



## **All Party Group for Allergy Meeting Young People and Food Allergy Dec 3<sup>rd</sup> 2009**

On December 3<sup>rd</sup> 2009 the All Party Group for Allergy and the National Allergy Strategy Group (NASG) hosted an event in the Boothroyd Room at Portcullis House on the subject of Food Allergy and Young People. 50 young people who live with various food allergies came along to speak out to MPs and the Department of Health on the issues that matter to them as they manage their lives with a potentially severe allergy.

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 lack of specialist services and little action to support GPs with education in allergy.

Young people attending the meeting feel strongly that more should be done to support their needs in a number of areas and the event, hosted by Jo Swinson MP, gave them the opportunity to have their views heard. The All Party Group and the NASG are keen to see young people with allergy taken seriously and want improved NHS care across the UK. The meeting also brought up the need for a greater understanding of the issues affecting those with food allergy such as eating out, provisions for schools and lack of knowledge in primary care.

The NASG is working towards an improvement in NHS care for all those living with allergy and were encouraged that the young people at the meeting felt able to share their views with those who make decisions on our behalf. Many of these children have never seen an NHS Allergy Consultant and have been living with potentially severe allergies for most of their lives with no support or management advice. It is important that the Department of Health recognise that allergy is a growing epidemic and that we must act now to ensure long term care is available for all.

Dr Adam Fox, Consultant Paediatric Allergist at the Evelina Children's Hospital at St Thomas' gave the key address and made the following points:

- Specialist paediatric allergists hear stories of the impact food allergy has on their patient's lives in every clinic. Allergy affects quality of life for the allergic child and the whole family.
- Many of the difficult situations patients find themselves in could have been eased by better informed healthcare professionals, teachers and food industry workers.
- Specialist allergy services aim to provide holistic care and supportive follow up. Not only has this been shown to improve outcomes for patients but also acts as a base for clinical research.
- Many children with multiple allergic disease are not receiving specialist care which is impacting of their quality of life – they deserve better.

The meeting heard from two young people with food allergies, Joshua Gaventa and Jaime Brown (copies of their speeches are attached) and then heard the following comments, prepared by the young people who attended the event:

### **Joshua Ilan**

I have a severe nut allergy and I am also asthmatic which makes my allergy more serious, as this can cause difficulties with my breathing. I have to carry emergency medication and adrenalin injections with me at all times. Shopping is very difficult for me, because of products being labelled so defensively where 'traces of nuts' appears on almost everything, when this is not the case. Going out to eat also causes problems as staff are either over cautious or totally unaware of the risks involved. This makes me feel embarrassed and not able to join in properly with my friends. I would be so much happier if the general public and health professionals had more insight and accurate information on dealing with and treating allergies.

### **Bethany Long**

My comment is that a few times I have had an anaphylactic shock in a club or a restaurant both times in Worcester PCT and Burton on Trent I have been treated if I was drunk. The emergency treatment had been delayed this meant I missed more time from my studies which put me further behind. I do not have the typical signs of an anaphylactic shock i.e. the facial swelling or rash. But I have low blood pressure, constricted airways, dizziness, confusion, itchiness, and cough.

I feel that more medical training should be focused on anaphylaxis and the different symptoms, across the UK. Including the affects off an airborne allergy on wards.

With my airborne allergy going to friends houses and going for meals and for a coffee is difficult as people don't always understand what it is and the consequences. They don't understand why I prefer them to come to my house to meet and not theirs or in a cafe. I think it needs to be publicised across the general public including schools and universities.

### **Bill Cunningham**

The biggest problem I have with my allergy is eating out with my friends, because many restaurants don't have ingredients lists available. If it was possible to introduce legislation that required all caterers to have ingredients list available, this would make life much easier.

If there was also a recognised "Allergy card" which could be shown in restaurants stating your allergy, this would identify allergic people to the restaurant with minimal embarrassment and maximum clarity.

### **Kirsten Greenwood**

My name is Kirsten Greenwood and I live in North London

I do not believe that nut allergies are taken as seriously as they should be. Many people believe that an allergic reaction is just a rash or a sore throat, but for so many people it is much more serious. My friends have often asked me what would happen if I eat nuts, and

when I tell them the symptoms that I get, they are completely shocked. Nut allergies are becoming much more common and I think it is important to make more people aware of this, and aware that it is potentially a life-threatening condition. Another big issue about being allergic to nuts is labelling on supermarket food. Shops, like Marks & Spencer, for example, place "Not suitable for nut allergy sufferers" labels on the majority of their processed food. Not only does this make it difficult to shop for food, it is also very vague as many people are only allergic to specific nuts. It would be much more helpful if shops could specify which types of nuts are possibly in their food or whether it is made in a factory or on the same line as one handling nuts.

Although it might be difficult for big supermarket chains to make their labels more detailed, they do not realise that on an individual level it can eliminate a lot of options and just makes it very difficult to buy food safely.

### **Harris Berthelsen**

I would like to know what I could buy to eat from the shops, without putting myself in danger of death. Labelling is unclear, inconsistent and over the top, and means I am unable to shop in many places, including Tesco. Please can a simpler and more sensible approach to labelling be enforced?

### **Hamish Martin**

I feel that the labelling on food products and especially sweets, chocolate, biscuits etc is sometimes misleading or even confusing. Like many my age there is plenty I dare not eat just in case it may contain traces of nut. I know this is down to production methods, but feel there should be stricter controls over this to stop contamination, so that it either does or doesn't contain nuts. I know some of the manufacturers are getting much better at indicating nut free etc.

I would also like to see more general advertising, especially on television etc to make people of all ages more aware and understand how serious it can be. Perhaps improving awareness in schools especially at senior school.

### **Archie Philipps**

I think a big point is about the nut warnings that now appear on almost everything. I've worked out that a lot of them are to protect the supermarkets rather than me but they drive me crazy especially when I notice them turning up on things that were previously OK or that have never even been near a nut.

It means when I go shopping with my mum looking at the food is a constant stream of disappointment when I turn products over and read the label. One of the worst cases we had was when I was already eating apple crumble with cream poured over it and suddenly noticed that the cream pot said 'may contain traces of nuts'. I yelped 'cream comes from a cow not a factory!'

## **Lorna Harrison**

One of the most important factors for someone with an allergy is information. This could be information from your GP, information on food packaging or information at a restaurant. For example at a local restaurant I could use an allergy information folder to find out about every component in the dish I wanted to eat. Similarly the staff were trained to know what to do when I asked about what I could consume at their restaurant. From this information I was able to make informed choices about possible risk of a particular dish.

Eating out is usually quite difficult for somebody with a food allergy. It would be better, in my opinion; if other restaurants could use the same method as the one I went to, as it would make dining out much easier for people like me.

It's about information, information, information.

## **Yusra Shahid**

I feel really upset because I have so many allergies to dairy, soya, eggs, nuts, fish, wheat and latex. I can't eat food that I would like to try, I feel left out in birthday parties, I feel that I am the only one with so many allergies and I think why me? I have had to use the epipen ten times since I was a baby. I wish that there could be more doctors so that they can find a cure so I could get better and be like everyone else.

## **Paul French**

I want people to know what anaphylaxis is and what to do about it. I want to go to a party or stay at a friend's house for tea without Mum and Dad watching over me. (I think after watching the advert on TV for what to do about a Stroke, why can't they tell people what to do about anaphylaxis? Too many of my friends at school/parents don't have a clue what it is and bring nuts etc. into school and are too frightened to feed me when I play at their house. I am also not allowed to eat my lunch near the other children at school and don't like being different.

## **Callum Smith**

I am 13 years old and live in Cumbria. I had my first reaction to a trace of peanut butter when I was one and a half. Although understanding at my local GP practice has improved tremendously over the past 12 years in the beginning my parents were told, by both a GP and a Consultant Paediatrician, to take me home and feed me peanuts - which of course they declined to do. They also had to be very firm in order to be prescribed more than one epipen.

Finally my Parents managed to find out that a Consultant in Paediatric Immunology occasionally visited Carlisle for an outreach clinic. A journey of 60 miles for him and 20 miles for me. I have had appointments and skin prick tests with him in 2003 and 2005 after which, as my reactions were so severe, I was told I would not be seen again until 2010. At my last appointment my parents asked questions they wanted to raise following reading articles in the newsletter of the Anaphylaxis Campaign. The Specialist was unaware of the issues they were raising.

Those with severe allergies have to deal with potentially life threatening situations 24 hours a day. When can we expect to see improved expert provision, particularly in the more isolated areas of the country?

### **Will Torgerson**

When I was diagnosed with peanut allergy I had to travel to Newcastle to see an allergy specialist instead of being able to see a specialist at York. Does the government realise it is vital to increase the specialist allergy services, so that every young person diagnosed with a severe potentially life threatening allergy has access to adequate services necessary for management of their condition, including access to advice and prescription of emergency medication? How widespread is the importance of the EpiPen communicated to GPs and other health professionals?

### **James Ridley-Jones**

I have lived most of my life with multiple food as well as airborne allergies. It has dominated my life and my family's in many ways:

- At home, food shopping, we virtually never eat out, visits to friends, holidays especially if they involve an aeroplane flight
- Problems at school – at lunchtimes, on school trips, I can't go on the Duke of Edinburgh scheme or join the Cadet Force
- Most school colleagues don't understand why I have to be careful and they think I am being silly.
- Bullying has become more of a worry and I have been physically attacked, held down and threatened with food stuffs that are potentially lethal to me.

The NHS Allergy services have very long waiting lists as there are so few centres. As a result it's difficult to obtain help when needed. On eventually seeing an allergy professional, appointments are short, basic, and the treatment (if any) inadequate. My experience (and a friend's) was that appointments tended to be about *monitoring* rather than *dealing* with allergies.

Consequently I became very ill, needing additional NHS attention. In desperation my parents sought private help. My problems were thoroughly investigated and treated decisively. My health became so much better, with less medical intervention for many years.

I am also allergic to grass and tree pollens. However, the desensitisation programmes for these aren't available on the NHS. If they were, there'd be a more than 90% chance of eliminating the hay fever/rhinitis, leading not only to a better quality of life, but also the reduction in the need for medical intervention (not just for the hay fever but also the resultant asthma), saving more money for the NHS in the longer term.

## **Dan Simpson**

I have had a nut allergy for the whole of my memory. I got taken into Accident and Emergency when I had a reaction. But it took a while before I was referred to the allergy clinic. After that they were very good at giving us information about my allergy, and how to keep a normal life going with it.

It is now so much easier to deal with my allergy. The people at the clinic have been keeping us very well informed. I recently moved school, and without a lot of hassle the school and the clinic organised epipen training for the staff. This has made my school life feel so much safer around food.

The only trouble I have now is going to independently run clubs. Often people are not trained and my parents end up teaching them about the pen. Why do groups still have to sort out their own training, instead of being approached?

## **George Foulds**

My name is George Foulds, I am 11 years old. I have had allergies all my life. I am allergic to milk, eggs and baked beans as well as various non-food allergens, as well I am asthmatic and have hay fever. Being allergic to these foods means I can't eat or touch them. I have occasionally been not able to join in with certain activities at clubs as it involved foods that I am allergic to. I also have had to take my own food to friends' parties and to my school prom. At school I have to carry my medical kit with me, and have even had an allergic reaction to just being in the food Technology classroom.

When I have a reaction, my eyes and lips have swelled; I get hives, stomach ache and have been sick. It's really itchy on my face, body and throat. Sometimes it really hurts and stings.

It's frustrating explaining all the time to people who don't understand, especially when the things I am allergic to are also often hidden ingredients, it makes eating out very difficult. I have to learn how to explain this politely to grownups too, who don't always understand just how many foods I have to avoid and substitute. Did you know that even some brands of tomato ketchup contain milk?

## **Fiona Myles-Hook**

My allergy interferes with everyday things, e.g. using public phones, make-up testers in shops, families of friends don't know what reasonable steps to take when visiting.

Single cream bought from Co-op had "may contain traces of nut" label – unexpected, since you wouldn't think cream gets anywhere near nut products. Over-use of "may contain traces of nut" on food products, so companies can cover themselves – can't take the risk.

Concerns about GM food – if products modified, how will you know the effect on allergy sufferers of the modification?

### **Daniel Fenner**

Is desensitisation going to be available on the NHS? It would make a big difference to my life.

### **Marcus Earl-Brook**

Hello, my name is Marcus and I've got a nut allergy. I'm scared about going to Secondary School because of nuts as they can't ban nuts like in my school at the moment.

Also, a few weeks ago I had a vitamin tablet as usual in the morning, but as I was eating my breakfast I read the ingredients out of interest and to my surprise it contained peanut oil. We normally check all ingredients on everything but I guess because it was a vitamin tablet designed for children none of us thought it would contain nuts, anyway, I had been taking them for quite a few days without a reaction so what does this mean? If I continued to take them would I desensitize myself to peanuts as in the studies that were carried out using small amounts of flour?

### **Anouszka Bundy**

I think the NHS and the government has a duty to make non-allergy sufferers much more aware of the dangers of allergies as I know I personally have come across both ignorance and intolerance from my friends' parents, teachers etc as they don't really understand how serious allergies can be - so, what can they do to further this cause?

### **Michael Liu**

Several times I have been given medication by my doctors and the chemist that I cannot have because it has milk in it. I have a severe reaction to milk and my mouth swells and I can't breathe. What can you do to make sure that doctors don't prescribe medication that has added things like milk in them when they know patients are allergic to these? I don't want to die. I have nearly taken steroid tablets given by the doctors that had milk in and thank goodness that my mum checks the packaging otherwise I wouldn't be here alive and speaking today.

### **Georgia Ellis**

I was born in North London and had my first serious allergic reaction when I was five weeks old. However my doctor and local hospital didn't take my reactions very seriously and it took nearly two years and lots of bad reactions before they properly diagnosed my allergy and gave me an epipen. I now live in Buckinghamshire where the doctors look after me and my allergy really well. I don't understand why support for people with serious allergies is so different in different parts of the country?

### **Ethan Horesh**

At activity Clubs and holiday schemes, a member of staff should be trained to use an epipen and that there should be someone trained to do this there all the time.

## **Holly Edwards**

I don't understand why you get given skin prick tests when they are sometimes unreliable when blood tests give you much better results. One time when I went for a skin prick test they said I could do a food challenge. I got there and they gave me another skin prick test and the results were totally different, they then gave me a blood test. Why didn't they give me the blood test in the first place?

## **Boaz Gaventa**

When I started primary school I had multiple allergies and everyone was so frightened that I would have an allergic reaction I had to be Statemented. That gave me a minder by my side all day so the teachers didn't have to worry or think about me.

Now I am at secondary school but I still have a statement and a minder which is really embarrassing and annoying. I am 13 and can speak for myself if something in class is bad for me and I am learning to take care of myself now.

I don't think teachers listen to children and then they panic. How can you make sure ALL the teachers get good advice and learn about looking after allergic children and listen to what children think?

## **Ellie Dunning**

As well as the importance of supporting allergy sufferers through better funding and services within the NHS, could the MPs support us in schools by making it an automatic suspension if any pupil threatens another pupil about their allergy? For example there is a girl in my class who thinks it funny to put chocolate cake on my desk and threaten to put yoghurt on my things. I am not dairy intolerant and she knows that. I will go into anaphylactic shock, so much so that the last reaction caused me to stop breathing while on oxygen in hospital; I can't even touch anything that has been contaminated with dairy or egg.

I know it is an issue that a lot of people of school age have their lives made miserable by it. Bullying in itself is a huge issue, but to bully someone through their allergy could have fatal consequences. For example in 2006 a boy was cautioned for throwing a slice of cucumber at a pupil who he knew had a life threatening allergy to. The media had a field day and thought it a big joke, as do many people - a police record for throwing cucumber! What people don't talk about is the fact that the boy who had the cucumber thrown at him and despite giving himself adrenaline, was in hospital for two days. It was the boy's parents who bought about the police involvement as the school failed to discipline the perpetrator. There are many more incidents my Consultants says, such as pupils think it's funny to put peanuts in the blazer pockets of pupils with peanut allergy. Such actions should be judged and disciplined in the same as bringing in knife into school. The intent to harm is there. Please help to make schools a safer and happier place for us and make it a suspendable offence.



## **Tom Wooldridge**

- I have to make sure there are no peanuts on any flight I go on and have to get special permission to carry epipens on to the flight in my hand luggage.
- Explain to security searches why I have to carry epipens.
- I haven't been able to have any school dinners until this year as they would not guarantee the lunch as nut free - that's 12 years of pack ups.
- I can't shop at Tesco's because their labelling is so defensive i.e. Factory no nuts, Recipe no nuts, Cannot guarantee nut free.
- Most cafes won't guarantee nut free - I can only eat at three restaurants I've found in York, even they say they can't absolutely guarantee 100%.
- I pay more for my travel insurance as a result of having a nut allergy.
- I have to check every meal if I'm away in a hotel or school residential therefore I've only been on four. The last trip was for a geography field trip when I had to check every meal, and had to draw the caterers' attention to a meal which contained peanuts.
- I have had to take my own food to parties.
- I have never been referred to an allergy specialist despite asking my consultant and GP as I was told I knew what I was allergic to so didn't need referring.
- It is extremely difficult and complex to claim for Disability Living Allowance when you have life threatening allergies despite the impact it has on your life and the people around you.

## **Destiny Dalby**

My Name is Destiny Dalby and I am 7 years old. My mum and Dad found out that I suffer from a fish and nut allergy, when I was 3. Fish is usually easy to avoid, but most chip shops cook Fish and Chips together. Some restaurants do not always keep fish separate from other foods. Nuts are more difficult to avoid because nuts are in a lots of foods and the labels are not always clear. My school is excellent because it is a nut free zone, but because I can have an allergic reaction if someone who has had fish or nuts outside school touches me. My most severe reaction is to peanuts. One day my mum's friend touched my hand after eating peanuts, within minutes I was covered in hives, I became very hot and itchy and thirsty. I felt as if I was going to faint, my mum gave me some piriton and cooled me down by taking off my jacket and she put a cold flannel on my fore-head. She kept talking to me, asking if my throat was ok. My mum got my epipen ready: she thought I was going to need it. After a few minutes I felt ok and I made a full recovery. I am a bit scared sometimes because even if I don't eat the foods I know I am allergic to. I know I can get an allergic reaction through touch. Please could you help us to get others to understand how difficult it is for people who suffer with allergies?