

National Allergy Strategy Group All Party Parliamentary Group for Allergy March 4th 2013

Patients continue to be failed by inadequate NHS allergy services

A meeting hosted by Jon Cruddas MP on behalf of the APPGA and the NASG highlighted the fact that the **NHS** is still failing the growing numbers of people with allergic disease despite it being ten years since the Royal College of Physicians highlighted the problem in its report: "Allergy – the unmet need"

The attendees were parents of allergic children; those who are allergic themselves; clinicians from primary through to tertiary care; pharmacists; school nurses and patient group representatives and all came together to **demand improved care** for the twenty million people who live with allergic disease in the UK today with Dr Pam Ewan stating that services are "completely inadequate for the allergy epidemic" and Professor Stephen Holgate telling the meeting that there is "a resistance by the Department of Health to recognise the issue of allergy in the UK".

National Reports over a decade

Despite a series of Government inquiries and reports including the 2006 DH review of allergy services which conceded an unmet need, the NHS is still unable to cope with the growing epidemic due to a lack of specialist services and little action to support GPs with education in allergy.

What allergy care offers

Specialist allergy services deal with the multiple expressions of allergy in each individual patient, identify the cause of each, and provide avoidance and other management as well as supportive follow up. The result is improved outcomes for patients, reduction of illness and cost savings to the NHS, yet many allergic people with, often, multiple allergic disease do not receive specialist care, which impacts on their quality of life.

The new NW centre

One of the outputs of the DH Review of 2006 was a recommendation to create a new allergy centre; the North West Region of England was selected. Roy Dudley-Southern, specialist commissioner at the time of the project reported on the outcomes which show commendable development in services, particularly in paediatric allergy. Disappointingly, the local commissioning team was constrained by having no funding for staff. Although new staff were appointed, resources proved inadequate to develop an allergy centre, which would provide specialist care and network with GPs and other providers to raise standards. There remains a wide gap between patient need and service provision. Mr Dudley-Southern confirmed that an inadequate care system in many parts of the UK led to "unnecessary"

suffering for patients". In particular it was highlighted that there are gaps for adolescents as they move from paediatric to adult care.

Patients' views

Living with allergy affects patients and their families in numerous ways and many of those attending the meeting had individual stories to tell of their own journey to access care. Here are some of the comments which highlight the concerns:

"I am disgusted by the lack of care and advice my family was offered"

"There is information out there but it is not getting to the right people"

"Life is a constant struggle living with anaphylaxis....we deserve better continuity of care"

"The importance and benefits of supporting parents cannot be over emphasized as the consequences of living with food allergy impacts so much on family life"

"I wish I received the same level of care as my four year old son for my own allergies and that we could be treated in the same hospital"

"Without paying privately for immunotherapy I would have been excluded from many aspects of life including doing the Duke of Edinburgh award and joining the cadets"

My son is now 20....he has never seen an allergy specialist or an immunologist. His many other specialists "manage" his allergies"

"Despite living in the South East of England I have struggled to access care for my son in numerous different places and we have had to be re-referred many times as a result"

"My GP told me there was no need to be referred to a specialist for my child's food allergies"

"The hospital told me to challenge test my son to milk at home"

"My nine year old son died last year following a reaction to peanuts. Despite him having asthma, eczema and hayfever and although we had numerous contacts with the NHS, no-one considered food allergy. They treated with drugs for the symptoms but never tried to identify a trigger."

What do patients want?

They want the DH to take allergy seriously and improve NHS Allergy Services. This requires a national strategy and cannot be left any longer to local efforts. This should include:

- 1. More consultants in allergy
- 2. More trainee posts in allergy
- 3. Improved knowledge of allergy for GPs
- 4. Making commissioners aware of the needs of allergy patients