



By email to [SeneddPeitions@assembly.wales](mailto:SeneddPeitions@assembly.wales)

Janet Finch-Saunders  
Chair, Petitions Committee  
National Assembly for Wales  
Ty Hywel  
Cardiff Bay  
Cardiff  
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19<sup>th</sup> May 2020

Dear Janet,

**Title: P-05-932 Education on Food Allergies in Schools and Mandatory EpiPen Training**

Many thanks for your letter dated 2<sup>nd</sup> April. Please accept my apologies for the delay in replying. Responding to the current Covid-19 situation has presented challenges to us all and unfortunately impacted on timeframes to respond.

From our meeting earlier this year we understand that the Welsh Government is currently reviewing its approach to allergies and immunology, including what we believe to be the crucial issue of awareness, and we look forward to participating in further engagement on this broader topic. I'd like to thank the National Assembly for Wales, and specifically the Petitions Committee for including Allergy UK in the discussion related to this petition. (In preparing our response we have taken note of the Welsh Government's "Supporting Learners with Healthcare Needs" which has been issued by the Welsh Ministers. This refers to Section 175 and Section 21(5) of the Education Act 2002 and places a duty on local authorities and governing bodies to make arrangements to ensure their functions are exercised with a view to safeguarding and promoting the welfare of children in school or another place of learning. This includes supporting children with healthcare needs).

Allergy UK's perspective is that awareness and understanding of allergy as a potentially chronic and serious condition is very low among the general public and that this lack of awareness and understanding extends into our public institutions, workplaces etc. While the tragic deaths of young people because of food allergy draw the media spotlight onto the seriousness of allergy, this is fleeting. As the leading charity for people living with allergy, we know from our day to day engagement with our community of the challenges that they face in many aspects of their daily lives, from accessing the diagnosis and treatments that they need to finding reassurance that their needs are recognised, understood and met at school, at work, in supermarkets and in restaurants.

People living with allergy, or caring for those living with allergy, can experience a lifetime of anxiety and fear. As you will know, an allergic reaction can be fatal and many parents who have seen their children experience an anaphylactic shock from an allergic reaction never forget the experience.

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As there is no known cure, just avoidance, many establish ways and routines to control the risk of losing their loved ones. When their children enter school the anxiety is enhanced, because they have to hand that control over to others with the expectation that they will keep their child safe at all costs. Sadly, 17% of fatal food-anaphylaxis reactions in school age children in the UK happen in schools<sup>(1)</sup> and 20% of anaphylaxis reactions in schools are in children with no prior history of food allergy<sup>(2)</sup>.

While there is no definitive data on current care standards in schools our anecdotal feedback suggests that standards are variable. We have received reports of both 'outstanding' schools and schools which have fallen short in the provision of care and support for pupils with allergy, and their families, and this inconsistency is the key issue which would be addressed by mandatory 'gold standard' policy guidance. **Note:** Allergy UK does not advocate for 'nut free' schools on the basis that this policy is difficult to police and can create a false sense of security and this is only one allergen among many others.

Schools have a very demanding and difficult role in a complex environment. We have, in recent years, seen an increase in legislation and statutory guidance for schools to support children with healthcare needs, such as the 'Supporting Learners with Healthcare Needs in Wales'. Allergy UK was instrumental in advocating and bringing about the statutory guidance whereby schools across the UK can now purchase a spare adrenaline autoinjector (AAI), laid down in the 'Guidance on the use of emergency adrenaline autoinjectors in Schools in Wales' in 2017. Most schools take their responsibility for children's health extremely seriously and we know that individual care plans are used in many schools. However, the steps forward we have made over recent years in legislation and statutory guidance still, in our view, need to go further to ensure all children living with allergy are safe in school.

Prevention of Future Deaths reports for Ismaeel Ashraf and Karanbir Cheema, both of whom died from a severe allergic reaction resulting in an anaphylactic reaction, highlighted issues around these schools' management of allergic pupils. The inquests flagged the key issues were lack of adequate staff training which resulted in the delayed and incorrect administration of adrenaline, along with policy implementation issues around adrenaline autoinjectors (AAIs) being out of date and not readily available. This has prompted a strong collaboration between Allergy UK, the Anaphylaxis Campaign and leading allergy specialists to lobby the Department for Education in England at a time when it is planning to review the 'Supporting Pupils with Medical Conditions' statutory guidance.

This is generic guidance for all medical conditions and as a collaborative group we are pressing for the development of a 'gold standard' model policy for the management of allergies in schools to be included as an annexe to the revised guidance. Whilst there is an appreciation that schools are supporting pupils with a range of complex medical conditions, there are children dying from allergic reactions whilst in school, so we believe more needs to be done to safeguard all children living with allergy.

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We would also welcome an opportunity to discuss this with the Minister for Education, Kirsty Williams, as a part of the review that is being undertaken on the approach to allergies and immunology by the Department for Education and Skills in Wales. We will also contact local authorities in Wales to discuss this in relation to the Supporting Learners with Healthcare Needs guidance, which is also generic guidance.

We are pressing for the guidance on generic adrenaline autoinjectors (AAIs) in schools (issued in October 2017 and detailed on the website [www.sparepensinschools.uk](http://www.sparepensinschools.uk)), to be made mandatory (as they are in certain states in Australia and the USA) with funding for both the purchase of AAIs and for comprehensive staff training. We would also like to see recommendations to extend the use of 'spare' AAIs for the emergency treatment of any pupil having an allergic reaction resulting in anaphylaxis, whereas currently only those who have already had an anaphylactic reaction are included for emergency treatment. The collaborative group would also like to propose mandatory measures would form part of Ofsted school assessments in the future.

This work began in earnest late last year and our last meeting with the Department for Education in England took place in February 2020, just before the Corona virus restrictions. The timing for the Department for Education review is not yet confirmed but we will be working on the development of the 'gold standard' allergy management model policy and the refinement of our recommendations around the current guidance on the use of adrenaline autoinjectors in schools to inform this review. We would very much welcome the opportunity to also work with the Welsh government on this to ensure consistency and safety for children living with allergy across the UK.

### **Allergy UK's Resources for Schools**

Allergy UK is committed to improving the standards of care for pupils in schools. Our work in this area has included the development of a programme called SAAG (School Allergy Action Group) which is available as a free downloadable toolkit on our website ([www.allergyuk.org](http://www.allergyuk.org)). This programme takes schools through a seven-step programme to develop their own robust allergy management policy and it involves the 'whole' school from pupils themselves to the management and catering teams. It also helps the development of a better understanding of what it means to have a food allergy, which can help deter bullying and prevent isolation.

Our programme is currently designed for secondary schools and there are currently over 100 schools signed up and working through this programme. We have had much interest from primary schools, and we are planning to adapt the programme for primary schools in the near future. This is not, of course, mandatory for schools but it provides a 'self-help' approach which will provide them with the information and resources to effectively manage and care for pupils with allergy safely and with increased confidence.

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The above summarises the work Allergy UK has been doing to bring about change in the standards of care for pupils with allergy while they are at school, with the provision of information and advice and with a policy development toolkit, all available via our website [www.allergyuk.org](http://www.allergyuk.org)

In the public domain we are working with other influencers to bring about change that will establish both consistency and accountability which we believe to be crucial.

We are very aware that some parents are very distressed about their school's ability to manage their child's allergy in a safe way and know of some who have taken the decision to stop sending their child to school. A similar petition was sent to Westminster last year from parents in England with children with food allergy calling for allergy management policies in schools to be made mandatory. This petition attracted over 10,000 signatures. Our policy prevents us from signing petitions, but we do align with the objectives.

We are working on behalf of all of these parents across the UK, along with collaborators who share our objectives.

In summary, the petition referenced very much reflects our own objectives. As the leading charity for people living with allergy, we are actively seeking the changes, which we believe are overdue, through our collaborations and connections with government and leading clinicians.

We would welcome the opportunity to provide further details on our SAAG programme but more importantly we would welcome the opportunity to work collaboratively with you to ensure that all children living with allergy in Wales felt safe in school. We would also be more than happy to engage with Mrs Murphy and Archie's Allergies if they would like to make contact.

I hope this information provides assurance of our commitment to advocate for the allergic community by working collaboratively with government departments and schools, who we know are also committed to pupils with healthcare needs being fully supported, to ensure all children living with allergy are safe in school.

Yours sincerely,

Carla Jones

**CEO, Allergy UK**

**References:**

- 1) Turner PJ, Gowland MH, Sharma V et al. Increase in anaphylaxis-related hospitalizations but no increase in fatalities: An analysis of UK national anaphylaxis data, 1992-2012. *J Allergy Clin Immunology* 2015 Apr;135(4):956-63.e1.
- 2) Muraro A, Clark A, Beyer K, et al. The management of the allergic child at school: EAACI/GA2LEN Task Force on the allergic child at school. *Allergy* 2010 June 1:65(6):681-9

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