



**National Allergy Strategy Group  
All Party Parliamentary Group for Allergy  
November 26<sup>th</sup> 2014**

**Allergy: the reality of the unmet need**

**Introduction**

On November 26<sup>th</sup> 2014 the All Party Group for Allergy held their annual AGM in conjunction with the National Allergy Strategy Group (NASG) to launch the report "Allergy: the reality of the unmet need". This report was compiled during 2014 following extensive discussions with families and individuals who are living with allergic disease to show how the condition impacts on quality of life a decade on from the Health Select Committee inquiry of 2004.

The meeting was hosted by Jon Cruddas MP with the work of the NASG introduced by Dr Pamela Ewan, Consultant Allergist at Addenbrookes, Cambridge. Dr Ewan highlighted the fact that 20 million people in the UK are living with allergic disease with 10 million of them being cared for in primary care. She stressed the need for an increase in the number of allergy specialists and an improvement in knowledge amongst healthcare professionals working in primary care and the community and explained how the NASG are campaigning towards these improvements.

**Key speakers**

The meeting's key speakers Jackie Gaventa and Sue Clarke, who are specialist Health Visitors, gave a poignant insight into the issues faced by many families as they struggle to get their infant children diagnosed and to manage their allergies.

One family whose baby, Izzy, screamed constantly as if in pain made constant visits to A&E, their GP and the Health Visitor and were simply told "it's only colic, don't worry, baby will grow out of it" This baby had faltering growth and in addition, continued fussing at feeds and screaming for hours afterwards, she also developed eczema, all by three months. Unfortunately the GP assumed the mother had postnatal depression and was not bonding with baby resulting in her being referred for CBT. In total it took the baby's first year to diagnose the allergy with extensive help from the specialist HV and she was finally seen in a hospital allergy clinic at age one year, diagnosed with severe reflux, allergy to cow's milk, soya, wheat and egg.

Now aged three, Izzy has outgrown the food allergies and the reflux is resolved. But she has ongoing dental problems caused by acid regurgitation when she was an infant and has developed food aversion, becoming fearful and anxious when eating is involved. She also now has asthma.

The constant stress and worry of not knowing how to help their child meant that the parents did not enjoy Izzy's first year and described this time as "living in a fog of exhaustion and worry".

The second case study was James. James developed moderate to severe eczema in the first few weeks of life and by the time he was four months old he had been to see the GP 11 times receiving four lots of antibiotics and various potencies of steroid creams and numerous emollients. He was miserable and the constant itching affected his sleep and consequently his family's sleep.

Eventually an allergy focused clinical history taken by a specialist HV suggested this was a milk allergy. James's Mum was encouraged to cut milk out of her diet as she was breastfeeding and two weeks later James's eczema was much better. However he then developed urticaria after exposure to egg. The advice to his Mum was to cut out egg from her diet and James was referred to the allergy clinic who confirmed the milk and egg allergy. Now, James is well as the HV has been able to spend time with the family educating about the management of the dry skin and eczema however this should have been resolved sooner which would have prevented four months of misery for the family plus the countless prescriptions for medication which didn't help and the cost of repeat visits to the GP.

The meeting agreed that with the right education for GPs, HVs and other primary care staff these families and many others could have been saved weeks of misery. The financial costs per child would be greatly reduced and essential services provided by GPs and A&E staff could have been diverted to help other patients.

### **Contributions and discussions**

Following these very in-depth case studies the meeting was opened to the floor to hear from attendees with similar stories to tell. Some of the experiences are outlined below:

Emma told us of her 20 month old son whose eczema was not picked up as a symptom of allergy and as a result she was told by both a paediatrician and a dermatologist that she should not cut any foods out of her diet whilst breast feeding. Even though her health visitor did suggest this as a course of action she felt she should go with the advice of the specialist

and highlighting the lack of consistency in knowledge and how parents struggle to get the advice they need. Her son was finally diagnosed with multiple food allergies after weaning and she feels strongly that greater education is needed for all specialties.

Denesh explained how his three year old started showing symptoms of allergy at three months but that he found they he was only treated for the symptoms which resulted in a very large number of referrals to organ based specialists. When he was finally referred to St Mary's he found such a high level of support both from the clinicians and the Anaphylaxis Campaign run parent support group that he feels this should be available to all.

Sue further confirmed that the team at St Mary's changed their lives with ongoing help with things such as treatment plans. She wanted to point out that with the lack of specialists available the stress on those seeing patients is considerable and may lead to others not wanting to train to join the speciality. Clinicians present at the meeting confirmed that there is increasing pressure on doctors with many specialist clinics receiving up to one hundred referral letters a week.

Katherine has two children aged five and one and told the meeting that five years ago there was very little help and that the doctors she saw seemed uninterested and under prepared to deal with allergy. She feels there is more help now however especially within the community and local baby groups. This highlights the need for more support amongst community healthcare providers.

Jo Walsh is a GP who stressed that some GPs do a good job in managing allergy and explained that often there is a frustration due to patients having been given advice from a number of different sources before coming to the GP resulting in them having to unravel the story in order to correctly diagnose and/or refer. Jo also pointed out the restrictions when referring families from more deprived areas of the country for whom travelling is often prohibitive.

The stories outlined above were backed up by the patient support organisations the Anaphylaxis Campaign and Allergy UK who confirmed that their helplines receive calls from anxious families every day.

## **Conclusion**

This meeting highlighted the fact that there is still a considerable unmet need for patients with allergy in the UK in 2014. Some improvements have been made including the three NICE guidelines for: food allergy in children; anaphylaxis and drug allergy and the excellent work carried out by the RCPCH to create the six allergy care pathways and the implantation

of this project by Professor Warner and the Itchy Sneezzy Wheezy team. Additionally there is now an increased awareness of allergic disease and a greater knowledge amongst some GPs due to growing number of training courses being offered.

However, there still remains an “unmet need” which results in families and allergic individuals struggling and the NASG will continue to work towards improvements across all levels of the NHS to reduce the burden faced by growing numbers of people.