Hon Dr Stephen Ladyman MP and Mrs Patience Wilson

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**Dr Ladyman:** I do not know whether Mrs Wilson will be able to add anything to this. That is not an area that I have reflected on but I will because I can see the point that you are making.

**Q222 Chairman:** Is my assumption correct? I see Mrs Wilson nodding.

**Mrs Wilson:** Yes, your assumption is correct, that under the previous regime for inspecting the independent sector treatment is regulated but diagnostic services do not fall under the same regulations. Some of the people who may be offering testing will be covered by other regulations simply because of the professional body they happen to belong to, if they belong to a professional body. Beyond that there is nothing that the Healthcare Commission has in its remit at the moment for that sort of thing.

**Q223 Chairman:** So this might be an area that you could give further consideration to?

**Dr Ladyman:** Absolutely. For example, there are diagnostic tests being sold through supermarkets which we do not recommend. There are postal services. You send off samples and they come back and tell you. Poppycock is the best way I can describe them. Yet they are available and some people believe that if they send some hair off somebody can write back and tell them what they are allergic to. It is clearly an area that we should be very concerned about.

**Q224 Dr Naysmith:** Can I return to an area that we have dealt with already? In fact, Richard and I have been talking on and off today with you about the Royal College of Physicians' model and whether you accept it or not. You say you do not accept it in all circumstances and you prefer people to go to their physicians. The interesting thing is that the model and the report to that propose that 85% of allergies are dealt with by non-allergists, other specialists and GPs. That was supported by the dermatologists and chest physicians. That still leaves three million patients who need to see an allergist. I know you have said that things are okay but could be better but what it reveals is a lack of expertise and a lack of leadership about what should be done about those

three million plus or minus a few hundred thousand patients. Do you not agree with that and do you think some of that leadership might come from the department?

**Dr Ladyman:** I am going to correct your premise first because I did not disagree with the model put forward by the Royal College. The Royal College and the models in that document are very useful and I would want local commissioners to be taking very serious account of those models as potential ways to sort out the problem. Where I was challenging was the assertion—and it was perhaps implied rather than stated by some of your earlier witnesses—that there was a clear consensus that people with allergies should be referred direct from GPs to multiple allergy specialists and in most cases there is no consensus to suggest that that is the right way forward.

**Q225 Dr Naysmith:** And that is not what the Royal College says either.

**Dr Ladyman:** That is not what the Royal College is suggesting. I am very happy with the Royal College suggestions and that they are taken on board by local commissioners. What I am not happy about is the view that might perhaps inadvertently have been put by certain allergy specialists that there was a better way of dealing with it other than going through a dermatologist or a lung specialist for certain people. For some people that would be the case: they should not have gone to a dermatologist or a lung specialist to start off with, but for many people the preferred route would be to start off with a dermatologist, a lung specialist or a dietician before they are referred on. That is the only point I was making. Do I then think that there are then three million people who are not receiving the specialist allergy service that they need? I do not accept that there are three million people, no. That is where I am struggling with our figures and all the analysis that we have done in preparation for this to come up with anything that would suggest that there is that level of unmet need.

**Chairman:** If there are no further questions we are very grateful to you both for a very interesting session. I hope the report will be of some use. We appreciate your efforts in contributing to it. Thank you very much indeed.

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# Written evidence

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## Memorandum by University of Manchester (AL 1)

### 1. AUTHOR OF THE MEMORANDUM

Peter David Arkwright works as the only Consultant Paediatric Immunologist within the North West Region of England. He is employed by both the University of Manchester (five half days a week) and the Central Manchester and Manchester Children's University Hospital NHS Trust (six half days a week) and helps to provide a specialist service for the care of children with severe or persistent eczema as well as severe and unusual allergies.

### 2. BURDEN OF ALLERGY IN CHILDREN

The Government Health Committee is obviously aware of the extent and real increase in allergic diseases (eczema, asthma, hay fever, specific allergies to foods, and other environmental triggers) within the UK population over the last few decades. The size of this health problem will not be reviewed in this memorandum.

### 3. SUMMARY

This memorandum covers the type and availability of allergy services for children in the North West region, particularly the supply of specialist services for children with severe allergies. It also addresses the major factors that determine the demand for these services. It does not address the paediatric services for children with eczema, asthma and hay fever, which are currently distributed amongst GPs and a variety of specialists including general paediatricians, dermatologists, respiratory paediatricians and paediatric otolaryngologists.

### 4. CURRENT SPECIALIST PAEDIATRIC ALLERGY SERVICES WITHIN THE NORTHWEST OF ENGLAND

There is one weekly specialist paediatric immunologist led clinic for management of children with severe allergies in the whole of the northwest region. It is based at St Mary's Hospital, Manchester. The clinic is run on alternate weeks by Dr P D Arkwright, a Consultant Paediatric Immunologist and Dr R Pumphrey, a Consultant Adult Immunologist and an internationally recognised expert on anaphylaxis, who has for 20 years collaborated with paediatricians in providing this service but who has no formal training in paediatrics. The clinic is supported by one specialist adult immunology nurse with training in allergy but not paediatrics. With the present staffing levels the service is unable to meet Government recommended waiting time initiatives. Royal College of Paediatrics guidelines recommend that children should be seen by doctors and nurses trained in paediatrics and this clinic only partly meets this recommendation. Booth Hall Children's Hospital, also within the Central Manchester and Manchester Children's University NHS Trust, runs an oral food challenge service for the region with a current capacity of assessing one child per week. One specialist community paediatric allergy nurse specialist covers training of teachers in schools within the region. The NHS Trust presently does not have the financial resources or impetus to expand this current service.

### 5. CURRENT NON-SPECIALIST PAEDIATRIC ALLERGY SERVICES WITHIN THE NORTH-WEST OF ENGLAND

Children with severe allergies are also seen by paediatricians with an interest in paediatric allergy working in a number of District General Hospitals in the region, including Wythenshawe (1), Booth Hall Children's Hospital (2), Tameside (1), Stepping Hill (1), Macclesfield (1), Leighton (1), Barrow on Furness (1) and Billinge (1). Immunologist/Allergist assistance is provided in some of these clinics by Dr Richard Pumphrey. None of these paediatricians have recognised formal sub-specialist paediatric training in paediatric immunology/allergy. Their expertise is based on clinical experience over their career.

### 6. FACTORS DETERMINING DEMAND FOR PÆDIATRIC ALLERGY SERVICES

The demand for paediatric allergy services is driven by two factors over and above the prevalence of allergic diseases in the community: (1) public awareness and (2) public knowledge of the management of allergy. Many allergies are mild and management involves the common sense avoidance of the triggering factor. In contrast, public awareness is often based on information provided by patient/parent self-help groups and the media, groups that are likely to highlight the more severe or even fatal allergic reactions, which are rare. There is currently minimal specialist-lead public education on the management of allergy. The result is a high demand on the allergy service to provide basic as well as more complex patient-by-patient/parent management of these diseases.

## 7. RECOMMENDATIONS FOR ACTION

(1) SUPPLY: The currently available specialist NHS service for the management of children with severe allergy in the North West of England is negligible. Immediate expansion of both medical and nursing personnel is required to provide adequate care for children with this problem in the region. Development of regional centres of excellence which have a critical mass of staff and services is to be preferred to a small fragmented service in many towns and cities. (2) DEMAND: A government funded paediatric allergy/immunology specialist led national education programme should be set up to provide the public with practical guide to management of mild allergies. More than any other factor, this is likely to be the most cost effective means of reducing an ever-increasing demand on the current paediatric allergy services.

8. I am happy to provide oral evidence on the topic of paediatric allergy within the UK if this were to be required.

*May 2004*

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### **Memorandum by Barts and the London NHS Trust (AL 4)**

#### THE NEED FOR IMPROVEMENT IN SERVICES FOR ALLERGY AT BARTS AND THE LONDON TRUST

The Allergy service at Barts and the London takes tertiary referrals from east London and the Southern part of East Anglia, and secondary referrals from general practitioners in East London.

There is a once weekly adult allergy clinic led by two Consultants. One is a respiratory physician with an interest in allergy, and the other is a consultant specifically trained in allergy as well as immunology. We are fortunate to have the latter specifically trained specialist consultant but this specialist is employed on a very limited part-time basis. The imbalance between this restricted workforce and local demand is such that there is currently difficulty in seeing new patients within seventeen weeks.

These consultants in addition oversee an immunotherapy service which is restricted by financial constraints to treating four new patients per year. As a result, there is frequently an unacceptable delay for patients with disabling hayfever or serious allergy to wasps or bees.

Financial constraints affect other aspects of our service. Our combined ENT/Allergy and Immunodeficiency/Allergy clinics are restricted to occurring once monthly. Our service for assessing allergy to anaesthetic drugs can be held only three/four times per year, while that for assessment of suspected allergy to penicillin is held only two/three times per year. Thus, although the expertise is available, lack of adequate funding delays the management of complex and frequently life-threatening allergic reactions, known as anaphylaxis, to anaesthetic and antibiotic drugs.

The Paediatric service is equally underfunded with only one clinic per month leading to unacceptable waiting times. The service is run by two Consultants, one full time academic and one from the neighbouring paediatric unit. There are no junior/training staff and no specialist nurses. By working closely with the adult service it would be possible to maximise the use of scarce resources.

For an adequate provision of allergy services in this Region, a full time allergy consultant, a part-time specialist registrar, and one part-time nurse are required in addition to the current workforce. This will allow:

- An acceptable waiting time to first appointment in the allergy clinic, and adequate time for education of patients.
- Appropriately prompt management of severe allergic conditions such as anaphylaxis or angioedema.
- The implementation of specialised services related to drug testing and desensitization.
- The creation of combined organ specific clinics in dermatology/allergy and gastroenterology/allergy as well as extension of the immunotherapy service.
- Systematic teaching for future generations of medical and nursing trainees.
- Up-dating of protocols for the management of allergic diseases and allocation of time for audit and clinical research.
- Liaisons with the pharmaceutical industry will facilitate the development of novel therapies.

*May 2004*

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**Memorandum by South and West of England and Wales Clinical Immunology Audit Group (AL 5)**

I note that your Committee is to examine the provision of care and treatment for allergies by the NHS and by the independent sector. I am writing to let you know that in October 2004 further useful information may be available to you, should you wish to avail yourself of it.

I chair the South and West of England and Wales Clinical Immunology Audit Group. There is a North of England Clinical Immunology Audit Group that also meets six-monthly and a third group for London and the SE that meets less regularly. As you may glean from other letters to you, like organ-based specialists and Allergists, Clinical Immunologists across the UK also see patients with suspected allergies. We are thus in a position to be able to contribute data and informed views regarding the provision of clinical and laboratory diagnostic services and management of patients with allergies. It has been for some months our intention to carry out a detailed survey across the UK of our workload in allergy. This will encompass both the numbers of patients seen and laboratory data. There are 48 Immunologists in England, five in Scotland and one in Wales. As a group we contribute appreciably to the diagnosis and clinical management of patients who have allergies.

We intend to perform a survey of our annual allergy workload from July to mid-September and to report and discuss the data at a joint meeting of the UK Audit Groups in Birmingham on 7 October. We will imminently be drawing up the questionnaire that we will use to gather all relevant data. I am sure you will understand that it will take a few months to gather this information. It is however our intention to have as near as possible a complete set of relevant data to discuss at the October meeting in Birmingham. We would be most happy to submit a report of our data and conclusions for your consideration after the meeting. Representatives of Clinical Immunologists working in the UK would also be most happy to give evidence and answer questions in person at any hearings of the Select Committee, should you wish. I would be most pleased to co-ordinate any communications that you might wish to have with the Clinical Immunology Audit Groups in the UK about these matters.

*May 2004*

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**Memorandum by Dr Michael Tettenborn (AL 6)**

1. I would like to add my voice to that of, I anticipate, many others that are asking that the House of Commons encourage the DoH to give priority to the development of services for the management of allergies in adults and Children.

2. I have no doubt that you will receive many representations from clinicians, but you may not be aware that the vast majority of clinicians with a special interest in allergy have significant allergies themselves and have moved into this field after recognising how poorly they have been served by Health Services in the past. I myself had the good fortune to live, as a young child, in the catchment area for Dr Harry Morrow-Brown, one of the founding fathers of allergy management in the UK.

3. You will also be aware that the current "Allergy Specialists" are largely self taught, perhaps with some additional experience gained overseas. This is because Allergy has never been treated as a specialist area in the UK, despite the fact that data indicates that Allergic disease is responsible for more ill health than many other conditions. ie

4. Hay Fever affects at least 18–20% of the population and can be very disabling—not only causing bouts of nasal congestion and sneezing, but also causing marked irritability, underperformance at school and work, and increased risk of involvement in Road Traffic Accidents. The CSM (as it was) placed severe restrictions on desensitisation some 20 years ago, however newer research studies, with newer techniques have indicated that this is now an effective and very cost effective approach to management of Hay fever and some other allergic diseases. (A key measure in studies on desensitisation is reduced prescribing of other medications). Due to the lack of allergy teams in this country most patients who would benefit from this treatment do not have access to it.

5. The current MCRA advice is that desensitisation effectively needs to be carried out in a hospital setting, requiring a team at the local hospital to provide the service. Allergy providers, such as they are, are already well aware of the importance of multi-disciplinary working, such that any services that are developed in the future would be in line with current trends towards appropriate skill mix in service delivery.

6. Asthma affects about 15% of our Child Population, and although not always related to allergy, there is frequently an allergic component and in other instances parents want reassurance that there is not an allergic element.

7. Some 15% of babies develop eczema, and although many improve with age, whilst affected by their condition it can be extremely disabling and distressful. Many parents of children with severe eczema get little or no sleep because of the irritation in their babies, but about half of these babies can be helped by advice from an allergist. Most have no access to such a service.

8. Acute Peanut allergy affects 1–2% of our population and causes considerable anxiety as it may precipitate sudden death. Deaths themselves are less common, but still occur and are potentially preventable, as are the five to 10 deaths per year from allergic reactions to insect stings. There are also deaths from other acute allergies such as to milk, egg and many other foods, which could be prevented with an expert allergy service.

9. Studies indicate that up to 20% of the population feel that they have a food intolerance (“allergy”) triggering a wide range of symptoms. Although some studies indicate that the true figure for actual intolerance may be much lower (1–2%) these studies have severe weaknesses in their methodology, which may explain the lower figure. Whichever figure is correct the population served by the NHS requires an adequate service either to support them with the management of their intolerances, or to help them to recognise that these are not real. At present many patients and parents spend large amounts of money on unreliable tests, which sometimes lead to more harm than good when false positive and false negative results are inappropriately interpreted. They require access to a service that will either substantiate their “intolerance” as a cause for symptoms whilst ensuring that more sinister pathology is excluded, or help them to recognise that other factors may be relevant to their problems. This can only be achieved if the NHS offers a service that is comprehensive and does not turn these individuals away as “cranks”, which is what happens to many at the present time.

10. We need to recognise that in Germany there would be one allergist for every 1–2,000 of the population, whilst in the UK the figure is perhaps 1:100,000, but with many of these being clinicians with a special interest, rather than formally trained allergists. This discrepancy would suggest that the NHS is currently not serving the needs of the population. Our current approach of simply prescribing anti-histamines and steroids in most instances is not cost effective and is associated with significant problems with side effects. An investment in this area could save the NHS money as well as reducing mortality and significant morbidity.

11. It is likely that at least one member of the committee will have Hay Fever. Those members of the committee who do suffer from Hay fever may well recognise the disabling effect of this condition, with reduced intellectual performance at the time of symptoms. It seems wrong to continue to ignore the needs of a large group of the population who are affected during specific seasons of the year. As a clinician I am disheartened that there is so much more that I could achieve locally in return for a very small increase in resources.

May 2004

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#### Memorandum by NHS Grampian (AL 7)

I write in response to the recent call for submission of information to the Health Select Committee enquiring into provision of Allergy Services. I write as a Consultant Immunologist working full time in the National Health Service, as Chairman of a national UK-wide Group of Consultant Immunologists and as Specialty Advisor in Immunology to the Scottish Executive Health Department.

#### SUMMARY

The professional clinical Immunology community in the United Kingdom commends publication of the Royal College of Physicians document *Allergy, The Unmet Need, a blueprint for better patient care* (June 2003). I would endorse the findings and recommendations of this document. In the present model of service provision the specialty of Immunology makes a major contribution to provision of specialty hospital-centred Allergy clinical and diagnostic services. The specialty of Immunology supports the recommendation for growth and development of specialist clinical allergy services throughout the United Kingdom. It should be recognised that growth of specialist clinical Allergy services is essential, will take a considerable time to become a reality and that during any major developmental phase of service growth, consideration requires to be given to existing models of service provision which can provide interim care and integrate with planned development of specialist clinical allergy services. There is existing published evidence of inequity of, and inadequacy of, current services for patients with allergic disease.

#### AVAILABILITY OF ALLERGY SERVICES (GEOGRAPHICAL DISTRIBUTION, ACCESS TIMES, PATIENT CHOICE)

1. Provision of secondary/tertiary hospital-based clinical allergy services by trained, qualified consultant-grade Allergy specialists (Consultant Allergists) is confined to a small number of Centres in the United Kingdom. The majority of clinical allergy service provision within the NHS is provided at a Primary Care level, though few medical or nursing staff working in a General Practice environment will have had significant training in allergy practice or education as to the scientific basis, diagnostic approach and optimal management of allergic disease. Similarly, within the hospital environment, most allergy care throughout the UK is provided by non-allergy specialist organ based clinical teams (Dermatology, ENT, Respiratory Medicine etc). For much clinical allergic disease this model of care may be adequate (if not optimal) but

particular problems arise for patients who do not fit neatly into an organ-based system of practice or who require specialist methods of diagnosis and/or treatment (eg anaphylaxis, multisystem disease, drug allergy, food allergy, cases where allergy may be difficult to diagnose or occurs as part of a spectrum of wider disease, disease which is difficult to manage, disease which requires a specific therapeutic approach such as usage of specific drugs or immunotherapeutic agents or requires utilisation of specialist techniques such as desensitisation). The specialty of Immunology, within its clinical service provision arm, currently provides direct delivery of hospital-based, specialist Allergy services in many areas (*National Health Service Allergy Clinics, British Society for Allergy and Clinical*

#### RE: NEW HEALTH SELECT COMMITTEE ENQUIRY—THE PROVISION OF ALLERGY SERVICES

*Immunology*). In many regions Immunology provides the only hospital-based specialist Allergy service available to deliver care to the patient groups noted above. As a result Immunology training programmes for medical graduates throughout the United Kingdom have come to incorporate significant levels of defined allergy teaching and training as an integral part of the training programme. Where specialist, defined Allergy services exist there is generally close co-operation and collaboration between Immunology and Allergy over patterns and mechanisms for referral, clinical diagnosis and management, diagnostic laboratory support and provision of general liaison advice in relation to allergic disorders. Where local specialist Allergy services are not available these roles tend to be undertaken by Immunology Services. Although provision of specialist Immunology services is not uniform, adequate or optimal across the whole of the country the existing service structure is perhaps more robust and developed than is currently the case with clinical Allergy. There is however firm evidence from Scotland (*Immunology and Allergy Services in Scotland, Scottish Medical and Scientific Advisory Committee, Scottish Executive, 2000*) that Consultant-led Immunology departments which provide secondary/tertiary specialist allergy services as part of their remit are currently overwhelmed with substantial inequities and inadequacies across the country and between centres, and with substantial restrictions in patient access and in the range of services provided. In spite of this, these Immunology services provide the only available mechanism for access to and delivery of specialist Allergy care for those patients who cannot be managed adequately within Primary Care or within an organ-based hospital environment. The waiting time for patients to be seen at such specialist Immunology clinics is frequently measured in years and some services restrict access and patient referral only to those cases where disease is life-threatening.

2. The national strategy outlined in *Allergy, The Unmet Need*, should be supported by the healthcare community, service planners and commissioners and by the public but the mechanisms for achieving a sufficiently robust and widespread mechanism for clinical allergy service provision are necessarily long-term in their aims, view and the timescale within which they can be achieved. Consideration needs to be given as to underpinning and expanding existing mechanisms for service provision in the interim. In both the short and long terms this will require a higher level of prioritisation for commissioning and underpinning clinical Allergy service provision within the local as well as national healthcare psyche.

May 2004

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#### Memorandum by the North-West Lung Clinic (AL 9)

##### DIFFICULTIES IN ESTABLISHING ALLERGY SERVICES IN THE NORTH-WEST OF ENGLAND

- The North West Regional Specialised Commissioning Group at its meeting on 6 June 2001 decided to obtain advice on the current and future provision of allergy services in the Region.
- A sub-group was convened which developed a draft document which was circulated to providers and commissioners across the Region.
- It proved possible to incorporate or otherwise address most of the comments from around the region.
- This resulted in “A Framework for an Adult Allergy Network in the North West: The North West Integrated Clinical Allergy Service (NWICAS)” (see annex). This document reviewed the current and future provision of services for adults with allergic disease in the North West of England.

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- The document highlighted the following:
    - The current situation is highly unsatisfactory, with long waiting times exacerbating discomfort and distress for patients.
    - There is no regional allergy service and most of the patients are not being appropriately identified and treated.
    - There is little or no provision for primary care allergy testing in the community and no community care for allergy sufferers.
    - There is no full-time allergist-led NHS service provided in the North West.
    - The provision of services in the North West is inadequate as evidenced by the long waiting times of patients referred to the patchy service that does exist.
    - Most patients with allergic disease in the North West never see an allergist.
    - Patients and GPs have difficulty in accessing the currently available services and, as a result, desperate patients seek help from non-validated sources.
  - The NWICAS document proposes a solution for these problems. A North West managed clinical network would be comprised of a group of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner to ensure the equitable provision of high-quality clinically-effective services in allergy in the North West of England.
  - The members of the North West Specialised Commissioning Group endorsed this proposal 15 months ago (in January 2003).
  - Despite these facts (ie the huge identified need; the completed and endorsed proposal for setting up an appropriate service) it has proved impossible to date to persuade local commissioners to provide financial support for the development of the service.

May 2004

## Annex

### A FRAMEWORK FOR AN ADULT ALLERGY NETWORK IN THE NORTH WEST: THE NORTH WEST INTEGRATED CLINICAL ALLERGY SERVICE (NWICAS)

#### 1. WHAT IS ALLERGY?

1.1 The specialty of Clinical Allergy involves the management of a wide range of conditions that cross the organ-based disciplines. Allergic disease is increasing in prevalence at the rate of 50% per decade [1–3]. Most allergic disorders are chronic and they may be debilitating, involving periods off work or school (eg asthma, urticaria and angioedema). Furthermore, some of the conditions may be life threatening (eg nut anaphylaxis).

1.2 Allergy is a clinical speciality in which investigations are important but, as sensitisation may not always indicate disease, the clinical history is paramount. The most common clinical conditions managed by Clinical Allergists include asthma, eczema, rhinitis (seasonal and perennial), bee and wasp venom allergy, food allergy, latex allergy, urticaria and angioedema, drug allergy, anaphylaxis and food intolerance.

1.3 The Department of Health has included Specialist Allergy in the national list of services that require specialised/collaborative commissioning arrangements (see section 11).

#### 2. CHILDREN

2.1 This document does not specifically refer to allergy services for children. However, some of the staff working with adults also have clinical sessions in children's facilities. This would suggest that a broadly similar model to that proposed for adults (see paragraphs 12.5–7 and the table following) would be appropriate for children. The foci for this might be Alder Hey Children's Hospital and/or the Manchester Children's Hospitals.

#### 3. PREVALENCE OF ALLERGIC DISEASE

3.1 There has been a considerable increase in the prevalence of the common allergic disorders (asthma, eczema and rhinitis) in the last two to three decades [1–3]. Recent data from the North-West of England suggest that one third of the population now suffers from allergic disease and that almost half of the population has allergic sensitisation to one or more common allergens (eg house dust mite, cat, dog, grass pollen) [4]. Superimposed on this there has been a rapid rise in serious, life-threatening allergic disease.

3.2 Anaphylaxis has become increasingly common, occurring in one in 3,500 of the population per annum in 1994, and is rising [5, 6]. Peanut and nut allergy affects over 1% of children [7–9] and latex allergy, which was extremely rare before 1980, now affects up to 8% of health care workers [10, 11].

#### 4. PATIENTS' PERSPECTIVE

4.1 The current situation is highly unsatisfactory, with long waiting times exacerbating discomfort and distress. There is no allergy service in many parts of the country (source: British Allergy Foundation) and patients are not being appropriately identified and treated.

4.2 There is little or no provision for primary care allergy testing in the community and no community care for allergy sufferers. This results in patients not knowing where to go for advice. Furthermore, patients often want to take control of their disease by, for example, using allergen avoidance procedures rather than drugs but there is no provision for the assessment of their allergic status and a lack of appropriate guidance.

4.3 Patients with severe, multi-system conditions, such as allergy, need to see one person who can deal with the cause of the condition. The current system is too reliant on organ-based specialists with, for example, a patient seeing an ENT specialist, an immunologist, a respiratory physician and/or a dermatologist, as well as their general practitioner and various Accident and Emergency doctors. It should be possible, at secondary care level, for them to see a single clinician with a recognised qualification in allergy.

#### 5. TRAINING IN ALLERGY

5.1 The management of allergic conditions requires appropriate expertise. Unfortunately, little training is given on this subject in medical schools. Before the Calman changes in training, allergy was part of the Clinical Immunology and Allergy training programme, distinct from Immunology related to Pathology. Training programme changes and the delay in Clinical Allergy being included on the Specialist List have resulted in uncertainty and a loss of potential SpRs. A new, objective-based, Royal College of Physicians approved, Allergy training programme, leading to the Certificate of Completion of Specialist Training (CCST), was recognised for the first time in June 1999.

5.2 Clinical Allergy is currently a small speciality, with a great need for more SpRs and consultants if it is to meet the need.

#### 6. CURRENT PROVISION OF SERVICES

6.1 Most patients with asthma, eczema and rhinitis should be able to be managed adequately by primary care and district hospital organ-based specialists. However, allergy testing, which is necessary for the planning of allergen avoidance, is often unavailable in district general hospitals. As a consequence, advice on allergen avoidance is frequently inadequate. In addition, immunotherapy and specialised bronchial challenge in suspected occupational asthma are not generally available in district general hospitals.

6.2 Acute and chronic urticaria and angioedema are difficult conditions to manage and, whilst the majority do not have an allergic basis, the more severe cases need to be carefully investigated to exclude an allergic cause.

6.3 Anaphylaxis is becoming increasingly common and is potentially life threatening. Although acute attacks are managed in accident and emergency departments, the full evaluation of patients to identify the cause and then the availability of appropriate advice on allergen avoidance are essential. In addition, training in the use of the Epipen (self-administered adrenalin injection) can be life saving.

6.4 Despite the obvious need, the current provision of allergy services across the UK is extremely poor [12]. The British Society for Allergy and Clinical Immunology (BSACI) held discussions with the Department of Health (Allergy Task Force) to highlight the need and to press for improved services. This initiative is being taken forward by the National Allergy Strategy Group (NASG) launched at the Royal College of Physicians in May 2001. Current services and proposals for allergy care have been outlined [13]. There is a shortage of consultant allergists. Full-time services led by consultant allergists are virtually restricted to London and the South of England.

#### 7. FULL-TIME SERVICES LED BY CONSULTANT ALLERGISTS ACROSS THE UK

7.1 The six centres in the UK currently providing a full-time allergist-led NHS service are located mainly in the South of England. These comprise:

- Addenbrooke's Hospital, Cambridge—Dr Pamela Ewan
- Glenfield Hospital, Leicester—Dr Martin Stern
- Guy's Hospital, London—Professor Tak Lee, Dr Christopher Corrigan
- Royal Brompton Hospital, London—Professor Stephen Durham
- St Mary's Hospital, London—Dr Douglas Robinson
- Southampton General Hospital, Southampton—Professor Anthony Frew.

## 8. SERVICES IN THE NORTH WEST OF ENGLAND

8.1 There is no full-time allergist-led NHS service provided in the North West. The provision of services in the North West is inadequate as evidenced by the long waiting times of patients referred to the patchy service that does exist. Most patients with allergic disease in the North West never see an allergist.

8.2 The only consultant allergist-led (part-time) services for adults in the North West are based at the Royal Liverpool and Broadgreen University Hospitals and at Wythenshawe Hospital in Manchester.

8.3 A detailed list of clinical services provided by organ-based specialists and immunologists with an interest in allergy can be found in the British Society of Allergy and Clinical Immunology booklet [16].

8.4 Patients and GPs have difficulty in accessing the currently available services and, as a result, desperate patients seek help from non-validated sources (eg Vega test, homeopathic immunotherapy, hair testing) [14].

## 9. ACADEMIC ALLERGY IN THE NORTH WEST

9.1 In the North West Lung Centre at Wythenshawe Hospital in Manchester there is a large Allergy and Asthma Research Group led by Ashley Woodcock, Professor of Respiratory Medicine, and Adnan Custovic, Professor of Allergy. This group produces original research to a high international standard and is a world-leading centre in the area of indoor allergen research (70 peer-reviewed allergy publications; more than 100 invited presentations at national/international meetings; more than £2.5 million research funding, in the last five years). Dr Richard Pumphrey, Consultant Clinical Immunologist (Manchester Royal Infirmary), actively researches and publishes in anaphylaxis.

## 10. MODEL OF ALLERGY CARE

10.1 An ideal model of allergy care has already been developed [12] and is presented in a modified form below:

- Tier 1* Primary care will deal with mild allergic diseases.
- Tier 2a* Organ-based and other specialists with an interest (dermatologists, respiratory physicians, ENT specialists and immunologists) will provide a district-based referral framework, with referral to a local specialist allergy service.
- Tier 2b* The local specialist allergy service will be provided either by a district-based allergist or, on a sessional basis, from the Regional Centre.
- Tier 3* Regional allergy centres: these would deal with the more complex and severe disorders for the population of the North West. They would also provide some elements of a “tier 2a” service for their local catchment area and a “tier 2b” service for a large area because of the lack of such services across the area.

10.2 Currently in the North West there are considerable deficiencies in all the proposed tiers:

- The majority of general practitioners have little or no training in the diagnosis and treatment of allergy.
- The network of organ-based specialists with an interest in allergy is small and insufficient to deal with the demand.
- No local allergy services are provided by a district-based allergist.
- There is no Regional Allergy Centre.

10.3 The immediate aim is to develop a Managed Clinical Network in Clinical Allergy for the North West to provide expertise, improve geographical equity of access to care and act as an educational resource and training centre.

## 11. SPECIALISED COMMISSIONING DEFINITION

11.1 Clinical Allergy is designated under specialised commissioning arrangements where services to support patients with rarer health conditions are planned and developed to meet the needs of an appropriate population. A national review, on behalf of the Department of Health, has been undertaken to identify and define services that are deemed to be specialised. The aim is to develop a consistent approach to the commissioning (both planning and procurement) of specialist services at national, regional and local levels. In total 36 specialist services are identified, including “Allergy Services, Definition No 17”.

## 12. CHARACTERISTICS OF A MANAGED CLINICAL NETWORK IN ALLERGY FOR THE NORTH WEST

12.1 The development of managed clinical networks in clinical specialties has been progressing over a number of years. There are a number of key issues which need to be addressed including the role of the “hub” or “centre” in leading the network and setting the culture, the clinical governance issues of providing services or linking with services at other locations and the management of staff and physical assets.



In Scotland, a significant amount of work has been undertaken to progress managed clinical networks. Details of this are published in the Scottish health circular MHS MEL(1999)10.

The circular suggests the following requirements:

- Clarity about network management arrangements is essential with one individual as overall lead. Networks would produce a written annual report.
- A defined network structure indicating service delivery points should be developed.
- It should have clear clinical and service outcomes to be able to evaluate its effectiveness.
- It should use a documented evidence base and be committed to research and development.
- It should be multidisciplinary and include patient representation in its management arrangements.
- It should have a clear policy of dissemination of information to patients including those in primary care settings.
- All representatives in the network should sign up to explicit principles of working.
- It should have a quality assurance programme to ensure consistency of standards.
- It should develop links with universities and colleges and promote education and training.
- Audit data should be produced for open review.
- It should enable staff rotation to occur as part of the programmes of continuous professional development.
- It should be examined for the potential to achieve better value for money.

The regional centre(s) will have a crucial role in ensuring that effective links across the different sectors of care are established and maintained.

The establishment of managed clinical networks enables small and highly specialised services to be provided across a range of organisations, by a multi-professional team guided by clear reporting and accountability structures and working to agreed protocols and policies.

12.2 A North West managed clinical network would be comprised of a group of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner to ensure the equitable provision of high-quality clinically-effective services in allergy in the North West of England. The name proposed for the network is the North West Clinical Allergy Service (NWICAS).

12.3 To meet the expected workload, a NWICAS would require a minimum of:

- three whole-time equivalent (WTE) consultant allergists;
- three WTE specialist allergy nurses;
- two WTE dieticians; and
- appropriate technical support.

12.4 Initially, given the geography of the North West (for this clinical network probably also including North Wales) and its population distribution, it is suggested that the NWICAS should have three foci. The need for any additional centres should be considered after the first few years of its establishment.

12.5 Therefore, a model of service is proposed for the North West based on three Specialist Allergy Centres. They should be developed in parallel, with the commissioners for the population of North Wales deciding to which of the three that population should look. This service should ideally be based on hospitals which can provide excellent out-patient, pulmonary function and radiology services, with easy access to full immunology testing. Furthermore, a strong academic basis would be a significant advantage.

12.6 The intention is to create a multi-disciplinary/multi-professional network and ensure representation from patients' organisations (eg those included in the "Allergy Umbrella"—the Anaphylaxis Society, British Allergy Foundation, National Asthma Campaign, National Eczema Society). A chain of interconnected people and processes, working in partnership to maximise the benefits for all patients, would deliver care. Elements of the service would be delivered on an outreach basis from the centres (eg the immunotherapy service, with a specialist allergy nurse attending satellite clinics, with appropriate local medical support and facilities, to administer maintenance doses and thereby minimise the patients' need to travel).

12.7 To ensure clarity about the network management arrangements, the NWICAS would:

- Identify a person with overall responsibility for the operation of the Network.
- Have a defined structure setting out the points at which the service will be delivered to the patients (initial development needs are outlined in the following table).

## NORTH WEST INTEGRATED CLINICAL ALLERGY SERVICE

<i>Level</i>	<i>Service Offered</i>	<i>Development Needs</i>
Living at home, not using GP services	Advice	Community pharmacists trained to give advice, in particular in the use of over-the-counter allergy medication
Local GP surgery	GP consultation, screening for allergic conditions (eg allergic rhinitis, asthma) and onward referral	Joint protocols for managing allergic disease (eg anaphylaxis) with defined referral criteria agreed with network consultants
Specialist GP surgery	GP specialist undertaking allergy testing (eg skin-prick testing, spirometry) and nurse-led clinics held by visiting specialist allergy nurse	Training in procedures; defined referral criteria; specialist allergy nurse exports expertise from the Regional Allergy Centre
Community hospital/ district general hospital/ diagnostic and treatment centre	Organ-based specialists with an interest (dermatologists, respiratory physicians, ENT and immunologists) to provide a district-based framework. In the long term, development of a local allergy service including outreach allergy clinics, skin-prick testing, anaphylaxis clinics and immunotherapy clinics.	Agreed operating procedures and consultants with a major interest in allergy. In the long term, the appointment of a consultant allergist, core nursing staff with specialist allergy interests and skills and links to dietetic services. There are minimal equipment needs.
Specialist Allergy Centre (3 for the North West)	More complex and severe disorders (asthma/rhinitis, anaphylaxis/acute allergy, food allergy, urticaria, angioedema, drug allergy*) and provide "tier 2b" for the local catchment area	Specialist allergist, specialist allergy nurses and dietician with good communication networks enabling the transfer of patients to local services for the continuation of care (eg immunotherapy service)

\*Although it was envisaged, in Good Allergy Practice [17], that patients with non-specific/ polysymptomatic illness, which would include patients with chronic fatigue syndrome and multiple chemical sensitivity syndromes, would be assessed at allergy clinics, this would have considerable implications in terms of time, personnel and physical facilities.

## 13. THE PATIENT PATHWAY

13.1 Primary care would continue to deal with the simpler allergic diseases (such as mild hay fever). For more difficult-to-manage diseases, the general practitioner would refer the patient to either an organ-based specialist with a special interest or a local consultant allergist for secondary care. The most complex cases should be referred to the Specialist Centre from secondary care. The Specialist Centre should also provide secondary care for its local population.

13.2 *Primary care*

Primary care has a record of successfully managing chronic conditions through the use of agreed protocols of care. In terms of the provision of allergy care, the successful model of asthma care could be extended to the extremely common diseases like allergic rhinitis and angioedema/urticaria. Most patients with allergic diseases should be able to be treated in primary care.

A more coherent approach to modifiable risk factors (eg allergen exposure, environmental tobacco smoke exposure) will be encouraged and protocol-driven direct access to hospital-based investigations (eg specific challenge procedures) will be provided. Health professionals (eg specialist allergy nurses), working at the interface between primary and secondary care, will have an increasing role in implementing treatment protocols (eg for rhinitis, asthma, urticaria) and patient education and training (eg in the use of self-administered adrenaline for the treatment of anaphylaxis).

13.3 *Secondary care*

Integrated multi-disciplinary/multi-professional care for the patients with allergic disease, characterised by improved collaboration between primary and secondary care, should bring major benefits to patients. For example, it is now clear that the appropriate use of the adrenalin self-injector saves lives. Appropriate training has to be given not only to patients and/or members of their family but also needs to be available to appropriate individuals in schools and other high-risk environments.

### 13.4 Local collaboration

Primary Care and Hospital Trusts will be encouraged to collaborate in the establishment of local allergy services. This will be achieved either by utilising a consultant allergist and allergy specialist nurse practitioner from the regional centre, on a sessional basis, or by identifying an existing organ-based specialist with an interest in allergy and enabling them to receive training in general allergy to supplement their organ-based knowledge (the allergy nurse could support the service on a sessional basis, eg by providing a local immunotherapy service). Further support will be provided from the specialist centre by a combination of liaison meetings, consultant-to-consultant referrals and education meetings and by the development and implementation of agreed protocols. Thus the local allergy network will act as a source of advice to GPs, as a basic specialist service for those aspects of allergy in which the local specialist is acknowledged as being competent and as an access point to the centre.

## 14. SPECIALIST ALLERGY CENTRES IN THE NORTH WEST

### 14.1 Out-patient service:

- A core multidisciplinary/multi-professional team of clinical allergists, specialist nurses and liaison psychiatrists, physiotherapists and dieticians will provide the out-patient service; a suite of consulting rooms is necessary to allow the team to work together. A special room with skin-prick testing facilities and for the administration of immunotherapy, with full resuscitation facilities (drugs, IV lines and fluids, oxygen, nebulised bronchodilators, a tilting couch and a cardiac arrest box) should be available.
- Radiology, pulmonary function testing and immunology and other blood tests should be readily available.
- Allergy patients are usually complex and the taking of a detailed history is essential. Realistically, a minimum of 45 minutes per new patient is required and 20–25 minutes per follow-up. A reasonable plan for a consultant allergist would be to see four new and one follow-up, three new and three follow-up or two new and six follow-up patients per clinic session. Consultants would train doctors (specialist registrars, GPs and other consultants) and nurses in the out-patient clinics. One consultant can supervise one person per clinic but must allocate extra time to review the patients and teach trainees/students.
- Specialist allergy nurses will perform skin-prick testing and allergen immunotherapy, and in appropriate circumstances take clinical histories, examine, and assess patients in the clinic under the supervision of the doctor. In addition, they will explain the literature for the diagnosed condition (eg allergen avoidance) and how to use peak flow, food and symptom diaries. They will be equipped to train patients in the use of an Epipen, and inhaler devices, including those delivering adrenaline. They will also deal with telephone enquiries from patients, guided by the doctor, and give patients information on support groups (eg the Anaphylaxis Campaign).
- Dieticians are essential to the service as much of the work deals with food allergy/suspected food allergy. The dietician is needed to establish if a diet is nutritionally adequate and to provide advice on exclusion diets.
- Written management advice for a range of conditions should be available for the patients to take away.
- Waiting time for a routine out-patient referral should be no longer than 13 weeks (currently patients in this region wait up to three years).
- Urgent referrals (particularly for anaphylaxis patients) should be seen within one month (currently one to two years).
- Follow-up appointments should be available within three months of the initial consultation to convey results and their implications to patients in person. Some patients, having had a definitive diagnosis made at their initial appointment may collect the results of their confirmatory tests from their general practitioner or be sent them directly by post. Although many patients with anaphylaxis attend for annual (or bi-annual) review, most other patients will be discharged after a single follow-up visit.
- Pharmacy services are necessary to supply drugs for skin testing, prepare capsules for challenge studies and to give drug information to patients.
- Adequate secretarial support must be provided to aid communication with GPs.

It is likely that the spectrum of clinical conditions that would present to the Specialist Allergy Centres in the North West would be similar to those presenting to the service provided in Southampton. However, our numbers would be larger due to a bigger catchment area. The NWICAS would serve Cheshire and Mersey (2.4 million people), Greater Manchester (2.6 million people), Lancashire and South Cumbria (1.6 million people) and North Wales (c0.5 million people). In Southampton, the large Allergy and Asthma Research Group currently provides two NHS out-patient allergy clinics per week, plus a severe asthma clinic and a fortnightly medical immunology clinic. The case mix is roughly asthma/rhinitis 20%, anaphylaxis/acute allergy 10%, food

allergy 15%, urticaria/angioedema 30%, drug allergy 5%, the remaining 20% being immunological problems, chronic fatigue and bowel disturbance. They also run an immunotherapy service in parallel with the clinics, managing approximately 300 patients at any one time.

#### 14.2 *In-patient and day case service*

- Facilities for day cases will be available (this may be in the out-patients department) where patients undergoing challenge tests can remain all day (with appropriately trained nursing staff).
- Access to in-patient beds should be available for the *occasional* patient with adequate cover from junior medical staff.
- Allergists will also be expected to provide a consultation service for other specialists, particularly in respiratory medicine, ENT, dermatology, cardiology and general medicine, as patients with allergic conditions will be admitted under these specialties (eg a patient with an anaphylactic reaction may be admitted overnight on the acute medical take).

#### 14.3 *Network co-ordination and leadership*

The Centres, in collaboration with each other, will lead the development of clinical guidelines and protocols for all levels of care in the network and will co-ordinate the audit of their use.

### 15. TEACHING AND TRAINING IN THE NETWORK

15.1 The education and training potential of the network will be used in full through exchanges between those working in the community and primary care and those working in hospitals/the specialist centres. In particular, Consultant Allergists will be expected to co-ordinate and undertake multi-professional teaching including:

- Educating undergraduate medical students.
- Provision of training for Specialist Registrars in allergy.
- Training of Senior House Officers (particularly in the A&E department) must be a regular commitment, as many patients with allergic reactions present to A&E.
- Training of other professionals, especially practice and specialist hospital nurses, but including pharmacists, dieticians and others.
- Postgraduate teaching for General Practitioners and organ-based specialists in DGHs.

### 16. ACADEMIC ALLERGY IN THE NETWORK

16.1 There are many areas of allergy that need further research. Some of this research needs to be laboratory based but much is also clinical and involves following the natural history of environmental allergies, many of which are relatively new (eg latex allergy). It is important, therefore, to keep a database of diagnosed cases to facilitate this and to increase the clinical knowledge base. In addition the regional centre will co-ordinate clinical trials of new therapies.

It would be essential for the Specialist Allergy Centres in the North West Integrated Regional Clinical Allergy Service to have a strong academic presence. This would provide the opportunity to increase the clinical knowledge base, improve treatments for the population of the North West, with its relatively poor health status, and to begin to address the deficit in trained clinicians in this area and should not be lost.

### 17. STAFFING THE CENTRES IN THE NETWORK

17.1 The Specialist Allergy Network would need to have three WTE Consultant Allergists. In addition, three WTE specialist nurses and two WTE experienced dieticians and, possibly, a liaison psychiatrist and physiotherapist, would need to be employed as part of the team. A Secretary/Administrator would also be required. The hospital pharmacies would each need to identify a member of staff with an interest in allergy to help prepare capsules for challenge tests and for information on the ingredients of drugs and on drug reactions.

### 18. OPPORTUNITY FOR PREVENTION

18.1 There are currently several cohort studies of the effects of allergen avoidance on the development of allergies in childhood being undertaken around the world and, in particular, based on the North West Lung Centre at Wythenshawe Hospital in Manchester[15]. The results of such clinical trials should have a major impact on public health policy and the Specialist Allergy Centres would have an important role in disseminating information and guiding the implementation of such policies. Successful allergen avoidance in childhood could significantly reduce morbidity in later life.

18.2 There are many claims being made by manufacturers regarding the efficacy of their products in aiding allergy sufferers, much of which is unsubstantiated. The Specialist Allergy Centres should provide advice and clear information on what is of proven benefit, what is of potential benefit and what has been shown to be of no benefit, based on the best available scientific evidence.

## 19. NEW DEVELOPMENTS

19.1 There is a range of novel, immunotherapeutic treatments, currently undergoing clinical trials, which will probably enter clinical practice over the next two to three years. These treatments are likely only to be suitable for a carefully selected group of patients with particular conditions. The Specialist Allergy Centres would play a key role in selecting patients and delivering treatments in a safe and cost-effective manner.

## 20. COLLEGE ADVICE

20.1 The Allergy CCST was only recognised in June 1999. Currently there are very few consultant allergists and, consequently, very few specialist registrars in training.

20.2 A conference took place at the Royal College of Physicians (Allergy Services Conference, 15 May 2001) to discuss the demand for allergy services, the unmet need and to examine ways to improve service delivery. The recommendations included the development of Regional Specialist Allergy Centres (two allergy consultants, two nurses, one dietician, one secretary/administrator) and a further expansion in the number of allergy consultants to support the wider network. In addition, it was felt that more research was required fully to identify the burden of allergic disease.

## 21. COSTS

21.1 These will be identified when there is broad agreement that Clinical Allergy is an area of deficiency that should be addressed and that the model proposed in this paper is to be introduced. The “centre” components of the model currently envisaged would require funding for staff, in total, of the order of £400,000 per annum.

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#### SUB-GROUP MEMBERSHIP AND PROCESS

The then North West Regional Specialised Commissioning Group, at its meeting on 6 June 2001, decided to obtain advice on the current and future provision of allergy services in the Region. I was asked to convene a sub-group.

As relatively little was widely known about the current state of this service and the desirable future model of provision, it was decided to adopt a rather different approach from that used for other services. The following people were asked to meet to prepare a draft paper to be circulated to providers and commissioners across the Region:

Adnan Custovic, then Reader in Allergy and now Professor in Allergy, Wythenshawe Hospital.

Roy Dudley-Southern, then Deputy Director of Clinical Strategy, Manchester Health Authority, and now Strategic Planning Manager and Acting Director, Greater Manchester PCTs Collaborative Commissioning Programme.

Rosalind Jones, then Business Manager, North West Region Specialised Commissioning Team, now Assistant Service Development Manager, Cheshire and Mersey Specialised Commissioning Team.

Bridget Simpson, Clinical Nurse Specialist in Allergy, Wythenshawe Hospital.

Ashley Woodcock, Professor in Respiratory Medicine and South Manchester Clinical Academic Group Leader, Wythenshawe Hospital.

Miriam Woodman, then Consultant in Public Health Medicine, Manchester Health Authority (until October 2001), now Consultant in Public Health Medicine, Walsall Primary Care Trust.

Not unexpectedly the draft produced a range of responses. These were mainly supportive but there was also some criticism from those who felt their contribution had not been sufficiently recognised. A range of meetings and discussions took place across the Region, although diary difficulties made this a longer process than had been expected. It proved possible to incorporate or otherwise address most of the comments and this paper is the result.

I would like to express my appreciation for the time and effort that has been committed by the members of the sub-group to this endeavour and my thanks to those who took the trouble to respond to the consultation and to meet us.

January 2003

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#### Memorandum by the British Association of Dermatologists (AL 11)

##### SUMMARY

Many Departments of Dermatology in the UK provide an allergy service for patients with skin disease but there is a need to improve the provision so that all patients have access to a high level of service. Allergy testing includes patch testing for allergic contact dermatitis (including occupational dermatitis), prick testing or allergen-specific immunoglobulin E interpretation for latex allergy and prick testing or allergen-specific immunoglobulin E interpretation for allergies in patients with atopic eczema. The British Association of Dermatologists through the British Contact Dermatitis Society is actively involved in pressing for the improvement of allergy services for skin disease and in providing advice to allow governance of such services. The British Association of Dermatologists is not involved in the governance of independent sector providers except where such services are provided by its members.

1. Availability: Many Departments of Dermatology provide some sort of allergy services in relation to patients with skin diseases but the provision is not uniform and some centres do not provide the full range of expertise.

2. Skin allergies include the following:

- (a) Allergies—usually “immediate” type (type I), associated with atopic eczema, eg allergy to house dust mite, and food allergies particularly in children.
- (b) Allergic contact dermatitis (“cell-mediated”—type IV), eg to nickel, chromate, fragrance, rubber chemicals, preservatives and industrial chemicals.
- (c) Latex allergy (“immediate” type—type I), which can give skin symptoms (as well as respiratory effects and anaphylaxis).

3. Provision: Many Dermatology departments provide patch testing to assess for allergic contact dermatitis. This procedure involves the application to the patient's upper back of substances suspected of causing contact allergy. The testing requires the patient to visit the outpatient department three times in a week.

4. Atopic eczema and latex allergy: Testing for food allergy, house dust mite allergy or latex allergy is provided by some Departments of Dermatology and can be done by intradermal prick testing (on the arm) and/or by a blood test for allergen-specific immunoglobulin E, eg to latex protein (the so-called "RAST"). Some departments do not have the facilities or local expertise to provide this service.

5. Occupational disease: Skin disease caused by occupation is second only to musculoskeletal problems as a cause of loss of time from work, with a reported incidence of 13/100,000 workers/year. The commonest allergic causes are contact with rubber, nickel, epoxy resin, chromate, fragrances and preservatives.

6. Special interest: Larger departments normally have a consultant with a specific interest in skin allergies who oversees these tests. In smaller departments general dermatologists perform the tests. In many departments there are nurses with special expertise in the area of patch testing. Some nurses can do prick testing.

7. Training: The provision of patch testing services requires specialist training in Dermatology and specifically in the sub-specialty of contact and occupational dermatitis.

8. Priorities: The British Association of Dermatologists and the British Contact Dermatitis Society see the provision of allergy services for patients with skin disease as a priority and aim to improve these services by several steps including:

- (a) The development of better protocols for patch testing and the assessment of latex allergy.
- (b) The introduction of guidelines for investigating contact dermatitis including the availability of guidance on what series of allergens should be used for the test.
- (c) The use of computerized databases for the audit of patch test results.
- (d) The reporting of cases of occupational skin disease to the EPIDERM scheme based at the University of Manchester.
- (e) Through collaboration between centres in the UK and with colleagues in Europe, particularly with dermatologists in Germany whose data collection system is compatible with the British one.
- (f) Through lobbying for allergy services to be available to all patients with skin disease and not just those who are served by larger departments.

9. Independent sector: The British Association of Dermatologists are not aware of the extent of the provision of allergy services for patients with skin disease in the independent sector but expect such of these services provided by BAD members to be of a reasonable standard.

*May 2004*

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### **Memorandum by Norfolk Allergy Diagnostic and Advisory Service (NADAAS) (AL 12)**

#### **1. OBJECTIVES OF NADAAS**

- Recognition of the allergy patient/sufferer. Provision of allergy diagnostic assessment/skin prick testing.
- Provision of patient empowerment to manage and understand their allergic condition.
- To improve quality of life of the allergic patient/sufferer.
- To provide education and allergy awareness to fellow professionals in primary care.

#### **2. OVERVIEW OF THE SERVICE**

NADAAS was initially set up as a private service in 1986–87, following a submission of a paper on NADAAS cost effectiveness<sup>(1)</sup> in terms of health management and financial savings to the NHS. NADAAS was awarded a contract by the then Norfolk FHSA on a self-employed basis. The funding is on a cost per case basis, which includes the costs of running the service, travel, administrative help, (provided by my husband) and salary.

Patients are referred by their GP, hospital consultant or doctor.

The patients are seen for allergy assessment at their GP surgery or another designated local surgery. (The latter in order to cut waiting list time). Patients are offered a choice of venue and appointment time. Currently funding is provided by four PCT's and administered quarterly by one PCT on behalf of all four.

Administration of NADAAS is carried out from the providers' home office, where the referrals are received.

Following an holistic assessment of all the patient's symptoms, skin testing and advice on management, a full report is given to the patient, GP, Hospital consultant or Doctor. The consultation takes one to two hours and is a one-stop shop, in addition NADAAS offers a patient phone-in service between 6-7 pm Monday to Wednesday" evenings.

Clinic waiting list can be six to 12 weeks (depending on holiday leave etc).

NADAAS receives approximately 400 NHS referrals per year, funding allows for 300 patients per year, which is allocated on a cost per case basis. (32,900 per annum).

Appointments are initially arranged by phone then followed up by written confirmation.

### 3. OUTCOMES/BENEFITS OF NADAAS

NADAAS meets the requirements set out in the European White Paper (Brussels), Allergic Diseases as a Public Health Problem 1997,<sup>(2)</sup> which states "that the majority of allergy care can and should be managed in primary care". And the criteria stated in Containing the Allergy Epidemic the unmet need" from the Royal College of Physicians, 2003,<sup>(3)</sup> "Primary care must ultimately provide the front line care for allergy".

NADAAS has been able to demonstrate<sup>(1)</sup> in those patients found to be allergic over a period of 18 months post allergy assessment:

A reduction in prescription rates of 59%.

A reduction in repeated doctor consultation of 70%.

An improvement in well being of 70%.

NADAAS is able to demonstrate that 3% of patients assessed required review appointments and less than 3% required referring on to an organ based consultant with an interest in allergy or to the Regional Allergy specialist.

The overall cost of the service is cheaper than that offered by a hospital consultant/doctor.

The service is valued by the GP's, currently NADAAS has 120 surgeries on its books and a recent survey has shown that over the past five years 30 doctors from the local hospital have used the service. These include doctors from Respiratory, ENT, Pediatrics, Gastroenterology and Dermatology departments.

NADAAS is valued by the patients, they are (particularly children) appreciative of being able to be seen at their familiar surgery. Generally on arrival they are seen promptly but rarely more than five minutes later than the given appointment. Patients value not having long journeys to local or district hospitals, thus reducing the amount of time lost from school or work. There are no parking problems and no parking costs. They value the quiet one to one, one-stop allergy assessment.

NADAAS is recognised nationally and internationally.

In 1998-99 two representatives from the Department of Health, a Nurse advisor and an administrator spent a day in the NADDAAS clinic. They assessed the service to be a model of excellence, which should be emulated across primary care.

### 4. THE PROVIDER

She has presented papers nationally and internationally, written numerous articles on allergy and published a book on Skin Prick Testing in Clinical Practice. She has received travel scholarships and national awards for her unique work in allergy. She has been involved in professional education, development and implementation of education programmes.

She is Co-Founder member, past Trustee and current Vice-President of Allergy UK.

### 5. PLANNED DEMISE OF NADAAS

Reasons given for the cut in the service:

(a) Allergy is not a high priority in HA budget.

(b) Service is only patchily used.

(c) Allergy can now be managed in the local Dermatology Department and the Regional Hospital in Cambridge.

Some Doctors using and valuing NADAAS have written to advise that they were never consulted about the cessation of the primary care allergy service, despite published reports to the contrary.



## 6. RECOMENDATION

(a) It would be helpful if HA were to offer local education programmes for primary care workers in order to recognise the potential allergic patient, though it is apparent that those doctors who do not use NADAAS are less likely to attend allergy education programmes.

(b) Allergy management should be based on a pyramid plan with Primary care identifying the allergic patient, referring them (up the pyramid) on to local doctor/nurse with an interest or specialist skills in allergy who would then be able to identify the more complex allergic cases for referral to the regional allergist, (top of pyramid). This will reduce long-waiting lists at regional hospitals, and afford early education of the patient and carers on the management of their allergy.

## REFERENCES

(1) Brydon M J, The effectiveness of a peripatetic allergy nurse practitioner service in managing atopic allergy in general practice—a pilot study. *Clinical and Experimental Allergy*, 1993, Vol 23, pages 1037–1044.

(2) Van Moerbeke D et al, European Allergy Paper, Allergic Diseases as a Public Health Problem. May 1997. UCB Institute of Allergy, Brussels. ISBN: 2-87301-018-5.

(3) Royal College of Physicians, Containing The Allergy Epidemic. June 2003. Summary and recommendations of a new report from the RCP Allergy—the unmet need: a blueprint for better patient care.

May 2004

### Memorandum by Dr Tina Dixon (AL 13)

I have been a part time Consultant Allergist in Liverpool for 17 years. I run the allergy service at the Royal Liverpool and Broadgreen University Hospital NHS Trust (RLBUHT) and at The Royal Liverpool Children's NHS Trust (Alder Hey).

#### BACKGROUND OF THE LIVERPOOL ALLERGY SERVICES

There has been an Allergy Service in Liverpool for over forty years. With the reorganisation of the hospitals in the city in 1978, the service moved to the Royal Liverpool Hospital. At that time, there was a full time consultant allergist, a part time consultant allergist (three sessions), a full time receptionist/secretary, a full time nursing sister, a clinical assistant (two sessions), and a consultant ENT surgeon who did one allergy clinic/week. The full time consultant allergist did two sessions at Alder Hey Children's Hospital, and the clinical assistant did another two sessions at Alder Hey. When the sister retired, her role was taken over by the clinic sister in charge of that area, with adequate trained nursing support. During this time, in recognition of the wide catchment area of referrals to the clinic (approximately two thirds were from outside Liverpool), the unit was given District Managed Regional status and funded by the Regional Health Authority. In the early 1980s, the ENT surgeon retired and his successor took no part in the allergy service. In 1987, when the part time consultant retired, the three consultant sessions and four clinical assistant sessions were combined to make a half time (five and a half sessions) consultant post, which I have held since that time. With reorganisation of the Health Service, funding for the service was devolved to the individual NHS Trusts who both put it under the umbrella of the medical directorate. In the mid 1990s, we gained approval for a training post. The waiting time for a routine appointment in both trusts was about three to four months. However, in 1997, the full time consultant retired, both trusts decided that their priorities lay elsewhere, and he was not replaced. The waiting times increased.

At the RLBUH I was assisted by two senior registrars in Immunology and funding was obtained from the PCT's for an allergy nurse, though I suspect that the funding was geared to waiting lists rather than Allergy per se. As I am only part-time, we no longer have approval for an allergy trainee. One senior registrar gained a post elsewhere, the other filled the Consultant Immunologist vacancy that arose at RLBUH and, whilst required to do one allergy session, chose to do two. The waiting times for a first appointment continued to increase. At a time when the waiting times were over three years for a routine first appointment, referral guidelines were issued by both Trusts. In 2000 we carried out both clerical and clinical validation of the waiting lists but, by April 2001, they still stood at one hundred and three weeks. Therefore, an executive decision was taken to close the clinic to all but urgent referrals, and additional Waiting List Initiative clinics were done to bring the time down.

In May 2003 the North West Specialised Commissioning Group agreed to endorse proposals for the establishment of a North West-wide clinical network for adult allergy services, including a full time allergist, an allergy specialist nurse and dietetic support in Liverpool. Specialised Commissioning leads have agreed to work with local PCT's to progress plans but with an expectation that "additional resources are unlikely to be required until 2005–06".

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#### AVAILABILITY OF SERVICES

We still only see urgent referrals at RLBUHT, clinically validating all referral letters. There are five consultant clinics/week (three Allergist led, two Immunologist led), two nurse led clinics, a joint allergy/anaesthetic clinic once a month and an immunotherapy service. Waiting time is within the 17 week target.

At Alder Hey, although in 2001 a Paediatrician agreed to do one clinic/week and an Advanced Nurse Practitioner transferred from other responsibilities to do two clinics, we still struggle to keep within the seventeen week target.

There is still no dedicated dietician support for any of the allergy services.

The only other allergy provision on Merseyside is a paediatric allergy clinic in Warrington once a month and another at Arrowe Park Hospital, Wirral, once a month, both run by Paediatricians with an interest in the subject.

This history shows that the resources for allergy need to be identified and their funding ring-fenced so the service may continue and develop, despite the changing fashions of the time, whims of the management and the personal preferences of future incumbents.

May 2004

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#### Memorandum by Royal Brompton and Harefield NHS Trust (AL 14)

We face a major epidemic of allergy within the UK at present. There has been a two—fourfold increase in allergy related disorders including asthma, rhinitis and anaphylaxis. Allergy services within UK are grossly inadequate in the face of this serious public health problem which affects around 30% of the UK population. For example, there are only six full time specialist allergy clinics throughout the whole of England and no such service in Wales, Scotland or Northern Ireland.

My clinic at Royal Brompton Hospital is one of three such clinics in London and, like elsewhere, specialist allergy services are focussed in academic centres when much of the provision for NHS services is obtained piecemeal and dependent inappropriately, on university funding. My post is only funded 2/11ths by the NHS, together with one full time Specialist Registrar in Allergy and the support of a dietician with an interest in food allergy. Nonetheless, the service is supported largely by my clinical research fellows and specialist research nurse who provide a major service role for NHS patients. This situation is clearly unsatisfactory and not feasible outside an academic setting.

A major problem is that the typical allergic patient has diseases affecting the multiple organ systems including eyes, nose, chest, skin, gastro-intestinal tract with or without the risk of potential life-threatening anaphylaxis. A good example is the peanut sensitive child (currently 2% of children in the UK are peanut allergic). These patients are at risk of life threatening anaphylaxis, particularly in those who have associated bronchial asthma. A second example is the patient who has a life-threatening adverse reaction under general anaesthesia. Such cases require obsessional evaluation and investigation in a day care specialist allergy setting. A third example is the 5–10% of adult asthma patients who have an occupational cause for their asthma which requires detailed evaluation.

These cases emphasise the need *for a multi-disciplinary approach which can only be provided by a specialist allergy centre*. The current piecemeal service provided at secondary care level by individual organ specialists is inadequate. For example, a chest physician may be competent to evaluate the allergic component of asthma. He may or may not recognise that the patient has associated distressing allergic rhinitis requiring separate management. Almost certainly, he would not be equipped to investigate and diagnose associated food allergy. Neither could he deal with associated urticaria or difficult eczema. Such a patient requires one consultant allergist with a multi-disciplinary approach to diagnosis and treatment rather than the alternative, namely, four to five organ specialists to deal with multiple allergic problems.

The priorities should be as follows:

1. Establishment of regional centres throughout the UK, including Wales, Scotland and Northern Ireland. Such a regional centre should comprise two Consultant Allergists, a minimum of one Paediatric Allergist, a full time allergy nurse, two specialist trainees in allergy and a half time dietician with a specialist interest in food allergy.

Such a service should provide:

- (a) a supra regional service for tertiary referrals from organ-based specialists; and
  - (b) a local service for primary referrals of patients with multiple allergies.
2. Such a regional centre would be committed to training Specialist Registrars in Allergy for the future. Equally important, the regional service could provide training in allergy for organ-based specialists at secondary care level. A third important aspect of training involves education at primary care level of General Practitioners and Practice Nurses.

3. Finally, regional centres should ensure that allergy is a proper part of the under-graduate medical student curriculum in order to ensure that future doctors in all specialities and within general practice are aware of the current epidemic in allergy within the UK and the need for appropriate reform.

In Cambridge Dr Pamela Ewan has provided a role model for how an NHS-Funded regional allergy centre can provide a supra-regional and regional service and training at tertiary, secondary and primary care level. As a first step such NHS-funded centres could be set up throughout the 11 regions within the UK.

May 2004

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### Memorandum by Philip Doré (AL 15)

#### PROVISION OF ALLERGY SERVICES IN HULL AND EAST YORKSHIRE

##### 1. *Summary*

- The allergy service is based in Hull and serves a population of around one million covering up to Scarborough and over to York.
- The service is provided by a single handed Consultant Immunologist providing both adult and paediatric allergy and immunology services. There are usually six clinics run per week. For the clinical service there is an adult specialist nurse, a part time paediatric specialist nurse and a full time E grade nurse.
- There is a waiting list problem, initially around one year but over the last six months additional waiting list initiative clinics have been done to bring the wait down to 17 weeks to see the nurse specialist.
- Follow up of patients is delayed and once seen a further appointment may not be available for over six months.
- The Service would benefit from development of Centres along the lines of the developments in cancer care.
- There is a need for investment in new Consultant staff and nursing staff in the acute sector alongside the centres.
- It is important to use the current expertise available within the current providers (Consultant Immunologists) to develop and improve the service.
- There is a need for more education in the community sector and the development of lead General Practitioners and Nursing staff.
- A recent survey of schools shows a lack of understanding of managing allergic disease.

##### 2. *Service*

###### Weekly Clinics:

- One pre-assessment clinic run by specialist nurse
  - History, investigation by protocols
- One urgent clinic run by Consultant
  - Acute reactions requiring early intervention
- One paediatric clinic run by Consultant
  - General paediatrics and Immunology
- One procedures clinic in day unit
  - Immunotherapy, challenges
- One standard follow up clinic run by Consultant
  - Routine follow up
- One follow-up from pre-assessment clinic run by Consultant
  - New patients from the Nurse led clinic

Throughput currently 600–700 patients per year.

The clinic has been running since 1986.

##### 3. *Issues*

- Lack of clinical input and cover.
- There is a shortage of doctors with experience of allergy and immunology.

- Lack of resources to expand services.
- Allergy services are a low priority in the current NHS service and therefore funding to develop the services has been difficult to obtain.
- Lack of education within the community regarding referral of suitable patients and management of allergic reactions.

School Survey October 2003 looking at allergy management in 280 schools (59% response rate) showed:  
82% had no policy on allergic reactions;  
55% had had no training on dealing with allergic reactions; and  
67% of schools would like to receive training.

The main issues:

Allergies and anaphylax	51%
Treatment for allergies	41%
Implications for schools	59%
Emergency procedures	39%

#### 4. *Suggested Priorities*

Consultant staff:

- There are currently less than 10 full time allergists in the UK. The bulk of the service is provided by Clinical Immunologists (approximately 50). The aim should be to increase specialist allergists, this is best done by investing in the current Immunologists who are in a position to develop the service and train new medical staff. In the interim support needs to be given to the current Consultant staff to improve facilities and encourage both clinical and nursing staff into this area.

Nursing staff:

- Specialist nurses are ideally placed to assess patients quickly and can therefore act as a filter for those who need Consultant input. They are able to initiate management plans and may be all that is required for educational issues such as allergen avoidance measures. There needs to be an increase in provision particularly in the community setting where most patients with developing allergic disease can be seen. There is increasing evidence that early intervention in allergic disease can reduce progression to more severe problems.

Centres:

- Allergy centres should be considered to deal with the increasing burden of allergic disease. A good model is the current development of Cancer Centres and Units. It should be considered that where a cancer centre has been developed that this will have the correct population and geographical features to make it suitable for an Allergy Centre.
- Central funding or the development of PFI should be considered.

Other Allergy Services:

- Due to the lack of proper allergy services there has been a growth in this country of alternative medical services. These often manufacture illness and rarely treat allergic disease adequately. Part of the provision of allergy services is to re-educate patients as to what is occurring and to move them off restrictive diets.

Investment in a proper allergy service will improve the health of patients.

May 2004

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#### **Memorandum by Professor Tak Lee (AL 16)**

##### **INTRODUCTION**

This memorandum is being submitted by Professor Tak Lee MB BChir, MD, ScD, FRCP, FRCPATH, FMedSci. He is Professor of Allergy and Respiratory Medicine at GKT School of Medicine, King's College London; honorary NHS consultant and Head of the allergy service at Guy's and St Thomas' Hospital Trust (GST).

## AVAILABILITY OF ALLERGY SERVICES

Allergy services first developed at Guy's Hospital in 1970s, initially as an adjunct to an academic department and is now one of the largest clinical services in the UK, caring for both adults and children. It is also active in allergy training. The service is allergist-led and offers expertise for patients with all allergic diseases. While the majority of patients are referred from primary care physicians throughout the South-East (secondary care) a significant proportion are also referred from other specialists for tertiary care. The great majority of the clinical service is outpatient-based and provides help for patients with a broad spectrum of allergic disease including those with severe allergies. We are privileged to have such a comprehensive service at Guy's as there are very few clinics of a similar type in the UK.

Referrals to the allergy service at Guy's Hospital have increased significantly over recent years. In the 1997–98 year 1,090 new patients were seen, increasing dramatically to 1,922 patients by the 1999–2000 year. Since that time the number of patients seen has remained relatively constant, although the waiting list times for clinic appointments have fallen significantly to meet national NHS targets, because we appointed a full time NHS consultant allergist. In 2004–04 outpatient numbers seen are above target.

Referrals from Lambeth, Southwark and Lewisham make up 44% of new patients seen, with the rest coming from outside the local area, including significant numbers from Bexley, Bromley, Greenwich, West Kent, South East London HA, East Sussex, Brighton and Hove, East Surrey, Kent and Medway HA, West Sussex and Merton, Sutton and Wandsworth and smaller numbers of patients have been referred from over 35 other areas.

Following the appointment of a full time NHS allergy specialist in 2002 and a full time Allergy Specialist Nurse, the adult service has expanded, with innovation and more efficient use of resources. We now have a dedicated Drug Allergy Investigation Clinic, Food Allergy and Intolerance Clinic, an extended Asthma Clinic and an expanded Immunotherapy Clinic which offers treatment that has the potential for long lasting reduction in the severity of allergic symptoms. However, with present resources, only adults are treated in this immunotherapy clinic.

Paediatric referrals currently make up almost 25% of overall referrals and are increasing. Most allergic disease develops in childhood, with children often suffering several allergic diseases sequentially or simultaneously. There is increasing evidence that early treatment of paediatric allergy with, for example, immunotherapy may reduce the progression of disease and reduce new allergic sensitisations. There is therefore a real opportunity to halt the epidemic of allergic disease if the appropriate services and resources are provided. Unfortunately there is a dearth of paediatric allergy services in the UK and paediatric allergic disease is often managed by practitioners who may not be adequately trained in the specialty of allergy and, even when they are skilled, are probably under-resourced. This can result in suboptimal care

GST established a paediatric allergy service several years ago, which is in high demand and provides a seamless transition from childhood to adulthood in the care of patients with allergies. However the two consultants and clinical lecturer (seconded from the university), who supervise the paediatric service, work only part time in GST. They are employed predominantly in other hospitals with heavy general paediatric duties or in an academic department. It is therefore urgent that more full time NHS paediatric consultant posts with a special interest in allergic diseases are created to meet clinical demand, to satisfy waiting list targets, for governance reasons and to develop managed regional networks of allergy care (including education and training of physicians and nurses in primary and secondary care). Paediatric Allergy Specialist Nurses and dieticians are also urgently required.

Nationally, a significant contribution to allergy service delivery is provided by consultants in other specialties such as clinical immunology, respiratory medicine, dermatology and gastroenterology. This is invaluable and without their help, the provision of a NHS service for allergy would be in an even more parlous state. However, much of their contribution by necessity is part time because they have other commitments to their disciplines. While one of the obvious challenges to NHS allergy service delivery will be how to integrate and maximise these important contributions, it must be recognised that even with their full participation only a tiny fraction of the clinical demand will be met with the current workforce.

## PRIORITIES FOR IMPROVING SERVICES

It is impossible to dissociate expansion of an NHS allergy service from the requirement to have more trainees in allergy. The Department of Health workforce has recommended 20 new National Training Numbers between 2005 and 2007. However, there is no certainty that this will become reality as the quota was reduced from seven to nought last year. The specialty eventually received one new NTN after rigorous appeal. Allergy is in predicted negative growth by 2012 by Department of Health's own estimates; it is one of only two such specialties. The specialty cannot grow unless more trainees are provided. We did not find anyone suitably trained to appoint as a consultant allergist to GST in 2002 and had to recruit from New Zealand.

Expansion of the paediatric allergy service is critical where the clinical demand is enormous. Currently there are no training numbers in the specialised area of paediatric allergy.

The recommendation by the Department of Health that regional centres of excellence for allergy should be established, which was reiterated in the recent Report of the Royal College of Physicians (Allergy—the unmet need), should be implemented. These centres are essential for provision of leadership to develop local services, for networking with consultants with a special interest in allergy in other specialties and for training of GPs and other doctors. In this regard it is important to note that the integrated curriculum for allergy training was only established by JCHMT a few years ago and subsequently revised, so very few physicians have ever been through accredited training in allergy.

There are grave concerns, however, whether the current arrangements for commissioning are sufficiently robust to cope with the financial pressures and service aspirations of specialist allergy centres. There will be an inevitable debate on the funding of specialist services versus the funding of local initiatives. It is important for the commissioning process to understand the need to provide care for larger populations by specialist teams. This is essential not only to guarantee the quality of patient care but also allow time and space for the training of specialists, promoting innovation and research.

Allergy should be part of the General Practitioners with Special Interest (GPSI) initiative. Much could also be done by training nurse specialists in this area of health care.

#### GOVERNANCE

In the independent sector there are some excellent services provided but they are few and far between. This scarcity is compounded by the lack of NHS services and as a result practitioners in alternative medicine are being sought out by patients with allergies. However there seems little regulation of unorthodox practices. The failure to make a proper diagnosis and offer rational management can cause significant morbidity from, for example, use of inappropriate dietary elimination and other changes in lifestyle. This is not only expensive for patients but costs the country money because of time lost from work due to continuing illness. This eventually returns to burden the NHS because of complications caused by delays in treatment.

May 2004

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#### Memorandum by Dr Chris Corrigan (AL 17)

#### SENDER DETAILS

This report is submitted by Dr Chris Corrigan MA, MSc, PhD, FRCP, Reader and Consultant in Respiratory Medicine and Allergy at Guy's, King's and St Thomas' School of Medicine, King's College London.

I submit the report both in a personal capacity, running a busy and comprehensive allergy service at Guy's Hospital, and as Secretary of the British Society for Allergy and Clinical Immunology, the professional body representing NHS clinical and academic allergists in both primary and secondary care in Great Britain, and as secretary of the Joint Committee for Higher Medical Training in Allergy, the Royal College Committee responsible for the training of new doctors as specialist allergists.

#### EVIDENCE BASED ON TERMS OF REFERENCE

*Availability of allergy services (including issues such as geographical distribution, access times and patient choice) and specialist services for patients with severe allergies*

The availability, geographical distribution and access times for NHS allergy services are woefully poor countrywide. The full details are set out in a recent publication from the Royal College of Physicians: *Allergy, the unmet need: a blueprint for better patient care* (London: Royal College of Physicians, 2003). For accurate appraisal of the situation, the Committee should be thoroughly familiar with this document. In brief:

We are in the middle of an epidemic increase of allergic diseases. Allergic diseases are by far the commonest diseases today in the UK. In any given year, 12 million people in the UK (one fifth of the population) are likely to be seeking treatment for allergy. Peanut allergy, which may in some cases produce fatal anaphylaxis, now affects one in 70 children (that is, one child in every year of every school in the UK). Asthma and allergic rhinitis (hay fever) rank top of the list of causes of loss of time from school and work in the UK. Approximately 20% of the population, both adults and children, suffer from hay fever in the UK. Although this disease does not have the glamour of cancer or heart disease, it must be taken seriously. About one third of the 12 million people who suffer report that the symptoms adversely affect their work, home and social lives. Among children and teenagers in particular, hay fever can cause learning difficulties caused by fatigue and inability to concentrate, with poor examination results. Hay fever at exam-time is so troublesome that it is cited as one reason for considering a change in the traditional three-term school year.

In the USA, which has a similar prevalence of hay fever to that seen in the UK, two million lost working days, three million lost school days and 28 million days of decreased productivity annually are attributed to this disease alone.

The Royal College of Physicians report notes that there are only six fully staffed allergy clinics in the UK. These have developed around centres with an interest in allergy research, and do not represent the product of NHS planning or support. They are located mainly in London and the South East, creating a marked geographical inequality in service provision. Allergy barely features in the undergraduate training curriculum for medical students, and the lack of specialists means that virtually no clinical training is available. Consequently, most medical practitioners are ignorant of the practice of allergy, and have no idea of the diagnostic and therapeutic benefits potentially open to these millions of sufferers.

What other allergy services do exist in the UK are run part-time by consultants in other disciplines (immunology, dermatology, paediatrics, respiratory medicine, ENT). While excellent in their respective fields, these clinics do not have the capacity to cope with the rising tide of allergy or with the increasing complexity of allergic disease (for example, a child with peanut allergy who also has eczema, hay fever, asthma and glue ear). Allergy is increasingly a multi-system disorder and must be managed accordingly.

Patients with severe allergic diseases simply do not know where to turn. As evidence of this I present a selection of pleas reproduced *verbatim* from (anonymised) patients received on the BSACI web site ([www.bsaci.org](http://www.bsaci.org)) between January and April of this year. During this period the web site received 1,117 “hits” on the section providing information on what allergy services are available in the UK.

From South Wales:

My son has severe eczema I would like to know if you could help. I have tried almost everything he is six and is getting very aware of his appearance.

*Nearest clinic Cardiff, 20 miles away, staffed by consultants whose primary speciality is not allergy.*

From Cleethorpes, Lincolnshire:

I would appreciate a list of allergy clinics in the UK, particularly in Lincolnshire, Nottinghamshire and Yorkshire. I live in Cleethorpes, North East Lincolnshire.

*Clinics in Scunthorpe, Leeds and Sheffield, nearest 25 miles away, all staffed by consultants whose primary speciality is not allergy.*

From Kent:

My name is —, I am 30 years old and I am from Italy. I moved to England in 2000 and since I have had problems in finding a doctor specialised in Allergology. Unfortunately, since I can remember, I have always suffered of severe forms of allergy, including anaphylaxis, and I had a specialist in Rome who used to take care of me. At the moment, and after a couple of year of apparent calm, I am experiencing high discomfort due to some “minor” forms of allergy/intolerance—urticaria, rashes, vomiting/diarrhoea—I forgot to mention that most of my allergies are related to food (legumes, maize, most fruits and vegetables, shellfish, porc etc), even though I badly suffered in the past from insect stings, pollen and dust (I had very bad asthma in my childhood). After a serious reaction to asparagus—which ended up in hospital—my GP referred me to a dermatologist, however, this doctor could not do anything for me, apart from prescribing some adrenaline to carry. At this moment in time I would like to have a more thorough investigation of my allergies, possibly with some more tests to be carried out, in order to find out which are my allergies now—I am under the impression that they have slightly changed in time and that I am now avoiding the wrong food and eating something that is actually “poisoning” me. For these reasons, I would like to ask you if you can kindly give me some information on a specialised clinic/doctor in my area (south-east of England) or, worst case scenario, in the whole country, who could help me better understand my condition. Thank you in advance for your understanding.

*Nearest clinics Southampton or London.*

From Aberdeen, Scotland:

I have had 10–15 allergy attacks in last two years with two × anaphylaxis emergencies. I cannot connect with any pattern of food or exercise and waiting list in Aberdeen to see a consultant is two years. Any help would be appreciated very much. I am prepared to travel anywhere in the UK and pay for the help.

*No clinics in Scotland run by consultants whose primary speciality is allergy.*

From Chaddesden, Derby:

I am particularly interested in finding out where I can get my children food intolerance tested due to behavioural problems. Please can you contact me as soon as possible as this is now of an urgent nature.

*Nearest clinic Nottingham, staffed by consultants whose primary speciality is not allergy*

From Lyme Regis, Dorset:

I live in Lyme Regis and I am curious if there are going to be any clinics near us—the Devon/Dorset border? Thank you.

*Nearest clinic Plymouth, staffed by consultants whose primary speciality is not allergy*

#### *Priorities for improving services*

These are set out in the RCP report referred to above. I earnestly and urgently request, on behalf of the existing allergy specialists and the 12 million suffering patients, that the government consider and implement these.

The provision of allergy care in the NHS must be led by specialists trained in allergy, so that appropriate standards of care can be achieved and maintained. Although the front line of allergy management will be in Primary Care, with no Primary Care skill base from which to work, clinical leadership must come initially from specialist centres.

Consequently, the NHS needs to move forward on two fronts. As a first step, more consultant posts and funded training posts in allergy are required. These will provide the basis for a national training and clinical development initiatives, as well as the basis of a genuinely national allergy service for NHS patients. This will require recognition of need, and then appropriate action from the Department of Health, the Workforce Numbers Advisory Board, Primary Care Trusts, Regional Commissioners and Trust managers. Allergy is also recognised for regional specialist commissioning, and this must be implemented.

More specifically, the RCP plan envisages that each of the eight NHS Regions in England (as configured in 2001, each with a population of five to seven million), as well as Scotland, Wales and Northern Ireland, should have an absolute minimum of one specialist allergy centre staffed by a minimum of two whole time equivalent consultant allergists, a minimum of two full time allergy nurse specialists, one half time adult dietician and one half-time paediatric dietician with specialist training in food allergy, two consultants in paediatric allergy supported by paediatric nurse specialists and facilities and funding for training for two specialist registrars in allergy.

The regional centres would provide specialist expertise for adult and paediatric allergic disease, manage allergic disease which cannot be dealt with in primary care, act as an educational resource for the Region and facilitate local training in allergy for non-allergy specialists, GPs and practice nurses.

In addition, further consultant allergist posts need to be created in other teaching hospital and district general hospitals in each Region to deal with local needs. All teaching hospitals should have an allergy service provided by a consultant allergist. One model might be for a shared appointment between Trusts.

The training of GPs and practice nurses in allergy must be improved. A key part of this will result from interaction with consultant allergists, and the inclusion of clinical allergy training in the undergraduate curriculum.

#### *Governance and regulation of independent sector providers*

Although some qualified allergists work in the private sector, these are very few and far between. It is understandable that patients, in their desperation to receive help, have turned to less orthodox techniques of allergy diagnosis, often with no proven merit. For example, many High Street health food and other stores, fitness centres and similar establishments advertise diagnostic tests for “allergy” which in many cases are of unproven scientific worth. There appears to be little regulation or national governance of these tests and practises. They often cost considerable sums of money. The failure to make a proper diagnosis and offer rational management can add to patient suffering, for example by enforcing inappropriate or unnecessary dieting or other changes of lifestyle. Quite apart from the loss of productivity this entails, not to mention the chance of significant illness and even death, these patients will eventually come back to the NHS, adding further to the NHS healthcare burden.

#### *Additional comments on training issues*

Training of new specialist allergists is one of the cornerstones of the priorities for improving allergy services referred to above. Speaking as secretary of the Royal College of Physicians Joint Committee on Higher Medical Training for allergy, which is responsible for setting the training curricula and standards for trainee allergy specialist registrars across the UK, I must voice concern on behalf of the Committee about the paucity of centrally funded allergy training posts made available in the UK since allergy was recognised as a unique speciality.

The Department of Health Workforce Numbers Advisory Board has recommended 20 new, centrally funded National Training Numbers for trainee allergists between 2005 and 2007. Our experience shows, however, that there is no certainty that these recommendations will become reality, as the quota was reduced from seven to nought last year. The specialty eventually received one new NTN following rigorous appeal. In the previous year, just one post was funded. Excellent training centres hotly contest these posts, and it is



a constant source of frustration that so many applicants are disappointed. At present, the JCHMT estimates that there is immediate capacity in existing allergy centres to commence training of 12 new specialist allergists. Allergy is predicted to show negative growth by 2012 according to the Department of Health's own estimates; it is one of only two medical specialities in this situation. The speciality cannot grow unless more trainees are provided. On behalf of the BSACI, JCHMT and as a personal plea, I respectfully request that the government intervenes directly to make more allergy training posts available as a matter of urgency.

The appointment of new trainees must progress in concert with the establishment of new allergy centres with specialist trainers and suitable training facilities. This will happen if, and only if the recommendation by the Department of Health that regional centres of excellence for allergy should be established, which was reiterated in the recent Report of the Royal College of Physicians Working Party referred to above, is implemented. There are grave concerns, however, as to whether the current arrangements for health care commissioning at regional and national levels are sufficiently robust to cope with the financial pressures and service aspirations of specialist allergy centres. In short, it seems possible that many of these commissioning bodies simply do not appreciate the size and urgency of the problem. At best there will be inevitable debate on priorities for funding of specialist services nationwide as opposed to addressing local issues and initiatives. It is also understandable that regional funding and commissioning bodies look inwards, rather than outwards, no matter how inappropriate this may be. It is therefore important for the commissioning process to understand the need to provide care for larger populations by specialist teams. This is essential not only to guarantee the quality of patient care, but also to allow time and space for the training of specialists, promoting innovation and research. For these reasons we respectfully repeat our earnest and urgent request that the government take direct action in this matter to ensure that the needs of 12 million UK citizens are met by their National Health Service in a timely and equitable fashion.

May 2004

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#### Memorandum by North of England Clinical Immunology Audit Group (NECIAG) (AL 20)

##### A. SUMMARY

This memorandum of evidence is submitted by Dr William Egner on behalf of the North of England Clinical Immunology Audit Group (NECIAG).

The function of the group is to provide a supra-regional Audit Facility for Clinical Immunologists within the North of England and Northern Ireland. NECIAG's function is to survey laboratory and clinical practice and workload in Immunology and Allergy, to derive agreed clinical and Laboratory standards and to audit practice against these. Currently there are 17 UK Immunology centres participating in its audit activities.

Dr Egner is the Chair of NECIAG had been asked to submit a memorandum to the Enquiry on behalf of NECIAG in order to:

1. Re-iterate the full and unequivocal support of the Immunology Consultants within NECIAG for the creation of Regional Specialist Allergy Services led by Full-time Allergists as detailed in "Allergy: The unmet need. A blueprint for better patient care", and to re-iterate the urgent need for additional centrally-funded SpR training posts in Allergy (and indeed Immunology) as part of a long-term strategy to develop supra-regional centres of expertise.

2. Alert the inquiry to a forthcoming audit of Allergy service provision and workload within Clinical Immunology units, planned since early 2004, and to be performed in conjunction with the South West Clinical Immunology audit group. This will provide the committee with additional and extensive evidence regarding the availability and pressures on Allergy services within England. This is due to report in October 2004.

3. Summarise the experience of Clinical Immunologists in the development of specialist Allergy care via local initiatives in the North of England and their difficulties in obtaining funding, which emphasises the need for additional Consultant Allergists and a centrally co-ordinated approach to the provision of funding for such activities. These services include those Allergy activities specified within:

- The National Specialised Services Definition set for Specialist Allergy Services (Number 17).
- "Good Allergy Practice: Standards of Care for Providers and Purchasers of Allergy Services within the NHS" (RCP/RCPPath 1994).
- "Allergy the unmet need" (RCP, 2004).

4. Clarify that; while "Allergy: the unmet need" states that "most organ-based specialists, who have traditionally dealt with allergic conditions such as asthma, allergic skin disorders and allergic rhinitis, have no training in Allergy", Immunologists are an exception to this in that they do have formal training in the diagnosis and management of allergic disease as part of their current and previous training curricula.

5. In addition to supporting the creation of Specialist Regional Allergy Centres, NECIAG ask the committee to also consider mechanisms for improving patient access to expert care in the short to medium term, since the lead-time for the development of allergists as envisaged in “Allergy the unmet need” is the creation of eight Regional Allergy Centres in England requiring 16 Consultant Allergists. There are currently only six full time Allergists in the UK at present, with five Allergy SpRs in training. If each of the eight centres trained two SpRs (taking five years plus two to three year higher degree) it is clear that sufficient Consultant Allergists are not likely to be available for at least 10–14 years to service such an Adult expert network. The situation for Paediatric Allergy specialists is much worse. Consideration should be therefore be given in the interim to potential solutions, perhaps including Immunologists and Allergists working in tandem to provide the earliest improvement to specialised services for patients, and make the most efficient use of existing resources.

6. Alert the inquiry committee that the short and medium term provision of improved and equitable access to Allergy services for the whole of England will depend on appropriate funding and development of relevant specialist services in Teaching hospitals, including those currently developed by Immunology, in parallel to the development of Regional Specialist Allergy services.

7. To emphasise that access remains poor to Allergy services of any description in the north of England, and that obtaining funding for Allergy services from PCTs or Regional Commissioning Groups is extremely difficult, and requires a national initiative and direction. Pressure on the services that do exist, continues to increase in line with the observations in “Allergy: the unmet need”.

## B. TERMS OF REFERENCE

### 1. *Availability of allergy services*

#### Geographical Distribution

NECIAG incorporates the following Immunology centres all of whom provide Clinical and Laboratory Allergy services: Nottingham, Leicester, Sheffield, Pathlinks (Scunthorpe, Lincoln, Boston and Grimsby), Hull, Central Manchester, Salford, Belfast, Newcastle, Sheffield’s Children’s Hospital, Liverpool, Leeds, North Birmingham, Preston, Middlesbrough. We also collect data from New Zealand, where similar service models for Allergy provision apply. Most of these Immunology centres are providing Allergy services to a variable degree, many of which incorporate specialised Allergy service components as defined in the National Services Definition Number 17 for Specialised Allergy and several include components of Regional Allergy Centres which are defined in “Allergy: the unmet need”. Namely; Expertise, management of multisystem allergic disease, multidisciplinary support, infrastructure for management of allergic disease which cannot be dealt with in General Practice; Educational resource; Support at local level for GPs and nurses in the management of common allergic problems in primary care.

The services provided within NECIAG include desensitisation therapy, allergen challenge procedures, training in rescue medication use, school liaison, GP education and assessment of complex drug allergies, as well as the usual angioedema, foods, aeroallergens and other allergens. Many of the Immunology Centres are carefully governed by guidelines, protocols and information sheets and have formalised training programmes for the use of rescue medications including adrenaline, utilising Quality Management Systems similar to those developed for Specialist Primary Immunodeficiency Services as defined in Specialist Service Definition number 16: Specialised Immunology and necessary for accreditation against the service standards produced by UK PIN (UK Primary Immunodeficiency Network).

In addition, Sheffield’s Children’s Hospital hosts a dedicated Allergy service staffed by a 0.8 WTE Consultant in Paediatric Immunology and Infectious Diseases. A similar paediatric arrangement exists in Manchester, and Newcastle (the largest centre). These specialist Paediatric services are extremely rare indeed, as most Paediatric services in the UK are supplied by general physicians with no specialist training in Immunology or Allergy. It is of note that, unlike other specialties, past and present Immunology training programmes contain specific training in the diagnosis and management of immune system disorders including Allergy and that many Clinical Immunologists subsequently undergo further training and extensive post-graduate experience in the management of specialised Allergy, as a result of personal interest or patient demand for the provision of specialized Clinical Allergy services. In this respect these clinical services are quite different from the limited part-time organ-based Allergy service provided by physicians in other specialties such as Dermatology.

Some Immunologists have developed, or are attempting to develop the widest range of Specialist Allergy services to meet patient demands, in the face of lack of funding for such developments, lack of central direction, and the acute shortage of Allergists and Immunologists.

While the NECIAG audit data is not yet available I can illustrate the extent of the provision of Specialist Allergy Services by Immunology teams and the difficulties involved within the NECIAG grouping from information supplied by colleagues and myself.

Access to Allergy services is especially poor in the North of England (as detailed in “Allergy: the Unmet Need”) In Sheffield there is a single Consultant Immunologist (Dr Egner) with support from a GP Clinical Assistant. An SpR in Immunology will join us later this year. We see approximately 500 new Allergy patients

per annum, approximately 750 follow-up patients and approximately 200 day case attendances per annum for desensitisation and allergen challenge. The Sheffield Teaching Hospitals trust has actively supported the development of Specialized Allergy services in parallel with Specialised Immunology services and a new dedicated clinical day case unit is due to be built on site within the next month. The Trust has invested in additional Nurse Specialist support to develop the outpatient and day case clinical services for both Allergy and Clinical Immunology in parallel, since similar staffing and facilities are required, the governance and management requirements are similar, and because both activities are based predominately on day case procedures. Facilities suitable for immunoglobulin infusion and review are also suitable for allergen challenge and desensitisation clinics. Nurse specialists skills such as resuscitation, training, cannulation and the development of nurse-led services also cross over to a large degree, such that one nurse can service both activities. This sort of successful local initiative is unusual and dependent on local goodwill and specific opportunities, and has occurred in only three of the 17 centres within NECIAG. Other units in the North of England have not been so lucky, and gaining the interest of PCTs or regional commissioning groups is very difficult, as Allergy is very far from the top of their agendas. Designation of Regional Centres with appropriate central funding will be necessary to ensure equity of access and enhance the likelihood of equitable access nationally. The paediatric service in Sheffield has so far failed to obtain any significant dedicated funding for its activity. Data on the situation in other units will flow from the NECIAG/SWCIAG audit in summer 2004.

Like other units within the Northern audit group we have been active in promoting the development of the service in the face of acute shortages in central funding for the establishment of new training posts, as effects of previous under-funding of trainee numbers in Immunology work through the system. Newly qualified Immunologists are an extremely rare breed at present (although not as rare as Allergists) and many centres such as Sheffield have vacancies, which cannot be filled in the current absence of trained candidates. According to Phil Quirke, Consultant vacancy rates in Immunology in the UK are now an appalling 16%.

In Sheffield we have therefore had to look to the development of both Immunology and Allergy clinical services using Nurse Specialist-led clinics, to free Consultant Medical staff for more specialised and difficult caseloads and most of our nurses are receiving training in both the care of both Immunodeficient patients and Allergy patients, including immunotherapy and challenge day case procedures under supervision from the medical Consultant. This model is utilised in at least three of the major centres in the North of England. It is a model which is also applicable to Regional Allergy Centres, and is part of the recommendations of "Allergy: the unmet need". These Immunology centres within NECIAG have shown that it is a workable service model. It is likely that over the next year our capacity to provide allergen challenges with short waiting times, improved access to desensitisation procedures through additional support of nurse-led services and the use of clinical assistant staff will enable us to match one of our sister units in the North, who currently also provide most of the Specialist Services incorporated into Specialist Service Definition number 17 using a similar arrangements. They are currently seeing twice the number of new and follow-up patients as Sheffield and four times the number of Allergy day case procedures utilising approximately double the number of staff at all grades. In that centre, as with my own, the amount of Allergy activity exceeds the Immunology by a factor of four to one for new patient activity, 1:1 for follow-up activity and there is approximately twice as much Allergy day case activity as Immunology day case infusion activity. On the back of this, several centres aspire to be able to offer outreach services in district hospitals throughout the region to improve local access to patients over the next few years.

In a recent survey of Allergy clinics in the North West, there were approximately four times as many Allergy clinics provided by Immunologists than those provided by pure Allergists, emphasising the need for increased numbers of Allergy Consultants. This reflects the relative numbers of Immunologist and Allergists currently available, but emphasizes the point that any interim solution for the provision of Allergy services will require the support of the government for the development of local access to specialist services via a combined approach utilising existing regional services, where much of the infra-structure and expertise is either already in place or could be rapidly acquired with the appropriate funding and support.

## 2. *Priorities for improving services*

1. Funding for the establishment of eight dedicated Supra-Regional Allergy Centres, led by Allergists is urgently required as detailed in "Allergy: the unmet need".

2. This should be accompanied by new centrally funded Specialist Registrar posts in Allergy to enable to the long-term development of Specialist Allergists with CCST's in Allergy.

3. In the interim, improved Allergy services cannot depend on increased provision of Allergists, as there are so few available. Immunologist are also in short supply but are already in a national network and there are a larger number of Immunology trainees in training with approximately 21 currently due to obtain CCSTs by 2008 (although not all will take up UK NHS service posts and most will extend training by two to three years to acquire a higher degree such as MD or PhD). Despite this, additional central funding of extra Immunology trainees will also be necessary if they are to fulfil a role in the additional development of Allergy services outside of the Specialist Regional Allergy units.

4. In view of the similarities in the physical and organizational needs of both Immunology and Allergy out-patient and day case services, the inquiry should give consideration to whether it would be most efficient to develop Teaching Hospital-based Regional Allergy and Immunology services in parallel, initially developed utilizing the existing available infrastructure. This would promote a win-win situation whereby patients have short- to medium-term improved access to specialist Allergy services, and enable the basic framework for improved Allergy services to be developed prior to the availability of significant numbers of Allergy trainees. As SpRs in Allergy become available for Consultant appointment they will then have the choice of joining an existing service with a view to professionally directing and developing an expanded range of Regional Specialist Services across the country or join one of the smaller number of Supra-specialist Regional Allergy centres, to improve the training capacity and the academic base of Allergy practice in the UK. This suggested arrangement would potentially provide excellent clinical governance and the best opportunity to provide increasing education and support for Allergy care and education in primary care, reaching the widest number of people in the shortest time in the most efficient and cost-effective manner.

5. The government should urgently consider adding Allergy and Immunology to the list of specialties for which GP's with specialist interest (GpWSI) can be developed.

6. The government should consider the funding of Nurse Specialist's or Nurse Consultants in Allergy or combined Immunology and Allergy utilising the models detailed above.

### *3. Governance and regulation of independence sector provided and links between the NHS and the independent sector*

NECIAG has no data or proposals to make on this area.

## C. CONCLUSION

The NECIAG and SWIAG survey of Allergy services and workload should be available prior to our joint meeting in October 2004 in Birmingham.

NECIAG will be happy to submit this data to the health committee inquiry on request. I have little doubt that it will provide further clear evidence of the growing need for Allergy services, the current inadequate provision of Allergy services in England (and Scotland, Wales and Northern Ireland), service models that currently exist and the need to rationalise the way in which specialist services are delivered both in the medium and long term, to make the most effective use of a limited Consultant Workforce, while investing for the future.

I would be happy to relate this evidence to the inquiry in person, if required.

Whatever the final recommendations of the inquiry, in view of the existing acute lack of appropriately qualified Consultant Allergists or Immunologists which cannot be rectified in the short term, it is clear that access to improved Allergy will not be possible on a meaningful timescale without the creation of Regional Allergy Centres, staffed by Allergists and without also developing the existing infra-structure of Allergy services which are currently inequitably distributed.

May 2004

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### **Memorandum by Dr R S H Pumphrey (AL 21)**

Dr Richard Pumphrey is a consultant Immunologist and Clinical Manager of the Immunology Laboratories that provide a Regional Immunology Service for the North of Wales, East Cheshire, Greater Manchester and northwards. His unit also provides a full time allergy clinic service and has done much to develop and support both adult and paediatric allergy services for the North West. He also acts as a medical adviser to the Anaphylaxis Campaign (a patient protagonist group for patients with severe allergies).

#### SUMMARY

This memorandum is to bring to the attention of the inquiry the ongoing epidemiological studies on severe allergic reactions carried out at the Immunology Service at Central Manchester and Manchester Children's University Hospitals Trust.

#### SPECIALIST SERVICES FOR SEVERE ALLERGIES

1. A register of all fatal anaphylactic reactions in the UK has been maintained since 1992. This has provided invaluable information about the basic epidemiology of fatal acute allergic reactions, what makes allergies dangerous and where efforts should be concentrated to reduce fatalities. It has been

possible to confirm only 20 acute allergic fatalities each year but there are reasons to believe this is an underestimate. Work continues to improve the accuracy of diagnosis in such fatalities. Publications arising from this include:

Pumphrey RSH. Lessons for management of anaphylaxis from a study of fatal reactions. *Clin Exp Allergy*. 2000;30:1144–50.

Pumphrey RSH. Fatal anaphylaxis in the UK, 1992–2001. 2004. *Anaphylaxis*. Wiley, Chichester (Novartis Foundation Symposium 257) 116–132.

Pumphrey RS, Roberts IS. Postmortem findings after fatal anaphylactic reactions. *J Clin Pathol*. 2000; 53: 273–6.

Pumphrey RSH, Davis S. Under-reporting of antibiotic anaphylaxis may put patients at risk. *Lancet*. 1999 Apr 3;353(9159):1157–8.

Pumphrey RSH. Fatal posture in anaphylactic shock. *J Allergy Clin Immunol*. 2003;112:451–2.

Pumphrey RS, Nicholls JM. Epinephrine-resistant food anaphylaxis. *Lancet*. 2000; 355: 1099.

2. A clinic database with details of patients with anaphylaxis, their reactions and the treatment given allows epidemiological analysis of causes, treatments and outcomes. The information held goes beyond any that will be incorporated in the ICRS (electronic patient record). The Food Standards Agency helped fund the development of this database. The findings from this remain largely unpublished but we have published a report on the early findings:

Pumphrey RS, Stanworth SJ. The clinical spectrum of anaphylaxis in north-west England. *Clin Exp Allergy*. 1996;26:1364–70

3. In the course of these studies the author has audited the accuracy of both death register and hospital discharge ICD-coding for anaphylaxis and would urge the inquiry to use statistics from such data with extreme caution. ICD coding works well for common conditions but poorly for uncommon ones: anaphylaxis poses particular problems because, for reasons described in detail in the references listed above, it is unexpectedly difficult to diagnose accurately.

#### PRIORITIES FOR IMPROVING SERVICES

1. Deaths from allergic reactions to foods have been almost exclusively limited to those who have not had specialist advice about their allergies. The problem arises as much from the unwillingness of General Practitioners to recognise the importance of accurate diagnosis and appropriate management advice in those with potentially life-threatening allergies as from a shortage of clinics in which such patients can be assessed and advised. GPs have many demands on their attention and allergies are often seen more as a nuisance than a healthcare problem. Fatal reactions occur as commonly in those with only minor previous reactions as those who have had severe ones: appropriate advice needs to be given to everyone with IgE-mediated food allergy. Some way must be found to facilitate identification of, assessment of and advice to these patients.

2. Acute allergic reactions to foods are particularly common in children but fortunately not commonly life-threatening. They do, however cause great concern and often receive inappropriate management, exacerbating the anxiety, degrading quality of life and compromising the education and social development of the child. Most hospitals have a paediatrician with an interest in asthma and basic knowledge about allergies—very few have a specialist interest in helping children with allergies. Until more can be trained, outreach clinics from specialist allergy centres can make significant improvements in the management of children with such allergies by informing the local paediatricians: an alternative is for the DGH paediatricians to make regular visits to the allergy centre and contribute to the centres paediatric allergy capacity.

#### RECOMMENDATIONS

(a) It will be helpful to continue collecting detailed data on fatal anaphylaxis to inform recommendations for better management to avoid further fatality in future. The findings so far indicate that most anaphylactic deaths occurring outside hospital are avoidable.

(b) The author is aware of the potential if the ICRS for informing recommendations for improved healthcare but would wish to point out that the data in the ICRS will never be sufficiently detailed to optimally inform improvements in allergy management. Further development of specialised databases such as that partially funded by the Food Standards Agency in the author's Immunology Unit will provide invaluable information.

(c) Resources are needed to develop specialist centres that integrate paediatric and adult allergy services: many severe allergies cause problems just at the boundary between paediatric and adult care.

(d) Until such time as sufficient allergy and paediatric allergy specialists have been recruited and trained, the corpus of paediatric and adult immunologists with specialist interest in allergy should be supported in their efforts to improve services and in training specialist allergy nurses, whose remit may extend into primary care, helping GPs to recognise patients who would benefit by specialist assessment.

If required, the author would be happy to provide oral evidence on the topic of life-threatening allergy within the UK.

May 2004

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### Memorandum by Professor T J David (AL 25)

#### SUMMARY

1. This short document considers the needs of children with allergic disorders. The paper suggests that the care of such children should be provided by general practitioners and general medical paediatricians, and that the creation of separate and additional allergy services for such children is largely unwarranted and indeed such over-specialisation is likely to be detrimental. In essence, the paper expresses concern about the proposed move to a situation where all children with allergies are seen and treated by “pure” allergists or immunologists, akin to the arrangements in north America.

#### INTRODUCTION

2. I am a general medical paediatrician, with special interests (*inter alia*) in atopic eczema and allergy in children. As an academic, my work is split between NHS clinical duties (out-patient clinics, in-patient services, and general and specialist on-call duties), undergraduate and post-graduate teaching, and University administrative duties (involved in running aspects of the undergraduate teaching programme). I am the lead clinician for allergy at the Manchester Children’s Hospitals, and I run two clinics per week that see children with eczema and/or allergic disorders. Eczema and allergy are major clinical interests, but they are also major research interests, and of my 330 scientific and research publications (articles, chapters, books) about 90 are on the subject of eczema and allergic disorders. My current research interests include collaboration with an academic paediatric immunologist, studying various aspects of immunology, allergy and their relevance in particular to childhood eczema.

3. These comments are entirely confined to children, and make no reference at all to the needs of adults. The views expressed here are entirely my own personal views, and do not in any way represent the official views of either the hospitals or the University in which I work.

#### THE NEEDS OF CHILDREN WITH ALLERGIES

4. A high proportion of the childhood population suffers from some type of allergy (which implies involvement of the immune system) or intolerance (a broader term than allergy, and which includes other mechanisms whereby an individual can react adversely to a substance). Studies have shown that at least a third of all young children are reported to react adversely to foods or food ingredients; most of these problems are transient, and most children grow out of the problem in the first few years of life. In addition, there are large numbers of children who to a lesser or greater extent exhibit allergic reactions to non-food items such as pollen, dust mites and animals. In short, when planning services for children with allergies it must be recognised that a high proportion of children are affected in some way. The proposal that all these children should be seen by a newly created tier of allergy specialists would be costly, the benefit of such a strategy is unproven, and the treatment of such children by those who are uninvolved in the care of general paediatric disorders would be inappropriate in that it would fail to meet the overall medical needs of the child.

5. The thrust of the argument for a large expansion of NHS allergy services is:

- (i) the claim that existing NHS services are woefully inadequate;
- (ii) each region should have specialist and dedicated allergy services; and
- (iii) patients with allergies should be seen by “pure” allergy specialists and not by generalists or general practitioners. The view expressed here is that where children are concerned, the existing services are largely adequate, and that it is not in the best interests of children to greatly expand existing specialist allergy services.

6. The danger of narrowly focused specialists is that they tend to over-focus on that specialty. Lacking in the relevant skills and experience, these narrow specialists may fail to take into account the overall medical and social needs of the child. An example of this, the current difficulties in relation to the diagnosis of child abuse, which is also an interest of mine, are in part attributable to children being seen and assessed by those

for whom child abuse is the sole or major interest, with the result that all manner of symptoms risk being over-attributed to abuse. The same principle applies to pure allergists or immunologists. It is the general skills and experience of the general practitioner and general medical paediatrician that are required to differentiate allergic processes from other non-allergic disorders.

7. In our unit, we have seen a steady stream of children in whom an over-focused approach to allergy has led to a complete failure to recognise and manage non-allergic disorders. Recent examples include:

- 7.1 A child who suffered from intestinal malrotation (a congenital malformation of the gastrointestinal tract requiring urgent surgical treatment) misdiagnosed as suffering from food allergy.
- 7.2 A child with the symptoms of severe cerebral palsy due to intra-uterine infection with the cytomegalovirus incorrectly attributed to milk allergy.

8. The interface with child protection is especially complex, and is an area where again we have had to deal with some exceptionally badly managed cases:

- 8.1 A child who was needlessly receiving injections of adrenaline for supposed life-threatening allergic reactions; the reactions were in fact fabricated by the mother, and this was a case of Munchausen syndrome by proxy (MSBP) abuse (also now known as fabricated and induced illness—FII).
- 8.2 A child incorrectly diagnosed as having factitious diarrhoea (laxative poisoning by the parents). The child had been seen at two allergy clinics, both of which had in fact missed the correct diagnosis of a rare type of sugar intolerance.
- 8.3 A child misdiagnosed as suffering from MSBP abuse at an allergy clinic; the parents reported behavioural reactions to specific food ingredients, but the allergy clinic decided that these were not genuine reactions and rather than accepting that the parents might simply have been mistaken, the clinic's use of the MSBP label led to the deployment of full child protection procedures.

9. Another reason why children with allergic disorders should be seen by general practitioners and general medical paediatricians is that a high proportion of these children have associated medical conditions such as eczema, asthma, hay-fever and short stature or delayed growth. The general management of these disorders (eg the correct use of steroids, the management of bronchodilators, the optimum treatment for chronic skin disease, or the assessment of growth and nutrition) are the province of the generalist rather than the allergy specialist. The allergy is often a small component of the overall disease picture.

10. The idea that every child with an allergy must be treated by an allergy specialist or immunologist who lacks paediatric training and expertise is an erroneous notion fuelled by allergists, a notion that serves to create the misleading perception of a huge and unmet need.

#### UNORTHODOX ALLERGY TESTS AND PRIVATE ALLERGY CLINICS

11. The large number of non-NHS allergy services in the UK is a real cause for concern because of their use of unorthodox, unproven and quite often frankly bogus methods of diagnosis and treatment. The methods employed by the majority of these clinics, which generally do not operate within the framework of conventional private medicine, have either been investigated and proven to be invalid or have never been adequately tested. I share in the general condemnation of these operators. The methods which they use are often quite extra-ordinary, and include:

- 11.1 Radionics—samples of a patient's hair sent by post and tested by a radionic practitioner using a pendulum and deep concentration. By using duplicate samples of the same hair under different names, this method has been shown to be fraudulent.
- 11.2 Applied kinesiology—it is claimed that if a food to which an individual is allergic is brought near to the subject's body, immediate muscle weakness results. Allergies in babies are diagnosed by testing the mother twice, once while she is holding the baby, and then concluding that any differences between the two tests indicate the baby's allergies.
- 11.3 Pulse testing—it is claimed that an elevation or slowing of the pulse rate up to 1.5 hours after taking a food indicates allergy to the food.
- 11.4 Auricular cardiac reflex testing—it is claimed that if a substance to which a patient is allergic is brought within half an inch of the skin, then the auricular cardiac reflex, which is derived from a form of acupuncture, changes the wave form of the pulse at the wrist, and aids detection of the allergy.
- 11.5 VEGA testing—substances in glass phials are placed in series in an electrical circuit. Vega testing is used to test for food allergy, chemical sensitivity, and "organ stress". The observed changes in the readings are said to be partially "psycho-kinetic" affects and are therefore dependent on the psyche of the individual performing the test.
- 11.6 Lymphocyte cytotoxicity—comprises the observation of morphological changes in white blood cells incubated with a suspect antigen from the sample of patient's serum. The presence or absence

and degree of damage caused to the white cells is claimed to be an indicator of the presence of food or chemical sensitivity, or both, and is said to give some indication of its severity. This method has been proven to be totally unreliable.

- 11.7 Intradermal testing and “neutralisation”—having determined the “neutralising dose” with a form of repeated intradermal skin testing, “neutralising” solutions are then administered either by sublingual drops or by subcutaneous injection.

12. The existence of these private allergy clinics is partly attributable to the refractory nature of some of the associated medical conditions (such as eczema and asthma) and the parental fear of some of the treatments, most notably topical steroids. However the appetite for private allergy clinics is largely driven by the unreliable nature of simple conventional allergy tests (skin prick testing and RAST testing). Unfortunately skin prick testing and RAST testing (blood testing for the presence of IgE antibodies to specific allergic triggers) both suffer from numerous drawbacks, including the large number of false positive and false negative reactions (particularly, but not exclusively) a problem in children with eczema and suspected food allergy or food intolerance. Because these tests are so notoriously unreliable they have been largely abandoned in paediatric practice. In the case of suspected food allergy, direct food challenges are increasingly becoming the preferred approach, conducted in hospital in a general paediatric setting if there is a risk of a severe reaction. Several paediatric units in greater Manchester offer this service. NHS allergists and immunologists remain faithful devotees of skin prick tests and RAST tests, which has in turn served to generate a considerable demand for these tests which are widely over-valued by the public. While public demand for these tests has tended to exceed supply, leading to quite large waiting lists (for example in Manchester), the reality is that these tests are of very limited value and are often quite unnecessary.

#### FUTURE NEED

13. There is a continuing need for research, and there is a continuing need for training to be provided at an undergraduate and postgraduate level. In terms of research, as well as applied studies of new treatments there is a requirement for more basic research to address fundamental issues. One example is the so-called “hygiene hypothesis”. This seeks to explain the increase in atopic disease (eczema, asthma, hay-fever) and allergies as a result of increasing attention to hygiene in early childhood. The hypothesis is that greater exposure to soil and dirt may actually be beneficial, and a number of units including our own have been engaged in research studies in which children with eczema have received injections of extracts of a particular soil bacterium, *Mycobacterium vaccae*, with the aim of causing a fundamental change in the immune system leading to a diminution of the eczema. This is just one of many new avenues of research that are being studied in north America and Europe.

14. However the thrust of this paper is that simply providing more NHS allergy clinics is unlikely to benefit children with real or suspected allergies. As far as these paediatric patients are concerned, their needs will be best met within the existing framework of NHS primary and secondary care services.

May 2004

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#### Memorandum by Doris M Jones MSc (AL 26)

#### SUMMARY

Allergic phenomena, such as food allergies or intolerances, conventional allergies like asthma, hay fever or urticaria, extreme sensitivities to chemicals and other environmental factors such as pesticides, and adverse reactions to prescribed medications, are an integral part of many patients with a diagnosis of ME (Myalgic Encephalomyelitis), CFS (Chronic Fatigue Syndrome), FMS (Fibromyalgia Syndrome) or MCS (Multiple Chemical Sensitivities). Such problems go mainly unrecognised, are usually not acknowledged or deemed to be psychological by many GPs. Appropriate treatment within the NHS is all but non-existent and provision in the private sector scant and often expensive. There is an urgent need for a thorough re-assessment of necessary specialist treatment centres, NHS funding and suitable patient support groups.

1. This Memorandum is submitted as an individual.

2. I am an independent researcher and writer, with a particular interest in the effects of environmental factors on people’s health, in particular on their manifestation as allergic phenomena in patients suffering from disorders like ME (Myalgic Encephalomyelitis), CFS (Chronic Fatigue Syndrome), FMS (Fibromyalgia Syndrome) or MCS (Multiple Chemical Sensitivities). I was also a Reference Group Member of the CMO’s Working Group on CFS/ME between 1999 and 2001.

3. I first became aware of the fact that allergic reactions are very common in patients with a diagnosis of ME or CFS when completing an MSc thesis on these disorders in 1992. Such reactions consisted of food allergies or intolerances, conventional allergies like asthma, hay fever or urticaria, extreme



sensitivities to chemicals and other environmental factors like pesticides, and adverse reactions to prescribed medications. Indeed they were frequently an integral part of their often unrecognised health problems.

Almost without exception these patients reported experiencing extreme difficulties, not only in having these problems accepted as being real and serious components of their condition, but even more so in obtaining appropriate treatment, especially on the NHS.

A subsequent study on patients with a diagnosis of MCS (Multiple Chemical Sensitivities) provided further information on the difficulties such patients experienced in having their health problems acknowledged, recognized and treated:

Details on 76 patients showed that:

- (i) on average six GPs were consulted before a diagnosis was made;
- (ii) in 54% of cases six or more practitioners were seen;
- (iii) in 24% of cases a psychiatric diagnosis was made at least once;
- (iv) in 54% of cases practitioners were not prepared to consider environmental causes for health problems; and
- (v) in 31% of cases their MCS problems were not being taken seriously.

Frequently these patients were given various other diagnoses (often multiple), notably ME/CFS/PVFS (Post Viral Fatigue Syndrome). In a few cases pesticide or chemical poisoning was acknowledged, and in some health problems were deemed to be manifestations of depression. Their wide-ranging health problems in essence were ignored by NHS practitioners. Whilst in a few cases patients were successful in securing an ECR (Extra Contractual Referral) to a specialist private clinic for appropriate treatment of their predominantly allergic problems, most were given inappropriate treatments or their problems were ignored.

4. There were two notable specialist centres where some patients were referred to and did obtain appropriate treatments; one was the Breakspear Hospital, Hemel Hempstead, under Dr Jean Monro, the other was the Airedale Allergic Clinic, Keighley, Yorks, under Dr Jonathan Maberly or Dr Honor Anthony (this Clinic is now closed or may have been demolished). Patients with pronounced food allergies or intolerances were sometimes referred to Dr (now Professor) Jonathan Brostoff, then at the Middx. Hospital, London. There were some other GPs who specialised in treating patients with pronounced allergic problems, but most carried out only private treatment, which many patients could ill afford or not at all. ECRs evidently became increasingly difficult to secure, with inevitable increasing problems for affected patients.

5. Difficulties experienced by patients in having their health problems recognized and treated appropriately in part at least is because articles published in major UK medical journals like the BMJ or the Lancet have dismissed such problems as either non-existent or existing only in the minds of individuals (eg Howard LM, Wessely S: "The Psychology of Multiple Allergy", BMJ 1993;307:747-48); Howard LM, Wessely S: "Psychiatry in the Allergy Clinic: The Nature and Management of Patients with non-allergic symptoms", Clin + Exp Allergy, 1995;25:503-14; and many others). It is therefore unsurprising that GPs adopt a dismissive attitude to patients suffering from such allergic problems.

6. Details of my studies have been shown at international conferences and various meetings. They have also been submitted to the CMO's Working Group on CFS/ME.

7. I recommend that:

- (a) a thorough re-assessment be made concerning the establishment of specialist centres, where patients with such health problems can be referred to for appropriate treatment.
- (b) ECRs or new equivalent facilities, be made available to affected patients to enable them to obtain such treatments from the private sector until such time as the NHS can provide an equivalent service.
- (c) Affected patients can seek advice from suitable support groups, such as Allergy UK, Action Against Allergy, MCS International and others and that this information be made widely available in GP surgeries, Hospitals etc.

8. I will be available to give oral evidence should this be desired.

May 2004

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**Further memorandum by Doris M Jones MSc (AL 26a)**

**SUMMARY**

There are grave concerns amongst the ME/CFS/FMS community that the manifold allergic problems which many of these patients (and those suffering from MCS or GWS) experience, will remain unaddressed and untreated at new treatment centres for such patients, which will be set up shortly. These problems have been well documented in the international literature and in medical books. It is suggested that the Health Committee raises these issues with the DOH.

1. This second Memorandum is submitted as an individual.
2. I am an independent researcher and writer, with a particular interest in the effects of environmental factors on people's health, notably in patients with ME/CFS/FMS or related health problems (see AL26).
3. Following the first evidence given to the Health Committee on 17 June 2004, and after discussing briefly the multiple allergic problems and adverse reactions which many patients with ME/CFS/FMS or MCS have with Professor Stephen Holgate (a key witness who gave evidence on 17 June 2004), I wrote to Dr Stephen Ladyman at the DOH on 28 June 2004. I set out my concerns about the "treatment" and advice which is likely to be given to these patients at six new specialist treatment centres which will be set up shortly, and which according to a letter from Mr Robert Harkins, DOH, Leeds, of 25 May 2004, will be "headed up exclusively by psychiatrists". These patients' many allergic problems are unlikely to be either considered or appropriately treated at these centres, in part at least because the experts heading these centres are known to share the views of Professor Simon Wessely, who has frequently stated that such allergic manifestations in these patients should be regarded as psychological or psychosomatic problems (see point 5, AL 26). Furthermore, the only "treatments" (a more apt description would be "management strategies") to be used in the new part-MRC-funded trials (especially the PACE Trial), and administered at these centres, will involve regimes known as Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET) and PACING in addition to standard medical care. However, two of these, ie CBT and GET, have been shown to be the least effective and most harmful approaches respectively in four independently conducted surveys (on over 3,000 patients), which were submitted to the CMO's Working Group on CFS/ME.—This situation is tantamount to adding insult to injury, as far as patients are concerned. I have therefore asked the Minister to give these issues his urgent consideration, with a view to finding a more satisfactory solution. I have also pointed out to the Minister that many of these patients—especially the most severely ill, experience increasingly compounding problems, many of whom have died in the meantime from further developing serious physical health problems, such as cardiac failure, cancer or other subsequently developing serious physical health problems, like MS or Parkinson's Disease. A copy of my letter to Dr Ladyman has already been sent to the Health Committee for their Inquiry.
4. (a) As additional information on documented evidence of allergic phenomena seen in ME/CFS/FMS, MCS and other patients, I attach a document [Not printed] entitled "Allergy + MCS", which cites many articles and books which were published or were available by December 2001.
- (b) I would also point to the paragraph headed "Intolerances" in Annex 6 "Management of CFS/ME—Report Summary", p2, from the separate booklet containing Annexes 6 and 7 of the Report of the Working Group on CFS/ME, January 2002, which states:  

"Intolerances and sensitivity/alterd tolerance are common in CFS/ME. Alcohol intolerance is very common; many patients also experience intolerance of some foods, some medications (especially psychotropic medication), and other substances (sometimes described as "multiple chemical sensitivity").
- (c) In my own 1992 MSc study on 225 ME/CFS subjects, 85% reported one or more allergic or adverse reactions (ie hay fever, asthma, breathing problems, eczema or chronic skin rashes, own and/or relatives' food sensitivities or intolerances, environmental sensitivities and/or adverse reactions to vaccinations, antibiotics or oral contraceptives and in some cases also to other drugs), and assuming vaccines or antibiotics played a role in onset of the disorder.
5. Recommendations: I therefore suggest that the Health Committee raises concerns with the Government over the frequent manifold and multiple allergies which ME/CFS/FMS (and MCS and GWS) patients experience and that given the current situation, these remain unaddressed and untreated. Referral to specialist allergy centres or allergy specialists of such patients with these kind of additional health problems would therefore seem an urgent and necessary step.

*June 2004*

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**Memorandum by Professor A B Kay (AL 27)**

1. My name is Anthony Barrington Kay and I am Professor of Allergy and Clinical Immunology at the National Heart and Lung Institute, Imperial College. I am also an honorary consultant at the Royal Brompton Hospital. I am in charge of an NHS allergy clinic and a programme of research into mechanisms of allergy and asthma funded by the MRC and charities. I have been in my present post since 1980 during which time I have trained up about 30 or Research Fellows who have gone on to senior academic/NHS posts either in this country or worldwide. From 1993 to 1996 I was President of the British Society for Allergy and Clinical Immunology (BSACI)

2. I was also largely responsible for two reports on allergy practise published by the Royal College of Physicians. One appeared in 1992 (*Allergy: Conventional and Alternative concepts*) and the other, *Good Allergy Practice* was published jointly by the RCP and Royal College of Pathologists in 1994. These documents explained that good allergy practice is evidence-based and that, as in other branches of medicine, allergy tests and treatment require rigorous scientific validation. At the time it was pointed out that there was a very wide sale and use of highly dubious allergy tests which could lead to wrong diagnosis, inappropriate treatment and the institution of nutritionally inadequate diets which can be harmful, especially to children?

3. A potentially dangerous fringe group are the “environmentalists”, who have their roots in the clinical ecology movement founded in the 1950s. Environmentalists believe in a disease termed “multiple chemical sensitivity” which the large majority of mainstream conventional doctors believe does not exist. It is a term invented by the media and is basically a medical subculture in which gullible patients have their erroneous and often self-made diagnosis of allergy to chemicals in the environment reinforced by practitioners who very often have had no training in allergy and have never held a consultant appointment under the NHS. The environmentalist use a method of diagnosis and treatment called Provocation-Neutralization which has been largely discredited. Nevertheless they continue to flourish in private hospitals and often bill health authorities for their services under “extra contractual services”.

4. Closely linked to Provocation-Neutralization are a number of other unsubstantiated tests which are widely available but have never stood up to any real scientific scrutiny. These include serum IgG antibodies for food allergy (“Yorktest”), iridology, applied kinesiology (muscle testing), cytotoxic food testing—ALCAT, electrodermal skin tests—VEGA testing, ELISA/ACT and hair analysis.

5. Thus I fully support the Evidence to Select Committee on Allergy Services offered by the British Society of Allergy and Clinical Immunology (BSACI) and draw your attention in particular to their concerns regarding the uncontrolled proliferation of unconventional allergy services. In my opinion these flourish because, at present, the NHS is seriously lacking in main stream, evidence-based allergy specialists and attendant facilities.

May 2004

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**Further memorandum by Professor A B Kay (AL 27a)**

Further to my recent submission I wish to make a further point regarding severe summer hay fever which is often debilitating and on the increase. Most hay fever sufferers buy anti-allergic drugs over the counter. This is quite acceptable for mild and even moderate disease. However severe hay fever needs proper medical supervision. It is not appropriate for pharmacists to provide the main source of advice in this situation. A general lack of training in allergy means that this important group of patients are often poorly served by primary care physicians, and even the specialist sector.

May 2004

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**Memorandum by Dr Vibha Sharma (AL 28)**

Food allergy in paediatrics is still, in most District General Hospitals, a mainstream paediatric problem. Projected figures lead one to anticipate an overall increase in the number of sufferers of allergy. Presently, approximately one third of the population have allergies and one in 70 people are said to suffer from peanut allergy. I feel that there needs to be an appointment of a Consultant Paediatrician with special interest in allergy in each District General Hospital, who would link in with the Regional Tertiary Centre with geographical based leadership.

This would facilitate provision of allergy services nearer to the patients and obviate the need for sufferers to seek help from independent alternative practitioners, who may not employ evidence-based methods.

Tertiary Centres should have identified allergy services, for the referral of complex food allergy patients and to provide training and support for those working in the periphery, both in the District General Hospital and in Primary Care. When I took over an embryonic paediatric food allergy clinic, I found this training and support difficult to access in my own region.

Resources need to be identified and ring fenced to ensure the development and continuing provision of these services.

The alternative sector poses a major problem in management of patients with allergy in the paediatric age group. To quote an example, Vega testing, available in health food shops, can often lead to advice on certain food restrictions. These are non-evidence based. It is particularly a problem, in the paediatric population, as exclusion of certain food types can predispose them to nutritional deficiencies, which can affect growth significantly, and hamper a child's potential.

Presently there are ear, nose and throat and dermatology departments providing services for investigating various allergies. It would be useful to consolidate all these resources and provide a comprehensive service for investigation and management of allergies.

May 2004

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### Memorandum by Maureen Jenkins (AL 30)

#### WHY MOST ALLERGIC DISEASE IS BETTER MANAGED IN PRIMARY CARE

##### *Benefits to the Health Service*

1. Primary Care clinicians, ie, GP, Nurse Practitioner, Practice Nurse, Health Visitor are the first point of call for all problems
2. Allergy is the trigger for many of the most common reasons for visits or calls to any of the above professionals:
  - (a) upper respiratory: nose, sinuses;
  - (b) lower respiratory: wheeze, cough, shortness of breath;
  - (c) skin: rashes, irritation, eczema, Urticaria;
  - (d) eyes: irritation, inflammation, watering; and
  - (e) gastric: vomiting, diarrhoea, bloating with any combination of above symptoms.
3. All allergic symptoms that are not readily controlled lead to inflammation and possible chronic symptoms. Therefore, if recognised as allergy related quickly, it can be appropriately managed preventing chronic inflammation and possible progression of the disease. This is cheaper for the Primary Care as proper initial management may:
  4. Prevent repeated consultations (time and cost).
  5. Save on probable cumulative medication.
  6. Remove need for many hospital referrals.
7. Patients with serious allergy would be appropriately referred, rather than at present and also be seen quickly by a Consultant Allergist (at present, some patients may be referred to several specialists, eg respiratory, ENT, dermatology, gastro-enterology, paediatrician. It is possible that none of these recognises the allergic element that may be the cause of all the problems).
8. Reduce A & E episodes because of recognition and improved disease management.
9. Save vast amounts on in-patient—these patients are usually seriously ill and cost-intensive.

##### *Benefits to the patient*

10. Quicker diagnosis, management plan and probable prevention of chronic symptoms (wait for appointment at hospital Allergy Clinic can be six to 24 months).
11. Quicker access to other members of Primary Care team who may help in management, eg asthma nurse, eczema nurse, dietitian, school nurse.
12. Easier access to treatment for patients (dearth of Allergy Clinics means patients may have to travel long distances for appointments, be seen for very short time, then have to return again few weeks later—this is expensive and difficult).
13. Allergy often runs in families and also involves whole family so Primary Care team best placed to manage and advise family.
14. GP, Nurse, Health Visitor or School Nurse may recognise factors in patient's lifestyle (home, school, work) that are making allergy worse.

May 2004

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### Memorandum by Dr Gideon Lack (AL 32)

1. I am an NHS Consultant in Paediatric Allergy and Immunology at St Mary's Hospital, London where I lead the Paediatric Allergy Service. I am also Senior Lecturer at Imperial College London. I am writing to you regarding the lack of Paediatric Allergy Services in the UK. This is a subject that is very important to me. Our St Mary's Paediatric Allergy Service based at St Mary's Hospital in Paddington provides both a secondary service to local general practitioners and a tertiary service to paediatricians and other specialists nationwide.

2. I was appointed to the post of consultant in paediatric allergy nine years ago on the basis of perceived clinical need and the belief that this would be financed through GP fund-holding practices and ECR funding. This did indeed prove to be the case and we very rapidly built up three paediatric allergy clinics and over the course of two years demand was such that the waiting list for new appointments given was in excess of 12 months. At that point there clearly was a need to expand the allergy service but with new government NHS targets our long waiting list became a liability to the Trust. It was necessary to rapidly bring down our waiting lists. This was done through a series of allergy drives where extra clinics were set up to see more allergy patients. This temporarily decreased the waiting list but each time it climbed back up again. Given that many of our patients were highly complex and required follow up appointments our follow up waiting list is up to one year. This is completely unacceptable. Finally we have been forced to only accept GP referrals locally. If a GP from out of area refers to us an appropriate patient with complex allergies we cannot see that patient unless that patient is referred to us through a paediatrician. This creates a further unnecessary additional burden on the NHS in other areas.

3. It is clear that there are completely inadequate paediatric allergy services in the UK at the present time. With four specialist paediatric allergy centres in the UK, run in large part on academic rather than NHS funding, this is clearly an unacceptable situation. Our Trust has been extremely supportive, helping to organise allergy waiting list drives and employing paediatric allergy nurses. However, with allergy not being on the list of NHS priorities we have had no choice but to cut back on the referrals we see. I enumerate below points that are of specific concern.

3.1 Paediatric allergy services are virtually non-existent in the UK in contrast with countries such as Sweden where there are 96 paediatric allergists for a far smaller population.

3.2 Waiting list times for patients are unacceptable.

3.3 Children are suffering the consequences of not seeing paediatric allergy specialists in three ways.

3.3.1 Firstly they are denied proper diagnosis and care. These children are at risk of anaphylactic reactions (one in 50 children in the UK are allergic to peanut and similar numbers of children are allergic to tree nuts).

3.3.2 Secondly these children suffer nutritional consequences in the absence of adequate nutritional advice. They exclude multiple foods and have compromised diets. We have seen children with rickets, growth failure, developmental disorders and severe psychological problems all because they failed to receive proper specialist advice at the right time.

3.3.3 The third way in which these children suffer damage is that their parents are unwillingly forced into the hands of dangerous alternative practitioners who run private clinics where non-validated and often dangerous practices are used. I know of instances where patients have been morally blackmailed to receive expensive treatments that are potentially life threatening. The situation is analogous to the days when young pregnant women were forced into the hands of back-street abortion clinics.

3.4 I have been seeing increasing numbers of children with life-threatening anaphylactic episodes where the child and family have never received proper advice for years.

3.5 Children with allergies often have multiple symptoms affecting different organ systems. Instead of being taken care of by paediatric allergists they are sent to general paediatricians, gastro-enterologists, respiratory specialists, dermatologists and ENT specialists. This fragmentation of speciality care is detrimental to the patient, resulting in multiple NHS appointments and numerous days taken off work by the parents. This is an unnecessary waste of NHS services. A recent survey of A&E visits at St Mary's Hospital over one year showed that a least 6% were directly attributable to an acute allergic problem. Compared to children who presented to the A&E without an allergic diagnosis, those children who presented with allergic problems were admitted to hospital almost twice as frequently and were referred for outpatient paediatric subspecialty care or for GP follow-up twice as frequently. This clearly demonstrates how allergic problems are imposing a hidden burden on both acute and outpatient, hospital and community NHS services. An integrated approach to the care of these children is not taken and it is not unusual for these children to be receiving multiple steroid preparations through different routes without taking into account the overall medication that this places on the child and adverse health consequences.

3.6 The incidence and prevalence of allergies in children continue to rise. The last 10 years has witnessed a doubling in the prevalence of peanut allergy to a rate of 1.5%–2%. We have just completed a survey in the London school area showing that 2% of children aged five to 18 years suffer peanut allergy, 1% suffers sesame seed allergy, 2% suffer nut allergies and in total 6% of UK children have suffered allergic reactions to foods.

3.7 In view of the chronic nature of allergic disease, the increase in paediatric allergic disease will spill over into increased adult allergic disease: young children and adults facing a life of chronic food allergies, eczema, asthma and hay fever. We are only starting to feel the economic burden that this places on society.

3.8 There are virtually no centres that practice paediatric allergy in the UK and no training posts or consultant posts to enter. Thus an area with a huge unmet clinical need cannot be adequately provided for. Despite large numbers of interested paediatric trainees there are no training posts or consultant posts to which they can aspire.

4. In short, the situation is a national catastrophe. In view of the above a national service framework needs to be established for paediatric allergic services nationwide.

May 2004

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#### **Memorandum by Elizabeth Murphy (AL 33)**

##### **SUMMARY**

I am a professional children's counsellor working, with children and young people of all ages. I often see children who have behaviour difficulties and in my professional opinion may well benefit further from being referred to an allergy specialist; but there is no NHS allergy clinic or service in the area and many of the clients I see are unable to pay for private or alternative treatment.

1. In February 2004 I was employed to work one day a week in a local junior school in a deprived area to work with four referred children.

2. In March 2004 it became clear to me that all the referred school children may well be suffering from ADHD/PTSS and may well benefit further by having food allergy tests.

3. Children suffering from food allergies often display behaviour symptoms similar to ADHD/PTSS and get wrongly diagnosed and thus carry a label, which often continues throughout their lives. Or indeed if they are found to have ADHD/PTSS these children are often found to also suffer from food allergies and can be further helped by receiving treatment from a food allergy specialist.

4. I am unable to refer any of these children on for treatment as they and their families are unable to pay for the treatment and there is no NHS allergy service in the area.

5. I am therefore unable to give a full opinion on the cause of these children's symptoms and the children are denied the possibility of a treatment that many will benefit them further, or at least speed up the counselling process.

##### **RECOMMENDATIONS:**

1. I would like to see the establishment of more NHS allergy clinics also specialist NHS children's allergy clinics, run by staff that are fully trained in all aspects of allergy work.

2. Far better training regarding allergies for GPs, doctors, consultants, nurses, practice nurses, school nurses, midwives, health visitors, psychologists, counsellors etc.

May 2004

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#### **Memorandum by Bedford Allergy Support Group (BASG) (AL 34)**

We are a support group and for 20 years have helped and advised many people suffering from allergies due to chemical, food, plants, environmental pollution, and reaction to drugs prescribed by GPs and so on.

We are now on the point of asking our Primary Care Trust how they will deal with the fast increasing numbers of allergy sufferers locally because we find that the last few years have seen an increase in the number of people, especially children, suffering with allergies. It has reached a worrying level and mothers complain that GPs can't always help, as they have no expertise on the variety of problems.

People turn to many therapies and Dr Jean Monro from Breakspere Hospital has saved many people. The concerned mothers themselves are left to take care of their children on their own and follow their own instincts gaining as much information as they can, finally becoming quite expert though often feeling very isolated and distressed themselves.

Only last week one mother reported to us that her child has had a reaction to food with E numbers. She was referred to Adenbrooks Hospital Allergy Clinic. She was told that she was a worried mother and that there was no such thing as E number Allergies. She simply laughed at the statement and left. This is an

example of the sheer lack of understanding and competence of the problem even by specialists within the medical profession as a whole in our experience. It shows a total disregard of patient/parent experience and knowledge—knowledge that has been acquired through suffering and extensive research by the mother.

Two weeks ago we met with a group of mothers who had organised themselves into a group called “SAFE”—their children having all experienced an anaphylactic shock. They organised themselves together because of the inadequacies they found within the NHS professionals.

We were horrified to hear the stories they told us. Equally horrifying are the stories told to us from mothers with hyperactive children. We had expected that over these past 20 years the NHS provision for allergies would have improved but instead we find that the understanding of allergies and the provision of services has not improved much at all. A Consultant told one of the mothers with a hyperactive child made worse after eating certain foods, not to worry because the drug he was giving the child would control the behaviour. The child is now 10 years old.

Very young children are given unnecessary drugs, sometimes dangerous drugs like cortisone to control the signs and symptoms of their allergies without understanding and much thought of the underlying causes. One of our members, only this week, had a visit from a neighbour’s child, five years old who was scratching herself because she had been near a dog, she had eczema on her arms and swollen lips as well. The number of children at school on a special diet list is fast increasing and schools make mistakes, making the children ill.

We have been supporting adults in the main, who have suffered enormous amounts of pain and distress due to allergy problems, unrecognised and unaccepted by professionals. These people have often been labelled as having mental or psychological problems even when psychiatrists could not make a diagnosis. The waste of resources, professional and hospital time, wasted, spent to no avail, is enormous. And all the while people in despair and anguish.

One of our members died last week; we can confidently blame the Health Authority. Her GP was refused £150.00 for her to have a special test. Months later she became so ill that the Bill would have been £3,000.00. A few years later, finally, the PTC granted the GP £21,000.00 for special treatment. Unfortunately she was too far-gone, it was too late, and the treatment failed her. She survived so long on desensitising treatment only. Last August she attempted suicide—we don’t yet know the cause of her death last week.

Last year, as a support group, and through the Bedford Healthy Living Initiative we became part of the Bedford Primary Care Trust as an allergy support group.

We trust your committee will give careful consideration to this increasing and most distressing health problem. The number of people suffering, especially children, is increasing and the seriousness of the problem is worsening. As a group we are very concerned, for this is beyond our 20 years experience.

#### RECOMMENDATIONS

- Specialists Allergy Clinics are needed. These should involve a multidisciplinary team of professionals assessing the causes and the problems and prescribing treatment.
- Environmental issues, avoidance of pollutants eg mercury fillings, fluoridated water, household chemicals etc. Organic food should be encouraged.
- Access to a variety of treatments—both allopathic and alternative/complementary eg desensitisation treatment and internal cleanses for parasites. Psychological and Psychiatric help also should be available.
- Schools and parents should become fully involved.

We would whole-heartedly support such a clinic in our county.

May 2004

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#### Memoranda from Bedford Allergy Support Group in partnership with Bedford Healthy Living Initiative

#### NEWSLETTER—No 1 WINTER 2002

Welcome to all our members. After a long time with no regular communication, we will now be producing a newsletter twice a year. This first one aims to catch up with everyone, let you know what is happening, and ask everyone how they would like to be contacted in the future. Also we include some information on current issues, and articles of interest to people with allergic/intolerance reactions.

#### WHAT HAS BEEN HAPPENING?

Since September, Bedford Healthy Living Initiative, *b.healthy@bedford*, has been up and running. We are very excited to be involved with this project, which will last for five years. We are included along with nine other group projects, and although we will be running on exactly the same lines as before, we look forward to being involved with the larger community and having the prospect of reaching many new people.

1. *Information and advice;*
2. *Cultural and social activities;*
3. *Family support;*

Bedford Allergy Support group is involved in information and advice along with the Citizens Advice Bureau and the central team of *b.healthy@bedford*. This core project is in charge of (among other things) providing touch-screen technology within the community for health information. It is also charged with managing provision of Complementary Therapies on a referral basis to a limited number of practices in areas of need in Bedford, throughout the five-year period.

For more information on *b.healthy@bedford* please contact Diane Webb, Project Coordinator on 01234 792047

With this information theme in mind, we would like to give you all our up-to-date contacts, current programme, and ask for some feedback from you. We have been running for a long time, and are now hoping to make life easier for ourselves by using modern technology.

**[www.bedfordallergy.co.uk](http://www.bedfordallergy.co.uk)**

Did you know we are now on the worldwide web? Click on to the above site, to find out about the group, its Aims and Objectives, and how it all began. This site will also soon be updated with our new programme of events and eventually with the Bedford Directory of CAM. If there is anything you feel YOU would like to contribute to, either the website or the newsletter, please contact us. We are committed to getting in touch with as many people as possible, and any suggestions will be very useful.

#### MEMBERS ON EMAIL

The distribution of information is so much easier by email. If you have an email address and would like to receive newsletters and information, please send a message to Sue so you can get into the system. See telephone/contact list!

#### AAA—ACTION AGAINST ALLERGY

Cynthia has joined AAA and has some extremely interesting information sheets and publication lists. We will include some of these next time. If you want to know more now ring Cynthia!

#### COMPLEMENTARY MEDICINE IN BEDFORD

Franca and Sue have been involved for several years in the Bedfordshire Integrated Health Group. The group has two professors from De Montfort University, a local GP, a pharmacist, and a NHS representative and has just completed a document:

#### PROVISION FOR COMPLEMENTARY AND ALTERNATIVE MEDICINE PRACTITIONERS (PRIVATE AND NHS)

##### *Directory for the Bedford Area*

This Directory has been made available to Bedford Primary Care Trust, GPs, and Pharmacists; Heartlands Primary Care Trust, GPs surgeries; Several Luton Primary Care Trust, GP Surgeries and is available to the public at:

Libraries in Bedfordshire

Pharmacies in Bedford as listed in yellow pages

On the Web available soon on BASG's website.

Bedfordshire County Council, Bedford Borough Council, De Montfort University, and Ford End Rd. Gurudwara Temple funded this project. Vicki Manners (a DMU PhD Student) did all the research and compilation, with the support of the committee.

#### ARTICLES FROM BREAKSPEAR MEDICAL BULLETIN AUGUST 2002

##### *On the Market: Provocation/Neutralisation and Vaccines*

The technique of using provocation/neutralisation "vaccines" was refined in 1960 by Dr J B Miller in America. It is a safe, effective treatment for sensitivities to all kinds of foods, chemicals or inhalants.

The vaccines used for treatment must first be individually tested by injection into the skin (intradermal testing) or by using drops under the tongue (sublingual testing). Testing begins with a solution of a substance to which allergy is suspected and the reaction is assessed after 10 minutes. A series of weaker solutions may then be tested until the correct (neutralising) strength is reached. This gives an indication of the degree of



sensitivity and will often stop any symptoms provoked by the substance. The neutralising strength is used in the preparation of treatment vaccines. Vaccines may be taken by daily injections or by drops under the tongue two to three times per day.

A neutralising cocktail is a mixture of several neutralising doses (end-points) together in a solution. It may contain end-points for up to 25 substances. These cocktails should be kept frozen (in the ice-box or deep-freeze) and last for three months.

After the patient's initial consultation with a doctor, specially trained nurses start testing and may advise on which substances to test, in the light of the doctor's recommendations and treatment plan. The time required for testing depends on the number of items tested. Usually the broader the range of vaccine covered, the better the results. Patients will require varying amounts of testing time, as the programme provides individualised therapy.

This technique is used successfully by Breakspear Hospital, Hemel Hempstead.

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## Memorandum submitted by the Royal College of Paediatrics and Child Health (AL 2)

### INTRODUCTION

This document has been produced on behalf of The Royal College of Paediatrics and Child Health, which aims to raise the standards of medical care provided to children in the United Kingdom.

### SUMMARY

#### 1. *Availability of allergy services*

- (a) Patients have difficulty obtaining help and information from the medical profession about their children's allergies.
- (b) GP's feel that NHS allergy services are of poor quality and poor provision of specialist services is a major problem.
- (c) Hospital provision of paediatric allergy services is haphazard. There are very few hospitals offering a full range of paediatric allergy services and in large areas of the UK there are no specialist paediatric allergy services. There is therefore an inadequate skill base to support development of paediatric allergy services in primary care.

#### 2. *Priorities for improving services*

- (a) A hub and spoke network with paediatric allergists supporting GP's, general paediatricians and organ based specialists based in local hospitals needs to be developed.
- (b) GP's with a special interest in allergy need to be created in primary care. They need to have access to diagnostic laboratories.
- (c) General paediatricians with an interest in allergy need to be created in teaching hospitals and district general hospitals to deal with local needs.
- (d) Regional allergy centres need to be created to manage more complex cases. These will need to be staffed by consultants in paediatric allergy, paediatric allergy nurse specialists and paediatric dieticians. They will need to have adequate day case, outpatient and laboratory facilities.
- (e) The Royal College of Paediatrics and Child Health has a training programme for consultants in paediatric allergy, however additional paediatric allergy training posts are needed to support this.

#### 3. *Governance and regulation of independent sector providers*

Paediatricians who are members of the Royal College of Paediatrics and Child Health participate in the Continuing Professional Development Programme of the Royal College of Paediatrics and Child Health. A lot of allergy advice is provided by unregulated individuals and organisations.

##### 1(a) *Availability of allergy services*

Allergy charities frequently encounter deep anxiety among families affected by allergies. Lack of information is usually the cause of this distress. Patients commonly report that they have been unable to obtain adequate help and information from the medical profession. Patients with allergies say they need to be taken seriously by primary healthcare professionals, require investigation of potential triggers and education about allergen avoidance and treatment options, appropriate management and an integrated healthcare service. They need convenient access to a service appropriate to their needs with adequate staffing and resource to meet the need, education of primary healthcare professionals in allergy, simple diagnostic

tools (eg skin prick testing) and appropriate management, patient education in allergen avoidance and the use of inhaler devices, secondary care centres with facilities for specialised testing and tertiary support in regional centres with adequate staffing by allergy specialists. More than 80% of GP's thought NHS allergy services were of poor quality with poor provision of specialist referral possibilities being the major problem.

The majority of care for children with allergies is provided by general paediatricians or fragmented care provided by organ based specialists (paediatric gastroenterologists, respiratory paediatricians), ENT surgeons and dermatologists with no allergy training. This leads to inappropriate care, bizarre and poor practice. Whilst these specialists have an important role in the management of allergic disorders, a partnership needs to be developed with specialists in paediatric allergy. Additionally, a large number of children are seen in adult allergy clinics, contravening the National Service Framework for Children. Many allergy cases are dealt with by their GP's, who have no clinical training in allergy. In regions with a non-existent services (much of the UK) allergy lacks a voice. Allergy is often confused with immunology and not understood by Primary Care Trust's (PCT's) or regional commissioners.

*(b) Availability of specialist services for patients with severe allergies*

There is currently a severe lack of trained paediatric allergy specialists in the UK. There are only four centres offering a full range of paediatric allergy services; St Mary's Hospital and Kings College Hospital in London, Southampton and Leicester. There are no paediatric allergy clinics in Scotland, Wales or Northern Ireland. This contrasts poorly with countries such as Sweden, who have 96 trained paediatric allergy specialists. The increase in serious allergic disease has driven the demand for specialist services resulting in long waiting lists for paediatric allergy appointments. The number of paediatric allergy specialists is totally insufficient to meet the need and there is only one trainee in paediatric allergy. There is therefore no skill base to support paediatric allergy management in primary care. Current provision fails to meet standards of clinical governance and the lack of care leads to morbidity, mortality and subsequent cost to the NHS, most of which is avoidable.

*2. Priorities for improving services*

Allergy needs a "whole system" approach in which it is treated as a condition in its own right rather than as a series of diseases depending on the organ system involved. Most patients with simple allergic disease will be dealt with in general practice. It is envisaged that allergy services will progressively become primary care led, with expertise from the hospital setting for more severe and complex problems. A more effective partnership is required between allergy specialists and primary care who will need to provide the bulk of the day to day support for children with allergy. A hub and spoke network with allergists supporting GP's, general paediatricians and organ based specialists based in local hospitals needs to be developed.

At PCT level, children with allergies could be managed by a team comprising the general practitioner, practice nurse, the practice lead in allergy and GP's with a special interest in allergy offering allergy diagnosis and testing, symptom management and referral to specialist services where appropriate.

General paediatricians with an interest in allergy need to be created in teaching hospitals and district general hospitals to deal with local needs. One model may be for a shared appointment between trusts and a regional allergy centre (examples already exist in Ashford, Kent and Hillingdon). A designated community paediatrician needs to be identified within each primary care trust to co-ordinate the management of children at schools and in nurseries at risk of severe allergic reactions. General paediatricians will continue to contribute to allergy care and to have primary responsibility for patients with single organ or uncomplicated allergic disease. Networking with specialist centres should improve allergy services.

"Allergy; the unmet need"<sup>1</sup> proposes the development of regional allergy centres to manage more complex cases, offering equality of access to paediatric allergy services throughout the country. Each of the eight NHS regions in England as well as Scotland, Wales and N Ireland should have an absolute minimum of one regional specialist allergy centre staffed with two consultants in paediatric allergy supported by paediatric nurse specialists and paediatric dieticians with facilities for training SpR's in paediatric allergy and general paediatricians with an interest in allergy. Regional allergy centres will provide specialist expertise for managing difficult allergic disease throughout their region (tertiary care), care for allergic disease in the local population which cannot be dealt with in general practice (secondary care), act as an educational resource for the region, network with and enable local training in allergy for general paediatricians, support training at local level for general practitioners and nurses in the management of common allergies in primary care and to be supported by appropriate laboratory resources for in vitro allergy testing.

Given the scale of the national allergy epidemic, primary care must ultimately provide the front line care for allergy, but considerable development is needed. Given the current lack of training and knowledge in primary care, allergy services will initially need to be led by paediatric allergy specialists working in hospitals. More consultant posts in paediatric allergy and funded training posts are required. The Royal College of Paediatrics and Child Health has recently drawn up a dedicated training programme in paediatric allergy, in line with the European Board of Paediatrics Training Syllabus in Paediatric Allergology.

<sup>1</sup> Allergy—The Unmet need : A blueprint for better patient care. Royal College of Physicians 2003.

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Specialists in paediatric allergy, working in regional allergy centres, are needed to achieve and maintain appropriate standards of care. There is a need for facilities for accurate diagnosis and management of paediatric allergies, day case facilities for challenge testing and allergen immunotherapy in appropriate settings. New and expensive ways of treating common conditions, such as the use of anti-IgE to treat food allergy, will need careful assessment and supervision. Clinical leadership must initially come from specialist centres, taking on the dual role of diagnosis and management of the most complex cases and supporting the development of capacity within primary care. More consultant posts and training posts in paediatric allergy are needed to generate a core leadership for a national training and clinical development initiative for the whole service. The creation of these posts and their appropriate service development context requires recognition for them by primary care trusts and trust managers.

The devolution of financing and purchasing of services to primary care trusts means that it is difficult to set up new initiatives because of fierce competition for resources with established specialities. Those responsible for regional commissioning should recognise the necessity for specialist paediatric allergy services.

### *3. Governance and regulation of independent sector providers*

A very small number of doctors working in the independent sector have received training in paediatric allergy and are members of professional organisations such as the British Society for Allergy and clinical Immunology, through which they can maintain continuing professional development. This is policed by the Royal College of Paediatrics and Child Health. These are mostly general paediatricians who run allergy clinics. In addition there are a large number of unregulated individuals and organisations who operate “alternative allergy” testing and advice which is more easily accessed by the general public. Because of long waiting times for hospital appointments and lack of awareness of allergy in primary care, patients often resort to alternative allergy testing prior to being seen in a NHS clinic.

*Susan Leech*

*May 2004*

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**Memorandum by Queen's Medical Centre Nottingham, University Hospital NHS Trust (AL 35)**

Allergy services in the Nottingham area have been developed over the last five years. Initially run by one consultant and one specialist nurse, demand has led to the service expansion and a further nurse specialist. Over 60 new allergy referrals are made to the clinic every month. Each new patient seen will require a 45-minute to one hour appointment. At this level our team are continually struggling to keep patient waiting times down to hospital acceptable levels

A recent application to the local PCT's to maintain this service failed to secure funding, indeed recommendations were returned to dissolve the allergy service currently provided. This decision demonstrates the lack of prioritisation for allergy services at a local level. At the present time we are striving to maintain a specialist service and running additional clinical sessions to meet waiting list targets. NHS funding started to support one clinical nurse specialist in 2003. Commercial funding has run out for the second nursing post. Clinical impact of the lack of support for allergy services include:

- Increased waiting lists. Clinical risk associated with those requiring urgent review.
- No capacity for training or the dissemination of expert knowledge across other related hospital based specialities, ie paediatrics, dermatology, ENT and respiratory medicine.
- GPs unaware of the service on offer. The misdirection of GP referrals to inappropriate specialties, resulting in waste of time (patient and NHS) and resources.
- Limited capacity to introduce specific paediatric nursing support. Currently paediatric referrals are seen by adult-trained nurses with little knowledge of the inter-disciplinary problems that this special group of patients demonstrate.

The alternative allergy tests were reviewed in detail in Chapter 9 "ALLERGY the unmet need". Patients that look for allergy tests within the independent sector largely fall into three groups:

1. Patients who suspect that they are having food related problems.

- At least 20% of the UK population perceive they have a food problem. A brief Internet search or a visit to the local chemist reveals various alternative allergy tests and a certain frequently accessed test costs £260.00. On the basis of this non evidenced based testing, major and widespread inappropriate dietary avoidance/rotations are often recommended and these lifestyle changes can lead to clinical nutritional deficiencies further impacting on the individuals health. Patients can and do become prisoners in their homes consequent upon the food avoidance measures recommended by these mail order companies. Reality—the majority of food allergy patients only require limited albeit strict food avoidance and are encouraged to live a normal lifestyle.

2. Patients with nettle rash and swellings.

- Urticaria (nettle rash) and angioedema (swellings) affect 20% of the population at some stage of their lives. Sufferers often implicate food, pollution, chemicals, food additives etc and again alternative tests are readily available in the high street. Reality—in the vast majority of patients no cause will be found for these rashes and swellings and appropriate treatment is antihistamines.

3. Patients with hay fever type symptoms.

- Symptoms of itchy, runny nose and eyes whether seasonal or perennial can be exceedingly distressing and embarrassing for patients. Establishing a cause for such symptoms can be helpful in successful patient management. Unproven alternative tests (eg VEGA testing) purport to identify causes and often suggest expensive avoidance measures such expensive bed encasing covers and cleaning products, Reality—The VEGA test cannot identify allergic from non-allergic individuals hence the recommendation of expensive avoidance measures (> £200) is utterly inappropriate.

Patients appear to resort to alternative testing as conventional allergy advice at the General Practitioner level is poor and easy rapid access to allergy specialists is simply not available. Considerable anger is often manifested in NHS clinics when the reality of these alternative tests is revealed particularly when patients have spent considerable sums of money to no avail.

I acknowledge the value of some forms of complementary medicine such as acupuncture and certain herbal remedies and hence this paper is not part of a dismissal of complementary therapy. Rather it is to highlight the real issues faced by patients when trying to address their allergic problems without the ability in most areas to access an expert in allergic conditions.

May 2004

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### Memorandum by Tayside University Hospitals (AL 36)

I enclose the following documents for consideration by the Enquiry Committee:

- the background discussion document which led to the formation of Tayside's Allergy Advisory Group in 2002;
- the Group's first four newsletters for healthcare staff in our Region (not printed);
- our response to the "Take Allergy Seriously" card, currently being sent to MPs; and
- the covering letter for an ongoing survey of all Scottish GPs on management of anaphylaxis (not printed).

I hope that these will give the Enquiry an understanding of some of the practical considerations and constraints that we encounter in providing an allergy service for our Region, and some of the initiatives we are involved with. I would be very happy to enlarge on these in person if felt appropriate.

### PROVISION OF ALLERGY SERVICE IN TAYSIDE

#### OVERVIEW

##### *Allergic diseases*

- are very common, and becoming more so;
- cause considerable morbidity; and
- can be fatal.

##### *Current NHS provision of allergy care is generally poor due to lack of*

- resource;
- formal training of healthcare staff; and
- accredited specialists.

##### *There is a recognised need to develop regional allergy centres to provide*

- specialist expertise;
- educational resource; and
- geographical equity.

##### *A proposal is suggested to form a multidisciplinary group to*

- promote integration of current providers of care;
- advise NHS Tayside on local allergy priorities and development;
- link regional centres and frontline staff; and
- oversee education and clinical governance.

#### BACKGROUND

##### *Definition*

The use and meaning of the term "allergy" has undergone many vicissitudes since it was first coined in 1906. Current use in conventional medicine describes the clinical manifestation of a hypersensitivity reaction to an external or "foreign" substance (an allergen) which is mediated by immunological mechanisms.

##### *Atopy*

This refers to an inherited tendency to produce IgE antibodies to naturally occurring allergens, and represents a predisposition to allergic diseases, although atopic individuals do not necessarily have clinical symptoms. The commonest atopic diseases are asthma, rhinoconjunctivitis (hay fever) and atopic eczema.

##### *Prevalence*

At least a third of the population suffer from allergic disease. Asthma, hay fever and atopic eczema were uncommon in the 1960s, but now affect 15–20% of UK children. Our current westernised lifestyle (eg overheated/underventilated housings reliance on processed foods, antibiotic overuse) and lack of childhood infection (hygiene and smaller families) are thought to be important factors in this rise.

##### *Allergens*

Allergens can be inhaled, swallowed, injected or come into direct contact with the skin/eye/mucous membranes. Common examples are house dust mite, weed and tree pollens, animal proteins, fungi, foods such as milk/egg/nuts, drugs, latex, insect stings and contact allergens such as nickel/cosmetics/medicaments. Some of these produce symptoms within minutes of exposure ("immediate" reactions), while others take longer ("delayed" reactions), due to different immunological mechanisms involved. Some allergens are able to cause both types of reaction.

*Anaphylaxis*

This most serious form of allergy can kill by upper airway oedema, bronchospasm or circulatory collapse. Deaths occur which should be avoidable. Anaphylaxis occurred in one in 3,500 of the UK population in 1994, and the incidence is rising. Nut allergy currently affects over 1% of children and allergy to latex occurs in up to 17% of healthcare workers—both are potentially fatal.

*Foods*

Food allergy is perceived as common by the general public, as many as 20% feeling that they suffer from this. The true prevalence however, when confirmed by appropriate food challenge, is estimated at 2–3%, although is higher in young children (up to 10%) due to their immature immune system. Milk, eggs, peanuts, tree nuts, fish and shellfish account for the majority of true allergic food reactions. Non-immune reactions to foods also occur, termed “food intolerance” and not allergic in nature.

## HOW IS ALLERGY CARE CURRENTLY DELIVERED IN THE UK?

*Primary care*

Most clinical allergy diagnosis and management takes place in Primary Care, but formal training for this is virtually non-existent. There is heavy reliance on the prescription of suppressive medication (antihistamines and steroids) without properly tackling the underlying causes. Inadequate training can lead to failure in recognising the problem as allergic in nature, dismissal of the subject in the face of “more important” competing disorders and inappropriate investigation.

*Secondary care*

In the UK, apart from children who attend a paediatrician, those who are referred on to Secondary Care are almost all managed by organ-based specialists who have an interest, but are not formally trained, in allergy. This works satisfactorily when the clinical manifestation is confined to one organ, but allergic diseases are wide-ranging and often cross organ-based disciplines. At present, there is an almost total lack of coordinated NHS provision for speciality allergy services in the UK.

*Investigation*

Investigation of allergic disease relies heavily on clinical history, which is time-consuming. This is backed up, when indicated, by skin prick testing (safe for aeroallergens but potentially dangerous for foods and latex), blood IgE levels (always safe to perform, but expensive and prone to misinterpretation by the untrained) and food challenge (time-consuming and potentially dangerous).

*Dietician*

Patients who are diagnosed with food allergy are referred to a dietician to supervise both the avoidance of foods that contain the allergen(s), and also to ensure that the diet is nutritionally adequate. This can be a very complex process, but at present there is limited dietetic resource available to guide patients through this potential minefield.

*Immunotherapy*

Immunotherapy is routinely performed for anaphylaxis to wasp or bee venom, and in some centres for severe hay fever unresponsive to medication. This treatment is now only given by trained staff in hospitals where there is access to resuscitative equipment, because of a number of anaphylactic reactions and deaths when this therapy was allowed to be performed in an unregulated manner in Primary Care by untrained staff in the 1970s and 80s.

*Epinephrine (adrenaline)*

Because of media attention and concern about anaphylactic reactions, many patients (> 30,000 in UK) are now being prescribed parenteral epinephrine (Epipen). However, this practice differs from centre to centre and guidance on its use is often inadequate. Furthermore, this treatment is not without potential hazard, and there is a lack of clarity on who should receive it.

*Complementary medicine*

Inevitably, because of rising trends in allergic disease, lack of specialists and public demand for diagnostic and therapeutic expertise, many people now directly consult practitioners of complementary medicine, where they are often subjected to dubious diagnostic methods and treatments by medically unqualified staff.

*Information*

There are many very good information sites on the internet for allergic disorders, and also some excellent voluntary organisations. These do give generally sound advice, but are not able to perform investigations or, more importantly, make a diagnosis and plan of management in the way that a Health Professional team are able to.

**HOW SHOULD ALLERGY CARE BE PROVIDED?***Priorities*

Allergic disease has been described as the archetypal modern “plague” of civilisation, and is recognised as the “number one environmental disease” by the World Health Organisation. Although cardiovascular disease, cancer, infections and mental illness dominate current health priorities, the Health Service requires a robust mechanism in place to tackle what will undoubtedly become a more pressing issue.

*UK lags behind*

Unfortunately, current provision of allergy care in the NHS is generally poor, and the steadily increasing demand by the public for professional allergy services is simply not being met. This need for high quality allergy care is recognised and developed in many other countries, but at present the entire UK has only six comprehensive multidisciplinary allergy centres (zero in Scotland).

*Allergy specialists*

The complexity, multisystem and life-threatening nature of many forms of allergic disease has led to recognition of the need to strengthen clinical and laboratory allergy services, with expansion of the number of Consultant Allergist/Immunologist posts. The Department of Health now recognises Allergy as a speciality in its own right and a new Allergy CCST was introduced in 1999, although it is likely to be many years before there are adequate numbers of specialists as this is a small speciality with limited training facilities.

*Regional centres*

The immediate aim therefore will be to develop regional allergy centres to provide specialist expertise, educational resource for both Primary and Secondary Care and geographical equity of care. Some recent reconfiguration of allergy care has taken place in Glasgow, with development of the anaphylaxis service and funding of a new Consultant, but a further Centrally-funded Consultant post for Scotland is currently unfilled.

*Links to frontline staff*

Regional allergy centres should be backed up by appropriate “Managed Clinical Networks” and educational programmes for all Health Professionals, with nurses, dieticians and pharmacists playing an increasingly important role in the delivery of allergy care. A comprehensive guide to allergy services for all NHS professional staff should be developed.

*Infrastructure*

It will be important for local providers of care to have an appropriate infrastructure in place to accommodate future developments in investigation and management of allergic disease.

*Anaphylaxis*

Patients with anaphylaxis require special mention. This condition is genuinely life-threatening, often affects young people, and provision of care has simply not been properly addressed, as these patients require rapid access for assessment by a trained allergist. It is important to have effective links with community paediatric teams to oversee the management of schoolchildren with anaphylaxis. A Scottish Registry and nationwide epidemiological study into this emotive condition is desirable.

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## WHAT IS THE CURRENT POSITION AND SCOPE FOR IMPROVEMENT IN TAYSIDE?

Allergy service in Tayside is currently provided, as in most parts of the UK, by organ-based specialists and paediatricians, backed up by a fully-accredited laboratory facility. Although much of this service is of high quality, with particular areas of expertise, there are often long waiting lists due to lack of support staff, and some areas are at present poorly developed.

### *Respiratory medicine*

At present, about 1,000 patients with allergic airways disease attend NHS clinics each year. A further 1,000 per year are screened by the University Asthma and Allergy Research Group for recruitment into clinical trials. In addition, the Research Group's mobile screening van has so far screened five Primary Care Practices for asthma and allergic rhinitis using skin prick testing and nasal/lung function, with results fed back to General Practitioners who may use the results if they wish. It is planned to extend this research based screening service to further practices in Dundee and Perthshire, and develop a satellite centre in collaboration with Child Health in Perth.

Skin prick testing for aeroallergens is usually performed at the time of clinic attendance, unless further investigation such as bronchial challenge testing is required. At present, however, there is limited scope for discussing the results with patients at the NHS clinics.

An improved open access service, dovetailing with the current set-up, could be provided by the appointment of a specialist allergy liaison nurse. This would allow skin prick tests to be performed and informed management decisions given at the time of consultation. This system could operate both within existing hospital clinics and also in Primary Care throughout Tayside, and would enable a proper one-stop service to be delivered for a large group of patients. Funding for this post might be considered from rationalising the use of blood tests for IgE levels.

Allergen immunotherapy is not at present conducted within the Respiratory Medicine Department, but might become a development in time. The Asthma and Allergy Research Group has one of the highest research profiles for airway allergy in the UK, publishing 47 peer-reviewed papers in the past two years. It is important that research staff are not used to prop up the NHS service.

### *Ophthalmology*

The Department has recently set up a service for corneal diseases, which include allergic disorders. A number of patients become allergic to eyedrops, particularly those with glaucoma, which can be investigated by patch testing in Dermatology.

### *Otolaryngology*

At present, treatment of allergic rhinitis varies depending on clinician, previous treatment and investigation waiting time, and patients are usually seen on three or four occasions over several months by different doctors. There is no current facility for skin prick testing at the time of consultation.

As with respiratory medicine, the service for these patients would be considerably enhanced by the ability to provide a diagnosis and management plan in a one-stop clinic. This requires a multidisciplinary approach involving technician, nurse and ENT surgeon, where questionnaire, naso-endoscopy and skin prick testing are all performed at one visit. A decision can be made there and then about the need for allergen avoidance, medical or surgical treatment or immunotherapy, and appropriate arrangements made. Savings from reduced clinic attendance may be a means of funding the nurse who would do the skin prick tests and counsel patients.

The Department is the recognised specialist centre in Scotland for delivering immunotherapy. This form of treatment for pollen allergy is not as yet funded by NHS Tayside, despite current guidelines that it "should be offered in specialist centres for those patients not responding to medical treatment". The cost of setting up a clinic for 10 patients is estimated at £12,000 pa, treatment courses lasting for three years. Expansion of this service from clinical trial to standard NHS treatment becomes feasible when the resultant reduced requirement for currently prescribed lifelong suppressive therapy is taken into account, particularly as there is evidence that immunotherapy may protect against the future development of asthma.

Similar to eyedrops in ophthalmology, a number of patients become allergic to eardrops, which again can be investigated by patch testing in Dermatology.



### *Paediatrics*

The Department provides a dedicated clinic for food allergy, which is much commoner in this age group than in adults, but is compromised at present by inability to perform double blind placebo-controlled food challenge (which is the “gold standard” investigation of these patients) and limited nursing (1.25 sessions per week) and dietetic (0.5 session per week) support. These deficiencies should be addressed to enable satisfactory provision of service for what is a common (10% of children) and increasingly recognised (by the public) condition.

The Paediatric asthma clinic is constrained by lack of facility for skin prick testing. Joint clinics are conducted with the ENT Department only at present.

There are four different Education Departments in the region, and a need for consistent allergy protocols, although the Scottish Office have recognised the importance of this by producing “Medicines for Children in Schools’. There are problems with pre-school egg/playdough, and lack of Epipen and general paediatric training in Primary Care.

### *Paediatric dermatology*

A specialist Paediatric Dermatology Service was introduced in Ninewells and Perth (one clinic each per week) in 1999, with a further clinic every six weeks at Arbroath. The Dermatology Department is looking to expand the frequency of these clinics in Angus to tie in with the new ADTC, and is actively considering expansion to include Grampian (at their request) and North Fife regions.

About 50% of the workload of these clinics is atopic eczema, which now affects 20% of UK children. Initial assessment of new cases takes at least 30 minutes, and a good deal longer is required to fully educate the parents about practical management. Ideally, this should be done by a trained specialist nurse, which at present only takes place at Perth. Treatment regimes for this condition can be complex, and failure of treatment is usually due to noncompliance/lack of knowledge, with resultant multiple and wasteful prescribing. There is therefore a pressing need for a specialist atopic eczema nurse, who would link between the hospital clinics and the community setting to enhance the care of these patients. Such an appointment would be expected to reduce costs currently incurred on wasted prescribing and avoidance of some admissions to hospital.

Many children with atopic eczema have or will go on to develop allergic rhinitis or asthma, and about 10% have concomitant food allergy or intolerance. A parallel asthma clinic runs alongside at Ninewells, and a concurrent food allergy clinic would also be desirable.

The Tayside Dermatology Department is this year inaugurating a National Course on Paediatric Dermatology for specialist trainees. There is a strong local research interest in Quality of Life in atopic eczema, with development of indices for children and infants.

### *Dermatology*

Contact allergic dermatitis is diagnosed by patch testing, annual attendance for this investigation 6–700. The commonest allergens are nickel, perfumes and cosmetics and topical medicaments. This service has for many years suffered from a lengthy waiting list, although reorganisation of Consultant duties has brought the waiting time down to a more acceptable level, allowing the Department to begin introducing an improved fast-track facility for some patients with eczema. Further improvements to this service could be made with a modest increase in nursing input, which would also enable development of a follow up clinic to determine allergy relevance for audit purposes.

Chronic urticaria (nettle rash) is a frustratingly difficult condition to both experience and manage. The Department has recently set up a clinic for this condition, both to aid investigation and develop novel forms of treatment. Nursing costs have had to be borne inhouse to allow this to proceed, and at present there is no dedicated dietetic input.

The Tayside Photobiology Department has an International reputation for investigation of diseases caused by ultraviolet (UV) light, many of which are thought to have an immune (allergic) aetiology.

### *Gastroenterology*

There is at present a general lack of consensus with regard to Interpretation of food allergy, although it is recognised that this is genuine in some patients. However, the current inflammatory and neoplastic workload preclude significant input into allergy service by Tayside medical staff.

### *Dietetics*

There is a need to determine best practice for dietetic intervention in food allergy, which requires time to examine the evidence. The dietetic service is currently prioritised due to lack of resource and pressure of workload in both Primary and Secondary Care. There is no dietician with specialist expertise available in Primary Care, and waiting lists are lengthy.

### *Anaesthetics*

The Department has expertise, with several publications, in local anaesthetic allergy. Investigation of such patients is complex and time consuming, each case taking about half a day. Occasionally other disciplines request skin testing for investigation of anaphylaxis, where expert resuscitative facilities are deemed essential. Latex allergy has considerable implications in the operating theatre environment, and there are occasional cases of allergic reaction to general anaesthetics. Training is also delivered to healthcare professionals on management of anaphylaxis. Definitive provision of a specific allergy service requires one Consultant NHD per week.

### *Latex allergy*

There have been 125 referrals (mainly nursing staff) from TUHT and TPCT to Occupational Health in the past two years for skin conditions, the vast majority for hand dermatitis, and increasing numbers associated with latex gloves.

TUHT currently has latex policies for the care of patients and operating theatre environment. There is however no policy or training on the provision and use of glove wear or hand care for healthcare staff. Some Practices in Tayside are still using powdered latex gloves, which is dangerous for those allergic to this (from mucosal contact with the latex containing powder which is freely liberated into the air when removing the glove).

All NHS Tayside healthcare staff should receive appropriate training, and be actively surveyed for latex awareness and practice. Latex allergy has potential medicolegal implications, and can be fatal. A recent study from the West of Scotland highlighted lack of awareness among the healthcare staff of two hospitals.

### *Anaphylaxis*

This is a problem in Tayside. Adult secondary care referrals are currently directed towards Dermatology or Respiratory Medicine, but neither department is comfortable managing these patients as the consultants are not trained “allergists” and do not have the necessary facilities for challenge testing. These patients require rapid access to a trained specialist, which is simply not happening at present. In addition, General Practitioners are receiving increasing numbers of requests for epinephrine injectors (Epipens), and require guidance on appropriate prescribing.

The Trust Resuscitation Officers are increasingly being asked to train healthcare staff in anaphylaxis management, but are encountering problems with insufficient warning of and large numbers of staff requiring training for immunisation programmes, differing guidelines circulating within Specialities and Trusts, and lack of standardisation of anaphylaxis kits which are not geared to speedy and safe emergency use.

### *Immunology*

At present, Tayside has a CPA accredited immunology laboratory which is able to provide a comprehensive range of investigations relating to allergy. It is important for Tayside that this facility continues, which requires the presence of a Consultant Immunologist.

Much of the allergy workload centres on measurement of IgE levels (RAST testing). Expenditure on this investigation has dropped from £86,000 (1,674 requests with 11,462 tests performed) in 2000–01 to £42,000 (1,583 requests with 6,163 tests performed) in 2001–02, achieved by rationalising allergen-specific testing and communication with senders about what exactly is being looked for. Further savings are unlikely unless skin prick testing is expanded, but funding of requisite nursing staff for the latter could be at least part-funded by this route.

There is currently a vacancy caused by the recent resignation of Professor Kerr. This presents a golden opportunity to advertise for a Clinical Immunologist with a special interest in allergy, who would be able to both oversee the laboratory immunology service, and also take forward a new clinical service for complex allergy conditions, including anaphylaxis. It is possible that the latter could develop into a Regional Service outwith Tayside.

### *Primary care*

Most cases of allergy are looked after in the community, where there is currently lack of both resource and formal training. Improved detection of allergies by skin prick testing would be expected to lead to reduced need for suppressive medication by adopting appropriate avoidance measures. This could be linked in to asthma clinics, which already run in many practices. A case could also be made for the development of similar community clinics for atopic eczema.

There is a need for comprehensive education of all Primary Care Health Professionals in the field of allergy to optimise appropriate referral and advice for patients.

### HOW SHOULD ALLERGY CARE DEVELOP IN TAYSIDE?

Because of current local deficiencies in allergy service, increasing public demand for this need and difficulties encountered by individual departments when trying to improve matters, a group of senior staff recently met to discuss how best to take this forward. It was agreed that an important first step would be to form a multidisciplinary advisory structure (an “Allergy Advisory Group”), which would have the following benefits:

1. It would allow those with a specific interest in allergy to share expertise and promote integration of services where appropriate.
2. It would enable those departments providing allergy service to collectively agree local priorities so that funding is targeted at the most appropriate areas.
3. It would act as an advisory and educational group to provide guidance to Tayside public and healthcare staff on matters relating to allergy that is clear, concise and consistent.
4. It would network with regional centres of allergy expertise for appropriate advice and referral when necessary, and to keep abreast of recent developments.
5. It would act as a fulcrum for audit, clinical governance and research.

It is envisaged that membership would include representatives from:

- Immunology;
- Respiratory Medicine;
- Otolaryngology;
- Paediatrics;
- Dermatology;
- Anaesthetics;
- Ophthalmology;
- Occupational Health;
- Gastroenterology;
- Dietetics;
- Resuscitation;
- Nursing; and
- Primary Care.

With allergy now recognised as a distinct speciality and a pertinent report on the status of Immunology and Allergy Services recently produced by the Scottish Executive, it is opportune for NHS Tayside to consider how best to deliver this currently under-resourced service in the future for the patients it serves.

The proposed Group would be able to feed into the new NHS Tayside structure in an advisory role, giving a clear picture of local priorities with regard to the future direction of allergy care in Tayside, and how this could most cost-effectively be provided. There is a strong feeling that much could be improved at little extra cost.

It should be recognised that there is considerable allergy expertise already operating in the region, and NHS Tayside might consider the possibility of developing a Regional Allergy Centre. A pre-requisite for this would be the appointment of a Clinical Immunologist with a special interest in allergy.

The proposed Group wish to seek formal recognition within the local Healthcare structure.

May 2004

### Tayside University Hospitals response to the Take Allergy Seriously Card

Thank you for giving me the opportunity to comment on the “Allergy Card” that was recently sent to Kate McLean. I am well aware of this card’s existence, as it has been sent out to all members of the UK allergy patient support group on whose Executive I sit.

In general, I agree wholeheartedly with its content and message. Despite the huge increase in allergic disease in this country in recent years, the Government seems to be turning a blind eye to its existence. A token report was produced by the Scottish Executive on Immunology and Allergy Services in Scotland in September 2000, but it has had zero effect in Tayside to date other than stimulating the formation of our Allergy Advisory Group. I enclose a copy of the paper that made the case for the Group’s inception and subsequent endorsement by NHS Tayside Clinical Board in 2002. A subsequent report produced last year from the Royal College of Physicians “Allergy—The Unmet Need” echoed similar messages.

It is curious, and also alarming, that allergy is not taken more seriously in this country. Its emergence as a direct consequence of a civilizing process/changing environment has perhaps generated a certain scepticism (eg “allergic to Mondays”), but at the same time we simply cannot escape from facts such as a recent seven-fold increase in admissions for anaphylaxis over 10 years in England, one in five of all UK children suffering from atopic dermatitis, a third of Scottish teenagers with asthma, etc.

To defend “our patch” in Tayside, I would highlight the following:

- We fully recognise the National problem, and as far as I am aware are the only Region in the UK with a multidisciplinary “Allergy Advisory Group”. This novel approach led to an invitation to attend a British Society for Allergy and Clinical Immunology “Think Tank” strategy meeting last year.
- We have set up a website on NHS Tayside Intranet, where newsletters and information sheets are posted.
- We are actively planning an Allergy Awareness Event for Tayside healthcare staff so that we can be in a position to better respond to the needs of the healthcare professionals who deal with the vast majority of allergic disease—in Primary Care.
- Most allergy service in Secondary Care is currently provided by organ-based specialists and paediatricians who have an interest in the subject. We actually have considerable pockets of allergy expertise in Tayside, which I for one had not realised until we set up the Group, particularly in the fields of asthma, rhinoconjunctivitis, childhood atopic dermatitis, paediatric food allergy, local anaesthetic allergy, contact dermatitis and latex allergy.

We do not at present have a Consultant Clinical Immunologist. We are actively recruiting for one, but there is a National dearth of suitable applicants. Nevertheless, last year we were able to set up a new anaphylaxis clinic for investigation of adults with life-threatening allergy, which is a much needed development.

- Children with atopic allergic disease often have multisystem involvement. In recognition of this, we have realigned our paediatric dermatology, airways disease and food allergy clinics to run concurrently.

In terms of deficiencies, I would highlight:

- Lack of a consultant clinical immunologist, who would provide appropriate expertise for the complex and multisystem allergic patients. As a Teaching Hospital, we should certainly have one in post.
- Providing the necessary and ongoing education and information for frontline staff, who have to deal with allergic disease day in and day out. This would be for awareness and identification of allergy, appropriate investigation and referral, treatment strategies and what we can offer in Secondary Care. Too few staff are aware of our web-site at present, or of what expertise is available in hospital.
- Deficiency of specialist nursing staff to assist with the huge workload of allergy diagnosis and patient education. For example, we should be skin prick testing to aeroallergens and giving avoidance advice when patients attend asthma and rhinology clinics; this could also be undertaken at asthma clinics in the community. A further example is atopic dermatitis, a devastating condition for many families requiring considerable time to explain and encourage management to the parents—we simply are not able to do this as we would wish to at present.

We are not able to perform double blind placebo-controlled food challenge testing, the recognised gold standard investigation for food allergy. Dietetic services are not sufficiently resourced to provide the service they would wish to for food allergen avoidance. The gastroenterologists cannot even contemplate investigating food-related disease due to other workload. And yet 20% of the UK population perceive themselves as having a food allergy.

In summary, NHS Tayside provides a good, in fact very good, service for some allergic diseases, but for others we quite simply do not. No doubt it is the same for other Regions. In Tayside, we urgently require to improve information and education of frontline staff (with web-based technological expertise) and specialist nurse support for clinicians. Hopefully, a consultant clinical immunologist will appear from over the horizon before too long.

I would strongly urge the Scottish Executive to wake up to this archetypal modern plague of civilisation, and give it the resource it deserves. Obesity is at last becoming recognised as a major problem in our society, but is that simply because it is so patently visible? Allergy kills some and causes misery for millions—what will it take to make this “visible” to politicians also?

I would be grateful if you would give this letter verbatim, along with the paper, to Kate McLean. The card is targeting Parliament, not our Trust. This letter will give the MSP some background to the allergy problem nationwide, and I would be only too happy to enlarge on this if asked to.

#### **Memorandum by Dr Edward Kaminski and Christine Symons (AL 39)**

In 1996, I was appointed as the first Immunologist in Devon and Cornwall. My clinical remit includes Cornwall (Truro), South and West Devon (Plymouth and Torbay), East Devon (Exeter) but not North Devon (Barnstaple). At the time of my appointment there were a number of organ based specialists providing allergy services and these were predominantly ENT surgeons, Respiration Medicine Specialists and Dermatologists. Since 1996, there has been a dramatic increase in the availability of allergy services by clinicians who have received significant training in allergy and whose workload includes a significant number of allergy cases. The following is attempt at summarizing the services provided in Devon and Cornwall.

#### **PROVISION OF GENERAL SERVICES WITH AN ALLERGIC COMPONENT**

Asthma—this is generally dealt with by respiratory physicians at all four sites.

Eczema—this is generally dealt with by Dermatologists and Paediatricians at all four sites.

Rhinitis—this is generally dealt with by ENT physicians at all four sites.

#### **PROVISION OF MORE SPECIALIZED ALLERGY SERVICES**

##### *Exeter:*

- Mr Richard Garth, Consultant ENT Physician—ENT allergy, desensitization for bee, wasp and grass pollen allergy.
- Dr Andrew Collinson, Consultant Paediatrician—paediatric allergy.

##### *Plymouth:*

- Dr Edward Kaminski, Consultant Immunologist—general and specialised allergy (sees referrals for difficult adult cases from most of Devon and Cornwall).
- Second Consultant Immunologist—general and specialized allergy (appointment to be made soon).
- Sr Christine Symons, Immunology Specialist nurse—runs nurse-led clinic.
- Dr Clive McGavin, Consultant Respiratory Physician—respiratory allergy and desensitization for bee, wasp and grass pollen allergy.
- Dr Alan Cade, Consultant Paediatrician—paediatric allergy.
- Prof Stephen Strobel, Paediatric Immunologist from GOS (recently appointed)—paediatric allergy.

##### *Torbay:*

- Dr New Sue, Associate Specialist in Paediatrics—paediatric allergy.

##### *Truro:*

- Dr David Gould, Consultant Dermatologist—general allergy, desensitization for bee and wasp allergy.
- Dr Richard Sporik, Consultant Paediatrician—paediatric allergy.

I have been working alongside the Consultant Immunologist, Dr E R Kaminski at Derriford Hospital in Plymouth, since the beginning of 1996. In that time we have seen countless people with allergy many of whom have waited for considerable lengths of time to see us. Very often the patients' main complaints are that GPs underestimate the severity of their symptoms or the impact on their quality of life which delays their referral. In addition waiting times to see a specialist have increased over the period. All are relieved to have finally seen someone to confirm a diagnosis of allergy and to receive advice about treatment and how

to live with what, in some cases, is a life-threatening disease. In addition to our service, other physicians in the South West do see patients with allergy; I have also been offering a Nurse-led Allergy clinic for the past three and a half years.

Over the eight years that I have been looking after people with allergy, one of the major concerns of those with a food allergy is the poor labelling of food products which makes food shopping such a nightmare for them. There needs to be a better way of warning people that a food does or does not contain the ingredient they are allergic to—the current labels are often misleading and inappropriate.

Sadly, many of our patients have sought private consultations with “alternative” practitioners charging high prices because of the long wait to see anyone on the NHS. These people can give inaccurate diagnoses and advice which may adversely affect the health of those who have consulted them. I would like to see better regulation of those who set themselves up as advisers in this way.

Thank you for taking the time to read this letter. I hope I can look forward to a dramatic improvement in the recognition of Allergy as a serious health problem with the Services needed to improve the lives of those with Allergy undergoing a radical reappraisal as a result of this Committee.

May 2004

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### Memorandum by Lancashire Teaching Hospitals (AL 40)

#### SUMMARY

It is proposed that given the geography of the North West the model of Allergy Care should include three foci for Allergy in the North West each based within Strategic Health Authorities (SHA). Lancashire Teaching Hospitals (LTH) is based in the Cumbria and Lancashire SHA and has a significant infrastructure for allergy and it is essential that the current expertise is recognised and used in developing the Allergy Services in the North West. The specialist and complex allergy already performed at LTH should be consolidated by the appointment of a Consultant Allergist with appropriate support such as specialist allergy nurse and dietitian. This would ensure that the Allergy Model is patient-focused providing equitable access to specialist allergy services for all patients in the SHA. The model should allow patients from Barrow, Lancaster, Blackburn, Burnley and Blackpool to be seen in their local hospitals, and those who need specific immunotherapy only need to travel to Preston. In addition the allergy centre should work with PCTs so that they could offer *Advice and Treatment Centres* for common allergic disease like hay fever, in the community. LTH is of the opinion that Paediatric Allergy Services should be included in any allergy strategy and the proposals by LTH would support and strengthen the existing paediatric allergy services already provided by LTH. Laboratory support for allergy services should be consolidated into one laboratory in the hospital where specialist expertise is situated.

#### BACKGROUND

1.1 It is recognized that access to and the provision of high-quality care for patients with allergic disease is unsatisfactory in the UK. The provision of allergy services North West is no exception to this.

1.2 The geography of the North West is such that we would recommend that an allergy centre be sited in each of the three Strategic Health Authorities within the old North West Region.

1.3 The Cumbria and Lancashire SHA is geographically large and the patient should have the choice to attend an allergy centre closer to where they live. For example it would be inappropriate for a patient living in Barrow-in-Furness to attend an allergy clinic in Manchester.

1.4 At present Lancashire Teaching Hospitals (LTH) provide Allergy services to most of the Cumbria and Lancashire SHA. This service is provided by a multidisciplinary team consisting of a Consultant Immunologist, a Consultant Otolaryngologist and there is increasing involvement of a Consultant Paediatrician.

1.5 The LTH have provided significant clinical and laboratory services for allergy in the Lancashire and Cumbria SHA for several years. Much of the infrastructure required for allergy is already in place and clinics, including the provision of immunotherapy and management of more complex and severe disorders, already occur. A consultant Immunologist has three clinical sessions per week devoted to allergy and the Consultant Otolaryngologist has one clinical session per week devoted to allergy. There is significant referral between the consultants and Nurse support is present.

1.6 The current level of service provided by LTH already includes specialist and complex allergy services.

1.7 In addition, the Pathology department in the LTH has one of the largest Immunology departments in the country providing a comprehensive in-vitro allergy diagnostic service.

1.8 The Clinical Immunology Department based at Royal Preston Hospital has been providing allergy services to the whole of the Lancashire and South Cumbria area for many years.

1.9 At the moment the Allergy service in Immunology is consultant led. The clinic not only offers diagnostic services and professional advice regarding allergen avoidance in allergic diseases but also offers conventional specific immunotherapy. The Preston allergy clinic is one of four centres in the whole of the Northwest region that offers this form of therapy for various allergic diseases. This clinic, unlike some others that specialise in organ based allergic disease, offers a full range of allergy services. The allergic diseases that are seen include, seasonal and perennial rhinoconjunctivitis, atopic asthma, food allergy and food induced anaphylaxis (nut allergy, etc), insect sting anaphylaxis, drug allergy, and assessment of patients who have had reactions during anaesthesia, urticaria and angio-oedema. The consultant also closely liaises with school health nurses and community paediatricians from the Chorley and Preston areas regarding the management of children with peanut allergy and other serious food allergies.

1.10 Presently a joint clinic is being set up with a Paediatrician in order to see children with allergic diseases, with the aim of providing specialist services for children.

1.11 The Clinical Immunology department has seen a large number of patients with a range of allergic diseases. A range of procedures are carried out routinely; skin prick tests, intradermal tests, food challenges, training for self-injectable adrenaline and specific immunotherapy for bee venom, wasp venom, grass pollen and on specific cases, for animal danders.

1.12 The Clinical Immunology department receives a significant number of referrals from hospital consultants and some general practitioners in the Lancashire and South Cumbria region.

1.13 The Royal Preston Hospital also hosts specialist services for *otolaryngological allergy* by a Consultant Otolaryngologist, Mr J de Carpentier, who also has a special interest in rhinitis and is a member of the British Society of Allergy and Clinical Immunology.

1.14 There is close collaboration between the consultants regarding patients of mutual interest.

## 2. LABORATORY SERVICES PROVIDED BY THE LANCASHIRE IMMUNOLOGY SERVICE

2.1 The Lancashire Immunology Service is one of the largest immunology Laboratories in the UK and is based within the Pathology Directorate at LTH. It provides an extensive range of routine and specialist immunology for the local Trust and for several Trust in the Lancashire and South Cumbria area.

2.2 The Lancashire Immunology Service provides an extensive *in vitro* allergy diagnostic service. Total IgE and specific IgE assays are performed in-house, and are about to be fully automated. At the present time some 80–100 allergens are kept in stock, tests involving more esoteric allergens are referred to a Protein Reference Unit. A total Clinical and Laboratory service is performed for Trusts in Preston, Chorley, Blackpool and Morecambe Bay, while rare allergens are tested for Blackburn.

2.3 The department is one of the larger *in vitro* allergy services in the UK. A significant proportion of the work comes from the Clinical Allergy service operating from RPH and hence it serves patients drawn from an even wider area.

2.4 An interpretive service is provided and this is particularly used by GPs whose understanding of the significance of allergy testing results is sometimes limited.

2.5 It is proposed that as part of the Pathology Modernisation Programme, Laboratory support for allergy services is consolidated within one centre in the SHA. This would ensure economies of scale and a focus for interpretative expertise.

## 3. AEROBIOLOGY SERVICES (POLLEN COUNTING)

3.1 As part of its clinical and laboratory allergy service the Immunology Department at LTH offers a full pollen counting service for the benefit of hay fever sufferers. The Preston Laboratory is the only laboratory to offer this service in the Northwest. It is one of 14 European Aeroallergen Network sites in the UK, which count a full range of pollen grains (grass, weeds and trees) for about 11 months of the year. Data from Preston is fed via the Pollen Research Unit at University College Worcester into the European database at Vienna. The service is self-financing by selling the data to news media and pharmaceutical companies for research and monitoring.

## 4. THE ALLERGY FRAMEWORK

4.1 The development of a framework for an adult allergy network in the North West is supported.

4.2 It is recognised that the provision of allergy services in some geographical areas of the NHS is poor and that there is a huge unmet need. It is also recognised that there are few consultants and few trainees in Allergy. There are not enough Allergists in post or in training to meet the allergy needs of the UK in the short and medium term. Existing allergy services must therefore be used to continue with the patient care whilst ensuring adequate training is available to train the allergists of the future. It is therefore critical that existing expertise is used to develop the Allergy support in the UK.

4.3 LTH have a significant infrastructure for allergy and it is essential that the current expertise is recognised and used in developing the Allergy Services in the North West. The current service and LTH includes many specialist and complex allergy service and this expertise should be developed for patient care and the training of Allergists.

4.4 The geography of the North West is such that there is a risk that if allergy centers are too remote from the population of Cumbria and Lancashire then the allergy service would not be patient-focused and will not provide equity of access for these patients.

## 5. PROPOSALS

5.1 It is proposed that given the geography of the North West, the model of Allergy Care should include three foci for Allergy in the North West. This would ensure that the Allergy Model is patient-focused providing equitable access to specialist allergy services for all patients in the North West.

5.2 It is proposed that the existing Allergy expertise in the LTH is consolidated and is used as part of the Allergy Strategy. The model should allow patients from Barrow, Lancaster, Blackburn, Burnley and Blackpool to be seen in their local hospitals, and those who need specific immunotherapy only need to travel to Preston.

5.3 It is proposed that the complex activity already performed at LTH should be consolidated by the appointment of a Consultant Allergist with appropriate support such as a specialist allergy nurse and dietitian.

5.4 In addition it is proposed that the allergy centre should work with PCTs so that they could offer *Advice and Treatment Centres* for common allergic disease like hay fever, in the community.

5.5 It is important that the model recognises the importance of supporting and developing a paediatric allergy service. Paediatric allergy services are already provided by LTH and it is proposed that the development of specialist allergy centres should address paediatric allergy services.

5.6 It is proposed that once the allergy service is consolidated, LTH should be involved in the training of SpRs in Allergy.

June 2004

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### Joint memorandum by Dr Nigel J N Harper and Dr Richard Pumphrey (AL 41)

The process of anaesthesia in any individual patient requires the administration of as many as 10 different drugs, in high concentration, directly into the circulation. Approximately five million anaesthetics are administered each year in the UK. The incidence of *life-threatening* anaesthetic anaphylaxis, extrapolated from the French register, is approximately 1:10,000. There are no data for the UK.

Life-threatening anaesthetic anaphylaxis can occur on first exposure because some of the antigenic determinants are ubiquitous in everyday life. Conversely, a previous uneventful anaesthetic is not predictive of safe future anaesthesia. There is strong evidence of cross-sensitivity between some anaesthetic drugs, ie the paralysing curare-type agents; six different drugs of this type are in common use. If a patient survives anaphylaxis to one of these drugs, the subsequent administration of a different paralysing drug could cause fatal anaphylaxis.

Because patients are exposed to so many potential allergens during anaesthesia, including skin antiseptics, antibiotics, analgesics, anti-emetics, and latex, it is clear that each case of anaesthetic anaphylaxis should be expertly investigated. For each case of true allergic anaphylaxis there are approximately four cases where the life-threatening event was not allergic in origin.

The investigation of anaesthetic anaphylaxis across the UK is currently extremely variable. In some geographical areas, facilities are good, but the majority of the population has no convenient access to an expert clinic. The British Society of Allergists and Clinical Immunologists (BSACI) has identified only nine allergists/immunologists in the UK who investigate anaesthetic allergy. Some patients would need to travel over 100 miles to a clinic.

Because the process of anaesthesia is complex, it is important that these patients are investigated *jointly* by an allergist/immunologists *and* an anaesthetist with a special interest in anaesthetic allergy.

The Association of Anaesthetists of Great Britain and Ireland (AAGBI) has worked with the BSACI for several years and has produced joint clinical guidelines. The AAGBI is supporting the development of a national database for anaesthetic anaphylaxis and a web-based reporting process so that UK data can be collected.

The interdisciplinary outpatient clinic operated for seven years by the authors of this submission is the first of only two or three in the UK. Approximately 20 such expert joint clinics are needed in the UK. Meetings organised by the authors at the Royal College of Anaesthetists and the AAGBI have demonstrated



that there is no shortage of interested allergists/immunologists and anaesthetists. What is needed is a relatively small amount of funding to be made available nationally to expand existing clinics and to develop new interdisciplinary clinics so that patients can be expertly investigated regardless of where they live.

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#### Memorandum by Alan M Edwards (AL 42)

I am a Clinical Assistant at the David Hide Asthma and Allergy Research Centre based at the St Mary's Hospital NHS Trust, Newport Isle of Wight. I am responding to a letter sent to Dr SH Arshad, Medical Director of the Centre. Dr Arshad left the Centre in December 2003 to take up a post as Senior Lecturer at a new medical school in Stoke on Trent. The Centre is currently seeking to appoint a new Medical Director.

The David Hide Centre was established in the 1980s to undertake research into allergy and allergic disease. One of the research projects undertaken, the investigation of the effect of dietary artificial colours and preservatives on childhood behaviour (Attention Deficit and Hyperactivity Disorder), did hit the national press, television and radio last week after its publication. The Centre is a private trust but is located in the confines of St Mary's Hospital and in addition to research also provides a NHS allergy service to the island. The staffs are employed as either NHS personnel, joint NHS/Research or Research only.

I joined the Centre in April 2001. Previously my main career had been in the clinical development of drug treatment for allergic disease in the pharmaceutical industry but I have worked as a clinical assistant in two other allergy clinics, at Leicester General Hospital, Leicester in the 1970s and 1980s and in the Royal South Hants Hospital, Southampton from 1995 to 2001. I was also a member of a working party set up by the British Allergy Society to examine allergic disease in the 1990s.

The population of the Isle of Wight is 137,000 but does increase in the summer months with visitors. The Centre provides up to eight allergy clinics/week covering both adults and children and just about manages to keep the appointment waiting times down to less than six months. One factor in this is the large increase in allergy and allergic disease amongst the population. The prevalence of three manifestations of allergy, asthma, allergic rhinitis and eczema has been compared in two birth cohorts, one being the 1,536 newborns born on the island between January 1989 and April 1990 with the 969 newborns born between September 2001 and August 2002 (Pereira BN *et al.* EAACI presentation 2003). The cumulative prevalence of reported asthma amongst parents and siblings of these newborn infants increased from 8.64% to 21.58%, that of allergic rhinitis from 15.54% to 25.03% and that of eczema from 12.55% to 24.04%.

Allergic disease is a consequence of the reaction between the individual genetically predisposed to become sensitised, and substances (allergens) in the surrounding environment. These substances can be airborne, as exemplified by house dust mites, plant pollens and animal material or swallowed as foods and drinks or act as contact allergens such as soap powders. Sensitisation and exposure to airborne allergens results in asthma, allergic rhinitis, and allergic conjunctivitis and allergic eczema and to contact allergens as contact dermatitis. Exposure to food allergens can result in a range of clinical manifestations some of which are controversial but anaphylaxis, urticaria and angioedema, allergic eczema, allergic asthma, allergic rhinitis, irritable bowel syndrome, behaviour disorders (ADHD) in children and cow's milk allergy in infancy are all conditions that are recognised being caused by food allergens in certain cases. Certainly these are all conditions that are referred to allergy clinics for investigation.

The staff required to provide allergy services need to be a team of medical personnel covering a range of disciplines and skills. The doctors need to be able to deal with both adults and children and to have a working knowledge of respiratory disease, ENT disease, ophthalmology, dermatology, gastroenterology, behaviour disorders in childhood as well as basic immunology and resuscitation techniques to allow the use of immunotherapy. There is a need for specialist nurses skilled in the administration of inhaled drugs, in the use of topical treatments for skin diseases, and able to carry out lung function tests, allergy skin prick tests and allergy patch tests, to advise on methods of reducing exposure to allergens and also able to administer immunotherapy injections. There is a need for specialist dieticians with knowledge of allergy and immunology who are able to use elimination and reintroduction diets and challenge tests in the investigation

of food allergy and intolerance. Finally the allergy unit placed within a general hospital so that access to specialists in the clinical disciplines is available for referral for the diagnosis and treatment of those patients who are not suffering from allergies.

We are very fortunate at the David Hide Centre in that due to the foresight of its founder, Dr David Hide, (sadly deceased), all of the medical, nursing and dietetic skills are available. The referred patient is able to see at a single visit, the doctor to make the diagnosis, the specialist nurse to carry out the necessary allergy tests and to advise on allergen exclusion, on the correct use of inhaled drugs and the use of topical skin preparations including wet-wrapping. They are also able to see a specialist dietician who will start the process of elimination and challenge for food allergy and intolerance and advise on the details of exclusion diets. In addition we can carry out immunotherapy treatments and conduct single blind or double blind challenges for food allergy. For children these may need to be carried out in the children's ward in the hospital, to which we also have access. All this is against a very active background of allergy research.

I suspect that the allergy service provided at this centre is unique. Certainly at other allergy clinics at which I have worked where access to specialist nurses and dieticians was not always available, the service provided was less than adequate.

Allergic disease is not always regarded as a disease that requires specialist investigation and treatment. It is mostly not life threatening apart from the increasing problem with anaphylaxis to peanuts which can and has resulted in the death of teenagers. However the chronicity of allergic diseases, particularly eczema and asthma in both adults and children can cause a great deal of distress. There is also an increasing problem of ADHD in young children causing distress at home and at school. All of these conditions deserve adequate investigation and treatment by specialist teams.

As an example of why a specialist and team approach is necessary; I have recently had referred two healthy young men, aged 15 and 16 who wish to join the armed services as a career. They were diagnosed as having peanut allergy as infants or children. This has been successfully managed by avoiding eating peanuts. It is apparently now a rule that the armed services will not accept anyone with peanut allergy. Why? We are having to carry out skin tests and blood tests to confirm and evaluate the allergy. The nurses and dietician will then perform peanut challenges (with physician backup) under controlled conditions to see how great a risk still exists. It would be sad if these young men are denied a chosen career on the basis of a theoretical risk. However it is going to require the skills and knowledge of a specialist team to evaluate the nature of this risk.

Finally I must make it clear that the views expressed in this memorandum are my own personal ones and may not reflect the views of my colleagues at the David Hide Centre, nor the Trustees of the centre nor the staff and management of St Mary's Hospital NHS Trust.

June 2004

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### Joint memorandum by Dr Julia Clark and Professor Andrew Cant (AL 43)

#### INTRODUCTION

This evidence is submitted by Dr Julia Clark, Consultant in Paediatric Immunology and Infectious Disease and Professor Andrew Cant, Consultant in Paediatric Immunology and Infectious Disease.

Professor Cant and Dr Clark run paediatric allergy services at Newcastle General Hospital, providing tertiary services for the North East of England and secondary allergy services locally. Professor Cant is a member of the British Allergy Society and his allergy clinics are listed by them.

This document relates specifically to services for *children* and discusses the authors' own experience in the North of England, which has a paediatric (0–15 years) population of approximately 500,000.

#### 1. AVAILABILITY OF ALLERGY SERVICES

1.1 *Overview.* Childhood asthma, eczema, rhinitis, food allergies and hay fever are usually seen by general paediatricians and/or organ specific specialists. These may be paediatricians but can often be adult doctors such as dermatologists, ENT surgeons, immunologists or allergists, despite the suggestion in the National Children's Service Framework that all children should be seen by paediatric trained doctors. Food allergies are more common in children than adults. More complex food allergies such as multiple food allergies, unexplained allergic reactions, chronic urticaria and angio-oedema, latex and drug or anaesthetic allergies, as well as severe hay fever or severe rhinitis require more specialised input, but at present are usually seen by a range of adult or paediatric specialists or generalists with a large variety of approaches. In terms of clinical governance, such cases should be seen in a tertiary paediatric allergy service; nationally there are about 10 centres providing this sort of service to some degree, although only three have a dedicated paediatric allergist.

1.2 *Current provision of paediatric allergy services in the Northern Region; Secondary Service.* We have recently assessed the amount of paediatric allergy work done in the Northern Region by circulating a questionnaire to clinical directors in all districts with a 100% response rate. All are undertaking some paediatric allergy work but none can fully quantify it. Six out of 10 districts have a paediatrician with an interest in allergy but these doctors are not necessarily supported by a dietician or nurse specialist, who nonetheless do exist in some districts without an interested paediatrician. Most districts offer some form of service for investigating allergic disease, all performing blood tests and 80% skin prick tests; some perform challenge tests on children. Most dispense Epipens but with a hugely varied incidence. 80% could not quantify the burden of allergic disease in their district nor had hard evidence that the burden was increasing. We therefore know that in the North East 40% of Trusts do not have a paediatrician with an interest in allergy. 70% have no paediatric allergy dietician and 60% no nurse.

1.3 Children with asthma or eczema are generally looked after by general paediatricians, respiratory paediatricians or dermatologists. All Trusts within the North East of England are well served by all of these professionals, thus local communities have relatively rapid access times and some degree of choice depending on the number of paediatricians available in each centre.

1.4 However, there is a huge variation in the services available to children with food allergies or recurrent chronic urticaria/angio-oedema. All Trusts outside Newcastle upon Tyne NHS Trust would either have only one paediatrician with an interest in allergy to see children, or arrange for all children seen by any available paediatrician without a specific interest. Thus GPs referring cases with food allergy or urticaria do not have any particular specific service to refer into. As food allergy is more common in children than adults, in children it is by far the most common reason for allergy advice. Advice is primarily food avoidance and a comprehensive management plan including age appropriate antihistamines and adrenaline auto-injector where appropriate. Dietetic information is paramount, a paediatric dietician is therefore essential. Education in the safe and effective use of adrenaline auto-injector and liaison with schools about this is time consuming but essential and nurse input at this level is also required. Few local hospitals at present have these combined facilities.

1.5 Newcastle upon Tyne NHS Trust does have a paediatric allergy service both for secondary and tertiary care. Access for secondary care usually refers to referrals from GPs to the local hospital and hence covers the population served by the Trust. However, about 20% of new referrals come from outside this Trust as GP secondary referrals. This means that some children are travelling significant distances to a paediatric allergy clinic when referred by their GP for “non specialist” allergy services that should be provided more locally.

## 2. CURRENT SERVICES OF PAEDIATRIC ALLERGY IN NORTHERN REGION; TERTIARY SERVICE

2.1 Newcastle upon Tyne NHS Trust provides a paediatric allergy service at Newcastle General Hospital. There are five paediatric immunologists who all contribute to providing a paediatric allergy service and one of whom provides specific grass and tree pollen desensitisation, drug and anaesthetic diagnostic investigations. There is one WTE paediatric allergy nurse specialist, one senior dietician who covers all paediatric allergy clinics, but these personnel are not specifically funded for the allergy service and also cover other areas of general and specialist paediatrics. There is unfunded pharmacy support.

2.2 This service actually provides secondary care for its local population and tertiary care for the region. Some secondary allergy care is also provided by other paediatricians within the Newcastle upon Tyne NHS Trust. We are able to quantify the number of children seen with allergy within Newcastle General Hospital clinic, although for secondary referrals to the Trust this will be an under estimate as it does not include those children seen by other paediatricians. In the year 2004–04 360 children were seen as new referrals, 34% (122) of whom were tertiary referrals. 46% (56) of these were referred from the rest of the region.

2.3 At present the tertiary regional centre at Newcastle General Hospital provides most of the services outlined in the Specialised Services for Allergy (definition No 17) document. These include:

- Diagnosis and assessment of patients with allergic disease.
- Provision of skin prick testing facilities.
- Facilities for challenge testing.
- Facilities for immunotherapy.
- Protocol and facilities for diagnosis and management of adverse reactions during general anaesthesia.
- Protocol and facilities for the diagnosis of local anaesthetic allergy.
- Systems for the investigation and management of anaphylaxis including identification of cause, avoidance advice, written treatment plans with appropriate training.
- Diagnosis, investigation and management of adverse drug reactions.
- Diagnosis and management of latex allergies.
- Expertise in the diagnosis and management of angio-oedema and urticaria including C1 esterase inhibitor deficiency.

- Advice on allergen avoidance.
- Advice on dietary exclusion/reintroduction if suspected food allergy or intolerance.
- Consultation service to other specialties.
- Access to immunology laboratory service.
- Access to in-patient facilities.
- Education and teaching.

2.4 Waiting times for paediatric allergy clinics at Newcastle General Hospital are from 12 to 16 weeks. Outreach immunology/allergy clinics are provided once a month to Carlisle in the North and North Tees in the South, waiting times for these are 16 weeks and 22 weeks respectively. These waits reflect the huge demand for these services.

2.5 To try and improve these access times, a weekly specialist allergy nurse led clinic has just been established. A specialist allergy nurse prescriber sees children with well-defined allergies for diagnosis and management.

2.6 If tertiary services are required from the rest of the region, then children may have to travel up to two to three hours to get to the tertiary centre.

### 3. PRIORITIES FOR IMPROVING SERVICES

3.1 Allergy services for children as well as adults have been recognised as one of the 35 nationally designated specialised services. The development of a regional paediatric allergy network is the ideal and the model towards which many regions are trying to move.

3.2 Good links with adult allergy and immunology services are vital and linking paediatricians into already established services providing for children is essential.

3.3 In the North East we would like to see a regional managed clinical network. This is supported by all centres. A co-ordinated approach to the investigation and management of paediatric allergy is desirable. From a clinical governance and best practice point of view this also provides patients with equity of access and consistency of approach and clinicians with a support and advice network.

3.4 In a regional managed clinical network, local paediatricians and organ based specialists would continue to provide well-defined secondary care in district general hospitals whilst working as part of a managed clinical network with a tertiary centre seeing more complex cases. This would include specific mutually agreed guidelines for certain allergic conditions seen, indicating what can and should be managed locally and what centrally. A quality assurance programme ensuring consistency of standards and delivery would need to be agreed by all involved.

3.5 In order to move towards this goal, district general hospitals do need further services. Each DGH should have a paediatrician with an interest in allergy providing clinics at least two sessions per week. These must be supported by a paediatric dietician and a paediatric allergy nurse. Each local DGH should have facilities for skin prick testing and blood allergy testing and day unit facilities for specified food challenges.

3.6 The tertiary centre could drive the regional managed clinical network, creating and disseminating agreed guidelines, facilitating and encouraging peripheral sites. To do this in the North East a specialist paediatric allergist would be required. Increase in the co-ordination, provision and delivery of services both secondary and tertiary could then be expanded. Services such as desensitisation and drug and anaesthetic testing, which are highly time consuming and at present only offered to a very small and select population, could be offered to a wider population. There are exciting potential new advances in treatment such as monoclonal antibodies against IgE receptors, genetically engineered specific and genetic vaccines for food allergies for which there will be huge public demand and paediatric allergists will be required in the not too distant future to co-ordinate and deliver these.

3.7 Dietetic services are essential in the effective provision of food allergy advice for both children and adults and an effective paediatric allergy clinic cannot be run without paediatric dieticians with skills in allergy. Service improvement cannot be advanced without the provision of further dietetic time.

3.8 Nurse led clinics. Specialist nurses and nurse consultants are increasingly developing their role within sub-specialties. They have a huge potential to play within specific paediatric allergy services and nurse led paediatric allergy clinics are now being introduced in Newcastle. They can provide a comprehensive service for specific defined allergies such as food allergies including egg, wheat, milk and peanut, continuity of care and support. There is a potential increasing role throughout the region for nurse led clinics.

#### 4. GOVERNANCE AND REGULATION OF INDEPENDENT SECTOR PROVIDERS, AND LINKS BETWEEN THE NHS AND THE INDEPENDENT SECTOR

4.1 We have little experience of providers who provide paediatric allergy care within the independent sector in the North East. Some general paediatricians do provide private consultations and there are some clinics offering alternative therapies. There are no providers for tertiary paediatric allergy services in the independent sector. To our knowledge no one that has provided independent paediatric allergy consultations has also been able to provide dietetic advice, skin prick testing, or nurse advice about avoidance and Epipen administration.

#### 5. RECOMMENDATIONS FOR ACTION

5.1 Encourage each district general hospital to have a paediatrician with an interest in allergy, paediatric dietician with an interest in allergy and paediatric nurse with an interest in allergy.

5.2 Every region should have a tertiary service that provides specialist paediatric allergy services which is staffed by a paediatric allergist, paediatric allergy nurse specialist and paediatric dietician.

5.3 Increase specialist nurse led paediatric allergy clinics in the context of a managed clinical network and specific guidelines.

5.4 Facilitate tertiary centres to implement managed clinical networks with DGH's in their own region.

*June 2004*

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#### Memorandum by Mr Malcolm Stamp CBE (AL 44)

I am the Chief Executive of Addenbrooke's NHS Trust, the University of Cambridge teaching hospital.

Addenbrooke's is a thriving, modern 3-star NHS hospital based in Cambridge, with more than 6,000 members of staff, nearly 1,100 beds and a budget in 2003–04 of £254 million.

The hospital fulfils a number of important functions. It is the local hospital for people living in the Cambridge area, a specialist centre for a regional, national and international population, the teaching hospital for the University of Cambridge, and a world-class centre for medical and clinical research.

The hospital shares its site with a number of other organisations including the University Clinical School, the National Blood Authority, and laboratories funded by the Medical Research Council (MRC), the Wellcome Trust and Glaxo SmithKline. The University of Cambridge Hutchison/Cancer Research UK (CRUK) Cancer Centre, which will house 30 research groups using the latest techniques to target cancer, will open in 2005.

Last year in Addenbrooke's:

- 55,168 men, women and children were treated as inpatients;
- 59,208 people attended accident and emergency;
- 369,491 people visited outpatient clinics;
- 22,000 operations were carried out;
- 350 student doctors were trained; and
- 4,801 babies were born.

The Trust has 24 operating theatres, five intensive care units, 14 clinics and 42 wards. It provides emergency, surgical and medical services, and is a centre of excellence for specialist services for liver transplantation, neurosciences, renal services, bone and marrow transplantation, cleft lip and palate reconstruction, treatment of rare cancers, medical genetics and paediatrics. The Trust also includes the Rosie Hospital, which provides a full range of women's and maternity services.

Addenbrooke's medical staff hold clinics in 14 different regional hospitals so that patients do not have to travel to Cambridge. Over 100 Addenbrooke's consultants hold some form of joint appointment with a dozen neighbouring hospitals.

Addenbrooke's is a teaching hospital for medical undergraduates and postgraduates, as well as nurses and students in other clinical professions, and has a variety of initiatives to encourage life-long learning. Many training schemes are in place in our National Vocational Qualification Centre, Postgraduate Medical Education Centre and Learning Centre. Training schemes include cadet schemes in nursing, office technology, science, modern apprenticeships in clinical engineering and supporting training placements for biomedical scientists.

The Trust welcomes this opportunity to present evidence to the Health Select Committee. The Allergy service at Addenbrooke's is nationally recognised as a centre of excellence—arguably the best allergy service in the UK—and provides a model for the development of a regional allergy centre. However it also illustrates the difficulties in developing a “new” service and the demands placed on it.

## BACKGROUND

The Allergy Clinic was established in 1988, set up by Dr Pamela Ewan, then an MRC Clinical Scientist and honorary consultant, with academic funding. From small beginnings—a single consultant doing two clinics a week—it has developed over the years and now provides a service for the local population, a Regional service for the East of England (providing for a population of over five million), but also has national referrals.

It provides a specialist service in all aspects of allergic disease, focussing on the more complex cases. Specialist work includes immunotherapy, challenge procedures and other complex investigations, for example for drug allergy.

Over the years, NTIS funding has been built up and the service is now mainly NHS funded, and thus strongly based. This is in contrast to most other major allergy centres whose existence is dependent on the continued appointment of the lead academic(s) and therefore vulnerable. There are three NHS funded consultant allergists, two full time (Dr Ewan and Dr Nasser) and one part time (Dr Youlten) and one paediatric allergist (Dr Clark) recently appointed on fixed term academic funding (grant supported). Other NHS funding provides for two specialist allergy nurses, and a dedicated team of allergy trained nurses running the clinic. And importantly a dedicated secretarial service, with real knowledge of allergy and the services provided. The service also has adult and paediatric dietetic support.

## MODEL ALLERGY CLINIC

The Addenbrooke's clinic provides a model for a specialist allergy clinic, illustrating the benefits to the NHS. Key features are:

### *Clinical care*

- Nationally recognised centre of excellence, with high quality clinical care, and expertise in the broad and multiple manifestations of allergic disease.
- In great demand: the referral rate increases year on year, and has risen by 49% over three years from 2000–03. (The workload has increased substantially eg outpatients seen up 390% from 1993–99, and by 29% from 2000–03, and day cases (more complex procedures) up 1,000%.
- At the same time the case mix has changed, so that the majority of patients now seen have more severe or complex allergies, adding to the clinical burden.
- Provides local, regional and national care, depending on the condition. 94% of the work is “regional” from the East of England, with referrals as follows: 76% of patients are from Norfolk, Suffolk and Cambs PCT (serving a population of about 2.2 million); 12% from Essex (serving a population about 1.6 million); 12% from Beds & Herts (serving a population of about 1.7 million) and 6% of the total case load are national referrals from out-with this area.
- A service is provided for the Region for various specialist problems including anaphylaxis, drug, food and venom allergy, multi-system allergic disease and difficult to control mono-system allergy.
- Specialist investigation and treatment (immunotherapy ie desensitisation for life threatening conditions eg wasp sting anaphylaxis) is provided through a day case system. This service is particularly overstretched highlighting the need.
- An essential part of the service is an expert secretarial team. The pressure (from waiting list targets) to put complex patients with long standing disease through the system in a single consultation then pass them back to primary or secondary care—where there is a lack of expertise—generates frequent telephone calls for advice. There are three (2.2 wte) dedicated secretaries in the team providing immediate access and contact for patients, doctors and nurses from 8 am to 5 pm, in addition to the 24 hour medical on call service.

### *Efficiency*

- 5,000 patients, all with sufficiently severe or complex disease to be accepted (letters are screened and some problems are diagnosed by telephone discussion with the GP), are seen each year. 40% are children. Many are seen once and discharged with an accurate diagnosis and a management plan. This requires a streamlined system, input before and after the clinic attendance, protocols and a team approach.

- We have established networks to deliver allergy care eg with community paediatrics, schools (for children at risk of anaphylaxis), and other networks for referral.
- This is a cost effective system for the NHS at large, preventing on-going illness and reducing further acute reactions. A single allergy consultation can replace a series of referrals to other specialists eg ENT, chest, dermatology, paediatrics, and do this more effectively. This is because the allergic trigger is identified and measures put in place to reduce the risk of re-exposure. Also it is recognised that a series of conditions are interdependent. Control of allergic disease means reduction in admissions, A&E attendances, and consultations with other specialists and GPs.

#### *Educational Role*

- An important role is to provide specialist training in Allergy for young doctors (Allergy SpRs) wishing to become allergists. We are an approved training centre.
- A centre with a consultant allergist always available is an educational resource for doctors in the region, for example:
  - Training for GPs and consultants through telephone advice and clinical feedback over cases. Many GPs call for advice, which may prevent a referral.
- Training consultants, trainees and nurses from other centres in the UK and from primary care, by attachments to clinics. We receive many requests for staff from all over the UK to sit in on our clinics, as our clinical practice offers excellent training opportunities. But this adds further to the pressure on the staff.
- Thus the clinic has raised standards and awareness of allergy in GPs in the East of England, allowing more patients with allergy to be dealt with in primary care.

#### *Research*

- Clinical research carried out in the department has led to proposals for good practice, defined new disorders, evaluated tests and provided evidence based management. This is an important role for regional allergy centres, as there is a lack of evidence based guidelines for the diagnosis or management of certain forms of allergy.

#### **FUNDING**

- Although the clinic has better NTIS funding than other allergy clinics in the UK, this has been slow and difficult to achieve, and funding has always fallen behind demand. This has required constant effort and time from Dr Ewan, over many years. Despite a persuasive case, funding has been difficult or impossible to obtain.
- Regional funding was obtained for a consultant salary in 2001 from Health Authorities in the Eastern Region, under the old Regional commissioning system.
- A bid to the lead PCT (Norfolk, Suffolk and Cambridge LSCG) for Local Specialised Commissioning in 2003–04 was unsuccessful, although highly rated, because demand for LSCG funding greatly outstripped available funding. Only four of 17 bids could be funded. It is notable that although funding was refused, the same GPs which the PCT represents “vote with their feet” and continue to refer more patients.
- Allergy is on the DH National Specialised Definitions Set (number 17, allergy—all ages). This defines disorders which should be seen in a specialist allergy service. Yet those making funding decisions do not appear to support the referral of patients with these serious disorders.
- As a result patients are shunted around other services in the NHS, where their allergic problems are not properly addressed. This is evident from the patients eventually seen at Addenbrooke’s. These inefficient practices are not good use of NHS funds.

#### **SERVICE PRESSURES**

Whilst Addenbrooke’s prides itself on meeting government waiting list targets, it remains unacceptable that patients with life-threatening disease have to wait up to nine months at the present time to be seen as day cases for complex investigation. This is inevitable when demand continues to grow, and there is no comparable service in England to the west or to the east of Cambridge, while the nearest to the north is Leicester and to the south, London.

The whole allergy team is constantly under pressure, to accept more patients in real and urgent need. (eg for a life threatening reaction during anaesthesia when surgery was abandoned, and a further anaesthetic cannot be given safely until the cause is identified) yet workload has been pushed beyond reasonable limits.

This is because there is no other specialist allergy service in East Anglia and few in England as a whole. The lack of such services throughout the country means that we are being asked to accept patients from far a field. Patients with complex allergy problems cannot be dealt with properly in non-specialist allergy clinics.

#### SUMMARY

It is therefore important that the Department of Health recognises the great need for improved *specialist* allergy services in England. The Trust hopes the Committee will endorse this and recommend the creation of regional allergy centres. This requires more funded allergy training posts and consultant allergy posts. Those responsible for funding decisions need guidance, otherwise allergy services will not develop and the NTIS will continue to fail patients. I would be pleased to provide further information and to help the Committee in any way I can.

June 2004

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### Memorandum by Professor Anthony J Frew (AL 45)

#### BACKGROUND TO EVIDENCE

Within Southampton University Hospitals NHS Trust we have provided a clinical allergy service for over 15 years. This service emerged from the out-patient clinics run by clinical academics researching the causes, mechanisms and treatment of asthma and related diseases. Over the years, and under successive NHS funding systems, many attempts have been made to bring NHS funding in to support the NHS components of the allergy service, but neither the hospital nor the commissioning bodies have seen it as a priority area. As of 2001, we calculated that our academic group is subsidising the investigation of NHS allergy patients to the tune of about £70,000 per year (at 2001 prices).

Our workload has increased steadily, both from within our area, and from surrounding areas, especially after the closure of allergy services in surrounding areas. Suggestions that block contracts should renegotiate to reflect workload have led either to advice that the service should be closed down, thereby solving the Trust's waiting list problem, or else that we should absorb the activity as the service has been in existence for so long.

#### PROFESSOR FREW'S EVIDENCE

The academic respiratory group at the School of Medicine, University of Southampton has a longstanding interest in the causes, mechanisms and treatment of asthma and allergic diseases. Our NHS clinical service has evolved over the years, but finds its roots in the NHS clinics contributed by Prof JB Howell and Prof ST Holgate. In 1988 Dr P Howarth was appointed as Clinical Senior Lecturer, and expanded the interest of the clinic, especially in relation to allergic rhinitis. In 1992 I was appointed as Clinical Senior Lecturer, on temporary funding, and since that time Dr Howarth and I have run a combined NHS asthma and allergy service. A separate paediatric allergy service also exists in Southampton, but will not be discussed further in this evidence.

A satellite adult allergy service was established in Bournemouth in 1995 with additional funding from East Dorset HA. The Bournemouth service has expanded considerably since then, without any additional funding. When this was discussed with local managers and commissioners, attempts to obtain further funding have foundered, as the service is not perceived as a priority. Waiting lists for this service are close to six months and periodically we are asked to undertake waiting list initiative clinics to bring this within prescribed limits, but a long term solution is needed.

Our clinics receive most of their referrals from Hampshire, West Sussex, Wiltshire, South Berks, and Dorset. Some referrals are received from wider afield, including Brighton, Eastbourne, Somerset, Swindon and even Devon, reflecting the lack of provision of specialist services in those areas.

We have recently established a Wessex Allergy Network, to bring together all the clinicians who currently provide allergy services in the region, and agree appropriate care pathways, so that patients who can be dealt with locally are seen locally, and only referred into the regional centre when there is a clear clinical need. The network also provides a platform for spreading knowledge and best practice out to the surrounding districts, so that clinicians providing allergy services can gradually upgrade their service if they wish to do so.

#### SUPPORT STAFF

In 1993 we obtained funding for an NHS senior registrar in allergy & general medicine. Subsequently this post was converted into a specialist registrar position, in allergy & clinical immunology, and we later obtained an unfunded training number to allow us to appoint a second specialist registrar in allergy & clinical immunology, using part funding from a research charity. Full funding for this second post has now been secured from the Wessex deanery.



Technical support for our clinic was provided for many years by research nurses, who were funded by commercial projects. These nurses would come to the NHS clinics and undertake skin tests and some allergen challenges. However, with the reduction in commercial clinical trial activity, and operational changes within the university, we are no longer able to use research income to support what is exclusively an NHS activity.

We now use three days per week of a university-funded technician to provide skin testing support, but this is also under threat, due to reorganisation of technical staff within the School of Medicine. Steps are being taken to restructure the lung function laboratory and to integrate the allergy and respiratory investigation work currently performed by university staff into the NHS portfolio. However, the revenue consequences of this are not yet agreed.

Our immunotherapy service started life as an NHS service, treating patients identified in the allergy clinic as suitable for desensitisation. As we run a substantial research programme on immunotherapy, we have allowed NHS patients to be treated in research space. This has economies of scale and improves safety. In the last three years we have gradually transferred responsibility from our own, soft-funded staff to the research nurses employed by the Trust in the Wellcome trust Clinical Research Facility.

In Bournemouth, we have been fortunate in getting the local Trust to allow us to train up a staff nurse who now provides the skin testing and advice service to the allergy clinic. This has allowed us to withdraw our soft-funded research nurses from the Bournemouth NHS service, although they still go there for research purposes.

#### NARRATIVE OF BARRIERS AND PROBLEMS ENCOUNTERED IN PAST 10 YEARS

In April 1995, Portsmouth & SE Hants Health commission wrote to us acknowledging that “allergy is a major problem in the community, which is managed by GPs and several specialities in district general hospitals. Often these services are badly managed”.

In May 1995, Prof Holgate wrote to our medical director suggesting that we should rationalise the clinical service that we provide. This followed approaches from, and discussion with Health Commission (HC) in Dorset, Portsmouth and the Isle of Wight aimed at helping them to establish the provision of allergy services in their localities, in line with the recent RCP report. This was aimed at finding salary support for a consultant post, and providing adequate infrastructure for the service.

June 1995: letter from Medical director agreeing that we should be reviewing allergy and immunology services across the region.

August 1995: request from us to include dietetic service in business case.

September 1995: business case submitted.

February 1996: direct approach from Prof Holgate to Chief Executive of Southampton & SW Hants HC, pointing out that the allergy service is not really within the block contract, and that the service is under pressure due to changes within the University funding system.

October 1996: feedback from Health Commission indicates that it did not consider the business case. They suggest that the service should be built into the block contract.

February 1997: summary from Prof Holgate to Clinical Service Director (CSD). Notes that the current service includes a clinic, skin testing and other diagnostic tests, as well as an immunotherapy clinic, that have never been funded by SUHT and are not built into the block contract. Identifies need to build a proper funding stream from the clinical work, perhaps by identifying income from fund-holders and ECRs. Despite lobbying the HC and two separate bids to the Authority's Development Fund, on each occasion, the HC has indicated that this is not a priority in comparison to other services.

September 1997: Clinical Service Manager (CSM) for medicine asks for allergy services to be costed on a higher tariff. States that she is not sure if this can be accounted for separately on the PAS system.

Autumn 1997: academic consultant post funded by SUHT on back of general medicine commitment, and part funding from Bournemouth. No funding provided in respect of Southampton allergy service.

January 1998: Allergy clinic tariff agreed.

March 1998: final ECR tariff 1998–99 agreed.

May 1999: proposal for service improvement plan submitted to Trust planning dept. Notes increasing prevalence of atopic disease, increasing awareness of health economic burden of allergic diseases, as well as issues around emergencies and waiting lists.

October 1999: following the cessation of the allergy service in Reading I wrote to local managers to ask them to make sure that the additional activity that was likely to come our way was captured and properly charged for. Letter describes the background: on retirement of Dr Rita Brown, a decision was taken not to replace her but to farm out the workload. Around the same time, the immunologist in Oxford who used to deal with some allergy work there, moved on to a post in Leeds. AJF notes that accepting the increased workload has meant an increase in waiting times for local patients and patients from our usual catchment area.

Advice from Trust managers is to decline the referrals; our preference and repeated request is for the managers to ask for the referrals to be paid for.

January 2000: clerical service to allergy clinic overloaded due to increasing patient throughput.

February 2000: following internal promotions and reorganisation within the academic department, we wrote to the Trust medical director asking for three sessions of NHS time to support input to the service from Dr Hasan Arshad.

March 2000: positive response from medical director, but no money. Dr Arshad employed for three sessions on our research funding and deployed to support Bournemouth allergy clinic to substitute for Profs Holgate and Frew.

March 2000: blueprint for development of service prepared by AJF with a view to submission to Central South Coast specialist Services Commissioning Group (CSCSSCG). Covering letter explains that we have taken on services for patients from Salisbury, Reading and Oxford, as well as expanding the local satellite services.

September 2000: steps taken to streamline correspondence and typing load for secretarial service.

September 2000: booking pattern expanded to 20 new patients per clinic, to help cope with increasing waiting list.

December 2000: letter to CSD medicine pressing for additional investment to support the NHS allergy service. Despite support in principle from Medical Director, subsequent meetings with managers had shown that there was little enthusiasm for pursuing anything that was not a National Service Framework. Waiting list now exceeding 13 week target, so there is clearly demand for the service, but nobody wants to pay for it. Clinic is staffed almost entirely by University personnel. AJF says that we are willing to help the Trust to attempt to meet its targets, but there is a limit to how much additional time and staff we can deploy to support this service. Emphasises that Dr Howarth and AJF have not been out touting for custom, but there has been a steady increase in the number of patients referred to us, and a tangible increase in workload since the retirement of allergists in Reading and Oxford. Despite numerous attempts to point this out to the Trust and the suggestion that we should be bringing in money for the additional workload, we are not aware that any progress has been made to bring in extra money on the back of the additional work that we are undertaking.

26/6/01: letter from GP in Brighton asking whether we can help investigate patients with allergic disease. This is following the closure of the allergy clinic in Great Ormond Street, where the GP used to refer his patients previously. Small numbers of patients from Brighton and surrounding area start to flow into the clinic

March 2002: further streamlining of clinic letters to contain secretarial workload.

May 2002: at request of Trust, detailed analysis prepared of costs of NHS activity performed by Academic dept in calendar year 2001. Total costs calculated at £69,275.30 per year, all of which is currently being funded from University income. NB these costs include the technical staff time, but do not include equipment depreciation or the costs of the research nurses and doctors. We also omitted any tests that could be regarded as research or experimental and were not suitable for inclusion in an NHS-funded routine service. All the above costs are borne by the academic department and funded from the income of commercial clinical trials.

June 2002: following submission of this business case, notice served to our junior technician who will have to leave in September 2002 if no funds are forthcoming.

July 2002: response by CSM to earlier correspondence re new referrals from Bristol, following cut-backs in the allergy service provided there. Agrees that we should be seeking specific funding. "In effect Southampton are being looked at as a new referral route, but this can only happen with appropriate funding. To progress this I will need to notify the relevant PCTs and get authority that they will fund the treatment".

September 2002: Junior technician leaves as no funding forthcoming. Following departure of junior technician, number of new patient slots at allergy clinic reduced to 18 instead of the 26 to 28 that were being seen previously.

23/9/02: letter from medical director responding to my note about out of area referrals. States that it will be raised with the acting head of finance to see if anything can be done.

7/11/02: histamine challenges skin tests and induced sputum measurements now only available on three days/week, due to redeployment of chief technician.

December 2002: research dietician joins allergy service for trial period of six months.

7/1/03: waiting list for downstream allergy challenges has now gone up to seven weeks (previously one to two weeks maximum).

18/7/03: AJF writes to referring clinicians in SUHT to advise that open access to skin testing facilities have had to be withdrawn, due to reduced availability of technician time, and increasing delays in handling our own patients. Letters of support received from Ophthalmology and Anaesthetic departments.

July 2003: discussions reopened with Trust managers about capturing allergy investigation activity taking place in academic unit.

September 2003: proposal to extend dietetic support if funds can be identified; Since no funds, service mothballed.

October 2003: exploratory discussions about bringing some allergen challenge and investigation work into an NHS area. Originally this was done by the NHS registrars and our research nurses in the clinical investigation unit, but the research activity has been moved into the Wellcome Trust Clinical Research Facility, and they will not allow us to conduct NHS work in their space.

October 2003: following resignation of Dr Arshad to take up a post in Stoke-on-Trent Dr Howarth, Prof Holgate and Prof Frew reorganise to cover the clinics in Bournemouth and Southampton, which run concurrently. Temporary arrangements developed while a possible NHS appointment in Immunology is discussed. Plans made to move Southampton Wednesday morning allergy clinic to Monday afternoon at Royal South Hants Hospital slot to avoid double-booking of consultants on Wednesday mornings.

April 2004: NHS Immunotherapy clinic moved out of Wellcome Trust Clinical Research Facility, where it has been located for past three years. Drive for change is need to make space for more research activity. Two slots condensed into one as no NHS admin and clerical support available to service the two slots previously serviced by NHS registrars. Business case needed to extend this service beyond April 2006, when current commitment from research nurses is phased out.

April 2004: letter from AJF to CSD asking for help in pushing forward with the process of capturing all the allergy work that we do, and making sure that it is properly charged for. Despite several conversation with Trust managers, this appears to be a low priority item and we are sure that patients who should be charged for, and generate profit for the Trust, are in fact being investigated and treated without charge. Hence we are seen as a drain on the Trust economy when we should be an income-generating asset.

May 2004: approached by out-patient manager to ask what we plan to do about the waiting list as this is now showing signs that we will breach trust targets. No funding or additional slots offered.

#### SUMMARY AND OPINION

Our allergy service started life as part of the NHS clinics that were provided by clinical academics. We have not advertised it widely, as our primary objectives are research and education, and we cannot contribute more session to NHS work ourselves, although we would welcome the opportunity to expand the service if appropriate consultant-level appointments were made. We have been selective about the type of referrals that we take, and have dealt with many referrals by letter, but our workload continues to increase year on year. Ongoing perception that we are a problem service because we may damage trust waiting list targets, but little attempt being made to use the increased workload to bring in additional funding to allow us to expand the service.

We now have two trainees funded by NHS, and we contribute to the local MSc course in a allergy management. We are seeking to rationalise service provision through the development of the Wessex Allergy Network. We are well placed to deliver secondary care to our area, to support other care providers in primary and secondary care, and to provide tertiary care for the region. However, our service is under threat, because much of the existing service is supported by university-funded staff, whose continued input to the service is threatened.

All this has been done against a background of relative lack of commitment from the hospital Trust and local healthcare purchasers, who have chosen to focus on what they perceive to be national service framework priorities. Where business cases have been developed, they have been rejected on priority grounds, or kicked into the long grass. Hopes for the commissioning of the service were raised when the CSCSSCG was operative, as that seemed to us to be the appropriate level for planning the service. However, following the latest reorganisation it has been impossible to identify anyone or a lead PCT responsible for allergy services.

As clinical academics we have a limited amount of time and energy to put into developing the service. We are happy to contribute our expertise, and to be constructive partners with the NHS, but the expectations of our employers are clear: NHS service work cannot take precedence over the research and educational missions of the school of medicine. While the provision of the allergy service does help us in prosecuting our research, this is primarily by raising our profile and we do not use the clinic to recruit patients for studies (most patients for clinical trials are recruited by advertisement). The clinical service remains vulnerable to reorganisation of the school of medicine, to changes in strategic direction of the school of medicine, or the relocation of key staff members.

We would welcome a clear, central directive about the future of allergy services, so that we can enter into constructive discussions with our hospital Trust and our local PCTs, and deliver a service that meets the reasonable expectations of the many patients with allergic problems in our area and region.

*June 2004*

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**Memorandum by Paul Cullinan (AL 46)**

**OCCUPATIONAL ASTHMA**

We are writing to draw your attention to asthma caused by agents inhaled at work. This is known as “occupational asthma”, which in the majority of cases (90% or more) is caused by allergy to materials encountered in the workplace. Occupational asthma is the most common occupational lung disease currently reported in the United Kingdom each year; some 2,000 new cases of occupational asthma are reported to a voluntary reporting scheme—Surveillance of Work and Occupational Respiratory Disease (SWORD). This, of course, only includes those cases which come to the attention of a chest physician and occupational physician and there is some evidence to suggest that the true estimate is double this number. This surveillance scheme has been in operation for some 15 years, and the number of cases reported each year has remained unchanged during the 15 year period; the agents responsible, and the occupations in which they have been met, have also largely remained unchanged during this period. Although over 300 different agents have been reported as causes of occupational asthma, the great majority of cases are caused by some 10 agents, which are concentrated in a relatively small number of occupational settings. Paint sprayers (eg automobile repair), bakers, those who work with laboratory animals, electrical assembly workers and health care staff are amongst those whose jobs put them at the highest risk of developing occupational asthma.

It has been estimated that occupational factors contribute to some 10 to 15% of all new or recurrent cases of asthma in adult life. Of particular importance, occupational asthma is the one circumstance in which asthma developing in adult life is readily preventable and often curable.

Its recognition, diagnosis and management require particular skills that include a proper knowledge of its medical aspects, ready access to specialist diagnostic techniques and an understanding of the relevant workplace issues. Since many patients with occupational asthma, to avoid further exposure to its cause, lose their jobs as a result, a correct diagnosis is especially important, as is appropriate care thereafter. The prognosis of the disease is improved when it is recognised, and when appropriate measures are taken, soon after its onset.

The UK is the birthplace of the medical care of occupational asthma. In spite of this there are now a handful only of hospitals that are able to offer expert advice; on most cases waiting lists are long and direct access via the workplace difficult. Both of these are highly detrimental to the continuing employment of those suspected to have occupational asthma.

Occupational asthma also represents an important opportunity for vocational rehabilitation. It often develops early in working life amongst persons able and well motivated to return to work. The only work from which they should be excluded is that in which they will be re-exposed to the cause of their asthma, which will provoke a recurrence of disease. However, frequently they find it difficult to return to the labour market and a number of studies have shown that, up to five years from the time of diagnosis, patients with occupational asthma can remain unemployed.

Occupational asthma also provides an important opportunity for academic medicine and industry, to work closely together to develop the means to reduce the incidence of the disease and, if possible, prevent its occurrence. The epidemic of latex allergy, for instance, in the mid 1990s has been effectively reversed in many hospitals by the introduction of non-powdered low latex gloves.

*June 2004*

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**Memorandum by Dr Mazin Alfaham (AL 47)**

**Introduction to Paediatric Allergy Services in Cardiff & Vale NHS Trust/South Wales.**

1. The children’s allergy service is co-ordinated in a dedicated Children’s Asthma and Allergy Centre which operates within the Directorate of Women & Children’s Health. The Centre organizes clinical services as well as clinical governance, clinical research and educational activities in relation to allergic diseases in children.

The Centre was established in May 1992 primarily to meet the increasing prevalence of respiratory illnesses particularly asthma. Over the last decade the service has had to expand to meet the increasing demands of other atopic conditions such as atopic eczema. The service activity continues to increase. The predominant conditions that are mostly dealt with are atopic eczema, hay fever, food allergies, as well as asthma and severe anaphylactic reactions.

## 2. A MULTI-DISCIPLINARY APPROACH

The Service is truly multi-disciplinary, with the involvement of the following Child Health specialists: Consultants, Medical Trainees, Specialist Nurses in asthma, allergy and eczema, a Dietitian and a Pharmacist. There is also a clinical input from a Consultant Clinical Immunologist.

## 3. SUPPORTIVE CLINICAL AND LABORATORY INVESTIGATIONS

There is provision for skin prick testing, patch testing for food allergies and specialist allergy blood testing through the Immunology laboratory within the same Trust. Supervised, standardized, food challenges against probable food allergens are regularly undertaken. Lung function testing is undertaken as necessary.

## 4. COMMUNITY/SCHOOL LINKS

Strong links have been established with our Local Education Authority, School Nursing Service and Community Medical team. This is an essential component of the Service in order to meet the growing number of children/adolescents accommodated on school premises with multiple allergies, especially food allergies.

## 5. EDUCATION AND TRAINING

The demands placed upon the Service for education and training from various professions (Health Visitor, General Practitioner, School staff, Nursery school staff) is extremely challenging.

## 6. GEOGRAPHICAL DISTRIBUTION

The Service is available to all patients in South and West Wales. Primarily it was set up to serve the catchment area of the Cardiff & Vale NHS Trust. However, we receive unfunded referrals from Primary and Secondary care from all over South Wales and West Wales. We endeavour to see these children within the constraints of our current Service.

## 7. ACCESS TIMES

The Allergy Service is quite time consuming. Currently it is being run alongside a busy General and Neonatal Paediatric Service, hence the access times would be influenced by a capability to provide all such services by a limited number of people. The waiting time to access the clinic is up to six months. Shorter clinic access times are achieved through extra work cutting into break times and quite often running overtime.

The increase in the number of referrals to our Allergy Services is exemplified by the following:

The number of Allergy Skin Prick Testing procedures completed in:

1998 was	79
2001 was	188
2002 was	253
2004 was	330

## 8. PRIORITIES FOR IMPROVING PAEDIATRIC ALLERGY SERVICES

1. Improving the Children's Allergy Service would require more Personnel, including Paediatric doctors and Paediatric nurses, as well as dieticians. The establishment of Allergy Clinics within Primary Care should be the long-term aim, so that Specialist care would be targeted for the most complex cases. There are many similar clinical examples currently such as asthma, chronic obstructive airway disease and diabetes, where the majority of patients are managed in Primary Care and others would attend hospital if they require more specialist care.

### 2. *Independent Sector Providers:*

There are no links between the NHS and the independent sector. There is very little activity of Allergy Services within the Independent Medical Sector. There are Alternative Medicine and Complimentary Health Clinics available. The appropriateness of their approach is not proven or controlled via mechanisms such as the process of clinical governance that takes place within the NHS.

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9. SPECIFIC RECOMMENDATIONS FOR IMPROVING PAEDIATRIC ALLERGY SERVICES

1. To enhance the number of trainees in Paediatric allergy and the establishment of full-time posts in Paediatric Allergy.
2. To improve the training for Primary Care Physicians and Nurses in order for them to undertake allergy testing as well as allergy diagnosis and management.
3. Funding and maintenance of managed clinical networks.
4. Appointment of Paediatric Allergy Nurse Specialists and Dieticians as an immediate short-term necessity.

May I please refer you to the Publication from the Royal College of Physicians entitled *Containing the Allergy Epidemic/Summary and Recommendations/Allergy—The Unmet Need: A Blue print for Better Patient Care* published in June 2003, [www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)

Other professionals who contributed to the above report:

Dr D Tuthill Consultant Paediatrician Llandough Hospital

Mrs E Spear Respiratory/Allergy Clinical Nurse Specialist Llandough Hospital

June 2004

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**Memorandum by Dr Rita Brown FRCP (AL 48)**

With reference to the enquiry I would like to bring to your notice the following relevant information.

1. NEED FOR ALLERGY SERVICES

It would be difficult to add to the reported facts so clearly laid out in the booklet “Allergy—the unmet need”, published in June 2003 by the Royal College of Physicians. This publication expounds an impressive array of evidence detailing the pressing need for major expansion in the allergy services in the UK.

2. AVAILABILITY OF ALLERGY SERVICES

An allergy service was provided at the Royal Berkshire Hospital, Reading for many years before the formation of the Royal Berkshire & Battle Hospital NHS Trust. The medical input was provided by myself alone, in a team with one, occasionally two nurses.

The clinic provided state-of-the-art expertise in Allergic and Irritant Contact Dermatitis, urticaria and across-the-board investigation and management of all types of allergic disease. Though solely an outpatient service, there was cooperative, mutually beneficial interaction with all relevant departments in the hospital for treatment of patients severely affected.

This thriving clinic was closed down in year 2000 when the incumbent full-time consultant allergist (myself) retired, after providing the sole medical input for 25 years. At that time more than 1,000 new patients were seen each year. The waiting list was in excess of 12 months for initial consultations and patient referrals originated from a wide area of Southern England and the Midlands as well as further afield, emphasising the need for allergy services at that time as well as total lack of provision in many areas. This resulted not only in absence of patient choice but also in unacceptable distances and inconvenient, or absent means of travel often denying treatment for all but the most robust.

The need for allergy services, clearly seen and widely discussed by those of us then working in the field has been resoundingly demonstrated to continue to escalate.

The clinic was closed as a result of lack of acceptance by managers of information provided by myself, referring consultants and general practitioners, concerning the needs of patients suffering from allergic disease, the emergence of new allergens including latex rubber and the increasing number of cases of multisystem disease. Many patients suffered severe, sometimes life-threatening illness. The jostling for allocation of available finance by other needy specialties was an added incitement for closure.

The extinction of this efficient, well-established and integrated, wide-ranging NHS allergy service will be costly to reinstate. It has meant that there is no longer informed and organised local pressure for services for allergy patients which are without doubt sorely needed as the detail above demonstrates.

I trust that the information will be useful to your enquiry.

June 2004

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**Memorandum by Dr Andrew Clark (AL 49)**

I am a consultant paediatric allergist in Addenbrookes NHS Trust, Cambridge, a tertiary centre. I work with two colleagues who specialise in allergic diseases of adults.

1. The prevalence of allergy is rising and demand greatly exceeds the supply of specialised care to children with severe and complex allergy (asthma, food allergy, anaphylaxis, hay fever and eczema). Only six paediatric allergy consultants serve the childhood population of the UK (11.6 million in 2002). My post is the only one north of London, yet I receive no NHS funding and my position is supported by a limited tenure academic grant (to expire in 2007). Currently, many children with severe and complex allergy are cared for by general practitioners or general paediatricians whose training and expertise are variable and therefore quality of care for these children depends on where they live, with children in the north and West of the country being at a significant disadvantage. To illustrate the demand for specialised paediatric allergy services a recent survey showed that between February and May 2004, there were approximately 1,000 allergy consultations in our clinic. Nearly 360 consultations (36%) were for children, and two thirds of these were for peanut or nut allergy—a severe and complex allergy, requiring regular (usually annual) reappraisal. Resolution of nut allergy is unusual and this large group of children require annual review appointments for many years.

2. A core principal of The National Service Framework for Children is that professionals who care for children in hospital should be appropriately trained and experienced. Interpreted in the context of allergy this implies that children with complex and severe allergy referred to tertiary level clinics should be cared for by paediatric allergists. Currently this is not the case. Overall, we are referred over 500 new paediatric allergy patients per annum, of whom at least 300 will require annual follow up appointments and year-on-year; this adds a significant extra workload. As a consequence, even in our specialist centre, not every child can be reviewed by a paediatric allergist.

3. There is a need for improved under-and post-graduate training in allergy. The creation of more consultant posts in paediatric allergy together with recognition of specialist training will improve the care of children with severe allergy and facilitate the spread of expertise and knowledge from tertiary to primary care, improving provision of allergy services for all children.

May 2004

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**Memorandum by Dr Adrian Morris (AL 50)**

**1. AVAILABILITY OF ALLERGY SERVICES (INCLUDING ISSUES SUCH AS GEOGRAPHICAL DISTRIBUTION, ACCESS TIMES AND PATIENT CHOICE) AND SPECIALIST SERVICES FOR PATIENTS WITH SEVERE ALLERGIES**

With increasing public awareness of allergy related diseases, the inadequate provision of National Health Service (NHS) allergy diagnostic and treatment clinics has become apparent. Even the few available NHS allergy clinics found mainly in and around London have waiting lists in excess of 12 months. In their desperation to seek alternate allergy services (after failing to get General Practitioner (GP) referral to NHS allergy services) many genuinely allergic people will end up in the hands of fringe allergy practitioners, where they receive poor advice regarding their allergies. They then endure years of unnecessary dietary restriction, inappropriate treatments and wasting income on costly and unnecessary food supplements.

This obvious under provision of specialist allergy services in the NHS is highlighted in the Royal College of Physicians (RCP) Report and leaves no doubt that allergy specialist services in England are grossly inadequate.

1. *Royal College of Physicians, Allergy-the unmet need: a blueprint for better patient care: London RCP 2003*

**2. PRIORITIES FOR IMPROVING SERVICES**

Long-term solutions for improved services include: Better undergraduate allergy education as part of basic medical training, increasing General Practitioner allergy awareness during Registrar training and encouraging GPs to acquire better allergy diagnostic skills as part of ongoing Professional Development Plans (PDP). Central funding for more NHS specialist and nurse driven allergy clinics in community hospitals and regional hospitals is necessary. Creation of more Senior Registrar and Consultant posts for Clinical Immunologists and Allergists over the next few years will only have a positive clinical impact in five or more years' time.<sup>2</sup>

Certain short-term strategies can implement immediate improvement in services. Many NHS allergy diagnostic services and allergy courses are available but this is not common knowledge.

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<sup>2</sup> Levy ML *et al*: Inadequacies in UK primary care allergy services: national survey of current provisions and perceptions of need. *Clinical and Experimental Allergy*; 2004; 34; 518–519.

A number of organizations already offer accredited allergy training courses for GPs and Practice Nurses including National Respiratory Training Centre in Warwick, Allergy UK Allergy Days, Southampton Hospital MSc Course and the British Society for Allergy and Clinical Immunology (BSACI) Basic Allergy courses.

Allergy testing is readily accessible at NHS pathology laboratories in the form of improved versions of the RAST (Radio-Allergo-Sorbant-Test) known as a CapRAST or UniCAP test—this blood testing facility is currently available to most private and NHS Specialists and General Practices in England.

The GP simply has to complete a standard request form for the specific RAST test and send a clotted blood specimen in the usual way (as simple as requesting a cholesterol check). Utilising this facility, a GP would immediately be able to confirm the cause of suspected life-threatening food anaphylaxis and not have to wait one year for a specialist consultation in London or perhaps never be able to confirm the diagnosis if in North England (where no referral allergy clinics exist). Allergy self-test kits marketed by certain supermarket and pharmacy chains for home testing provide rather “hit and miss” results and are of debatable value.

There are over 450 individual UniCAP RAST tests available for anything from Almond to Yeast. There are about 90 NHS pathology laboratories in the UK that offer these UniCAP RAST tests and those that don’t can refer the tests to reference laboratories. This has been confirmed by personal communication with the UK suppliers of UniCAP RAST to these 90 NHS Hospitals (Sweden Diagnostics (UK)).<sup>3</sup> RAST tests are relatively expensive at approximately £8 per allergen, but essential for allergy confirmation prior to a life-time of specific allergen avoidance and prescribing of expensive Epipen (or Anapen) adrenaline auto injectors (£72 as two are issued annually) for suspected anaphylaxis.

As most NHS pathology departments provide fixed rate services to Primary Care Trusts (PCTs), it is currently not in their budgetary interest to encourage the use of these little known tests. Most GPs are not aware that these tests are indeed widely available. The short-term solution to inadequate allergy clinic provision is to encourage use of existing test facilities in a controlled and responsible manner. To achieve this, GPs would need “information algorithms” on how to request the most appropriate RAST tests for each specific allergic condition.

Recent reports indicate that many GPs are of the view that allergy testing is a futile and unreliable exercise, and are uncomfortable interpreting test results. Many feel ambivalent and lack confidence in (or have any interest in) Allergology. But simple management protocols and algorithms can be designed by organisations such as the National Institute for Clinical Excellence (NICE), BSACI and RCP. This simple strategy could facilitate large numbers of allergic conditions being adequately treated in the primary care General Practice setting. In this way existing allergy diagnostic services would be better utilised and the burden on specialist allergy clinics reduced.

### 3. GOVERNANCE AND REGULATION OF INDEPENDENT SECTOR PROVIDERS, AND LINKS BETWEEN THE NHS AND THE INDEPENDENT SECTOR

The unregulated private allergy sector is a source of great concern. Allergy sufferers despondent that they cannot get access to an NHS allergy diagnostic service then approach the unregulated private sector. Often practitioners are not even medically qualified and the testing methods usually have no scientific basis nor have been validated. These pseudo-diagnostic tests usually designed to identify multiple “sensitivities” include VEGA testing (black box), Applied Kinesiology (muscle test), Hair Analysis and the leucocytotoxic tests (marketed as Nutron or ALCAT tests), all of which have been discredited over the years. Unfortunately the plethora of these tests and pseudo-diagnoses are growing at an alarming rate. These practises provide no useful role in allergy diagnosis as they confuse the public about their allergies and put individuals onto unnecessary and sometimes dangerous diets. This leads to social deprivation, unnecessary anxiety and occasionally death from misdiagnosis of a severe underlying allergy.

There is an urgent need to introduce regulatory bodies to act as gatekeepers to and check on unconventional practices. This should involve utilising reputable complementary health practitioners in a regulation process to ensure registration of all complementary practitioners purporting to diagnose and treat allergies. In this way only trained ethical practitioners would be allowed to practice independently and standards of service would improve. The public would then be protected in a similar way to which the General Medical Council operates in protecting the public from unscrupulous practitioners masquerading as allergy experts.

1. “Which” Report: *Allergy Testing* 1998.

2. *Allergy: Conventional and Alternative concepts*. A Report of the Royal College of Physicians Committee on Clinical Immunology and Allergy 1992.

<sup>3</sup> MacLachlan K, Manager. **Sweden Diagnostics (UK)Ltd**, CBX2 West Wing, 382–390 Midsummer Boulevard, Central Milton Keynes MK 9 2RG.



3. *Health shops stoke up fake allergy fears* (page 8) *Sunday Times* Newspaper 29 December 2002.
4. Morris AJ *Complementary medicine and allergy—a review of the facts* *Current Allergy and Clinical Immunology* 1996: Vol 9 No 3.  
May 2004

### Memorandum by Dr Katherine Sloper (AL 51)

#### 1. INTRODUCTION

I am Dr Katherine S Sloper and I work as a Consultant Paediatrician at Ealing Hospital NHS Trust, Uxbridge Road, Southall, in a busy district general hospital in North West London. I am also Honorary Clinical Senior Lecturer in the Imperial College School of Medicine, and I am involved in teaching undergraduate medical students, doctors in training and postgraduate doctors, and I also take part in research activities. I am a General Paediatrician with special interests and training in allergies, in addition to respiratory medicine and immunology. I trained in the allergy clinic at Middlesex Hospital (Professor Jonathan Brostoff) in London as part of my Paediatric training. While in receipt of a research training fellowship in the immunology department at Middlesex Hospital, I studied clinical and immunological changes in allergic children with atopic dermatitis (eczema), and was awarded a Doctorate of Medicine (DM) from Oxford University for my thesis on this work. After further training in General Paediatrics and Respiratory Paediatrics (at The Royal Brompton) I was appointed as Consultant Paediatrician at Ealing Hospital in 1988. I have developed a Paediatric Allergy and Asthma service within Ealing Hospital, as well as working in an honorary basis in the Paediatric Department at the Royal Brompton Hospital.

#### 2. PROVISION OF LOCAL ALLERGY SERVICES

- (a) Adult services: there is none in the local hospital and patients have to travel to a tertiary centre.
- (b) Paediatric allergy services based on Ealing Hospital: serves the local community (seeing patients mainly from the Boroughs of Ealing, Hounslow and Hillingdon) and a few from Harrow. This service provides a secondary level specialist service for patients with moderate to severe allergies. The service offered by our Specialist Paediatric Allergy Centre includes management of a full range of allergic disease, diagnostic testing, day case challenge testing, advisory service including allergen avoidance, primary and secondary allergen prevention, coordination with the community school nursing service for management of children at risk of anaphylaxis in nursery's and school's, specialist dietetic service, education and local source of advice for General Practitioners. We do not have facilities for immunotherapy. We cover the wide range of atopic dermatitis, asthma and wheezing, allergic rhino- conjunctivitis, food allergies, multiple food allergies and children at risk of anaphylaxis. Allergic conditions are present in up to a fifth of all children, with about 5% of children needing advice from these specialist services.

The out patient allergy service at Ealing Hospital is run by myself with a Specialist Community Paediatric Sister (based in the Hospital team) backed up by a colleague, and she also acts as the Specialist Asthma Sister for the children in the hospital and surrounding area. We have the support of a paediatric dietician who attends all the clinics, and our day case ward are experienced in assisting with allergy testing and day case challenges with allergens. Training support for the community school nurses and general primary support is organised through myself and the specialist community sister.

The paediatric allergy clinic runs weekly in conjunction with the paediatric asthma clinic, and we have an additional monthly clinic for new referrals. The clinic is held in Ealing Hospital, but some of the support to families by the Specialist Community is carried in homes and schools. We receive referrals from local General Practitioners and practice nurses, school nurses. At present there is no identified separate funding for this service, and the waiting list is between 13 and 15 weeks for new patients.

- (c) I have discussed the availability of allergy services for adults with Dr William Lynn, Medical Director, Ealing Hospital NHS Trust. He asked me to report to you that in his opinion and experience the services available for adults are grossly inadequate in this part of London. He knows of instances where patients requiring investigation for life threatening allergies could not have an appointment in the nearest specialist allergy clinic for adults (St Mary's) for many months.

#### *Priorities for Improving Services*

The incidence of allergies and in particular potentially fatal allergies such as that to peanut, has been increasing rapidly in this country and worldwide over the past 20 years. Research has shown that patients with such serious allergies need to be followed up from time to time in specialist clinics to support the initial management plans and follow the progress of their allergies. Allergic patients tend to have illnesses affecting

a number of systems, often more than one at the same time (such as skin, chest and gastrointestinal disease), and the allergy clinics need to have adequate funding to provide this support role for these patients, and to give advice to their primary carers such as General Practitioners. Our local PCT has not recognised allergy services as a separate entity with defined funding provision, although there is an ever increasing demand for us to give advice and treat such local patients and their families for this illness which is not well understood by the general population and where there is much misleading advice available. We regularly train nurses and other support staff from the community both locally and nurses training from other centres. However, there are no Specialised Paediatric Specialist Registrar posts in allergy to help develop the services which will be needed in the future, and our clinic could be part of a specialised training programme if paediatric allergy were recognised as an important individual specialty (rather than one treated in different ways by different specialists). I recognise that central resources to go into new SpR training posts in allergy and central support for new Consultant allergy posts.

Our specialist allergy clinic links into the London Paediatric Allergy Group which has been set up recently, and I am and the other staff in the department are closely involved with liaison with other specialist allergy services in London including those in tertiary units. The need for regular liaison and training meetings needs to be recognised within job plans for Consultants and associated staff, but is not adequately recognised at present.

The Ealing PCT Commissioning Department was not aware of the unmet or increasing needs for patients locally who have serious allergies. They are now interested in exploring with me how the community and hospital can support each other in developing allergy services, and we will be meeting together to look at these services. The Ealing PCT Commissioning Department has not identified the need for allergy services apart from recognising that some patients were seen in the allergy clinic at St Mary's Hospital. They did not know that there was a local Paediatric Allergy Department. They do not fund any local adult service, and I know from the experience of patients who have asked me about it, that adults have not been able to have any specialist local advice.

PCT is involved with planning with the hospital (Acute Sector) for local paediatric needs. The Paediatric Consultants in Ealing Hospital are finding it very difficult to cover the many increasing roles that they have with the clinical load (acute and chronic disease), staff training and community support as well as liaison work as part of clinical networks with tertiary centres. As the new Paediatric Clinical Director at Ealing I will be including the need for the work we cover in the department in providing a specialist allergy service to be recognised when the overall Consultant Paediatric service development is being reviewed.

I would be willing to give oral evidence to the Committee.

### 3. INDEPENDENT SECTOR

I have some experience in treating patients with allergic diseases in the private sector. My approach to patients in both sectors is the same in terms of investigation and treatment. However, I recognise that there is a need for clinical governance and auditing of work to be developed in the same way that it has been developed over the last few years in the National Health Service. The long waiting list for the local allergy services means that many children are seen by a number of therapists in the independent sector. Some of these services offer treatment which are not evidence based, and on occasions dangerous to patients (for instance research has shown that a significant proportion of creams prescribed for eczema from some alternative health workers in London have contained a high level of cortical steroids unknown to the patients, given the potential of severe long term side effects. Mechanisms need to be developed to make sure that there is a consistency of reproach in the NHS and independent sector, that we can each learn from the other in our approach.

With facility to increase local services here we would be able to give better support to our local patients and practitioners in management of allergic diseases, using treatments within the framework of clinical guidelines (which is how we work from our clinic) and with known doses of properly researched drugs.

Both and severe allergies carry a mortality in both childhood and adult life and there, and therefore it is vital that patients should have access within a reasonable length of time to knowledgeable specialist allergy service.

The evidence above is my personal opinion, but I fully support the views of the British Society of Allergy and Clinical Immunology for which I am a long standing member.

*June 2004*

## Memorandum by Asthma UK (AL 52)

### INTRODUCTION

1. The following submission is produced by Asthma UK, the new name for the National Asthma Campaign. Asthma UK is the charity dedicated to:

- Improving the health and well being of people in the UK with asthma by building and sharing expertise about asthma.
- Asthma is serious. One person dies every seven hours from asthma in the UK, yet 90% of these deaths are preventable.
- Asthma is widespread, 5.1 million people have asthma in the UK—one in five households is affected, and if you don't have asthma yourself, you will know someone who has.
- Asthma is controllable. 74% of people with asthma suffer symptoms needlessly.
- Approximately 12 million people in the UK are seeking treatment for allergy and it is estimated to cost the NHS £900 million a year.

2. Asthma UK works together with people with asthma, health professionals and researchers to develop and share expertise to help people increase their understanding of asthma and reduce the effect of it on their lives. We are working towards our vision of "Control over asthma today, freedom from asthma tomorrow."

3. Asthma UK is part of the Respiratory Alliance, an informal group of medical charities, organisations and professional bodies with an interest in the provision of respiratory healthcare services. In January 2003 the Alliance published a report "Bridging the Gap", part of which covered the provision of services for people with allergies and outlined the levels of service that people with allergies could reasonably expect from the NHS.<sup>4</sup> The full Bridging the Gap report can be found on the British Thoracic Society website ([www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk)). Asthma UK has also endorsed the report of the Royal College of Physicians, "Allergy: the unmet need" published in June 2003 and several of the points noted below are from these two reports.

4. As our submission will show, there is clearly a need for better allergy services for people with asthma but also for people with anaphylaxis, nut and other allergies. The need for allergy services is therefore to provide a lead for research and education and for clinical care of those with difficult allergic problems which are often not organ specific.

### *Availability of Allergy Services (geographical distribution, access times and patient choice) and specialist services for patients with severe allergies*

5. "Bridging the Gap" pointed out that before examining the current provision of allergy services in the UK we must first look at problems that exist in medical training. Currently, allergy is not part of the undergraduate medical curriculum at most medical schools and GPs receive virtually no formal training in allergy with current resources for post-graduate allergy training limited.<sup>43</sup>

There are too few specialist allergy clinics within the UK (defined as consultant NHS allergists offering five allergy clinic sessions per week), with most located in the south east. Out-patient waiting lists for referral to these centres varies from three months to two years. Specialist provision is equivalent to one whole-time allergist per 2.1 million of the UK population, compared with one consultant per 90–100,000 for chest physicians.

The report goes on to recommend that to address the geographical inequality in allergy provision, each of the NHS-regions should have a minimum of one specialist allergy clinic, consisting of at least two full-time allergists (or equivalent), a full-time specialist nurse in allergy, a half-time dietician with an interest in allergy and a minimum of one Calman specialist registrar in allergy (or two specialist registrars seeking dual accreditation in allergy and general medicine)

### PRIORITIES FOR IMPROVING SERVICES

6. Why are allergy services important?

For people with asthma, the latest British Thoracic Society/SIGN guideline (2004) on the management of asthma states that:

- allergy tests may be helpful in seeking causal factors, and in making a general diagnosis of atopy<sup>ii</sup> and that
- allergen avoidance measures may be helpful in reducing the severity of existing disease<sup>iii</sup>

<sup>4</sup> Bridging the Gap 2003.

From the work we have done with the National Asthma Panel, we know that allergic triggers are common for people with asthma <sup>iv</sup>:

- 45% identified dust
- 35% said pollen
- 32% said pets

According to our research, 37% of people with asthma surveyed in the National Asthma Panel think that the NHS provides allergy testing to help identify triggers <sup>v</sup>, only 26% have been offered any allergy testing <sup>vi</sup>

7. Asthma UK believe people with asthma should have the full support of the NHS in managing their condition. This includes providing allergy services where needed to help avoid known triggers. In primary care, patients should be diagnosed and their triggers identified and managed. These services need to be organised to provide maximum benefit to people with asthma. This would involve convenient access to a service appropriate to needs (ie through a pharmacy or primary care team) with adequate staffing and resource to meet the need. The developments within the NHS offer the opportunity for allergy services in a community setting—nGMS and pharmacy contracts, GpWSIs and practice based commissioning.

But this all needs to be backed by appropriate training and support of health care professionals to ensure the safety of people with asthma (resuscitation facilities etc). In addition, it is important that GPs are able to interpret results and begin appropriate care and treatment with on-going support and advice for patients with potentially fatal allergies.

#### 8. The role of allergy testing in asthma

Allergy tests such as skin prick testing can help to identify specific triggers and allergen avoidance measures can help in the management of asthma symptoms. There are several things that healthcare professionals can do to improve services specifically related to asthma. Asking about triggers, which the person with asthma has noticed worsen their condition is an essential part of management. This might include prompting questions regarding exacerbations after viral infections, occupational exposure, premenstrual worsening or worsening after use of aspirin, or deterioration in certain seasons or after exposure to certain animals. As a rule, allergy testing is by no means essential for most people with asthma and allergy testing can only play a positive role when it is:

- conducted in the appropriate clinical setting, by a trained professional and; and
- the results will influence choice of treatment or management by the health professional, or if the outcome is likely to change the behaviour of the person with asthma.

Not all people with asthma have allergies as a trigger and this is reflected in the current SIGN/BTS Guidelines that don't suggest as forming part of general diagnosis. Allergy testing is something that people with asthma are asking for, but the evidence we have from the Asthma UK Adviceline is often to determine whether or not they are positive to dogs or cats so that if they are negative to these they can go out and buy a dog or cat. However this could be dangerous as allergies often develop according to how often a person is exposed to a particular allergen and they could develop an allergy to cats and dogs even though they were originally negative on skin prick testing. Allergy testing does not aid diagnosis of asthma but may help to identify a person's asthma triggers. Therefore it may not be appropriate for all people with asthma to be tested but may be useful for some people with asthma.

### GOVERNANCE AND REGULATION OF INDEPENDENT SECTOR PROVIDERS, AND LINKS BETWEEN THE NHS AND THE INDEPENDENT SECTOR

9. Asthma UK is concerned that the number of independent clinics that offer services without proper regulation. Claims of benefit from non-standard approaches to allergic disease are often made by independent clinics and commercial organisations. This can lead to those with allergies spending money unnecessarily. Added to this, some alternative therapies can be harmful and few have been subjected to satisfactorily rigorous evaluation. This subject is extensively reviewed with regards to allergic asthma in the British Asthma Guideline.

### CONCLUSION

10. Allergy testing can be of use in helping people with asthma manage their asthma. However, lack of capacity and availability of allergy testing in the NHS leads many people with asthma to seek services in the poorly regulated independent sector. People with asthma should therefore be offered the option of allergy testing within the NHS, which would help them to properly manage their asthma. This means increasing the availability of these services by the NHS but also ensuring that GPs and practice nurses are aware of the role that allergy testing plays in managing asthma. Ultimately this will enable these and other healthcare professionals to understand more about asthma and help them to make informed decisions about when a referral to a specialist would be appropriate.

## NOTES AND REFERENCES:

<sup>i</sup> Bridging the Gap 2003i Reasonable expectations for patients with rhinitis and other allergies (Respiratory Alliance. Bridging the gap. 2002)

Patients with symptoms consistent with an allergic condition have a right to be taken seriously by primary healthcare professionals

Education of primary healthcare professionals on allergic conditions

Collection of a careful history encompassing all potential manifestations of allergic conditions and evidence of atopy in other family members

Consideration of the impact of symptoms on patient quality of life

Patient with a potential allergic condition have a right to investigation of potential triggers and education on allergen avoidance

Allergen testing by appropriately trained healthcare professionals in primary or secondary care (as appropriate and according to local service configuration)

Education of patients about avoidance of allergens as a way to control symptoms

Patients with allergic conditions have a right to appropriate management

Awareness of possible manifestations of allergic disease, with appropriate treatment in line with management guidelines

Specifically asking all patients with rhinitis about asthma symptoms, and all patients with asthma about rhinitis symptoms, and ensuring that management of each manifestation takes the other into account

Education of patients about warning signs for severe allergic reactions, with appropriate actions to take

Patients with allergic conditions have a right to integrated healthcare services

Care in the primary sector for the majority of patients (ie diagnosis, identification of triggers and management)

Referral to specialist allergy services when appropriate (eg for allergen testing where this cannot be carried out in primary care, or for suspected occupational asthma)

Multidisciplinary care (eg dietetic advice, respiratory specialists, specialist nurse support) On-going support and advice for patients with potential fatal allergies

<sup>ii</sup> 2.2 Feb 2003 version

<sup>iii</sup> 3.2.1 Feb 2003 version

<sup>iv</sup> NOPWA

<sup>v</sup> Asthma Panel 2003

<sup>vi</sup> Asthma Panel 2003

June 2004

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**Memorandum by Dr Penny Fitzharris (AL 53)**

This personal submission is by Dr Penny Fitzharris, MBChB, MD, FRACP, FRCP; Full-time NHS Consultant in Allergy at Guy's and St Thomas' NHS Trust.

**PERSONAL BACKGROUND TO MY SUBMISSION**

I am a New Zealand graduate, trained in the specialty of Allergy and Clinical Immunology in the Royal Australasian College of Physicians. The great majority of my clinical work has been in allergy.

I was a Consultant in Allergy at St Mary's Hospital, Paddington from 1988 to 1993, and Director of the Frankland Allergy Clinic. This five year post was funded by the University of London (50%) and the National Asthma Campaign (50%). Unfortunately, at the end of the five year post, no NHS funding was made available to continue the consultant post. The clinical work was continued by part-time consultants, largely funded by the university.

Despite large demand from the public for allergy services, no other NHS consultant level post was available in the UK at the time and I therefore returned to New Zealand, working as a specialist in Allergy, with teaching and research activities in an academic role.

In early 2002 I was recruited to return to the NHS, to a newly created full time NHS consultant post at GSTT, established after many years of development by, amongst others, Professor Lee, Head of Service here. Unfortunately, family pressures have led to my taking the decision to return to New Zealand next year (2005). (My children, though born in the UK, have developed a strong preference to live in NZ!).

This, however, gives me a dispassionate viewpoint to look at the Allergy Services in the UK.

1. One important concern is that there are few, if any, obvious UK-trained candidates to take over my post. This situation arises largely because of a lack of trainee numbers. It is quite possible that, once again, Professor Lee may have to recruit from overseas. This may not be easy.

Recommendation: A substantial increase in funded trainee posts is essential to allow both for expansion of consultant numbers, and replacement of consultants approaching retirement age, or leaving the UK.

2. I am involved in providing specialist services within allergy, particularly desensitisation for patients with severe allergy to bee and wasp stings, and the investigation of severe drug allergy, including anaphylaxis to anaesthetic agents. These patients travel large distances for their care, as there are so few services available. Yet the South-East is better served than many other areas, so the situation outside the South-East is worse. Desensitisation requires multiple attendances, so patient inconvenience and costs are high.

Recommendation: Expansion of consultant numbers both at regional centres (for complex disease) and at smaller hospitals.

3. Much allergic disease arises in childhood, yet there are very few centres for paediatric allergy. There is increasing evidence that early life intervention may reduce the development of new allergic sensitivities in children.

Recommendation: To encourage establishment of new services for paediatric allergists, with appropriate trainees.

4. The level of knowledge of management of even very common allergic disease in primary care is very patchy and often poor.

Recommendation: Expansion of hospital consultant numbers should allow these specialists more time for training of GPs and Practice Nurses. (For example at present we are usually able to run only one Allergy Training Day for GPs and practice nurses each year here at GSTT. Additional sessions would undoubtedly be useful). Training of other specialty SpRs, and medical students could also be increased.

5. There are some excellent, experienced practitioners who work in the private medical sector. Others, like myself, do not have time to do so, thus those patients who could be seen in the private sector sometimes do use the NHS, because private expertise is so limited. Because of lack of services many patients seek help from practitioners of a range of alternative methods. Unfortunately these methods have rarely been assessed with sufficient rigour, to be able to make a scientific assessment of their likely value to a patient.

6. Allergy is a mainly outpatient based specialty and perceived as rather “low tech”. There are few procedures and much of the interaction with the patient is based on detailed history taking. The specialty is rarely perceived as essential in the way that, for example, interventional cardiology is perceived, although quality of life for patients is often severely affected, and there is a risk of fatality in severe allergy. I suspect this may have contributed to the rather slow development of allergy within the UK. It is much better developed in Continental Europe, North America and Australasia. In the past, although less in recent years, there has also been a perception amongst poorly informed medical practitioners that much allergy is “in the mind”, and without clearly defined causes and thus services are unnecessary. Anyone who has a child with or who themselves has food allergy, eczema, allergic asthma, severe hayfever, drug allergy, urticaria, angioedema, latex allergy or anaphylaxis of whatever cause will know that this is not so.

May 2004

#### Memorandum by Anaphylaxis Campaign and Allergy UK (AL 54)

1. The Anaphylaxis Campaign and Allergy UK are the leading patient charities supporting those living with allergy in the UK.

2. The Anaphylaxis Campaign and Allergy UK have monitored attempts being made by Members of Parliament to establish the priority being attached by Primary Care Trusts to commissioning allergy services. This follows individual patient approaches to Members of Parliament to ask for their help.

3. We have recorded the replies below making no attempts at this stage to validate the statements being made about service coverage and adequacy, or to check the nature of the evidence being used to underpin the replies given.

The following 13 MPs wrote to their local PCT in February and March and obtained a reply:

- Sir Sidney Chapman—Barnet PCT.  
Barnet PCT confirms severe allergy is dangerous but says it is rare and that the Trust copes well with the local needs. No shortfall in services.
- Mark Todd—Derbyshire Dales and South Derbyshire PCT.  
Derbyshire Dales and South Derbyshire PCT quotes the Royal College of Physicians’ report, “Allergy, the Unmet Need”, and says that the PCT acts the same as many other centres in that it offers allergy services as part of its clinical practice. These specialists cover dermatology, ENT and general practice.

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- Jim Cousins—Newcastle PCT.  
Newcastle PCT says it operates an effective allergy service in Newcastle.
  - John Taylor—Solihull PCT.  
Solihull PCT says that it does not commission specialist allergy services but that if and when the service is required it would make a judgment on a case-by-case basis. The PCT says it has asthma and dermatology covered.
  - Dr Liam Fox—North Somerset PCT.  
North Somerset PCT says it has no specialist service but the population are able to access through GPs and other local contracts.
  - Nick Hawkins—Surrey Heath and Woking PCT.  
Surrey Heath and Woking PCT says it is within government waiting times. No problems reported.
  - Andrew Hunter—North Hampshire PCT.  
North Hampshire PCT commissions allergy services for both adults and children. Service offered by a GP with special interest along side consultant paediatricians. Waiting time routinely 11 weeks.
  - John Cryer—Havering PCT.  
Havering PCT outlined services available. Mr Cryer has also contacted Harold Wood Hospital in Havering concerning the availability of patch skin tests but has not yet had a response.
  - Geoff Hoon—Ashfield PCT.  
Ashfield PCT says three specialists serve the needs of the Ashfield constituency.
  - Jim Dobbin—Heywood and Middleton PCT.  
Heywood and Middleton PCT says that allergy patients are passed to dermatology.
  - Stephen Twigg—Enfield PCT.  
Enfield PCT says that GPs are responsible.
  - David Amess—Southend-on-Sea PCT.  
Southend-on-Sea PCT admits it offers no specialist allergy service but says that the local GPs are able to refer in a number of ways, namely to Southend General Hospital. The PCT also lists two specialists in the region, General Paediatrics at Princess Alexandra and Respiratory Allergy at Broomfield Hospital.
  - Jonathon Shaw—Medway Teaching PCT.  
Medway PCT says that it provides an outpatient service for those living with allergy across Kent and Medway, using a range of nurses and consultant led clinics. Desensitisation is offered where appropriate. The PCT recognises that need is growing and is looking at future development.

#### COMMENT

4. The responses gathered from the various Primary Care Trusts give the impression that all is well with allergy provision in England and Wales. However we are aware that the reality is very different. Importantly, the PCT responses reflect lack of understanding of what is needed to provide an adequate allergy service. Patients struggle to get an adequate referral and sufficient information to cope with their allergies.

5. Allergy clinics specialising in conditions such as dermatology, ENT or asthma are not adequate for those living with many allergies including anaphylaxis, food and drug allergy.

6. Many PCTs claim they are within standard government waiting times; these figures are only relevant if the patients are being referred in the first place and to a doctor with the appropriate expertise.

7. A final comment is that Barnet PCT says that severe allergy, although dangerous, is rare. This is inaccurate as current figures suggest that one million of the population experience severe allergy. One in 70 children lives with a peanut allergy, which is unpredictable and often severe.

8. The following 17 MPs contacted their PCT but had not passed on a reply by 17 May. They were then contacted by email but no reply has been received to date (27 May).

Sir George Young—confirmed he had not received a reply from Mid Hampshire PCT

Michael Fallon, Sevenoaks PCT

Keith Hill, Lambeth PCT

John Whittingdale, Maldon and South Chelmsford PCT

John Redwood, Reading PCT

Tony Coleman, Wandsworth PCT

Geraint Davies, Croydon PCT

Mike Hall, Cheshire West PCT

Sir George Young, Mid Hampshire PCT

James Paice, East Cambridgeshire and Fenland PCT

Peter Pike, Burnley Pendle & Rossendale PCT

Cheryl Gillan, Chiltern & South Bucks PCT  
Virginia Bottomley, South West Surrey (PCT not known)  
Christine Russell, Central Cheshire West PCT  
Gregory Barker, Bexhill & Rother PCT  
Ann Widdecombe, Maidstone & Wield PCT  
Harold Best, Leeds North West PCT

June 2004

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### Memorandum by Royal College of Physicians (AL 55)

Royal College of Physicians is grateful for the opportunity to comment on the terms of reference for the above inquiry and attach our comments. We have already sent you a copy of “Allergy: The Unmet Need—A Blueprint for better patient care” which we produced in June 2003.

The College has at its core aim the promotion of the highest standards of medical practice in order to improve health and healthcare. To this purpose it defines and monitors programmes of education and training for physicians at all stages of their careers as well as providing professional advice and support for career grade physicians and those in training. The College has approximately 11,000 Fellows worldwide—of whom approximately 8,900 are in the United Kingdom—and nearly 7,300 Collegiate Members. The Fellows are senior members of the medical profession, usually hospital consultants or physicians working in university departments of medicine.

In formulating our comments we have received advice from our Joint Specialty Committee for Clinical Immunology and Allergy and we are sure that a representative would be happy to contribute to the hearings later in the year if that would be helpful.

### COMMENTS OF THE ROYAL COLLEGE OF PHYSICIANS

#### 1. AVAILABILITY OF ALLERGY SERVICES

1.1 The College believes that allergy services in the NHS are totally inadequate and cannot cope with the rising amount and increasing severity of allergy in the UK. An acute shortage of allergy consultants and specialist centres has meant patients face major difficulties in obtaining accurate diagnoses, advice and treatment.

1.2 The provision of allergy services has not kept pace with the growth of allergy itself—only six major centres staffed by consultant allergists offer a full-time service with expertise in all types of allergic problems. A further nine centres staffed by allergists offer a part-time service. The remaining 86 allergy clinics in Britain are run part-time by consultants in other medical specialties. However, they do not have the facilities to cope with the sheer number of referrals, nor patients with multi-system disease.

1.3 Due to the shortage of specialists, many patients with allergy are treated by their GP, who in most cases will have no specialist training in allergy. The shortage of specialists means it is also difficult for GPs to access specialist advice.

1.4 The College has published guidance on the conditions necessary for effective practice of internal medicine and its specialties including allergy under the title “Consultant Physicians Working with Patients”. This guidance is currently undergoing revision and we are enclosing a copy of the section on allergy from the third edition of this publication (forthcoming 2004). This document sets out a model allergy service. The summary on page 18 gives workforce calculations which demonstrate a need for 520 allergy consultants for adult and paediatric services. There are currently only 26.5 whole time equivalent consultant allergists in England, and none in Wales, Scotland or Northern Ireland. The geographic spread across the UK is very uneven and allergy provision is an extreme example of postal code medicine.

#### 2. PRIORITIES FOR IMPROVING SERVICES

2.1 Allergy is a problem which the Royal College of Physicians has brought to the attention of the Department of Health and other stakeholders previously with publications on *Allergy—conventional and alternative concepts* (1992); *Good Allergy Practice* (1994) and, most recently, *Allergy: the Unmet Need* (2003).

2.2 As set out in *Allergy: the Unmet Need*, major governance issues are raised by the lack of adequate numbers of specialists that are trained to treat allergy. Consultants in other disciplines already deliver the majority of care to patients with single-organ allergies, for instance respiratory physicians looking after those with asthma. However it is important to recognise that allergic disease appears to be getting more severe with fatal anaphylaxis and multi-system allergic disease increasing in prevalence. It is mandatory for such patients to see a specialist allergist but for much of the country this is impossible.



2.3 Priorities for improving services include investing in an infrastructure of specialist staff both in adult and paediatric allergy to create regional centres in allergy. This would provide expertise and leadership to develop services and improve standards in primary and secondary care.

2.4 Urgent action needs to be taken to set up specialist allergy centres in each NHS region. The centres would provide specialist expertise for allergic diseases throughout the region, act as an educational resource, and enable training at local level for GPs and nurses to manage common allergies. However, these will not be easy to achieve as allergy has no representation in large parts of the country that can influence regional decisions. There are also grave concerns whether the current arrangements for commissioning are sufficiently robust to cope with the financial pressures and service aspirations of specialist allergy centres. There will be an inevitable debate on the funding of specialist services versus the funding of local initiatives. It is important for the commissioning process to understand the need to provide care for larger populations by specialist teams. This is essential not only to guarantee the quality of patient care but also allow time and space for the training of specialists, promoting innovation and research.

2.5 More consultant allergists must be appointed—an extra 32 to work in regional centres, and more to cover the workload in teaching hospitals, and district general hospitals.

2.6 It is impossible to dissociate the expansion of an NHS allergy service from the requirement to have more trainees in allergy. More training posts must be created and fully funded to meet the future need for more consultants. The Department of Health has recommended 20 new National Training Numbers between 2005 and 2007. However, there is no certainty that this will become reality as the quota was reduced from seven to zero last year. Allergy eventually received one new NTN after rigorous appeal. Allergy is in predicted negative growth by 2012 by Department of Health's own estimates; it is one of only two such specialties. The specialty cannot grow unless more trainees are provided.

2.7 In the long-term allergy services should be led by GP practices, with expertise available from hospitals for more severe and complex problems. To achieve this, there needs to be an improvement in GP education in allergy, and the development of general practitioners with a special interest (GPSIs) in allergy. Much could also be done by training nurse specialists in this area of health care.

2.8 An increase in consultant allergists would enable consultant physicians in other specialties with an interest in allergy to use the allergists and specialist centres as a resource.

### 3. GOVERNANCE AND REGULATION OF INDEPENDENT SECTOR PROVIDERS, AND LINKS BETWEEN THE NHS AND THE INDEPENDENT SECTOR

3.1 In the independent sector there are some excellent services provided but they are few and far between. This scarcity is compounded by the lack of NHS services and as a result practitioners in alternative medicine are being sought out by patients with allergies. The alternative practitioners often use approaches without any evidence base for diagnosis and/or treatment. For example, advertisements appear in women's magazines offering hair analysis, vega testing, various types of "magnetic and force field" tests, neutralisation therapies and tests for food allergy, and many more. In many cases these fail to make a proper diagnosis and offer rational management and can lead to significant morbidity from, for example, use of inappropriate dietary elimination and other changes in lifestyle. This is not only expensive for patients but costs the country money because of time lost from work due to continuing illness. This eventually returns to burden the NHS because of complications caused by delays in treatment.

## ALLERGY

### 1. *Description of the specialty and clinical needs of patients*

Allergic disorders are wide-ranging and cross organ-based disciplines. Allergists therefore require expertise specific to allergy and knowledge of diseases managed by a number of other specialties, particularly respiratory medicine, dermatology, ENT and paediatrics.

Allergic disease varies from mild to life-threatening. There has been a doubling in prevalence of the commoner allergic disorders, asthma, eczema and rhinitis in the last two to three decades. One-third of the population suffer from allergic disease,<sup>1</sup> resulting in considerable direct cost to the health service and impaired quality of life. Allergy is one of the commonest chronic disorders. It has been suggested that part of the increase in prevalence may be related to a westernised life style and lack of infection in childhood.

Superimposed on this there has been a rapid rise in serious allergic disease and the emergence of new disorders. Severe anaphylaxis, originating outside hospitals, occurred in one in 3,500 of the UK population per annum in 1994,<sup>2</sup> and the incidence is rising.<sup>3</sup> Hospital admissions increased seven-fold over 10 years and doubled over four years<sup>4</sup>. Anaphylaxis occurs in 1.2 to 16.8% of the US population depending on aetiology.<sup>5</sup> The incidence of peanut allergy—the commonest food cause of fatal and near-fatal reactions—has trebled over four years. Peanut allergy now affects 1.6% of children.<sup>6,7,8</sup> Up to 8% of health care workers have latex allergy, yet in 1979 only the second case was described.<sup>9,10</sup> Others are affected by drug allergy/intolerance, which accounts for 5% of hospital admissions, and by other food allergies. Much of this serious disease occurs in patients who also have allergic asthma, rhinitis and eczema.

Traditionally, much of allergy care has been provided by organ-based specialists or more recently immunologists and paediatricians with an interest, providing a part-time service in allergy as an add-on to their main specialty, usually in limited areas, or in general practice. There are a small number of specialist allergy services, run by consultant allergists, mainly in academic centres.

The rise in severe and life-threatening allergic disease and multisystem allergic disease—the allergy epidemic—has created a new and substantial demand for the expertise of a consultant allergist. Further, management of the newly emerged disorders (eg nut allergy, latex allergy and drug allergies) requires knowledge gained from dealing with large numbers of patients. For many patients, this need is unmet. It is not appropriate for these severe or non-organ based disorders to be dealt with by non-specialists. The lack of access to specialist care for many patients or long waiting lists is unacceptable in a modern health service. Further, this system of health care delivery leads to unnecessary cost to the NHS, as disease is not managed optimally.

This is a small specialty with its own training programme and CCST. There was an inadvertent reduction in the number of trainees at the time of the Calman changes in training when the specialty was renamed.

A Royal College of Physicians expert working party made proposals to improve patient care.<sup>11</sup> Key to development of services is the creation or development of at least one major allergy centre in each region (or population of about five million), staffed by sufficient adult and paediatric allergists. This requires an increase in the number of consultants and a substantial expansion in allergy trainees. Such an investment would provide the infrastructure and expertise to begin to develop services throughout the region. The proposed programme for change would provide care in the first instance for the more serious disorders and would act as the focus for education in primary and secondary care. In this way, there can be a rational approach to the construction of a new pattern of allergy services within the NHS in response to the developing epidemic.

## 2. Organisation of the service and patterns of referral

Allergy is a specialty recognised for specialist commissioning and disorders which should be seen in tertiary centres are listed in the Department of Health Definition of Specialist Allergy Services (Definition No 17).<sup>12</sup>

Currently allergy services are extremely poor and fail to meet the clinical need.<sup>13, 14</sup> Services have developed *ad hoc* in academic units, there is no tradition of NHS investment and large parts of England have no consultant allergist. Of 101 allergy services, six are run by consultant allergists providing a full-time service, nine by consultant allergists providing part-time services, and the remaining 86 clinics are part-time and run by consultants in other specialties who offer a limited spectrum of diagnostic and treatment facilities for allergy.<sup>15</sup> There is a shortage of consultant allergists and full-time services led by consultant allergists are mainly in London and the South-East. General practitioners who deal with the brunt of allergic disease have no training and little access to specialist advice. Patients have difficulty accessing allergy services, either because they do not exist or because demand results in waiting lists and some Trusts restrict access. The British Society for Allergy and Clinical Immunology (BSACI) held discussions with the Department of Health (Allergy Task Force) from 1998 to highlight the need and to improve services. This initiative is being taken forward by the National Allergy Strategy Group (NASG) launched at the Royal College of Physicians in May 2001. Current services and proposals for allergy care have been outlined, most recently in the Royal College Report “Allergy the unmet need. A blue print for better patient care”, 2003.<sup>11,14</sup>

In a model of allergy care there would be three tiers, as follows:

- (a) the simpler allergic disease would be dealt with in primary care.
- (b) consultant allergists in smaller centres in teaching hospitals and in DGHs would provide secondary care.
- (c) until the shortage of allergists can be corrected, organ-based and other specialists with an interest (dermatologists, respiratory physicians, ENT specialists, paediatricians, immunologists) would contribute to secondary care.
- (d) regional allergy centres would deal with the more specialised tertiary problems, and also provide secondary care for their locality. Currently, because of the lack of provision described at (b) above they provide secondary care for a larger area.

There is currently a lack of provision described at (b) and (d) above, in relation to clinical need, and the majority of general practitioners have little or no training in allergy. The Royal College has proposed, therefore, that immediate aim should be to develop regional allergy centres to provide expertise, improve geographical equality of care and to act as an educational resource and training centre for each region—to use these specialist centres as drivers for change, while giving access for the most serious allergy cases.

Prevalent severe shortages of allergists at all levels mean that major specialist centres must receive both secondary and tertiary referrals from within and outside their area. The Royal College proposals are designed to move the service towards a clinically rational and patient sensitive pattern of provision.

### *Special patterns of referral*

Because of the lack of allergists, major centres not only receive tertiary referrals but secondary referrals from outwith their area. There need to be systems to ensure that urgent referrals (anaphylaxis, life-threatening angioedema) are seen quickly. Anaesthetists need rapid access to their regional centre for diagnosis of anaphylaxis during anaesthesia and should establish referral systems.

#### *3. Working with patients: patient centred care*

- Opportunity for education and promoting self care.

Good allergy care requires accurate diagnosis; this means identifying triggers which may then be avoided.

Avoiding allergic triggers eg foods or drugs completely ameliorates symptoms. This means reduced acute attacks eg anaphylaxis, urticaria or angioedema, or reduced chronic illness eg asthma, rhinitis or eczema. In addition early whole system effective intervention prevents chronic illness developing (*Ref ETAC study JOW*).

- Access to information and patient support groups.

Patients can then contribute to self-care. Drugs are provided in management plans for self-treatment of acute attacks to contain symptoms in case of mistaken exposure to the allergic trigger eg food induced reactions, anaphylaxis to insect stings, glottal oedema. There is evidence that this reduces the burden of disease (see section 7). Where avoidance is not possible, symptom relief can be obtained by the use of medicines. Informing and involving the patient is an important aspect of effective allergy care and nurse specialists contribute to this.

The patient support groups, Allergy UK and the Anaphylaxis Campaign, are members of the NASG and support the RCP proposals. The commonest reason for calls to their help lines, is difficulty in being referred to an allergy clinic, or to one able to deal with their problem.

#### *4. Interspecialty and interdisciplinary liaison*

- Working with other specialists.

Allergists should work as part of a team, including specialist allergy nurses. Regional centres should have a minimum of two consultants and ideally in addition two paediatric allergists; and they need a larger clinical team, including allergy SpRs and specialist nurses, to provide an efficient service and because of the clinical risks involved in certain procedures (challenge testing) and treatments (immunotherapy). Links with adult and paediatric dieticians are important eg to ensure those avoiding foods long term have nutritionally adequate diets.

Allergists liaise with other specialists including respiratory physicians, dermatologists, immunologists, ENT consultants, and paediatricians. These consultants may refer patients or be involved in care of allergy patients. A clinical immunology laboratory service must be available (run by a consultant immunologist).

There need to be close links with community paediatric teams to provide care for children at risk of anaphylaxis in schools.<sup>16</sup>

- Community paediatrician: provision for children at risk of anaphylaxis in his/her area and liaison with colleagues in other health authorities. Close liaison and agreed protocols for school visits must be in place. It is essential there is regular liaison between the allergy team and the community paediatric team.
- Community paediatric nurses carry out school and nursery visits to train staff in avoidance of allergen (eg nuts), recognition and management of reactions. They should have access to the allergy consultant for queries.

Occupational health physicians refer staff with latex or other occupational allergies; and Adverse reactions to vaccination. The allergy and occupational health consultants should lead on the development, implementation and review of the Trust latex policy.

Allergists in regional centres should have liaison with anaesthetists over a wide geographic area and would be expected to have established systems for referral for patients with suspected anaphylaxis during anaesthesia. These patients need to be focused in major allergy centres with appropriate expertise and receiving a sufficient volume of patients.

Allergists in regional centres have an important role in educating general practitioners and other consultants who have to deal with allergy patients in their region.

- Multidisciplinary team working.

*Allergy specialist nurses* with appropriate training are essential and are key members of the team. They provide skin prick testing; advice on allergen avoidance; train patients to use self-treatments (adrenaline auto-injectors; inhalers); monitor patients undergoing immunotherapy and challenge tests; support doctors in treatment of acute reactions including anaphylaxis, some using questionnaires to support history taking in defined disorders; and they may support follow-up of certain disorders.

*Dieticians (adult and paediatric) trained in allergy* Assessment of nutritional adequacy of diet; advice on diagnostic exclusion diets; advice to patients on long term diets. Important role in paediatric allergy.

*Pharmacy and drug information service* Search for ingredients of drugs; provision of capsules for drugs for challenge tests; provision of drugs for skin testing and challenge tests; information on adverse reactions.

#### 5. Delivering a high quality allergy service

- Characteristics of a high quality service.

Consultant allergists should have completed an accredited training programme and be on the Specialist register of the GMC. Applicants from outside the UK will be expected to demonstrate comparable quality of training as assessed by the JCHMT of the RCP. Allergists should not work in isolation. They must have appropriate support staff including specialist allergy nurses.

The concept of a quality driven service, with standards of care clearly defined in contracts, provides a framework in which the allergy care for a community can be improved.

Standards should be set in relation to

#### The referral system

- Referral letters should be prioritised by the allergist.
- Explicit standards should be set for time from referral to first appointment for urgent and non-urgent cases.
- There should be sufficient consultant staff to provide 24 hour access to allergy advice for existing allergy out patients, for in patients, A&E and the admissions unit.
- Dedicated administrative support staff.

#### Out patient clinic appointments system

- Adequate time should be available to see complex cases.
- Appropriate investigations should be available eg skin test extracts and common foods needed for prick-prick tests. And to ensure efficiency, systems should be in place to ask patients to bring unusual foods which may be required for skin testing.
- Allergy specialist nurses should be available.

#### Day cases

- There should be an agreed definition of a day case and recognition of the time required to perform the various investigations, procedures or treatments.
- 24 hour advice should be available after discharge of day cases. The training of medical and nursing staff.  
The availability of appropriate facilities and equipment.  
Information for, and education of, patients.  
Storage and handling of medical records.

#### Resources required for a high quality service

The table below gives an overview of standards and resources required in any specialist allergy centre. Currently, this is what is proposed for the regional allergy centres—the change drivers which will establish the service and enable a more rational and patient sensitive model to emerge. Workforce requirements are described in the main text. The requirements should be linked to the new consultant contract, with explicit service quality standards.

<i>The service standard</i>	<i>Specialised Facilities and Resources Required</i>
<b>(i) Referral</b>	<b>(i) Referral</b>
All referrals letters prioritised by the allergist.	Sufficient consultant staff to provide 24-hour cover and access to allergy advice, for existing allergy out patients, for in patients, A&E, the admissions unit and GPs. Time for consultant to triage and review referral letters.
Explicit standards set for time from referral to first appointment for urgent and routine cases.	Dedicated support staff (secretarial, clerical).
24-hour advice from an allergist.	Standards (determined locally) for time to first appointment for urgent and routine cases. (Due to the shortage of allergists this is not always “a reasonable time”, but urgent cases should be seen

<i>The service standard</i>	<i>Specialised Facilities and Resources Required</i>
Dedicated administrative support staff.	preferentially.)
<b>(ii) Outpatients</b> Ability to diagnose and manage all types of allergic disease. Adequate time available for complex cases.	<b>(ii) Outpatients</b> Trained consultant allergists and adequate number of medical staff to provide a dedicated allergy team. Dedicated clinic space, with defined consulting rooms and facilities for day cases (see below). Integrated facilities with outpatient and day cases seen in the same setting improves efficiency and use of expertise.
Appropriate investigations available eg skin test extracts and common foods needed for prick-prick tests. To ensure efficiency, systems should be in place to ask patients to bring unusual foods which may be required for skin testing.	Specialist allergy nurses, with space to work; skin testing rooms; couches for safe management of at least 20 patients in one immunotherapy session, in case of anaphylaxis. Space for resuscitation around each couch essential.
Allergy specialist nurses should be available.	Inhalers, nebulisers, oxygen, peak flow meters, spirometry in clinic. Immediate access to treatment for anaphylaxis (this is treated by the allergist). All drugs, IV lines and fluids, oxygen, nebuliser, tilting couches, cardiac arrest box (adult and paediatric), latex free equipment.
Appropriate interpretation of skin prick tests.	Pharmacy service (the supply of drugs for skin testing or challenge; drug information service). Locked refrigerator and drug storage.
Appropriate interpretation of intradermal tests.	Dietitians—both adult and paediatric. A dedicated service must be available through the dietetic department. Standard methods of referral to (i) establish if a diet is nutritionally adequate and (ii) provide advice on exclusion diets.
Support from adult and paediatric dieticians with knowledge of allergy.	Easy access to, and close liaison with, lung function laboratory.
Defined number of patients per clinic. Allergy patients are usually complex, and detailed history taking is essential. 45 minutes per new patient is commonly required and 20–25 minutes per follow-up. Four new and four old patients per clinic, is the maximum, but will depend on case complexity and support staff.	Full investigations including immunology and imaging.
Established links with community paediatric teams.	Child orientated clinic. Paediatric play facilities in waiting area and (ideally) play assistants. Appropriate paediatric dress for nurses and doctors wherever children are seen.
Literature for patients to consolidate verbal information (see below).	Community paediatric team with dedicated time for support of children at risk of anaphylaxis in schools. Liaison with community paediatrician and agreed management plan and systems for implementation in schools (local area and distant). Proforma letters eg requesting a school training visit in a child at risk of anaphylaxis. Literature: handouts on various disorders (see below).
<b>(iii) Day Case management</b> An agreed definition of a day case and recognition of the time required to perform the various investigations, procedures or treatments.	Secretarial support. Dedicated staff trained in allergy terminology and policies (allergy practice generates many telephone enquiries from existing and prospective patients, GPs, nurses and other hospital specialists). <b>(iii) Day Case management</b> Adequate numbers of medical and nursing staff trained and experienced in allergy day case investigation.

<i>The service standard</i>	<i>Specialised Facilities and Resources Required</i>
<p>Protocols and agreed systems for approach to diagnosis.</p> <p>Sufficient case load of each category of day case seen to ensure expertise.</p> <p>Ability to investigate drug allergy.</p> <p>Ability to exclude or confirm drug allergy.</p> <p>Expertise and ability to carry out inhaled and oral challenges.</p> <p>Ability to interpret results of investigation and challenge, and provide a clear and high quality report eg for anaphylaxis during anaesthesia.</p> <p>High quality service.</p> <p>24 hour advice available after discharge of day cases.</p> <p><b>Immunotherapy clinic.</b></p> <p>Immunotherapy should be carried out by trained medical and nursing staff (an allergy team) with a large enough patient load to ensure continuing standards of care.</p> <p>Defined number of patients per session, eg 20–25 patients per two doctors, according to risk assessment. Ideally two doctors per clinic for safety reasons.</p> <p>Expertise in carrying out IT safely and facilities for resuscitation.</p> <p>quality standards for care of patients, decision making and monitoring for adverse reactions.</p> <p>Competence to treat anaphylaxis, acute asthma and other allergic reactions.</p> <p>Regular ALS training (adult and paediatric) of medical and nursing staff.</p> <p><b>(iv) In-patients</b></p> <p>Access to inpatient beds with junior staff cover.</p> <p><b>(v) Literature for patients</b></p> <p>Specialist literature required includes: treatment plans for acute allergic reasons eg anaphylaxis or glottal oedema; adrenaline auto-injector instructions; diet sheets—how to avoid foods; diagnostic exclusion diets; symptom calendars; allergen avoidance measures; proforma to whom it may concern letters eg for anaphylaxis during anaesthesia, hereditary angioedema, to highlight drug allergies; medical alert application forms etc. All this is essential as many patients have complex allergy and patients should be given written as well as verbal information.</p>	<p>Adequate numbers of medical and nursing staff trained and experienced in immunotherapy.</p> <p>Appointments system for day cases.</p> <p>Facilities for day cases (immunotherapy, challenge tests and most complex investigations) must be available (this may be in outpatients) where patients undergoing challenge tests can remain for a session or all day (with supervision by trained nursing staff).</p> <p>Challenge tests and immunotherapy are high-risk procedures which must be supervised by trained medical staff.</p> <p>Consent forms and information sheets for the above.</p> <p>Defined procedures and protocols, including monitoring for immunotherapy. Accurate record keeping including adverse reactions.</p> <p>Specialist allergy nurses and continuous nursing cover.</p> <p>Couches for safe management of at least 20 patients in one immunotherapy session, in case of anaphylaxis. Space for resuscitation around each couch essential.</p> <p>Inhalers, nebulisers, oxygen, peak flow meters, spirometry in clinic. Immediate access to treatment for anaphylaxis (this is treated by the allergist). All drugs, IV lines and fluids, oxygen, nebuliser, tilting couches, cardiac arrest box (adult and paediatric), latex free equipment.</p> <p>Locked refrigerator and drug storage. Standard system for use and storage of controlled drugs.</p> <p>Facilities to make up dilutions of drugs for skin testing in day care clinic.</p> <p>Pharmacy service (the supply of drugs for skin testing and drug/placebo supply for blinded challenge testing; drug information service.</p> <p>Procedures for advance ordering of drugs etc for testing or challenge.</p> <p>Systems to provide regular ALS training.</p> <p><b>(iv) In-patients</b></p> <p>Agreed access to inpatient beds with junior staff cover (often shared with respiratory medicine but to be determined locally).</p> <p><b>(v) Literature for patients</b></p> <p>Medical, nursing and secretarial staff to produce, explain and distribute literature.</p> <p>IT departments to produce high quality Websites for patients to access and obtain patient information sheets.</p>

<i>The service standard</i>	<i>Specialised Facilities and Resources Required</i>
<p><b>(vi) Patient Support</b> Information should be available and literature displayed.</p> <p><b>(vii) Records</b> Hospital notes should be available, with IT access as determined locally by the Trust.</p> <p><b>(viii) Communications with primary care</b> Letters should be sent to primary care outlining the diagnosis and proposed management.</p> <p><b>(ix) Office and equipment</b> Office facilities must be available for all members of the allergy team.</p> <p><b>(x) Data collection: workload</b> Coding of workload as allergy. Data collection for numbers of outpatients, day cases, inpatients, monthly and annually, and source of patients. Data on case mix. Audit of allergy work.</p> <p><b>(xi) Teaching and training</b> Teaching and training of SpRs, students and nursing staff in clinic. Clinical meetings to discuss cases and ensure standards are maintained.</p>	<p><b>(vi) Patient Support</b> Information should be available and literature displayed. Nursing and secretarial staff. Contact with patient support groups.</p> <p><b>(vii) Records</b> Trained administrative and appointments staff. Secretarial support. Storage for records in out patients. IT access to appointments system and laboratories for investigations.</p> <p><b>(viii) Communications with primary care</b> Secretarial staff. Full time allergy service. Agreed protocols and proformas. IT systems (locally determined).</p> <p><b>(ix) Office and equipment</b> Office space for consultants (ideally close to clinic). Office space specialist nurses and trainees. Secretarial offices. Clinic administrator space and appointments area with adequate record storage. Computers/IT facilities for the above.</p> <p><b>(x) Data collection: workload.</b> Trust IT support systems collect allergy data. Consultant/specialist nurse time to monitor demand, workload and case mix seen. Time for audit.</p> <p><b>(xi) Teaching and training</b> Adequate time allowed in clinic (adjustment of number of patients seen) and space. Weekly clinical meetings attended by medical and nursing staff.</p>

(ii) Workforce requirements: clinical and support staff:

- Consultant allergists should not work alone so a minimum of two is required.
- In addition, as paediatric allergy develops, they should be augmented by paediatric allergists.
- There should be at least two allergy SpRs in major centres to provide cover and to enhance training.
- Other medical staff including associate specialists and GPSIs should be encouraged as this.
- is a high volume specialty with complex patients where it is essential to have adequate cover at all times and continuity of service. A team approach is important to provide a high quality efficient service.

## 6. QUALITY STANDARDS AND MEASURES OF THE QUALITY OF SPECIALIST SERVICES

*Standards of care* need to be defined and developed. There is lack of validation of procedures for investigation of certain disorders. The BSACI is developing guidelines for investigation of specific disorders. The BSACI guidelines on immunotherapy are being updated<sup>17</sup>. An important role for consultants in major allergy centres is clinical research to produce evidence to support development of guidelines and to provide advice on best practice.

NICE is reviewing immunotherapy and has been asked to review the management of anaphylaxis.

### *Clinical governance*

Many of the requirements are listed under “Characteristics of a high quality service” (section 5).

### *Measures of quality*

Immunotherapy: Protocols for monitoring, accurate data collection including adverse reactions, systems to check dose, safe administration.

Challenge testing: information sheets, consent forms, protocols, use of appropriate investigations, diagnostic outcome, appropriate management of reactions.

Training of the entire allergy team, including nursing, secretarial and other support staff Systems to allocate appropriate appointment eg to specialist clinic or day case.

Outcome data eg incidence of further reactions in nut allergy; effective control of disease; identification of causes of anaphylaxis; etc.

Quality of the literature for patients, to support verbal advice. Literature appropriate for all disorders seen.

Paediatric facilities and staff expertise with children and families, in clinics where adult physicians see children.

Regular ALS training of medical and nursing—adult and paediatric.

Documentation of patient throughput (outpatients and day cases) and the nature of case mix. It is important to demonstrate adequate numbers of patients with specific disorders are seen in a tertiary service.

Patient satisfaction data.

GP feedback (including rate of referral).

## 7. OUTLINE OF CLINICAL WORK OF CONSULTANT ALLERGISTS

Most of the work is outpatient or day case based, with only a minimal inpatient component. Most NHS consultants do five clinics a week, some in general allergy and some in specialised clinics or day case sessions according to the consultant’s interest; for example, immunotherapy, day case challenge tests; anaphylaxis; venom allergy etc. Diagnostic challenge tests and immunotherapy are an increasing component of the work as allergic disease becomes more severe. In future, novel therapies to replace conventional immunotherapy are likely to increase workload.

Telephone/letter advice is an increasing workload providing advice without seeing the patient. Because of the shortage of allergists and lack of knowledge of allergy in primary care, an important component of work is in liaising with GPs, providing information and acting as an educational resource for GPs.

There is also considerable out of clinic work directly related to patient care in major centres.

### *Contributions made to acute medicine*

Allergists do not participate in the on-call rota for general medicine. However, consultants in allergy provide:

- Consultation service for urgent problems (anaphylaxis, asthma, angioedema).
- Consultation service for drug allergy including skin testing for penicillin allergy.
- Consultation service for anaesthetic problems pre-operative or post-reaction.
- Management of latex allergic patients on elective or emergency admission (in conjunction with Trust Latex Allergy Policy). Allergists should be the main contributors to writing a Trust Latex Policy.
- Consultation in A&E (eg anaphylaxis).
- Urgent training in use of adrenaline auto-injector before discharge from ward or A&E.

### *Direct patient care*

Outpatient work

General allergy clinics

The ratio of new patients to follow-up patients averages 1:1 to 1:2, varying with the complexity of referrals and type of service. The average numbers of patients are three to four new plus three to four old patients per doctor. When consultants are training doctors (specialist registrars, GPs, and other consultants) and nurses in outpatient clinics, a consultant can supervise two people per clinic but must allocate extra time to review the patients and teach trainees/students.



An immunotherapy clinic has 20–25 patients. Ideally this should be staffed by two doctors (because of the risk of anaphylaxis) and specialist nurses.

The number of patients in a day case challenge session depends on the number of doctors and nurses as well as facilities and local arrangements but typically is two patients.

Special clinics within allergy (optional depending on specialist interests and type of centre):

- Immunotherapy clinic.
- Challenge sessions, eg food and drug challenge.
- Paediatric allergy (the majority of children are currently seen by adult allergists because of the lack of paediatric allergists, but facilities and staff in clinic should be child orientated).
- Anaphylaxis clinics including nut allergy.
- Drug and general anaesthetic allergy clinics.
- Venom allergy clinics.

Specialised investigative and therapeutic procedures:

- Skin prick testing and intradermal skin testing.
- Immunotherapy.
- Challenge testing: oral and bronchial challenge tests.
- Occupational allergy testing.

### *Immunotherapy*

These patients are seen as day cases. Management protocols and specialist nurses are essential. Systems must be in place for monitoring patients (pulse, blood pressure and peak flow) pre- and at 30 and 60 minutes post injection and symptoms throughout, for early detection and treatment of allergic side effects including anaphylaxis. Staff must be trained in the treatment of acute severe allergic reactions. All drugs, oxygen, nebuliser etc must be immediately available. A patient having two injections will typically be in clinic for over two hours, if treatment is uneventful, but substantially longer if there is an adverse reaction.

### *Challenge sessions*

This applies mainly to the investigation of certain patients with drug and food allergy, or occupational allergy. These may require skin prick tests, intradermal tests and/or challenge. Some of these investigations are not validated, so a role for major allergy centres is to deal with larger numbers of these patients, where expertise is important. Where none exist, approaches to diagnosis can be evaluated and national standards set. Patients with antibiotic allergy, local anaesthetic allergy, general anaesthetic allergy, aspirin and NSAID sensitivity and other drug allergies and some food allergies are seen in this setting.

All clinics require adequate support staff including specialist nurses. The number of patients seen depends on the complexity of the procedure.

### *Work to support clinics*

A typical job plan for a consultant in a major centre should allow two hours per clinic for work relating to out patients. This includes:

- (a) reviewing referral letters; allocating these to the appropriate clinic,
- (b) giving GPs advice by telephone or letter without seeing the patient
- (c) on patients *before* they are seen: requesting information so this is available when the patient attends (eg requesting anaesthetic and drug charts in case of a GA anaphylaxis referral; writing to obtain details of drugs given and reactions caused in multiple antibiotic allergy etc). This avoids wasted consultations and the patient can proceed directly to a complex investigation or challenge test.
- (d) requesting additional information after the patient is seen eg ingredients of foods or other products to identify possible causes of anaphylaxis; planning/preparing substances for challenge testing.
- (e) requests relating to existing patients, not currently being seen, eg patients having further allergic reactions, dealing with schools in the case of children at risk of anaphylaxis; dealing with new acute allergies; updating treatment plans; investigating/identifying ingredients of meals to determine causes of anaphylaxis;
- (f) Letters are more complex, and often several are required, than in other specialties; and because of the severity of the reactions and high risk, absolute accuracy is essential. This takes more time outside clinic. For example:

A child with nut induced anaphylaxis requires:

- (a) letter to GP

- (b) written treatment plan outlining ( parent-) treatment of acute reactions
- (c) letter to community paediatric team (in or out of area) requesting school visit to train teachers
- (d) letter to head of school informing them of the allergy, the management and the proposed school visit
- (e) literature to parent on nut avoidance and on how to use adrenaline auto-injector

A patient with anaphylaxis during anaesthesia requires:

- (a) letter to referring anaesthetist, copied to GP
- (b) to whom it may concern letter to patient (copied to anaesthetist and GP) outlining the cause, drug(s) to be avoided and drugs likely to be safe for use in future general anaesthesia
- (c) completed application for a medic alert bracelet (allergist must complete the inscription).
- (d) entry in drug allergy/risk section of hospital notes.
- (e) report to MCA
- (g) Literature searches for complex or rare cases.

#### *Inpatient work*

Referral work: requests for an allergy opinion are common. Ward referrals will be seen on the wards or in outpatient clinics.

There are occasional inpatients. Daily ward rounds are required at a minimum as these patients are usually undergoing complex procedures. Rush immunotherapy requires the presence of a doctor at all times during treatment. Challenge testing, which may be done as a day case or in-patient, requires high doctor input and immediate availability to treat reactions. Patients occasionally need to be admitted after day case challenge to drugs if a reaction is protracted.

#### *On-call*

Allergy advice for emergencies and other specialties (eg anaesthetic allergy, drug allergy and latex allergy). Access to the allergist for telephone advice should be provided to patients overnight after day case procedures eg immunotherapy or after challenge testing.

#### *Clinically related administration*

See “Work to support clinics” above. This includes letters at point of referral ( advice to GP, refusing to see patient); prioritising letters; arranging day case procedures; writing protocols and guidelines for clinic; and literature searches.

#### *Work to maintain and improve the quality of care*

Service developments that deliver improved patient care:

- Referral of patients with nut allergy to specialist allergy clinics (reducing morbidity and mortality by reducing frequency and severity of further reactions, providing effective self-treatment should a reaction occur, reducing A&E attendance and hospital admission, and improving quality of life).<sup>18, 19</sup>
- Management of children with glue ear and rhinitis by allergists (recognition of allergic rhinitis as an important cause and treating this means that unnecessary ENT surgery can be avoided).<sup>20, 21</sup>
- Immunotherapy (efficacy; avoids complications of medical therapy; reduces chronic disease; reduces long term drug use; improves quality of life).<sup>22, 23, 24, 25</sup>
- A single consultation with a specialist allergist is more effective than multiple referrals to a series of organ based specialists eg dermatology, ENT, respiratory medicine, as the whole patient is dealt with and allergic triggers recognised. This often allows avoidance of allergens and leads to better control of disease and reduced need for drugs and further consultations.
- Diagnosis or exclusion of drug allergy by challenge testing.
- Challenge testing to improve diagnosis of food allergy/intolerance.
- Use of specialist nurses: to reduce waiting lists.
- Liaison with community paediatricians: to improve care for children at risk of anaphylaxis.<sup>16</sup>

## 8. ACADEMIC MEDICINE

There is a strong tradition of academic allergy in the UK. Most of the major allergy centres have been developed with academic funding and are headed by academics. Thus clinical expertise/service delivery relies heavily on academics and the NHS input into allergy is small. The NHS workload of academic allergists depends on their academic responsibilities and individual job descriptions. They make an important contribution to the work of the NHS Department and often set up tertiary services (specialised clinics). Academic allergists make a major contribution to clinical research and contribute towards the development of clinical guidelines. This is essential as in many areas of allergy, evidence based guidelines on diagnosis and management need to be developed. They also have a role in training allergy SpRs.

## 9. WORKFORCE REQUIREMENTS

At present there are 26.5 wte consultant allergists in England (DH workforce data 2003), and none in Wales, Scotland or Northern Ireland. For England, the RCP, and for Scotland, the Scottish Executive, have made recommendations for an increase in allergy SpR posts and in consultants<sup>11, 25</sup>

In total over 100 allergy clinics exist within the UK<sup>15</sup>. But most are run—in response to patient demand—by doctors with an interest in allergy, but without specialist training or expertise in allergy, and providing an add on service to their main specialty<sup>14</sup>. Whilst these consultants make a valuable contribution to patient care, these clinics are only a partial response to patient need, being an offshoot from the provision of another service. Service provision by other specialists doing allergy as an “add on” to their main specialty is no longer adequate: this needs to be augmented by a substantial expansion in the number of trained full time allergists providing a dedicated allergy service. To contribute effectively to a national system of allergy patient care, these consultants and clinics need to be networked with allergy specialist centres. Unfortunately, only six such centres, together with nine part-time centres, offer allergy services run by specialist allergists within the UK (five of which are in London or the Southeast).

This situation fails to deliver basic standards of care to allergy patients, fails to comply with clinical governance, and care is completely inadequate for the increasing number of patients with severe, multi-system or non-organ based allergic disease.

Substantial expansion is required to provide patients with a first class service, which matches what is available elsewhere in the developed world. Improvement is required across the board—within primary care; in both secondary and tertiary care; to achieve more equal access across the country to appropriate allergy services; and to gear the training of doctors and nurses to achieve the desired ends.

Both now and for the immediate future, demand will outstrip service supply by a very large measure. In that situation, a vision as to how a mature allergy service might be configured, and a change programme addressing how to get there, are both required.

This section addresses the workforce aspects of both.

### I. IMMEDIATE PROPOSALS: THE CHANGE PROGRAMME

The RCP report (supported by the British Society for Allergy and Clinical Immunology and the National Allergy Strategy Group) proposes that an initial investment is made in the creation of a network of regional specialist allergy centres.<sup>11, 14</sup> These would provide services in adult and paediatric allergy. This will provide expertise for the more complex disease, and provide training, research and leadership within the nascent national allergy service. They would also improve geographical distribution of allergy services. For the mature service these would become regional tertiary centres. This core of experts is essential to set standards and support developments in primary care, where the bulk of allergy care will eventually be delivered. Thereafter other developments can follow. There are two immediate needs:

1. To create or adequately staff regional allergy centres (a minimum of one per region)

This requires a minimum of two additional consultant allergists per region\* (to cope with demand and waiting times in established centres; and to set up services in regions where none exist) and two paediatric allergists.<sup>11, 14</sup>

The numbers of additional consultants required (phase 1 of development) are as follows:

England (8 regions)	16 adult + 16 paediatric
Wales	2 adult + 2 paediatric
Total (provision for adult and paediatric allergy)	36

2. To substantially increase the number of funded SpR posts

A large increase is needed to feed the consultant expansion recommended above, and even to maintain the present consultant workforce as DH data predicts negative growth.

## II. A MATURE SPECIALIST ALLERGY SERVICE (SECONDARY AND TERTIARY)

To create consultants other teaching hospitals and in DGHs.

Following the start up, the service would be extended to provide allergist-led services in each teaching hospital, then to develop the service in DGHs. The current provision is so inadequate that even a moderate improvement would require an enormous expansion of consultant numbers.

Calculations

Assumptions

### 1. Population/patient need.

It is estimated that 50,000 people per million need access to a specialist consultant allergist (5% of the UK population); about 300,000 in the UK.

And that 5,000 people per million need to see a consultant allergist in any year (workload spread over 10 years)

This estimate is derived as follows:

- (a) Epidemiological data: At least one third of the population and 40% of children have allergic disease.<sup>1, 11</sup>
- (b) Clinical estimates: Assume about 85% of these will be dealt with in general practice or in allergy clinics run by consultants in other specialities, or may not need to see a doctor. Therefore assume 15% of those with allergic diseases (about 5% of the population) need to see a consultant allergist. This figure is based on the prevalence of life-threatening, severe or multi-system allergic disease, drug, food, latex and venom allergy (see Introduction) and the need for complex investigation, challenge testing and immunotherapy.

It should be noted that for many disorders prevalence data is not known, but referrals to major allergy centres suggest that anaphylaxis and severe allergic reactions (eg glottal oedema and severe angioedema) are increasing in frequency; that there are many new allergies, particularly to drugs and foods; and that there is more multi-system disease.

Immunotherapy and diagnostic challenge tests: while the need for both is currently difficult to estimate, although world wide the use of both is growing, it is estimated that less than 60 cases per million require immunotherapy for venom and severe pollen allergy (with 50 attendances required per patient) and less than 150 adults pa for 2 million population for challenge testing (eg for drug allergy). These are minimum estimates. Immunotherapy and challenge testing both have specific safety requirements.

### 2. In order to calculate the consultant manpower needed to see these patients.

- (a) Patient throughput:
  - (i) It has been assumed that the workload to provide for the 5% of the population who need to see an allergist will be spread over a 10-year period. Thus 0.5% (5,000 patients per million population) will need to be seen each year as new patients.
  - (ii) Assume a high rate of discharge after a single out patient consultation (current practice; but a proportion are discharged earlier than clinically indicated because of considerable service pressures).
  - (iii) A ratio of new: old patients of 1:1 in out patients (again driven by service pressures but this is becoming less and less realistic as the proportion of patients with more complex disease increases).
- (b) Other assumptions in calculating consultant case load:
  - (i) A consultant works 42 weeks per year (allowing for annual leave, study/professional leave and bank holidays).
  - (ii) A Programmed Activity (PA) lasts for four hours under the new contract in England.
  - (iii) Five clinics per week.

### *Consultants needed per million population*

0.5% of one million = 5,000 patients with allergy require referral to a specialist allergist in any year.

One consultant five clinics per week, but the nature of work will vary according to the degree of specialisation in the centre. For example, in a regional allergy centre three to four of these would be outpatients, one immunotherapy and one challenge session). In a teaching hospital or DGH with a smaller allergy unit, there might be five outpatient clinics and no challenge or immunotherapy sessions. Numbers and nature of patients seen will vary. Further as services develop, the most complex cases, immunotherapy and challenge testing will largely be catered for in the regional centres.

The following calculations are based on specialist work in a major full time allergy centre offering a tertiary and secondary service:

## (a) Out-patients;

Four new + four old patients seen per out patient clinic—if adequately supported by specialist nurses = 504 new and 504 old patients pa per consultant;

## (b) immunotherapy session 20–25 patients per two doctors. Twelve patients per doctor per week 504 patient attendances pa (but 12–21 visits are required pa per patient. Thus 42–24 patients seen pa per doctor;

## (c) challenge session two patients per doctor per week = 84 pa;

One consultant, will see approximately 500 new, 500 old and 580 day cases (500 immunotherapy and 80 challenges) pa.

[Note: as service development occurs, some teaching hospitals providing a secondary service will have a different case mix, eg no day cases but more out patients.]

Ten consultants will see approximately 5,000 new + 5,000 old patients pa.

Thus 10 consultants required per million population (assuming that the at risk population is seen over 10 years). This equates to 2.5 consultants per 250,000 population; therefore 520 consultants are needed for 52 million population (England and Wales).

Present number	27
Additional number for regional centres (phase 1)	18 adult and 18 paediatric consultants = 36
Therefore number required for other centres (phase 2)	457

Thus, a total of 493 additional allergy consultants required, a considerable proportion of whom would be in paediatric allergy. The requirement for adult allergists could be reduced by, say 20%, as organ-based physicians, immunologists and general paediatricians with an interest in allergy continue to contribute to allergy care (eg in allergy affecting only one organ-isolated asthma or eczema).

*Specimen NHS consultant job plan (in a tertiary centre)*

This is an outline of the work of an NHS consultant allergist in a tertiary centre, as in a regional allergy centre in phase 1 of development of the service. It should be recognised that the job plan of an academic allergist in a major centre will differ. This job plan should not be seen as prescriptive, particularly as the service is developing, but gives an indication of the number of PAs to deliver a particular case load.

<i>Direct patient care</i>	<i>PAs</i>
Clinic sessions	5
Work related to clinics	2.5
On call	0.25
Work to maintain and improve quality of care	
Administration and management	0.5–1
Personal CME/CPD and audit	1
Teaching, training, clinical research (variable)	1–2
(those with a greater contribution to delivering undergraduate and postgraduate education and research will required more protected time for this work)	
Outside activities	0.5

*Calculation of clinical programmed activities (PA) required for a population of 250,000*

Thus approximately 11 PAs required to deliver five clinics.

So  $2.5 \times 11 = 27.5$  PAs (= 2.75 wte consultants) required for a population of 250,000.

*Trainee manpower*

There are few trainees at present. There is an immediate need to substantially increase numbers, otherwise even a minimal consultant expansion is unachievable. Eighteen additional NTN's are required to feed the first phase of development (at least one major allergy centre for a population of 5–7 million). In addition, because Allergy is one of only two specialties predicted to have negative growth (minus 6% by 2012, and minus 3% after one new NTN is appointed in 2004), two additional NTN's are required to maintain the present consultant workforce. Thus 20 additional NTN's are required to begin to grow the specialty. There is training capacity in the major allergy centres, most of whom can accommodate three trainees, and other allergist run centres, which are developing.

### Summary of workforce needs

- An estimated 5,000 people per million population have allergic disease of sufficient severity/complexity to see a specialist allergist in any one year.
- 2.5 consultant allergists (or 27 PAs) are needed to provide services for 250,000 population.
- This workload requires 520 allergists to cover adult and paediatric services (England and Wales).
- The assumptions used mean that these are minimum estimates, eg new case load now is seen over a period of 10 years.
- Development of an adequate allergy services is proposed in two phases.
- The start up to grow the service requires an immediate expansion of 18 consultant allergists, and 20 additional SpRs in adult allergy. Concomitant development in paediatric allergy is required, with 18 additional paediatric allergists and development/expansion of training in paediatric allergy. This would establish at least one major allergy centre providing adult and paediatric tertiary level services for a population of about five million (as well as secondary services for the immediate area), thus providing a core of expertise across the country and give better access for patients with more severe allergic disease.
- Phase 2 of development, to provide adequate secondary and tertiary services, requires a total of 520 allergists (for adult and paediatric services).

NOTE: In 2001 there was insufficient information available to allow a more precise estimate of the workforce requirements in this specialty. This recent estimate provides a firmer basis for workforce planning but this too will need to be reviewed in the light of developments in practice and service delivery.

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May 2004

### Memorandum by Dr G Scadding (AL 56)

#### SUMMARY

Allergy services in the UK are under-resourced with 26.5 whole time equivalent Consultant Allergists for a population where one person in four is allergic. My particular concerns are the lack of availability of adequate Allergy provision within ENT and Thoracic medicine.

#### AVAILABILITY OF ALLERGY SERVICES

1. We have an Allergy service at the Royal National Throat, Nose and Ear Hospital which consists of:
  - A general allergy clinic: two sessions per week.
  - A paediatric allergy clinic, together with a Consultant Paediatrician: one to two sessions per week.
  - A specialist allergy/immunology service for otorhinolaryngology (ENT): three sessions per week.

2. The special facilities which we have here are units where ENT patients are seen by both physicians and surgeons and are extensively investigated for underlying allergy or other immune problems. In 2003 over 3,600 patients were seen in these clinics, 40% new. The service is struggling to cope with increasing numbers of patient referrals.

There are only two units in the UK providing dedicated ENT allergy services, both in London. Both receive referrals not only locally, but from all over the UK.

3. ENT disorders are very common, accounting for one third of a general practitioner's workload. They reduce workplace and school attendance by 3%–4% and performance by 30%–40%. Secondary referral of ENT problems is usually to surgeons, but the majority of patients do not require surgery, as over 50% involve allergy and/or hypersensitivity. We have shown that medical treatment reduces the need for surgical intervention<sup>1,2</sup> for glue ear and for sinus surgery, and also improves quality of life.<sup>3</sup>

4. Interaction between the upper and lower respiratory tract is now appreciated.<sup>4</sup> Rhinitis is a risk factor for asthma development: treatment of childhood rhinitis by subcutaneous immunotherapy reduces progression to asthma and reduces the widening of allergic sensitisation.<sup>4</sup> Unfortunately, subcutaneous immunotherapy for children is practically unavailable in the UK because of the paucity of trained allergists. Safe and simple alternative methods need to be properly investigated. One of these is sublingual swallow immunotherapy which has proved beneficial in a recent meta-analysis.<sup>5</sup>

5. Rhinitis treatment reduces the need for Casualty visits for asthma exacerbations and reduces hospitalisation<sup>6</sup> for asthma. Practically all severe asthma patients have significant nose and sinus disease, chronic sinusitis treatment by medicine or surgery improves pulmonary symptoms and function.<sup>7</sup> Recent evidence demonstrates that one in five of adult asthmatics are aspirin sensitive and at risk of severe life-threatening asthma from painkillers. 80% of these were unaware of this until they underwent graduated aspirin challenge<sup>8</sup>, a technique familiar to allergists, but to few other doctors.

6. Chest physicians are not given ENT training and usually have little in the way of allergy experience. ENT surgeons are not encouraged to consider the lower respiratory tract and also undertake very little allergy training in the UK, unlike their European and American counterparts. The World Health

organisation ARIA guidelines<sup>4</sup> recommend that in patients with perennial rhinitis the lower respiratory tract should be examined and tested; and that nose and sinus problems should be considered in asthma. This is not happening in most of the UK.

#### PRIORITIES FOR IMPROVING SERVICES

1. Provision of further allergy national training numbers (NTNs), including one at the Royal National Throat, Nose and Ear hospital to ensure succession of this service as I am intending to retire in 2007.
2. Increased training of ENT surgeons, Chest Physicians and GPs in allergy and in treating the respiratory tract as one organ.
3. Large scale centrally funded trials of sublingual immunotherapy looking particularly at any effect on asthma development and on the progression of allergic sensitisation.

#### INDEPENDENT SECTOR

1. Independent sector providers flourish because of the lack of a complete, properly funded NHS allergy service. The quality of care provided by them is very variable. It can be both expensive and deleterious to the patients welfare, eg highly skewed diets, unverified therapies. One possible course of action would be prospective randomised, double-blind, placebo-controlled trials of the forms of diagnosis and therapy used in alternative practitioner's clinics, with cessation of the availability of those treatments which are shown not to be effective. However this option would be expensive and funding difficult. What must not be allowed to happen is NITS funding for unverified diagnostic methods and treatments in the independent sector as a short-term stop gap measure to pacify patient opinion.

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May 2004

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### Memorandum by The British Society for Allergy, Environmental and Nutritional Medicine (BSAENM) (AL 59)

#### SUMMARY

The BSAENM, a society of doctors, presents evidence that a large number of chronic conditions improve when treated as if they were allergies. Very few of the small number of NHS allergy clinics are prepared to treat these cases, which are presently left to GPs who try to suppress the symptoms with drugs. These conditions make a substantial contribution to the large numbers of the population with chronic complaints and to the poor morale of doctors.

#### 1. *The BSAENM*

1.1 The British Society for Allergy, Environmental and Nutritional Medicine is a Charity whose aim is to promote the study and good practice of allergy, environmental and nutritional medicine for the benefit of the public. Full members are doctors or dentists. This method of practice sets out to identify the environmental influences provoking chronic and recurrent illhealth, and arranging management by avoidance and/or desensitisation. As a result, the patients usually attain control of their symptoms and greatly increased wellness. We use the initials AEN to indicate this approach.



1.2 The logic of the AEN view of medicine was cogently expressed by Rapp in 1988 “Basically, if you have a sore on your foot caused by a nail in your shoe, the answer is to remove the nail, not to put a bandage on the sore”.

## 2. Allergy Services

2.1 When a large number of chronic complaints are treated as allergies the patients get marked relief, stop deteriorating, and are able to keep themselves more or less well. This is common even when there is a long history of symptoms and consultations with many different doctors, whether they have previously been given another firm diagnosis or have medically-unexplained symptoms.

2.2 The provoking exposures are commonly certain foods, low concentrations of volatile organic chemicals and biological inhalants. This is documented in many publications, and supported by symptom provocation on double blind challenge (see background paper and data pages A–G).

2.3 Allergies of this sort tend to get worse and spread to involve other factors unless they are controlled. Avoidance and/or desensitisation are effective managements for these conditions: well-managed, the tolerance of most patients improves.

## 3. Availability of Allergy Services

3.1 There are very few NHS allergy clinics to service the 30% of the population now suffering from allergies, and few of these are prepared to consider that chronic conditions may be provoked by food intolerance or chemical sensitivity. At the time the BSAENM published its report *Effective Allergy Practice* (enclosed), there were a number of BSAENM members in other specialties running clinics dedicated to this aspect of allergy but most have now retired and the clinics have been discontinued.

3.2 As a result, patients with these conditions who have noticed they are made worse by foods or chemical exposures tend to be dismissed as not allergic, and subsequently managed by symptom suppression by drugs, usually deteriorating gradually. However, most patients are not aware that they could be helped.

3.3 AEN methods need a prolonged first consultation and are not easily incorporated into standard NHS situations. In the longer term they give excellent results and are very cost and time efficient.

3.4 The BSAENM has 130 doctor members but most of these are struggling to do a little AEN as they find they are able, many of them already overworked in general practice. The others are practising privately because there are no NHS jobs in which they can practise this constructive medicine.

3.5 The environmentally-controlled inpatient facility (ECU) in Yorkshire which helped the more severely-affected patients was forced to close after the last reorganization of NHS funding because the Primary Care Trusts delayed approving funding for individual patients for one to two years because they were unsure how far their funds would go. An ECU is an essential facility for making a firm and complete diagnosis in patients with multiple allergies, and a prerequisite of good research in this area, particularly in respect of multiple chemical sensitivity.

## 4. Priorities for Improving Services

4.1 Financial support for training in AEN, currently funded only by the Trainees themselves.

4.2 Inducements to GPs to recognise patients whose chronic complaints would respond to AEN management, and to investigate and treat them using AEN methods.

4.3 Funding of the training and employment of specially-trained nurses and dieticians to work with GPs in helping these patients.

4.4 Establishment of posts for allergists interested in food intolerance and chemical sensitivity as well as traditional allergy in medical schools and in other hospitals, with some ring-fenced research money.

4.5 Pressure from the GMC to insist that AEN management is included in the medical school timetable, and that students are not taught that medically-unexplained symptoms are psychological in origin without evaluating the positive evidence to the contrary.

4.6 Establishing a comprehensive environmentally-controlled inpatient unit with a dedicated and specially-trained staff for the investigation and short-term management of the severely-affected and those with serious medically-unexplained symptoms, perhaps initially one unit with 10 to 20 beds but with the intention of expanding to one associated with each teaching hospital.

## 5. Governance, Regulation and Links

5.1 The BSAENM has set up a semi-autonomous Board of Registration to run an accreditation scheme for doctors which includes applicants attending a training course, doing clinical audit and preparing written case histories: the names of accredited doctors are entered on the newly-instituted Register of AEN Physicians, held for us by the Institute of Biology. There is no other training or qualification available in this discipline in the UK.

5.2 The BSAENM Board of Registration registers such members as apply for inclusion on the Register when they have satisfied the accreditation criteria. An entry implies that the Board is prepared to recommend the registrant to doctors and patients. Those who do not wish to be on the Register are free to continue to practise, and most, probably all, are thoroughly competent.

5.3 The Board of Registration has been provisionally accepted by the GMC to contribute to the revalidation of members practising AEN. This is similar to the role to be played by the Royal Colleges. Those of our members who are not on the Register will presumably take another route to revalidation.

## 6. Other Matters

6.1 The premises and staff of some of our members is being deemed to come under the National Care Standards Directive: if this is applied to them all, some will stop practising altogether because the heavy costs of complying with the regulations, and registering, will make part-time practice uneconomic. There are so few doctors practising this way that that would be a disaster.

## 7. Enclosures [Not Printed]

*A Background Document* including a brief survey of the evidence that this method of practice is effective, illustrated by data pages A–G.

*Effective Allergy Practice: a document on standards of care and management for the Allergy Patient.* Report of the BSAEM/BSNM 1994. 200 references.

*Multiple Chemical Sensitivity—Recognition and Management: a document on the health effects of everyday chemical exposures and their implications* Report of the BSAENM 2000. 285 references.

The Lancet review of the Textbook *Environmental Medicine in Clinical Practice*.

May 2004

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*NB. The initials AEN are used to indicate allergy, environmental and nutritional medicine*

## 1. INTRODUCTION

1.1 Approaching chronic illness using the concepts of AEN is a demanding but very rewarding way of practising medicine. This document summarises the methods we use and briefly surveys the evidence.

1.2 The chronic conditions caused by allergy/intolerance have been given the name Toxicant-Induced Loss of Tolerance (TILT), recognising them as sharing patho-aetiological mechanisms. In the future this concept is likely to prove at least as important and influential as the germ theory of disease. A key characteristic of this group of illnesses is that the link between exposure to the provoking agent and the development of symptoms is frequently obscured until after a break in exposure which relieves the symptoms, often after an initial worsening.

1.3 There are four main elements in the management:

- using elimination diets to expose the effects of hidden food allergy;
- using avoidance of everyday exposures to chemicals to uncover hidden chemical sensitivities (including those to cleaning materials, gasses given off from synthetic materials, combustion products, food additives, food and water contaminants, medication etc);
- considering whether allergies to biological allergens (pollens, moulds etc) may be having chronic effects in other systems as well as causing recognised allergies; and
- looking for, and correcting, deficiencies of vitamins and minerals which predispose to, and result from, allergic reactions, and which are an additional cause of chronic symptoms and of poor pregnancy outcome; deficiencies of vitamins and minerals are worryingly common (Block and Abrams. *Ann NY Acad Sci* 1993; 678: 244) and MAFF data shows intakes of zinc and selenium that are inadequate even for the healthy.

1.4 Many patients with chronic illness, including those with “medically-unexplained” illness, become virtually symptom-free without requiring medication if the environmental triggers of their symptoms are detected and avoided. This should be the bedrock of all medical treatment, but has been ousted by pharmaceuticals which are quicker and easier to prescribe although commonly less effective. Wider training and implementation of this constructive approach to chronic and recurrent illness would decrease drug bills and improve outcome, but most NHS consultations, both in primary care and in hospital clinics, are too short for the approach to be initiated, although in the longer-term the patients who benefited would consume much less medical time if treated this way. This form of management (which we term AEN) has been assessed

in the short-term using double-blind randomised trials, but such trials cannot be used to assess the long-term efficacy of therapies in chronic illness. Other methods are more suitable for the assessment of treatments for chronic and recurrent illness, and of any therapy which is based on the need to correct deficiencies or manage idiosyncratic reactions.

1.5 Patients get lasting relief after finding the triggers of the symptoms of irritable bowel syndrome (IBS), migraine, hyperactivity, depression, arthritis, eczema, asthma, rhinitis and other conditions using an elimination diet. Others find relief if they take rigorous action to reduce their exposure to house dust mite allergen, or moulds or volatile organic chemicals. Chemical sensitivity is particularly likely to give rise to psychological and cognitive symptoms, for instance varying difficulty with sleep, memory, word-finding and mood, and is responsible for some aggression and violence.

1.6 On the pages attached, the first page (Annex 1) [Not printed] shows references to papers which demonstrate that a wide range of symptoms can be provoked by food challenge (after symptoms have been relieved with an elimination diet), all confirmed by *double blind challenge*. The studies tended to choose patients with symptoms which could be confirmed objectively, so other symptoms are under represented.

1.6.1 On Annex 2 [Not printed] outcomes are illustrated by the changes in scores for hyperactivity (the higher, the more severe) which fell during the elimination diet and rose again with blind test food challenge but not with placebo. The lower half of Annex 2 shows changes in peak flow rate (high is good) illustrating similar effects in asthma, and showing that bronchospasm in reaction to a food may be prevented by Nalcrom, an anti-allergy drug.

1.6.2 Annex 3 [Not printed] shows the amount of *Life Disruption* reported by a series of severely-affected patients before AEN treatment and at long-term follow-up in a two-centre study. In half of these patients symptoms had got worse for at least 10 years before referral: one had seen 11 consultants in other specialities first. The darker, the more serious.

1.6.3 Annex 4 [Not printed] shows the percentage of these patients who reported each of 64 *symptoms* on presentation (top bars) and at follow-up (lower bars). The frequency and severity of each symptom were reported separately and combined to give a single grading. Again, the darker, the more serious. There was a statistically-significant improvement in almost every one of the symptoms.

1.6.4 Annex 5 [Not printed] shows some other long-term results in asthma and in rheumatoid arthritis, in each case involving diet studies in which the foods most likely to cause problems were omitted at first, and avoided long-term if they provoked a worsening of symptoms later. Over half the asthma cases were better at a year. As is shown, both symptoms and signs of rheumatoid arthritis were significantly improved after a year on the regime.

1.6.5 Annex 6 [Not printed] (top) shows the percentages of patients who benefited in a number of long-term studies, and (bottom) some data about cost effectiveness.

1.6.6 Annex 7 [Not printed] shows the medical costs of two patients before, during and after AEN investigations.

## 2. IS IT ALLERGY?

2.1 At present most of the patients with these complaints are being treated with symptom-suppressant drugs, or seeking help from complementary therapists, or from books, although a few find their way to the doctors who practice AEN, a mere 130 or so for the whole country, most engaged primarily in another field of medicine, mainly general practice.

2.2 The mechanisms by which foods and environmental factors cause such symptoms as hyperactivity and IBS are uncertain, and most of the conditions cited above are not due to IgE-mediated allergy (atopy), although many of the patients also suffer from allergic rhinitis. The hypothesis which currently best fits the data is that most are due to non-atopic types of immune reaction and probably involve Types II, III and IV of the Gell and Coombs mechanisms of tissue damage. Calling these reactions "allergy" raises objections from some conventional allergists, but allergists who fail to recognise these adverse reactions fail to help this type of patient.

2.3 The evidence is primarily *clinical*—that there are a lot of different symptoms which can be prevented by treating them as if they were allergies. This is practical experience supported by good clinical trials (see Annex 1). Acceptance has been slowed by the absence of reliable routine laboratory tests for non-IgE-mediated allergy. It would, in particular, be helpful to have a good laboratory test for hidden food allergy. None of the tests available to date shows sufficient reliability to be used as a basis of a long-term diet, though they may provide a useful starting point for exclusions. Although it would be more satisfactory to have established the mechanism, the absence of an accepted mechanism cannot negate the clinical findings.

2.4 The lergic hypothesis for these conditions is supported by their association with IgE-mediated allergy, by the fact that there have been parallel increases in prevalence, and by the role that desensitisation plays in each. Uncovering hidden food allergy can, on rare occasions, lead to acute allergic reactions on challenge (for instance anaphylaxis has been described in boys with a food-related eczema), and care is needed during the investigation of patients with severe asthma. Because of this, it is important that the medical profession

takes responsibility for investigating the role of environmental and food reactions in the aetiology of the wide range of chronic and recurrent illnesses. If not, patients will continue to get help from books, or from complementary therapists not trained to recognise or treat severe allergies, putting some patients at risk.

2.5 In practice, our members also use nutritional medicine because we have found that the best results may not be achieved unless the nutritional state of the patient is also considered; many allergic patients are deficient in essential nutrients such as B vitamins, zinc and magnesium. This has led us to study the nutritional literature and recognise that marginal deficiencies may also cause chronic symptoms, delay recovery from infections, operations and trauma, and contribute to infertility and poor pregnancy outcome. A balanced diet is clearly an essential preliminary to keeping well, but may not be sufficient for some. Patients who are markedly deficient, or are having repeated allergic reactions (which use up nutrients), or need an idiosyncratically high intake of some essential nutrients, will not achieve repletion unless they take additional supplements, often needing many times the recognised daily requirement. Shorter hospital stays could be achieved if the importance of replenishing levels of deficient nutrients were to be more widely recognised, making an important contribution to medical treatment and to the finances of the NHS. In particular, more use should be made of essential micro-nutrients in combating infections and aiding repair.

2.6 A textbook for doctors and other health professionals [*Environmental Medicine in Clinical Practice*] was published in 1997 and reviewed in the Lancet 1998; 351: 221–2. It covers the evidence that this approach is effective, the practical aspects about how to do it, and the social implications. A copy of the Lancet review of this book is enclosed.

### 3. BENEFITS OF AEN TO PATIENTS

- (a) Relief of previously intractable symptoms, some labelled *medically-unexplained* or wrongly attributed previously to psychological causes.
- (b) Coming to understand the causes of their symptoms, which takes away much of the fear and distress.
- (c) Ability to avoid provoking their symptoms.
- (d) Increased general well-being: partly from reduced medication but also because both adverse reactions and nutrient deficiencies cause malaise.
- (e) The power of choice: patients who suffered from severely-disabling symptoms usually choose to be very careful to avoid incitants, but others make day to day choices about where to go and what to do; with care, many recover their tolerance with time (months/years).
- (f) Relief at having their experiences listened too, tested, and often confirmed and extended: before referral to AEN many patients have been almost persuaded that they were psychologically disturbed.

### 4. BENEFITS OF AEN TO THE NTIS

- (a) Reduced burdens of consultations and investigations, after the initial period (see Annex 7).
- (b) Reduced drug bill (see Annex 6 bottom).
- (c) More satisfying practice: AEN patients whose sensitivities are ignored tend to get worse; they develop many different symptoms and need repeated prescriptions and repeated referrals to different consultants without much benefit; they are a severe drain on doctors' morale.

### 5. BENEFITS OF AEN TO SOCIETY

- (a) Reduction in chronic illness burden, shown by the General Household Survey to involve 20–40% of the adult population (depending on how it is ascertained).
- (b) Reduced sickness benefit and care and disability allowances.
- (c) Reduction in crime. A police officer co-operated in a study using AEN in boys involved in repeated criminal activity; criminal activity was reduced and most of the boys continued to avoid their incitant foods even after the end of the study (Bennett P. *Yorks Med* 1992; 4: 19); vitamin deficiency is a common cause of psychiatric symptoms and linked to crime (Schauss A. *Diet, Crime and Delinquency*. Berkeley, CA: Parker House 1980).
- (d) Healthier babies born to mothers who would otherwise have had allergic reactions during pregnancy and been depleted of essential nutrients.

### 6. WHY AEN IS NOT WIDELY ACCEPTED IN SPITE OF EVIDENCE

- (a) There is very little teaching about allergy, about chronic or recurrent effects of chemicals or about nutritional medicine in medical schools, or during postgraduate training.
- (b) It is only recently that allergy has been recognised as a specialism and there are very few allergists in the country in spite of at least a third of the population being allergic. Almost all of the few

allergy posts concentrate on atopy. Over the last 20–30 years a number of other consultants (mainly general physicians, chest physicians and paediatricians) started to practise AEN; in each case these clinics have had good results, been heavily used, and had long waiting lists, but have reverted to standard medicine when that consultant retired.

- (c) Allergy and nutrition are regarded as *difficulty*: allergy because of its inherent nature, nutrition because it requires more biochemical expertise than most doctors possess.
- (d) Doctors are taught as students that multiple symptoms are of psychological origin and so a psychological aetiology is generally assumed for conditions which are not understood. There is no evidence for this, and a lot against it.
- (e) Doctors have misplaced confidence in negative results of tests. Even when the appropriate test is used, a negative may not be capable of ruling out a condition; if the wrong test is used (for instance IgE testing in hidden food allergy or magnesium from serum levels), the results are totally misleading.
- (f) AEN patients have to take more responsibility for their own health than doctors are used to, making doctors feel threatened. Most doctors are used to, and happy with, a more paternalistic relationship in which they have a secure place, such as ranging laboratory investigations and prescribing medication which only they can do. AEN requires individual medical detective work and close co-operation with the patient.
- (g) Very little research money is available. Most medical research money either comes from the pharmaceutical companies or is distributed by committees whose members rely on such funds for their own department's research output. The pharmaceutical companies see AEN as a threat.
- (h) The pharmaceutical companies fund a lot of postgraduate training; AEN training has to be paid for by those attending it.
- (i) The blacklisting of nutritional supplements for NHS prescribing implied to doctors that they are of no use, which is contradicted by the evidence. When a DHS committee concluded that Vitamin B6 was dangerous, on very poor evidence, this discouraged doctors further from using supplements. In contrast to drugs (which cause thousands of deaths each year) nutritional supplements are extremely safe; the most serious adverse reactions (to tryptophan and to germanium) occurred with manufacturing failures.
- (j) Many doctors are now too overworked and disheartened to be thinking creatively or reading anything new or demanding.
- (k) The report published by the Roy College of Physicians in 1992 entitled *Allergy: Conventional and Alternative Concepts* dismissed environmental approaches without examining the published literature in the scientific fashion that would be expected of such a prestigious body. This report has been repeatedly cited as indicating that there is no scientific basis for the types of management the BSAENM advocates, although it was selective and biased in its coverage. A critique of the report was published the same year (Downing D, Davies S. *J Nutr Med* 1992; 3: 331–49.), and the evidence has been considered in the three reports published by the BSAENM.

## 7. LIMITATIONS ON RANDOMISED CONTROLLED TRIALS IN CHRONIC ILLNESS

- (a) In long-term illness the patient has effectively acted as his own control for 10 years or longer: if they suddenly get better, and stay better, this is highly unlikely to be due to a placebo effect.
- (b) Long-term improvement is the prime endpoint in assessing the effectiveness of the treatment of chronic illnesses. It is difficult to maintain the integrity of intended treatment arms of RCTs long-term, particularly among patients doing poorly who will be tempted to try anything else; drop-outs and protocol-breakers introduce bias, whatever decisions are made about the inclusion of their data in the analysis.
- (c) RCTs compare two (or more) treatment regimes in randomised groups from a homogeneous patient population; women and the elderly tend to be under-represented, excluded because they often suffer from more than one recognised illness which is the norm for the characteristic AEN patient.
- (d) RCTs test uniform treatments; this is not appropriate for patients in whom there is a need to identify and correct individual nutrient deficiencies or identify individual intolerances so that the incitants can be avoided; the treatment plan must be valid for each patient and for AEN this requires personalised management.
- (e) The results of RCTs are generally disbelieved unless they have been carried out double-blind; blinding is impossible with hands-on treatment, and with all management which relies on the patient to modify their lifestyle or diet. For maximum clinical effectiveness, exclusion diets must exclude *all* food incitants; investigatory elimination diets must therefore first check all likely food incitants in order to identify control foods, which obviously cannot be done double-blind; double-blinding results in false negative results to some challenges.
- (f) Randomised referral trials are an adequate alternative.

## 8. WAYS IN WHICH WIDE-RANGE ALLERGY SERVICES COULD BE ENCOURAGED

8.1 Overcoming the barrier of disbelief. In our view, this is not primarily a matter of research—there are good research results published already—but of getting the evidence assessed impartially. We would be delighted if an influential, independent, unbiased individual (or small group of individuals) were to be asked to report to you, to the DHS and to the Royal Colleges after examining the literature and talking to clinicians, researchers and patients and, if necessary, examining trial notes, and patients' clinical notes, and/or following prospectively some patients treated in this way. The group would probably need to be able to appoint some independent staff to help them.

8.2 A randomised referral trial, in which patients are randomly assigned to standard medical management or AEN management, and then managed individually within those disciplines. This must be organised from somewhere outside AEN, as Dr Tom Meade did for the chiropractors. The patients might be a random sub-sample of patients with certain chronic symptoms identified either from a routine hospital department, or from a population survey.

8.3 Establishing clinical posts for allergists concerned about hidden food allergy and multiple chemical sensitivity in all the teaching hospitals, with provision for auditing their results and their workload, and a commitment to expand the service if or when effectiveness and demand are both recognised. Some of the last few NHS clinics of this sort for adults experienced very high referrals, and political pressure to keep down waiting lists contributed to the limitations imposed on them and ultimately to their closure. It would currently be impossible to fill posts in all teaching hospitals with experienced doctors recognised as being of consultant quality, and it might be necessary to appoint some temporarily at lower status. However, providing that the conditions were right, and facilities for training were developed, doctors with experience would be encouraged to get the necessary training, and others be attracted into the discipline. The BSAENM is looking at the possibility of introducing a diploma scheme for which the accreditation scheme running at present could be one introductory qualification.

8.4 Research Funding Although investigations of mechanism are needed, it would be important that clinical research had at least as high a profile, and that funds are available for professional studies of cost effectiveness. Since most medical research funding comes from (or is administered by groups indebted to) the chemical companies (to whom AEN is understandably anathema), ring-fencing research funds would be necessary to attract researchers to this area.

8.5 Establishing a comprehensive environmentally-controlled inpatient unit (ECU) and subsequently extending provision to provide an accessible service for patients from all over the country. The Airedale Allergy Centre (AAC) was the first purpose built ECU in the world. It was forced to close when the re-organisation of NHS finances left the primary care trusts uncertain about how far their money would go. Nearly all of them delayed agreeing to fund patients for investigations at the AAC, saying that they would reconsider in one or two years. This was a body blow for a small concern depending on staff who had to be trained specially. During the 14 years in which it functioned, it solved medical problems that were regarded as insoluble (Maberly and Anthony J Nutr Med 1991; 2; 83.) and converted hundreds of patients from chronic invalidism to more or less normal life (see Annexes 3 and 4): a number of these patients would undoubtedly have died without this. For some severely and chronically ill patients the role of the environment in provoking their illness can only be identified, or ruled out, by admission to an ECU. Admission (usually for three weeks) is only necessary for small minority of patients, but speeds up recovery in many other patients compared with even the best outpatient practice and makes the management of patients with anaphylaxis and severe asthma safer. ECUs make an important contribution to teaching AEN, make possible valid research into the problems of multiply-allergic patients, and are an essential facility for research into multiple chemical sensitivity.

## 9. COMMENT

9.1 We believe that the evidence available now is quite sufficient for the NHS to make AEN generally available. A rate of improvement as high as 60% (see Annex 6) has never been achieved by placebos, even in the short-term, and most placebo effects are of very limited duration. We see it as quite inappropriate, and very sad, that the few NHS facilities for AEN treatment for adults have been allowed to decline further. Most doctors seeing patients at private clinics have previously been in the NHS and have only left because they found it too difficult to practise this constructive medicine within it; few of them prefer to be private practitioners.

9.2 Before the changes in funding were introduced, patients were being referred under the NHS to the special inpatient facility and for outpatient management at a number of different private clinics; this funding almost dried up and is only slowly increasing again.

9.3 The spread of AEN management would be helped by the employment of specially-trained nurses and/or dieticians to work with these patients in general practice, under the supervision of GPs, but both ancillary staff and the GPs would need special training. The BSAENM is currently training our doctor members and we would hope to be able to extend this to the ancillary workers if funds were available. Because AEN practice is both tiring and time consuming initially (although it saves time, money, effort and heartbreak in the longer-term), doctors would probably need financial incentives at first to undertake training and to supervise ancillary staff. The advantage of having a specially-trained nurse to advise patients about reducing

exposure to aeroallergens and to do prick tests has already been demonstrated (Brydon M. Clin Exp Allergy 1993; 23: 1037). With more training, nurses could also do much of the history taking and play a part (with specially-trained dieticians or nutritional therapists if available) in supervising elimination dieting and subsequent exclusion diets.

9.4 The primary care teams would benefit from specialist allergists to whom to refer difficult cases, preferably with access to an environmentally-controlled inpatient unit (see paras 8.4–8.6).

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### **Memorandum by Dr Amolak Bansal (AL 60)**

#### **INTRODUCTION**

I work as a Clinical Immunologist and Allergist within the Department of Immunology at the St Helier Hospital in Carshalton, Surrey, which is part of the Epsom and St Helier University Hospitals NTIS Trust. I run the immunology and allergy service within this Trust and also at the Kingston Hospital, Kingston, Surrey and the allergy service at the St George's Hospital in Tooting. The catchment area for our allergy referrals is extremely large and includes much of South West Thames, Surrey borders and parts of Middlesex. At the St Helier Hospital I am joined by one further consultant in immunology and allergy. We also employ two nurses both of whom divide their work between immune deficiency and allergy. There are no supporting personnel at Kingston Hospital or at St George's Hospital.

1. While the allergy service at the St Helier Hospital offers a comprehensive range of diagnostic and therapeutic strategies, it is lacking in nursing personnel who are entirely devoted to the management of patients with allergic disease. Additionally, there are no in-patient facilities for the investigation and management of those patients with severe allergic disease or those who suffer anaphylaxis. Investigation of suspected drug allergy is also woefully inadequate, mainly because each of the senior staff do not have sufficient time to devote to the very lengthy and complicated investigations that these patients require. Desensitisation therapy is offered only at the St Helier Hospital and here too there are insufficient staff to cope with the increasing demand. The lack of facilities for desensitisation therapy makes it virtually impossible for those patients living far away from St Helier to comply with the demands of this therapy. This, of course, excludes desensitisation therapy on the basis of the patient's post code.

2. In order to improve the provision of allergy services there is an urgent need to increase the number of trained allergists and also nurses specialising in this field. In particular, the number of paediatric allergists certainly needs to be increased as there are less than a handful around the country. For the Epsom and St Helier University Hospitals NITS Trust that includes the Queen Mary's Children's Hospital, this is the area that requires most attention. Here my waiting list appears to be increasing very rapidly despite numerous attempts to bring this down. For the adult clinics, there is again a need for at least one fully funded nurse specialising in allergic disease. The same is also true for the allergy clinics I run at St George's and Kingston Hospitals. Only in this way can the ever increasing number of patients with allergic disease be seen, investigated and managed within a clinically acceptable time frame.

3. For the Kingston Hospital clinic, the local PCT's have withdrawn their support and referrals are vetted by the PCT with those that require treatment being sent to my St Helier Hospital clinic. This obviously presents many problems for patients in this area, especially the young and the elderly who have considerable distances to travel. I therefore believe that PCT's should be encouraged to support allergy services at their local hospital even though PCT leaders may feel that patients with cardiac disease or cancer deserve the greater attention. For the future, practice nurses within GP surgeries should be encouraged to perform skin prick testing and educational programmes of the sort that I hope to organise at St Helier Hospital, need support.

*June 2004*

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### **Memorandum by Dr Jonathan Hourihane (AL 61)**

#### **1. SUMMARY**

The administrative schizophrenia over local provision of allergy services needs proper attention from the centre as allergy is rarely viewed without prejudice in local health economies, despite its low cost and its place at the interface of community and hospital services.

#### **2. CREDENTIALS**

I am one of the five Paediatric Allergy Specialists in the United Kingdom. I am designated as such by my training (and higher degree) with Professor John Warner in Southampton and my possession of a CCST in General Paediatrics with sub-specialty training in Allergy, Immunology and Infectious Diseases. I am soon stepping down from chairing the Paediatric Subcommittee of the Council of British Society of Allergy and

Clinical Immunology (BSACI). I recently successfully negotiated the establishment in Southampton of the first training post for Paediatric Allergy, which was converted from a Respiratory training post rather than established *de novo*. I am the Convenor of the Wessex Allergy Network, which has commercial support and funding because it was impossible to identify any funding through the NHS, despite the stated aspiration to support such networks.

3. What follows is a personal submission as I have had sight of and commented upon several other submissions to the select Committee from the President of BSACI and other sources. I hope it will inform the Committee of life on the ground as a rare human resource in the NHS.

#### 4. AVAILABILITY OF ALLERGY SERVICES

The Committee will receive several submissions about how patients flounder in primary care or in organ-based clinics where the integrated profile of an allergic patient may not be appreciated. The fact that there is little perception for the need for allergy services in other parts in the country is because PCTs do not know what they do not have, or feel that traditional referral streams are adequate for allergic patients. MPs and families have struggled recently to identify who is leading for allergy in their PCTs.

5. My allergy clinic evolved from my higher degree project on peanut allergy. It is now one of the largest paediatric clinics in Southampton and has the longest waiting time for both new and review patients, exceeding all government waiting list targets for most of the year. We have to resort to extra evening clinics for which extra funding is used for the staff who deliver the extra service. The clinic is staffed by one trainee and me, a dietitian (inadequate 0.2 full time equivalence) and nursing staff. In the past we have had research fellows too which allowed us to see more patients, but we have no fellows at present.

6. One third of our referrals are from regional Paediatricians and from further afield, occasionally from as far north as Sheffield, Wales and Scotland. We obviously service the Channel Islands too. However the remaining two thirds of our referrals are from the local region and contiguous Primary Care Trusts, which have been traditionally associated with Southampton. This suggests that in Southampton, as in other areas of the United Kingdom that have allergy services, if you build such a service, the local health economy will send their patients to it.

7. I am in an Academic post. 50% of my post is funded by HEFCE and 50% is funded by the NHS Research and Development budget, to account for my role as Assistant Director of the Wellcome Trust Clinical Research Facility in Southampton. It is clear therefore that the NHS's Child Health Directorate in Southampton receives my clinical input, including out of hours work, for free. This is a recurring theme in areas where academics are providing clinical services; allergy seems to be a clear example of this in many parts of the country. When I was appointed in January 2001, the NHS made an explicit requirement of the appointment that there would be no service expansion. I have taken over one clinic from Professor Warner, so the national perception that there are two Paediatric Allergists in Southampton is not strictly accurate: we have two Academic Paediatricians covering the equivalent of one half-time Allergist. The service remains vulnerable to the variations of academic staff availability and also to the requirements of the research-driven agenda of the University. This is particularly the case in the current round of job plan revisions, where academic clinicians are being further discriminated against.

8. So at present John Warner and I provide a service that we all call "Allergy" in what is regarded nationally and internationally as a centre of excellence for the delivery of allergy care, but at present our Directorate considers us under its general paediatric tariff and does not want us to be advertised locally. Currently the Southampton University Hospital Trusts is in financial difficulty and the allergy "service" is at risk to reduce costs. Despite the fact that a new, national allergy code has been produced, I have been asked today not to use this costing code because "... this will automatically send the message that we are delivering a fully supportive service. If we are to develop this, it must be done in the correct manner as a concept paper and then business case, for which there is currently no financial resource available". Certainly that is a risk but I feel that properly badging our activity is more of an opportunity than a risk. In the days of extra contractual referrals we were very popular as our service is low cost but had high income. Our service remains the same but the quicksand of NHS configuration has changed administrative perception of its worth. I have started to develop to develop a business case but have received little concrete assistance from the NHS and have struggled with NHS terminology (being more experienced in the use of the different terminology needed for pursuit of academic funding). I have also been unable to identify an ally or at least an accountable person in local PCTs with whom I could develop such a case.

#### 9. PRIORITIES FOR IMPROVING SERVICES

The over-reliance on service delivery by academics funded by agencies other than the NHS appears to be the obvious place to start consolidating the provision of services and care for allergic individuals. This has been extensively dealt with in the RCP document "Allergy—the unmet Need" published in 2003.

10. Integrated personalised care plans for allergic children appear to decrease the frequency and severity of allergic reactions. This has been shown in the UK by Professor Ewan and her colleagues in Cambridge, published in *The Lancet* in 2002 and in France (Moneret-Vautrin *et al*, 2001). In the absence of the appropriate numbers of experienced staff in primary and secondary level care, the burden of this training



falls disproportionately on centres where an allergic interest has been declared. It is obvious that the expertise in these centres needs to be consolidated to allow the future diffusion of information and expertise from these centres into the regional health economy.

11. Paediatric allergists are ideally placed to deliver an integrated service to children with complex and severe allergies, including those that range from severe hay fever to anaphylaxis after insect stings or ingestion of foods. Paediatricians work in a more multi-disciplinary way than adult physicians. The care of children with severe allergies in the community is a complex process involving a lot of communication, education and reassurance of individuals and professionals who act in loco parentis. This in particular means schools and day care facilities. Children need to be seen by paediatricians, and children with allergies deserve the same access to expert advice as children with diseases for which ample or at least adequate provision is made at local and regional levels, such as diabetes and epilepsy. I attach an article recently published about a comparison of quality of life for children with peanut allergy and diabetes (Avery *et al*, 2003). It needs to be said in all cases where paediatric and adult allergy services coexist they flourish.

## 12. GOVERNANCE AND REGULATION OF INDEPENDENT SECTOR PROVIDERS

Children with chronic conditions, for which NHS services are so rare, must appear as a market opportunity for practitioners of unvalidated test systems. Paediatric Allergy services are plagued by the interventions of practitioners who are not qualified in what could be considered medical allergy. I certainly have personal experience of individual children who have had testing by homeopaths and other practitioners, which have demonstrated “safety” of foods. These children have gone on to suffer severe allergic reactions on exposure to that “safe” food. Conventional testing in our clinic with the foods turned out to be positive, showing the food to be “unsafe”. The absence of access to conventional allergy services must be what drives parents to access these alternative practitioners in many cases. However, even in Southampton, where we have an allergy service, our waiting times are so long that the families are driven by the excessive waiting times to seek answers elsewhere. It is difficult to regulate these providers, and I think from the BSACI and RCPCH point of view, their work cannot be considered proven safe in the way that the medical investigations performed by our medical services have been.

13. The other aspect of the independent sector is private practitioners. Certainly much of the work performed by private practitioners who work conventionally is to be applauded, though their access to the full range of diagnostic and therapeutic interventions such as, for instance, food challenges, is limited. They are therefore only able to provide an incomplete service in most cases for food allergy, although for other allergies it may be more possible to develop complete services in the independent sector.

14. In summary, as one of the few identified Paediatric Allergy Specialists in the country, I feel highly valued by my national and international colleagues in the field of allergy, where UK allergists punch far above our weight, but feel undervalued and overburdened within the NHS community at a strategic level, if not at a personal inter-professional level.

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June 2004

## Memorandum by Professor Aziz Sheikh (AL 62)

By way of introduction, I am Professor of Primary Care Research and Development in the Division of Community Health Sciences at the University of Edinburgh. I also currently serve on the Research committees of the British Thoracic Society and General Practitioners in Airways Group, and am Research Adviser to the National Respiratory Training Centre. Furthermore, I serve on the GP Hanging Committee of the British Medical Journal, am Editorial Advisor to the Primary Care Respiratory Journal and am on the International Editorial Board of the Journal of the Royal Society of Medicine.

My response draws on the following published work and work currently in progress:

# PUBLISHED

- Levy ML, Price D, Zheng X, Simpson C, Hannaford P, Sheikh A. Inadequacies in UK primary care allergy services: national survey of current provisions and perceptions of need. *Clin Exp Allergy*. 2004; 34: 518–9.
- Gupta R, Sheikh A, Strachan DP, Anderson HR. Burden of allergic disease in the UK: secondary analyses of national databases. *Clin Exp Allergy*. 2004; 34: 520–6.
- Walker S, Sheikh A. Managing anaphylaxis: effective emergency and long-term care are necessary. *Clin Exp Allergy*. 2003; 33: 1015–8.
- Sheikh A, Alves B. Age, sex, geographical and socio-economic variations in admissions for anaphylaxis: analysis of four years of English hospital data. *Clin Exp Allergy*. 2001; 31: 1571–6.
- Sheikh A, Levy ML. Costs are a barrier to GPs performing skin prick testing. *Br J Gen Pract*. 1999; 49: 67.

# WORK IN PROGRESS:

- Ryan D, Levy M, Morris A, Sheikh A, Walker S. Management of allergic problems in primary care: time for a rethink?
- Pinnock H, Sheikh A. Meeting the information needs for patients with allergic disorders: Partnership is the key
- Levy M, Price D, Walker S, Sheikh A. Identifying research needs for the primary care management of allergic disorders.
- Grant-Casey J, Pereira S, Scadding GK, Sheikh A. Audit of GP management of allergic rhinitis.

My response is confined to the first two terms of reference:

*Availability of allergy services (including issues such as geographical distribution, access time and patient choice) and specialist services for patients with severe allergies*

1. Geographical distribution of allergic conditions across Britain: Broadly speaking, most allergic conditions have similar disease prevalences across Britain. There is evidence however of a significantly increased risk of anaphylaxis in those resident in the south and in rural areas of Britain.

2. Access to primary care: All patients with allergy should have access to primary care services. These services should extend to the provision of high quality allergy care.

3. Quality of allergy services in primary care: There is however an increasing body of evidence to suggest that primary care provision of allergy services is frequently sub-optimal. This appears to be particularly true with respect to the rarer (and often more severe) allergic conditions such as anaphylaxis but is also true in relation to milder conditions such as hay fever. Key underlying reasons for this sub-optimal care are the dearth of training opportunities—at both an undergraduate and postgraduate level—in the management of allergic problems and the lack of appropriate diagnostic facilities (eg skin prick testing) in primary care.

4. Quality of NHS allergy services and access to specialist care: 80% of a nationally representative sample of GPs in our recent survey rated the quality of allergy care provision in the NHS as “poor”. Key problems highlighted by GPs were difficulties in gaining access to local specialist allergy services and long waiting times for these hospital assessments.

5. Patient choice: Many patients with allergic problems are opting with their feet and seeking care outside of the NHS—this is concerning because much of this private provision of care appears to be based on questionable science and, in some cases, may be dangerous.

# *Priorities for improving services*

1. More regional allergy centres: There is clearly a need for more regional allergy centres and these need to be distributed across the country so as to ensure comparable access for all patients.

2. More allergy consultants: These allergy centres will need to be staffed by appropriately trained allergy consultants and such posts now need to be created and accompanying training opportunities made available. An important role of the core of allergy specialists in regional centres would be to act as an education resource, and to assist with education in primary care. This would raise the knowledge and understanding of allergy in primary care over a wider range of GPs. That has certainly been shown to work well in Eastern region. Interaction with a specialist centre over referred patients and by telephone enquiry (avoiding referral) is a good education resource.

3. Practitioners with a Special Interest in allergy: The majority of patients with allergy can and should be managed within primary care and it is important that investment is made to create regional “Practitioners with Special Interest in Allergy” posts. These GPs and practice nurses can then play the dual role of managing demand on secondary care and also work proactively with GPs to raise standards in provision of allergy care..

4. Meeting the information needs of patients: There is at the moment no central means of developing and disseminating high-quality patient information materials to patients with allergic problems. This is concerning as self-management plays an important role in most allergic problems. Consideration needs to be given as to how this gap can effectively be bridged through working collaboratively with relevant royal colleges and special interest groups.

May 2004

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**Memorandum by Margaret Moss (AL 64)**

I am writing in response to your consultation about allergy services. I see many patients suffering from allergy, intolerance, or sensitivity to foods and environmental chemicals, who have failed to obtain help from the NHS. I suggest that we require:

- (a) more teaching on this topic at undergraduate level, for doctors, nurses and dieticians;
- (b) more postgraduate training on this topic for allergy specialists, paediatricians and GPs;
- (c) a broader approach than just IgE mediated immediate allergy, to consider biochemical causes of food intolerance and sensitivity to chemicals;
- (d) provision of good quality nutritional supplements, to address biochemical causes of food and chemical intolerance;
- (e) sophisticated laboratory services, able to perform reliable tests for nutritional deficiencies, and for biochemical defects that can lead to poor detoxification. Inability to detoxify leads to a lack of tolerance of substances which cause no obvious trouble to the rest of the population; and
- (f) employment of nutritional therapists in primary care, so that the majority of patients can be treated cheaply and quickly, without needing referral to a hospital.

There are many mechanisms other than the action of IgE antibodies, that cause food and chemical intolerance. For example, farmers short of the enzyme paraoxonase are susceptible to poisoning by organophosphates. People who cleave beta carotene too efficiently can build up a toxic load of vitamin A. Many of my patients with food and chemical sensitivity are inefficient at converting the amino acid, cysteine, to sulphate. Sulphate is required to deal with amines and phenols, which occur naturally in foods, and for the integrity of the gut wall. Patients may also be deficient in the phenolsulphotransferase enzymes, that transport sulphate. Some people lack the lactase enzyme, which splits milk sugar into simple sugars. Patients may fail to break down milk and wheat proteins adequately, so that fragments of protein, called peptides, including the opioids in milk and wheat, cause symptoms in the mind or body.

Allergy and intolerance should not be seen simply as acute problems with peanuts or pollen. The contribution of food and chemical sensitivity to chronic illness extends to schizophrenia, autism, ME, fibromyalgia, migraine, arthritis, irritable bowel syndrome and eczema.

You may wish to refer to the following:

1. Brostoff J, Challacombe SJ. 2002. Food Allergy and Intolerance. 2nd edition. Saunders. London.
2. Moss M, Waring RH. 2003. The Plasma Cysteine/Sulphate Ratio: A Possible Clinical Biomarker. *J Nutr Env Med* 13(4): 215–229.

May 2004

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**Memorandum by Dr Tim Wallington (AL 65)**

On behalf of many colleagues in Clinical Immunology and particularly those members of the South of England and Wales Clinical Immunology Audit Group, I am writing in response to the recent call for submission of information to the Health Select Committee inquiring into the provision of Allergy Services.

We have produced a brief document which we hope will help the Committee understand how Allergy Services are provided by the NHS in England and the role played by Clinical Immunologists in that provision. Also, our assertion that in response to the unmet and increasing need for Allergy services the plan should be that they grow in a balanced way, various medical specialities collaborating in the process.

We are available to answer the detailed questions of the Committee and so that current information is available, over the next few weeks we plan to conduct an audit of the Allergy Services that we provide and the pressures they are under, according to the criteria that the Select Committee has set out. We have a meeting of the UK Clinical Immunology Audit Groups planned for 7 October, where the data gathered can be discussed and a joint report finalised. We hope that this exercise will prove useful to the Select Committee as well as ourselves in managing our work and fit with the Committee's working timetable for this inquiry.

## SOME BRIEF INITIAL INPUT FROM THE CLINICAL IMMUNOLOGY COMMUNITY

There are a number of issues pertinent to the provision of Allergy Services by the NHS:

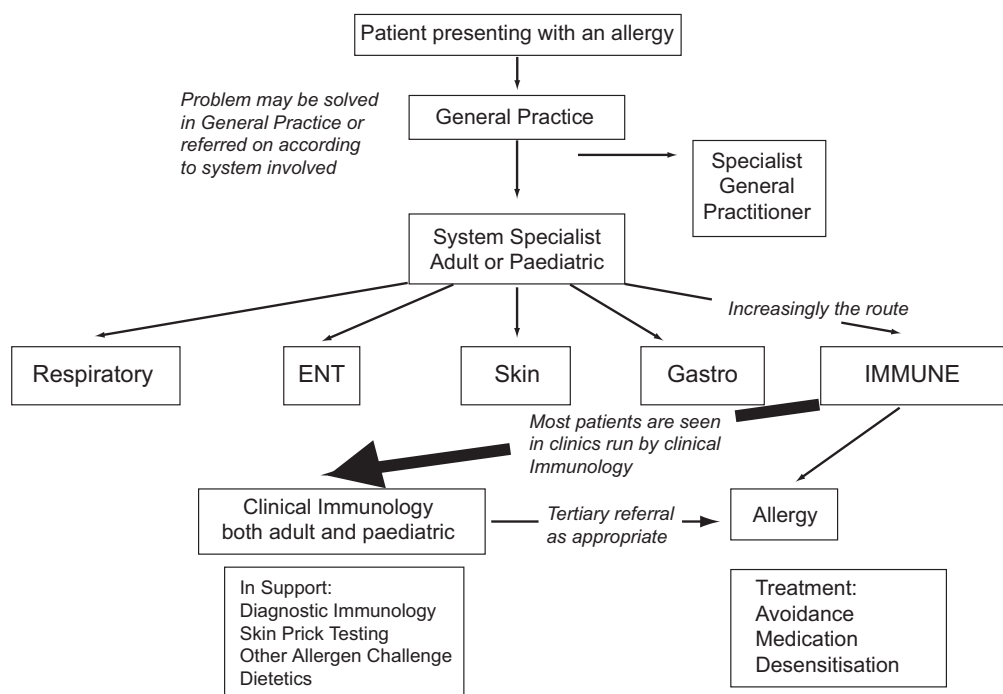
- Allergy has become much commoner in both children and adults and is the cause of both significant mortality and morbidity.
- The expectations of the public of their health care system have risen very significantly over the years especially as regards perceived ill health where a diagnosis and treatment are expected and “allergy” is often blamed.
- Current allergy services are not coping with this demand.

Against this background it is not surprising that there is a demand both from patient support groups and professionals specialising in the field for a program of action to improve the situation.

Clinical Immunology has developed significantly as a NHS specialism over the past 20 years and provides a large proportion of NHS allergy services at secondary level. Clinical Immunologists receive specific training for this during their Specialist Registrar years and it is one of the key areas of clinical practice in which as consultants they are expected to maintain competence. Clinical Immunologists, while endorsing the findings and recommendations of “Allergy, The Unmet Need, a blueprint for patient care.” Published by the Royal College of Physicians in June 2003, are concerned that any plan to improve NHS provision for allergy should recognise the services that are currently provided and how they interrelate. A “map” is provided as part of this short paper that outlines these arrangements. Being pragmatic, we believe that progress can be made most quickly by building on this foundation and at the same time as growing the speciality of Allergy strengthening the relationship between it and the other specialities involved so as to sustain targeted research, identify good practice and make sure that it is applied across the relevant services.

Clinical Immunology is keen to make direct representation to the Select Committee and will make detailed data available when it is needed. As an aid to that process the Clinical Immunology community will conduct an audit of the allergy services against the criteria for information set out by the Select Committee which will be available in the autumn for all those concerned to consider.

## Map of allergy services



In the NHS services for patients with allergies tend to be provided by clinical teams specialists in the system (such as the chest in asthma) involved. Increasingly there is sub specialisation within these teams such that one specialist sees the allergy. Over the past 20 years Clinical Immunology has grown as a speciality and services are available in major medical centres across the UK. Specialists in Clinical Immunology are trained both to provide professional direction to diagnostic immunology services and manage patients with illness mediated by abnormality of the immune response including allergy. Most Clinical Immunology services provide Allergy services which tend to see patients where more than one system is involved (such as anaphylaxis) The numbers of patients seen by these services has grown rapidly in recent years. Up to now

the speciality of Allergy stand alone is provided in a few teaching hospitals usually in an academic setting. Certain of these services are world leaders in research. They are all seen by clinical teams delivering allergy services as setting standards of best clinical practice and a resource for training as well as for tertiary referral of difficult cases.

Overall allergy services are underprovided in the UK. Waiting lists for outpatient consultations are long. A preferred solution might be to build on the alliance of services for Allergy mapped out above rather than focus on just one element of the services currently available.

May 2004

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**Memorandum by Dr Alasdair Stewart MD FRCP (AL 66)**

I am pleased to see that you are enquiring about the provision of allergy services in this country. As one of the first, and still the few, who have been specifically trained in allergy I had great difficulties in finding a Consultant post and eventually became a Chest Consultant and then used my skills in allergy to set up an allergy service for the people of Kent. Despite much badgering I eventually managed to achieve funding to see four new allergy patients a fortnight. This is funded now by one of the local PCTs but I am the only service in Kent and as such technically provide a service for 1.7 million people. As you would imagine the demand for an allergy clinic has been high and for a time our waiting lists lengthened to 70 weeks. That was not acceptable, but despite pleading, no additional funds were found.

In order to meet the Government targets my Trust has at its own cost and risk put on additional allergy clinics such that we now see 10 new patients a week. This has occurred without any additional funding. It is happened as additional work on top of my already busy week. Whilst I am happy to expand allergy services further I do feel that it is about time that the Department of Health and the Commissioners accept that there is an allergy need out there and funded it appropriately.

I work in a Trust which is year on year over spent. We are often over spent because of the additional work that we are putting on without funding. I look forward to hearing the deliberations of your Committee.

May 2004

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**Joint memorandum by Dr G P Spickett and Dr A Fay (AL 68)**

Thank you for asking us to comment to the Committee on the provision of allergy services. We are happy to provide information and comment based on our personal clinical practice in the Northeast. We are responding as individuals.

**1. BACKGROUND**

1.1 For background our Unit is an Immunology Unit that provides allergy services for adults. We currently have 2.6 wte consultant immunologists, 3.2 wte specialist registrars in Immunology 2.2 wte Nurse practitioners and 2.6 clinic nurses. We have 0.4 wte dedicated time from a dietician in support of the allergy service. We provide comprehensive clinical immunology and allergy services for the Northeast of England, but including North Cumbria and parts of North Yorkshire. We also receive allergy referrals from Southern Scotland, as there are no dedicated allergy services in Edinburgh. One of us [GPS] also undertakes a limited private practice. We meet all the requirements for an allergy centre which have been identified in the draft BSACI document, including staffing, facilities, workload and services provided. Disappointingly, we have not previously been included in lists of "allergy centres", although we believe this issue has now been resolved. The Head of Department is Dr Spickett who has dual training in Immunopathology and Clinical Immunology and Allergy [under the old system for higher training pre-dating the Calman reforms]. The other consultants within the Department are trained as Immunologists. A separate Paediatric Immunology and Allergy Department in Newcastle deals with Children. It has five consultants.

1.2 Following a widely publicised local death from nut anaphylaxis, in 1994, we have had an increasing number of allergy referrals. Three years ago the waiting list for routine referrals reached a peak of 15 months. As a result, in discussion with our Trust Management and Regional Specialist Service Commissioners, we have been able to completely re-engineer the service and we now have effectively no waiting list for routine allergy new referrals. At present urgent new patients are seen within two weeks, and routine patients are offered an appointment at a time of their choice within a four to eight week timeframe. This has been achieved by:

- (a) Trust investment in refurbishing premises to provide a dedicated Immunology and Allergy Unit with the physical capacity to handle the workload.

- (b) Funding from specialist service commissioners to appoint additional staff [0.6 wte consultant, 1 wte Grade G nurse, 2 wte Grade E nurses 0.4 wte dietician, 1 wte BMS-I and 1 AandC3].
- (c) Implementation of a partial booking system run, from within our Department, to maximise the responsiveness of the system to Departmental needs.
- (d) The training of three Nurse Practitioners in Allergy and Immunology. These have followed a training programme similar to the specialist registrars and have all completed the extended and supplementary prescribing courses.
- (e) The establishment of independent nurse-led allergy clinics, which now take 16% of the new allergy referrals.
- (f) Work with GPs through educational activities and referral advice to limit unnecessary referrals.
- (g) Re-organising clinics to separate new and follow-up patients, and striving to achieve a one-stop clinic for most allergy patients.
- (h) Ensuring that clinic timings are optimised to reduce clinic waiting times and improve efficiency.
- (i) Using additional waiting list clinics during the week and at weekends to clear long waiters: these are now no longer needed. These were approached on a “team reward” basis, to ensure that all participants in the clinics received an appropriate reward for their additional work. This involved a lower reward for medical staff but a higher reward for clerical and nursing staff. Saturday clinics were well received by patients and experienced a nearly zero “did not attend” rate.
- (j) Additional private clinics [GPS] for insured patients have also contributed to the reduction in NIIS waiting times. Now that the NITS waiting times are short, the demand for private referrals has dropped sharply.

1.3 Areas of ongoing pressure within the Department include meeting the need for allergic immunotherapy and testing for drug allergy: these are being addressed internally and are reducing steadily. We have complete flexibility within our Unit to address these issues.

## 2. CONCLUSIONS

2.1 Based on our experience in successfully managing the demand for allergy services in our region, we would make the following observations for consideration by the Committee.

- (a) Clinical Immunologists contribute substantially to meeting allergy demand; training for our specialist registrars in Immunology includes allergy. This has not always been recognised by the professional bodies [BSACI, Royal Colleges], although this is now being addressed.
- (b) We have been lucky in that our specialised services commissioners have been active and keen to engage in a dialogue over development of services, seeking plans for strategic development. This is not the case in most other Regions in England. Considerable work by professional bodies went into the development of the specialised service definitions and it is extremely disheartening to see that these have in the main been ignored and specific funding not made available. The DoH should be instructed to ensure that specialised services, as defined, are properly financially supported and developed, with penalties for PCTs/SHAs that fail to do so. Even in our Region our Commissioners are unable to meet the full financial implications of the supporting specialised services, the shortfall being approximately 66% of bid value.
- (c) Provision of dedicated outpatient and day case space within hospitals is essential to meeting the needs of patients with allergic disease in full and ensuring that a flexible system is developed.
- (d) The re-engineering of clinic systems has had positive benefits for patients (seen at their appointment times without waits) and for staff through improved working conditions with less stress.
- (e) The investment required to achieve this has been relatively small in capital and revenue terms.
- (f) The use of a “team reward” system for waiting lists had a positive benefit in improving team working and team spirit and markedly facilitated improved productivity.
- (g) The introduction of nurse-led clinics has been positively received by patients [and has been audited]. We believe that there is considerable scope for further expansion of the Allergy Nurse Practitioner role, and we intend to develop it further, both in terms of increasing the number of nurse-led clinics and the involvement of nurses in allergic immunotherapy and handling allergic emergencies. This model could be more widely used to meet clinical need.
- (h) Further expansion of the Nurse Formulary will be helpful, for example the ability to provide prescriptions for corticosteroids and adrenaline for self-injection. We understand that the MRHA is currently reviewing this. At present the restrictions placed on the development of prescribing nurses restricts our ability to further develop this role in Allergy.

- (i) Units cannot operate at full capacity all the time as this reduces the flexibility, stresses staff and leads to a poor service for patients. Time must be allocated for training. Training of the Nurse Practitioners placed a considerable load on the medical staff during the training period, but has been rewarded on completion of training by a sharing of workload.
- (j) The development of an independent clinical role for Nurse Practitioners has improved job satisfaction and career prospects for our specialist nurses. Serious consideration should be given to the establishment of Nurse Consultant posts in Allergy and Immunology, dedicated to service delivery [not pushing papers around a desk!].
- (k) Development of services to provide one-stop service is desirable: this requires integration with dietetics services and diagnostic facilities.
- (l) Education and involvement of general practitioners in the process is essential. More use could be made of GPs with a special interest [GPSI], both within hospitals but also operating in primary care supporting several practices. We hope to initiate this locally.
- (m) Provision of timely NITS services, responsive to patient needs, reduces the demand for private allergy services and will hopefully also reduce the number of patients using alternative, unvalidated, allergy diagnostic tests available through healthfood shops etc, that give misleading information. Greater restrictions should be placed on alternative practitioners selling unvalidated tests and allergy advice directly to the general public.

We hope that these comments are helpful to the Committee in its discussions and are happy to provide any further information required.

May 2004

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**Joint memorandum by Dr D E Lacy, Dr J Seager and Mr A Bardsley (AL 69)**

We enclose a memorandum from this Children's Unit in a District General Hospital. This follows the structure set out in the terms of reference. It includes an audit of the activity in this Unit over the last year together with our recommendations for Paediatric Allergy Services.

If you or the Committee would like us to attend to answer questions or clarify any points we should be happy to do so.

#### INTRODUCTION

This report is submitted to the Health Committee by Dr D E Lacy and Dr J Seager, Consultant Paediatricians and Mr A Bardsley, Directorate Manager on behalf of Wirral Services for Child Health (WiSCH), part of Wirral Hospitals NHS Trust which provides a National Health Allergy Clinic for children at Arrowe Park Hospital. Wirral is part of the Cheshire and Merseyside Strategic Health Authority. WiSCH provides integrated acute hospital and community paediatric services for three Primary Care Trusts, (PCT), Birkenhead and Wallasey, Bebington and West Wirral and Neston and Ellesmere Port, serving a population of 360,000 people (80,000 children under 19 years of age). As there is no paediatric allergy service nearer than Liverpool or Warrington the catchment area extends beyond the PCT boundaries in the direction of the adjacent city of Chester.

#### CLINICAL SERVICE

The Allergy Assessment Clinic is staffed (ref 1) by a Consultant Paediatrician, a Senior Paediatric Dietitian and an Allergy Nurse Specialist who is also the Paediatric Asthma Nurse Specialist for the Trust. At every third clinic a visiting Consultant Allergist is present. The clinic is held in a dedicated Paediatric Out-Patients Suite staffed by Children's nurses with appropriate waiting area and trained appointment staff. Acute paediatric wards, Accident and Emergency services and a Children's Day Ward are on the same site. School Nurses are managed by WiSCH so it is possible to ensure that where parents and children want this information and advice can be passed to teachers in all local schools. A written protocol is supplied (ref 2) and where necessary the Allergy Nurse can demonstrate the use of a pre-loaded epinephrine (adrenaline) syringe. Two members of the paediatric nursing staff are trained in the performance of skin-prick allergy tests and these can be done during the clinic or on the Paediatric Day Ward where food challenges are arranged by the Paediatric Dietitian and carried out by a nurse supported by the paediatric medical team where necessary. Food challenge protocols and emergency drug regimens (ref 2) are subject to regular review by the hospital Clinical Governance team and to appraisal by the Paediatric Pharmacist.

## PATIENT ACCESS

Access to the clinic is by direct referral by General Practitioners, by referral from consultant hospital or community paediatricians or from other consultants eg in dermatology or ENT. The proportion from each of these sources is detailed in the evidence below. Waiting time in the last year has been within Government requirements. All letters from OPs are reviewed by a consultant paediatrician and children are assessed as requiring an urgent, soon or routine appointment. Where appropriate children are referred for dietitian's advice +/- skin-prick testing prior to their clinic appointment.

## PARENTAL CHOICE

Parents can exercise choice by asking their general practitioner or consultant for referral to one of the more distant clinics at Liverpool or Manchester (where there is a professor of paediatrics with an interest in allergy), but perhaps because we are able to offer a reasonably rapid service which includes dietitian, specialist nurse and school liaison, we find that the referral trend seems to be slowly in the other direction. Not all local general practitioners are aware of the service we offer, but this situation is improving.

Local alternative medical practitioners offer various services (see the Vega testing leaflet ref 3). We do not know how widely these alternative services are used. Some parents come to us after they have had a battery of investigations done at their own expense and are concerned to know the implication for their child when, for example, a test is positive for wheat. This includes children who have had radioallergosorbent (RAST) tests done by privately run biochemistry laboratories where standards and quality control may be high, but no advice is given on the significance of the finding or the consequences of an exclusion diet for a growing child.

The evidence below has been gathered by examining records of the most recent 100 new patients seen at the Allergy Clinic up to April 2004.

AUDIT OF SERVICES PROVIDED AT ALLERGY ASSESSMENT CLINIC AT  
ARROWE PARK HOSPITAL

Age range (at next birthday):	1–15 years	
Referral by:	General Practitioner	71%
	Paediatrician	23% (this will include children who have presented to the emergency services in the hospital with acute anaphylaxis) 7% were referred by community paediatricians
	Other consultants:	4%
	Not recorded	2%

SUSPECTED ALLERGY TO: (NUMBER OF CHILDREN REPORTED)

Foods:	
Peanut	53
Egg	25
Mild	15
Hazelnut	7
Cereals	6
Cashew	5
Almond, brazil, strawberry	4
Peas, prawns, sesame	3
Apple, baked beans, blackcurrant, chocolate, fish, papaya, potato	2
Amaretto, aniseed, apricot, avocado, broccoli, cheese, cherry, grapefruit, ice cream, Jelly Tots, lentil, melon, nectarine, peach, pecan, plumb, rhubarb, raspberry, soya, tangerine, Thai fish sauce, tuna	1
Non-foods:	
Cat	17
Dog	14
Soaps, detergent	3
Hamster	2
Latex	2
Amoxil, Calpol, chlorine, diesel, Elastoplast, gnat bite, guinea pig, lanolin, Micropore, morphine, pine trees, Piriton, wax crayons	1



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Reported 5 or more non-food allergens:	3%
Insect Sting:	2%
Maternal Pica:	26%
Complicated Birth: (pre-term, LUSCS, forceps/Ventouse, intubated at birth)	5%
Breast Fed:	54%
	(breast-fed for more than one month 45%)
Previous eczema:	80%
Previous asthma:	52%
Previous hayfever:	32%
First degree relative with:	
Eczema:	32%
Asthma:	38%
Hayfever:	50%
Allergy:	38%
History of relatives with food allergy as sole reason for referral to the clinic:	5%

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### *Epinephrine Prescription*

Epinephrine pen prescribed at clinic or GP asked to prescribe: 26% (peanut 23, brazil 2, cashew 1)

Epinephrine pen already prescribed: 9% (peanut 6, wasp, cashew, pollen)

Parents advised and considering its use: 10% (peanut 8, almond, latex)

The epinephrine pen was prescribed or advised for 28 of the 34 children, ie 82% who had both peanut allergy and asthma. It was prescribed for 8 of the 18 children, ie 44% who had peanut allergy, but did not have asthma.

### *Skin-prick Tests*

These were performed on 26% of the children. Approximately 75% were positive, 25% negative.

### *Food challenges*

Total tests done 1.5.03 to 1.5.04. 62 (egg 27, peanut 13, milk 9, cod and hydrolysed feeding formula 3, almond, salmon, brazil nut 2, anchovy 1). Each challenge test takes approximately five hours from start to finish.

### *Associated Issues*

(a) High incidence of atopic disease including eczema, asthma and allergic rhinitis which is present in children referred with food allergy. Advice on eczema can easily be given in the setting of a paediatric clinic. A key requirement in the management of severe food allergy in children is to ensure good asthma control because in addition to anaphylaxis food allergy can trigger a life-threatening attack of asthma. This is much less likely to happen if regular appropriate asthma treatment is being taken. The Asthma/Allergy Nurse Specialist is able to pick up on these issues and address them at clinic or afterwards.

(b) Severe allergy might be defined as a history of life-threatening episodes in the past or by reported allergy to multiple different substances. In either case the problems are best addressed by the same team as is involved with the more routine cases as most of the issues are identical and support will need to be co-ordinated locally at home and at school. Emergency treatment will also need to be close at hand.

(c) Although enquiries about immunisation from general practitioners are generally directed to a consultant community paediatrician parents often raise queries about particular immunisations at the Allergy Clinic. This is a useful opportunity to answer questions and to discuss anxieties about some widely held misunderstandings such as the belief that MMR immunisation cannot be given to children who have egg allergy. When concerns persist the offer to do the immunisation on the Paediatric Day Ward will sometimes ensure that a child gets immunised.

(d) Finally, problems such as cow's milk allergy or intolerance are common in infancy and are generally dealt with outside the Allergy Clinic, either by the Primary Health Care Team or in general paediatric out-patients clinics. This seems entirely appropriate. However, severe or persistent problems would benefit from assessment in the Allergy Clinic. Milk and egg challenges can then, if necessary, be arranged on the Children's Day Ward.

(e) Desensitisation treatment would be referred to a Regional Allergy Clinic.

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## RECOMMENDATIONS

1. PCTs should be resourced to provide a paediatric allergy service with ready access to a clinic serving a population group of approximately 500,000 people. Central to this is the need for funding for an appropriate number of service sessions by the paediatric dietitian.
2. Allergy in children should be managed as an integral part of children's health services as it affects infant and child nutrition and growth and has important psychological and educational consequences.
3. Paediatric Allergy Clinics should offer the services of a paediatric dietitian, a paediatric allergy nurse, preferably with training in the management of paediatric asthma and a consultant paediatrician. Combined clinics with a consultant allergist on an intermittent basis are of great benefit if the clinic is held in a District General Hospital. As there is nationally a shortage of consultant allergists a service such as ours would benefit from increased numbers in that speciality.
4. Paediatric Allergy Clinics should have the facilities to carry out skin-prick and RAST tests and have ready access to Paediatric Day Ward facilities for performance of food challenges. Day Wards should have the immediate availability of medical staff trained in Paediatric Life Support. Challenges should be carried out according to regularly reviewed protocols.

## REFERENCES

- Ref 1: Full details of sessional time worked by Consultant Paediatrician, Senior Paediatric Dietitian and Allergy Nurse available from Directorate Management Team, WiSCH—tel: 0151-482 7868; fax: 0151-482 7875
- Ref 2: Copies of all protocols issued at the Allergy Clinic and protocols used for food challenges and emergency drug treatment available as above on request.
- Ref 3: A copy of alternative medicine (Vega testing) advertised locally and featuring a picture of a child undergoing assessment available on request.

May 2004

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### Memorandum by Professor Roger J Buckley (AL 70)

I am glad of the opportunity to comment on the forthcoming inquiry on the provision of allergy services.

1. Ocular allergy affects around 21% of the adult population of this country, usually on a seasonal basis.
2. Ocular allergy is not fully addressed by clinical allergists, dermatologists, pediatricians, ENT specialists, chest physicians, general practitioners or others who diagnose and treat allergic disease, principally because they do not have the equipment or training to enable them to examine the ocular tissues in detail. Insufficient ophthalmologists, even including those specialising in ocular surface and anterior segment disorders, have a specific interest in ocular allergy. The result is that the medical profession as a whole neglects this important area.
3. It is often left to nurses, pharmacists and the patients themselves to diagnose and treat ocular allergy, using Pharmacy medicines.
4. Whereas most ocular allergy does not threaten sight, there exist important severe chronic diseases (such as vernal keratoconjunctivitis and atopic keratoconjunctivitis) that are specifically sight-threatening. Such conditions should only be managed by ophthalmologists experienced in such work.
5. In conclusion, ocular allergy is a neglected area in this country. Professional bodies such as the Royal College of Ophthalmologists could address this issue by providing training programs, in the first instance for trainee ophthalmologists.

May 2004

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### Memorandum by Latex Allergy Support Group (AL 71)

## BACKGROUND

1. The Latex Allergy Support Group is a national voluntary self-help organisation founded in 1996, with 300+ members. The aims of the Group are to raise awareness of this allergy, provide support for those affected and promote the safe and appropriate use of latex products and equipment. An advisory panel provides advice on medical and technological issues.

2. Allergy to natural rubber latex (NRL) was first described in 1979 and, as with other allergies related to an underlying atopic susceptibility, the past 15 years has seen its recognition as a health issue of increasing importance. Latex allergy is thought to affect less than 1% of the general population, but is commoner in certain groups who are regularly exposed to latex, including healthcare workers from widespread use of medical gloves, and most notably patients with spina bifida exposed to gloves/catheters.

3. Latex allergy is generally taken to mean a reaction to the constituent proteins, of which there are several, and is an example of an “immediate” Type I IgE-associated reaction. The clinical effects are similar to those from allergy to peanuts, in that most will have relatively mild local reactions, some will have more troublesome local and respiratory problems and a few will be at risk of potentially fatal anaphylactic reactions.

4. It is not possible at present to predict which individuals may progress from mild reactions to anaphylaxis, or when a more severe reaction may occur. The greatest potential danger to an allergic individual comes from mucosal contact (surgical/medical/dental/obstetric gloves must be avoided) or from inhalation of latex (carried in the air by powder from glove or balloon). Patients presenting with anaphylactic reactions during surgery or with occupational asthma may be found on subsequent investigation to be latex allergic.

5. A diagnosis of latex allergy may have profound consequences for the patient from worry about the ubiquitous nature of NRL in the environment together with its potentially serious import. In addition, investigation of the allergy is not without hazard. It is therefore important that patients with suspected latex allergy be referred to appropriately trained practitioners to enable accurate diagnosis and sound advice to be given, generally by an allergist, dermatologist or other clinician with a sub-speciality interest.

6. Latex is a hazardous substance for the purposes of the Control of Substances Hazardous to Health Regulations 2002 (COSHH), and healthcare organisations are now expected to have in place robust policies, both to minimise the development of latex allergy in the workforce, and also to provide a latex-safe environment for allergic patients and staff.

7. There is an overlap between NRL (a plant product) and food (usually fresh fruit) allergy due to common/cross-reacting antigens. Allergic (including anaphylactic) reactions to, for example, banana, kiwi or avocado may be the first clinical presentation of a previously undiagnosed latex allergy.

#### SPECIALIST SERVICE

8. A recent and as yet unpublished postal questionnaire survey conducted by a consultant dermatologist and a consultant allergist of 417 UK specialists shows considerable variation in latex allergy diagnostic and management practice both within and between dermatology and allergy departments.

9. Many (75) of those who see patients with suspected latex allergy do not perform the most reliable diagnostic investigation of skin prick testing because of its potential for causing an anaphylactic reaction and/or lack of trained staff/facilities, and are therefore at risk of under-diagnosing this condition.

10. Provision of basic information to help allergic patients cope with what can sometimes be a very daunting prospect is neither standard nor consistent. Advice on the need or otherwise of self-administered adrenaline is also variable, reflecting a lack of national guidance on this issue.

11. Over 90% of allergists in this survey report no reduction in the number of patients they are seeing with latex allergy. Each region should have allergists in place to improve the management of latex allergy through educational and strategic partnership working practices.

#### LATEX POLICIES WITHIN HEALTHCARE

12. A recent and as yet unpublished survey conducted jointly by the National Patient Safety Agency (NPSA), the Latex Allergy Support Group and the National Association of Theatre Nurses shows that the policies and practices adopted by NHS trusts in relation to the potential dangers of natural rubber latex vary considerably. Some trusts (around 60% overall) have implemented clear policies and arrangements for managing or minimising risk. Others have done much less, relying on partial or ad hoc arrangements, or reacting to events rather than taking proactive steps. Three broad conclusions emerge from the survey.

13. First, despite national guidance, there remains a need for trusts to ensure that they have in place a comprehensive policy supported by efficient management arrangements for identifying and protecting sensitised staff and patients.

14. Second, trusts will need to be able easily and with certainty to identify whether or not a product and/or its packaging contains latex. Appropriate labelling and catalogue descriptions of products and packaging are therefore urgently needed.

15. Third, there is an obvious need for a greater choice of effective, suitable and cost-effective latex-free products and equipment. This remains a concern for many NHS purchasers and managers.

## SUMMARY

16. Natural rubber latex has many positive attributes. Comfort, strength, biological protection and low cost have made latex gloves the standard choice for use within healthcare. Recognition of the problem with latex allergy has led manufacturers to reduce the protein content and remove the powder from medical gloves, although it is not yet possible to completely remove all NRL allergens.

17. Reduction in NRL allergen content of medical gloves is likely to reduce the number of healthcare staff developing latex allergy, but the need remains to provide a safe environment within healthcare for already allergic individuals, a few of whom react to even tiny amounts of NRL in the environment. The recent NPSA survey shows there is still much to do to safeguard affected individuals.

18. Synthetic glove alternatives are readily available for use by or for allergic individuals, and advances in technology are producing improved synthetic gloves as a viable routine alternative to latex. Where there is no clear need for latex to be used, items of medical equipment are gradually being replaced with synthetic substitutes where possible, and this conversion should be actively encouraged.

19. Investigation and management of patients with latex allergy can be time-consuming. A lack of trained personnel and competing demands on time in specialist clinics will inevitably compromise optimal management for some. There is a need for an even geographic spread of expertise and support staff along with consensus national guidance to allow more consistent practice across the country.

20. There is a dearth of available data, but anecdotal evidence suggests that latex gloves are widely used out-with the healthcare setting, for example in garages, restaurants and hairdressing salons. We do not know how allergenic these gloves are, but the need to minimise costs is likely to mean that many are cheap, highly allergenic and powdered. If this is the case, the gloves will be a risk both for those who wear them (from developing allergy) and also for their customers (eg from transfer of latex allergens to car interior or food). It is possible that widespread use of highly allergenic gloves in such occupations will produce a similar outbreak of overt allergy that has already been encountered in healthcare. Further study is needed in this area.

21. The Latex Allergy Support Group sees the delivery of quality education (including general hand care) and information (including accurate labelling) for all healthcare staff, managers, employers and the general public as absolutely central to addressing this problem. We urge the Government to recognise latex allergy as an important health issue and provide the necessary funding to address it properly.

*June 2004*

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**Memorandum by Mid Sussex NHS Primary Care Trust (AL 77)**

We believe that you are conducting an enquiry into the provision of allergy services in England. As school nurses involved in this provision, we wanted to pass on some details on the workload we have re-allergies.

- Out of 16 schools in the area, 15 have children with severe allergies requiring adrenalin to be available at all times (50 children in total).
- Each of these schools requires an annual update of all teaching and ancillary staff (one to three hours/school).
- All newly diagnosed children and parents need a consultation with us (one hour).
- We are involved in the formatting of school policies with respect to allergies.

All of this is the minimum required after the child has been diagnosed and hopefully seen by specialist allergy services. As this is a growing problem, the importance of these services cannot be overemphasised.

*May 2004*

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**Supplementary memorandum by the Department of Health (AL 10a)**

Numbers refer to those in the uncorrected transcript of oral evidence of 1 July 2004.

[Related subjects have been brigaded together for ease of reference].

*Q148*

Dr Taylor raised a specific issue about the Brompton Hospital. My officials have made enquiries, and now understand that there has never been a Professor of Allergy at the Brompton. There are a number of consultants who specialise in the area and—in fact—the Royal Brompton has a number of internationally acclaimed allergy experts among its honorary consultants; but not a “Professor of Allergy” as such.

*Q180; Q181*

The Committee wanted to know about the incidence of anaphylaxis; whether GP practices are equipped to respond to such attacks; and how many kits for the self-administration of adrenaline are issued.

The best estimate available to the Department is that one person in 3,500 is at risk of anaphylaxis. When someone is identified as being at risk, their GP will—if appropriate—prescribe a self-administration adrenalin kit, and teach the patient (or their carer) in its effective use in the event that they should be exposed to the trigger agent (for example, food that has been contaminated with peanuts).

In 2003, 99,000 self-administration kits (Epipen and Anapen)—with a net ingredient cost of £4.792 millions—were dispensed in community pharmacies against prescriptions written by GPs.

In rare cases anaphylaxis can be triggered by immunisation administered by a GP or the GP's practice nurse; for example, "flu vaccines are contra-indicated for people who are hypersensitive to eggs because the recommended strain is grown in chick embryos. Practices administering such vaccines therefore monitor patients for about 30 minutes after administration, and—should a patient with no previous diagnosis of hypersensitivity to eggs—display symptoms of anaphylaxis, the practice will treat them with adrenalin (and, as appropriate, anti-histamine and oxygen).

The new GMS Contract rewards and provides incentives for the provision of high quality care, the Quality & Outcomes Framework (QOF) includes:

Medicines Management; the practice possesses the equipment and up-to-date emergency drugs to treat anaphylaxis.

This helps to ensure that patients suffering anaphylaxis—whether as an adverse reaction to vaccination, or as a result of animal bite, insect sting or other exposure—can access the necessary emergency treatment, quickly and close to home.

*Q197; Q198*

Mr Amess pressed me on the numbers of posts for specialists, and whether there are any unfilled posts.

Whilst the Department appreciates the need for expansion in the allergy workforce, this need must be considered alongside the priority for increasing numbers in shortage specialties such as histopathology and radiology, which are critical for the delivery of Cancer services and for achieving Access targets.

The large number of competing priorities for a limited number of centrally funded National Training Numbers (NTNs) has naturally resulted in some specialties being disappointed with the final outcome. It is true to say that no specialty has had its ambitions for centrally funded posts fully met.

Modelled projection of growth has shown that the allergy workforce will not expand without an increase in funded training numbers and growth has been negligible over recent years. As recognition of the need to increase the workforce, I can confirm that allergy was allocated an additional centrally funded post in 2004–05 and a further post has been allocated for 2005–06. There are also other ways to create Specialist Registrar posts. Trusts can either make further use of existing training opportunities (which is cost-neutral) or have the opportunity to fund posts locally. To date, no Trusts have opted to increase the workforce through these means.

My officials are currently liaising with the Lead Dean for allergy to determine the implementation status of the 2004–05 centrally funded post, which has been allocated to Leicestershire, Northamptonshire and Rutland WDC. Allergy has been allocated a centrally funded post in 2004–05 and a further post in 2005–06.

A large number of allocated training posts are not filled by trainees.

In 2003–04, there were six allergy training posts, of which one was unfilled. This is because recruitment has not yet taken place, but an exercise is planned, with appointment due before December 2005.

The specialty needs 10 funded numbers in 2005–06 and a further 10 in 2006–07 to establish a credible workforce.

At the specialty review meeting on 30 March 2004, key allergy stakeholders put forward the case for 10 centrally funded NTNs in 2005–06 and a further 10 posts in 2006–07. It was acknowledged that these increases would significantly boost the allergy workforce. However, it was made clear at the meeting that these requirements must be considered in the context of funding and training opportunities available and the priorities for all medical specialties. Allergy representatives were informed that their requirements could not be regarded as a definite future allocation.

*Q200*

Mr Amess asked for an update following a meeting I had with Jon Cruddas earlier this year.

At the meeting with Jon Cruddas in January, we discussed the fact that the training of doctors was a matter for the Royal Colleges; and that the Government doesn't make decisions on how money is spent locally on provision of services. Devolving power to the front line means that PCTs commission services locally.

I explained that the Long Term Conditions NSF and the Children's NSF would cover generic conditions which would benefit allergy sufferers, and that—at the end of the year—Ministers would need to decide whether other NSFs were needed.

I undertook to look into whether NICE could include guidelines on allergy services in their forward work programme; and also to ask the CMO to consider an Action Plan, similar to the Plan produced for epilepsy (with the Allergy Alliance, if they were willing to contribute their expertise).

*July 2004*

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