

## **Public Submission Inquiry into allergies and anaphylaxis**

Thank you for your consideration.

My child, now a young adult lives with multiple allergic diseases (food allergy, allergic rhinitis, atopic dermatitis, eosinophilic oesophagitis) and I would like to share a couple of experiences for consideration.

### **(4) Access to and cost of services, including diagnosis, testing, management, treatment and support**

Cost: having multiple allergic diseases is a financial burden to our family. Our family spends approximately \$4,500 a year at the pharmacy - the majority of which is for the treatment of our child who lives with allergic disease. Medications for management includes:

1. Moisturisers in large quantities
2. Over the Counter anti histamines (a packet a fortnight)
3. Over the Counter nasal sprays used daily
4. Calcium (dairy allergy)
5. Off label medication which is PBS listed – but not listed for eosinophilic oesophagitis. Even though this treatment is considered to be the best available treatment option today for this disease. If she had both asthma and eosinophilic oesophagitis, she would be eligible for these drugs on the PBS
6. PBS listed medications for anaphylaxis, atopic dermatitis and other comorbid conditions

Having a range of allergic diseases requires a team of health professionals: GP, immunologist, dermatologist, gastroenterologist, dietitian, psychologist – it's complex to get the right care from the right people at the right time. It is exhausting.

The management of allergic disease is expensive, and the very vast amount of medication costs are met by the family as they do not come under the PBS or the PBS safety net.

### **(3) The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis**

Hospitalisation and patient records: Our child has been hospitalised on numerous occasions as part of her ongoing management of eosinophilic oesophagitis and for removal of wisdom teeth. She has been admitted to 4 hospitals (both public and private) and the hospitals administrations system is unable to cope with the volume of allergies being declared.

Many hospital system admissions records have the first two or three allergies on the front page of the admissions form and then the rest of the allergies on a page further to the back. Nowhere on the admission document – do all of the allergies get listed in the one place. By way of example: On her most recent admission to a private hospital (July 2019) – this resulted in Egg and Dairy being listed on the front page and the remaining 10 on one of the last pages – When the admission staff was challenged on this, they (1) didn't know where

to find all the allergens in the document (2) hand wrote notes on the front page – confusing dairy allergy for lactose intolerance (3) when other staff were alerted to this didn't realise that the allergies were split across 2 pages. I had to then accompany my young adult to the pre theatre to ensure that the nursing staff knew I had safe food with me and understood the full range of allergens. Whilst I raised a written complaint via the hospital's website, I have never received a response.

In the diet section – we are rarely given an allergy diet and have to choose from a preset list of diets (for example: low sodium, diabetic, nut free, dairy free, vegan, gluten free etc). Why is she able to be admitted without a dietitian confirming her dietary needs? On an admission in 2017 – she was given one of her allergens in recovery – where she was refused access to parental support and at the age of 16 was arguing with hospital staff – while in recovery. Her treatment was far from adequate. We did receive both a verbal and written apology from the hospital.

The nature of my child's multiple food allergy and eosinophilic oesophagitis is such that she needs to have a meal made for her specifically. The only place that has ever managed to do this successfully was the major children's hospital in our state. Every other time she has been admitted to hospital (6 or so times) we have had to provide safe food for her.

We do not trust hospitals, cannot get sensible answers from admission or prior to admission on diet needs and generally feel that our child is at great risk if ever required to present to hospital without a parent or siblings there to assist.

#### **(5) Developments in research into allergy and anaphylaxis including prevention, causes, treatment and emerging treatments**

There are currently no treatments available in Australia for atopic dermatitis or food allergy. The only option is management. While this will work for many it does not work for all. For atopic dermatitis – there is a drug (Dupixent) available in both Europe and the US that is not available in Australia.

Why has this treatment not yet been made available to Australian consumers?

We pride ourselves on a world class medical system, but we can only read about the life changing effects this drug is having on those who live overseas. Atopic dermatitis is a painful and psychologically challenging condition.

We also read with hope, about treatment options in clinical trials for peanut allergy (including here in Australia) and we hope that this research will lead to breakthroughs in other food allergies and ease the burden. It is our hope that when ready, that these treatments will be made available to the community without delay.

#### **Conclusion**

Living with allergic disease, which includes the risk of anaphylaxis has had a huge impact on our family. In the early days I believed that my child would outgrow her allergies and atopic dermatitis before starting school. Unfortunately, now as a young adult – our best hope is

that she is well supported by her family, friends and the community – who have knowledge and compassion. It is not easy. Food is a very large part of how we form relationships and come together.

It has impacted on our quality of life since our child was 12 weeks old: managing severe atopic dermatitis, the emergence of food allergy and allergic rhinitis and finally with the diagnosis of eosinophilic oesophagitis.

I hope that from this inquiry, improvements can be made, more infrastructure, more training and support can be given to all (medical professionals, families, schools, food service staff, workplaces) and ultimately that the new treatment options that are in the pipeline for atopic dermatitis and food allergy can be made available to Australians to improve quality of life across the range of allergic diseases.

I thank you for taking the time to listen to a small part of our story and for giving us hope that the government is serious about supporting those who live with allergic disease.