



## National Allergy Strategy Group Parliamentary Reception November 3<sup>rd</sup> 2010

- On November 3<sup>rd</sup> 2010 The National Allergy Strategy Group hosted a parliamentary reception in Dining Room A of the House of Commons to raise awareness of Allergy: the effect on quality of life.
- Hosted by Jo Swinson MP, the event saw over 60 people, children and adults, parents and those allergic themselves, who live with various allergies come together and highlight the issues important to them. Over half attending had their MP or an MP's representative come and meet them to hear directly how allergies impact on their lives and we were also joined by Health Minister Anne Milton MP who spent some time talking with parents and allergic young people about the concerns they have around inadequate allergy care across the UK.
- It is estimated that there are around 7 million people in the UK who have allergy severe enough to require specialist care and there are many millions more who require care from their family doctor.
- Yet despite this, the NHS is unable to cope with the growing epidemic due to a lack of specialist services and little action to support GPs with education in allergy. One Mother of an allergic teenager summed up what many believe:

***“We quickly discovered we had to find out as much as possible ourselves as GPs seemed to have little knowledge of the condition.”***

- Many at the event had never seen an NHS Allergy Consultant and had been living with potentially severe allergies for most of their lives with no support or management advice This was highlighted by one of the key speakers, Ruth Holroyd, a 37 year old who has had multiple allergies for much of her life:

***“I was finally, at the grand old age of 36, referred to an allergy specialist at Amersham hospital. The information she has given me would have been so much more helpful back when I was a teenager and first discovering I had allergies and what should I do to avoid them.”***

- Specialist allergy services aim to provide holistic care dealing with the multiple expressions of allergy in each individual patient and supportive follow up, providing improved outcomes for patients and a base for clinical research, yet many allergic people with, often, multiple allergic disease do not receive specialist care, which impacts on their quality of life. As one attendee pointed out:

***“For something that touches so many people’s lives, there is a shockingly low level of support from the NHS. Early intervention and diagnosis helps reduce the***

***negative consequences of allergy and can prevent reactions becoming anaphylaxis.”***

- In addition to Ruth whose allergy started with nuts and over the years has grown to now include dairy and latex, the reception heard from Yussra Syed who is 9 years old and is allergic to dairy, soya, eggs, nuts, fish, wheat, oats, corn, rye, barley, chickpeas, buckwheat, lupin flour, watermelon, latex, dust and pets. She told of how she is hoping to raise awareness of allergies amongst medical experts to show how important it is to understand about anaphylaxis and Gea Roex a 17 year old severely allergic to dairy. She wants to help those who do not suffer from allergies themselves to understand what it is like to live with them and how they really do affect your quality of life.
- Living with allergy affects quality of life in numerous ways and all those attending had individual stories to tell of their own allergic journey including issues around:

**Shopping and eating out**

*“Food shopping: print is very small and may contain labels etc. very unhelpful”*

*“Meals out are difficult, have to trust waiter/ess will pass your message on to kitchen staff”*

*“Food labelling: each supermarket/product have a different way of labelling – this leads to confusion, is it safe or not? Generalisation of nuts: it would be so much more helpful to specify the nut which the product contains e.g. peanut.”*

*“Food labelling: what does “may contain” actually mean?”*

*“Grandparents find it hard to read and interpret food labels”*

*“Parties are a nightmare – doesn’t get to share the cake”*

*“Food labelling.....should be standardised.”*

*“Anna has good eyesight but really struggles to read many food labels where the ingredients are printed in a tiny font often either on transparent wrappers or a colourful background which makes it harder to read the information. A minor adjustment would make it easy to read.”*

*“There is no food labelling on restaurant menus and no restaurants will guarantee a nut free meal.”*

*“....this is simply a health and safety issue which many establishments are ignoring. She needs to know whether nuts are an ingredient not whether there is a risk of nut traces. Any food outlet should have information easily available; one should not have to call the manager and then find he/she can’t really speak English well enough to provide the information. It is really like playing Russian Roulette with Anna very often deciding that she will not take the risk no matter how well-meaning the restaurant staff.”*

## **Schools and day to day life**

*“Harris was nearly not able to join his local Cub group due to having a serious allergy as they felt unable to cope with him. Fortunately the leadership changed.”*

*“Childminders can be reluctant to look after him”*

*“Some friends don’t invite them over because they are difficult to cater for.”*

*“Some young people stop carrying their medicine because it’s embarrassing. Young people need help to develop confidence in managing their allergic needs.”*

*“As a private school we are fortunate to have a school matron. Firstly it is reassuring that she is there to help in an emergency. She also plans to raise awareness in the school by training staff and meeting allergy sufferers and their friends as groups so that when away from school, the friends will know what to do if one of their number suffers a severe allergic reaction.”*

## **Research**

*“I wonder what it is about our lifestyle that is driving this [the increase in allergy]. We need to work to build our understanding on this with Government investment otherwise I worry about the increasing burden on the NHS”*

*“Some people are allergic to peanuts and nuts only if they eat them, others from touching them, others from inhaling their dust; there is no way of testing for this.”*

## **NHS services**

*“On leaving A&E on a Saturday night [following severe reaction to walnuts], I was told that I would have to wait until I could see my GP on Monday before I could get another [adrenalin injector]. They did not have them at the hospital.”*

*“Having waited 8 – 9 months to have an appointment we then waited another 8 months before getting the results.”*

*“I have found over the 14 years of dealing with nut allergy/skin problems/asthma etc. that the nut allergy advice is very inconsistent. Some say to avoid all nuts, others don’t. The general impression one is left with is mistrust as such conflicting advice is given”*

*“As it is a problem constantly increasing, the NHS needs more resources to be given to this life threatening area of health.”*

*“We don’t have an allergy specialist/consultant in our area and have to travel 45 minutes to see ours in a different county.”*

*“When Harris was two and had his initial reaction to his allergen (nuts) we saw a doctor in our out of hour’s surgery. He had no idea how to cope with us, we sat with him for two hours and were never sent to hospital.....It was six months before we were seen and tested.”*

*“GP provision is inconsistent and generally poor. It is very difficult to get an appointment with a chosen GP and getting sufficient [adrenalin injectors] has become more difficult. GP’s knowledge can be non-existent e.g. ‘is Rory using the [adrenalin injectors]? No? Then why does he need any more?’”*

*“I am a Mother of a seven year old and a two year old both of whom suffer from food allergies. We would like to suggest that: a) GPs are better able to diagnose allergies, b) better access to specialists and c) better specialists.”*

*“I was diagnosed when I was three and was meant to be tested when I was eight. I am now nearly ten and I can’t even go through a local surgery because they can’t find my letter to see what I was tested on.”*

*“I am a 60 year old anaphylactic (nut allergy for 50 years). In the last six years I have been an inpatient three times and the operations/surgery and diagnosis of cancer (twice) were far less frightening than the fact that surgical, nursing and catering staff did not know how to deal with an anaphylactic.”*

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