



National Allergy Strategy Group Parliamentary Reception February 22nd 2012

- On February 22nd 2012 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 80 people, children and adults, parents and those allergic themselves, who live with various allergies come together with medics and patient group representatives to 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 their concerns around inadequate allergy care across the UK.
- It is estimated that there are around 5 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.
- 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.
- 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.
- Living with allergy affects quality of life in numerous ways and all those attending had individual stories to tell of their own allergic journey. Here are some of the comments which highlight the concerns:

“My son is allergic to milk, egg, peanuts and beans. GPs need more training. At three months old with top to toe eczema, our GP refused to diagnose eczema and told us nothing about allergies. After two mild reactions, having been told by the Health Visitor it would not be milk causing the reactions, he was kept in hospital for a week.”

“Two years ago our allergy specialist retired. Eventually a replacement was found and there are now over 100 children on the waiting list to be seen. There is no admin support leading to wrong appointments being booked, wrong tests carried

out and poor communication. Our hospital, Queens Mary's Sidcup, is rumoured to be closing, what will happen to the allergy clinic?"

"GP training in identifying allergies in children is an issue close to us. It took 12 months for several GPs and hospital A&E staff to identify our son's allergy. We ended up having to go privately to get the treatment we required. It is a sad state that in order to receive specialist treatment one must be able to afford private healthcare."

"Primary care knowledge of where to refer and knowledge of existence of care pathways is hit and miss."

"Hospital service for allergy/anaphylaxis in Brighton is an unofficial, non-commissioned service run by an enthusiastic consultant – if he goes what then?"

"There needs to be better planning for the forthcoming transition of large numbers of anaphylactic children into adult services within the next ten years."

"I feel very grateful for the specialist allergy services as that's how we have been able to live a normal life. I wish everyone across the country could have just as good a service too."

"I wear many different hats (mum, doctor, patient, carer of anaphylactic child) and the care and knowledge of healthcare professionals and services is again a postcode lottery. Every day we live with the fear today could potentially be the day where services and knowledge fail us and our son."

"We went initially to a private doctor – they gave us a trainer auto-injector, mentioned allergy bracelets and Anaphylaxis Campaign membership. When switching to a local NHS doctor we got no such advice. These small things are important for day to day living e.g. cotton comfort clothing for eczema is a massive help but never mentioned by any healthcare professional in countless meetings."

"My son was eventually referred to Addenbrookes after much pushing from me. His care under the consultants there has been excellent. He is confident about how to use his auto-injector and has had care and guidance throughout meaning he has learnt never to take risks."

"Another service I have found to be lacking is specialist diagnosis. My only specialist in the area is in the next city and I haven't heard from them since discovering another allergy to a different nut or since my last reaction in November. I still do not know if the positive skin prick test to macadamia nuts and a reaction to hand cream means I could be at risk of an anaphylactic reaction or not."

"More studies are needed for treatments such as desensitisation along with more opportunities to participate in trials. As well as this there needs to be more funding for research."

"Poor treatment leads to continuing illness and is not solving the problem."

“Ignorance is the enemy, not the peanut”

The comments above are just a selection of those recorded at the recent parliamentary event. We need your help to raise awareness of the growing allergy epidemic across the UK and the lack of adequate support offered by the NHS to manage this.

For more information on the work of the NASG please visit www.nasguk.org or email Mandy East mandy@nasguk.org