Inquiry into Allergies and Anaphylaxis

Thank you for reviewing my submission to the inquiry.

Background:

All members in our household have allergies, with two of us suffering anaphylaxis as a result of ingestion of specific foods. Since the birth of my youngest child who suffers with multiple food and environmental allergies and anaphylaxis (plus asthma and eczema), our lives have been impacted considerably due to the time in food preparation, cost of foods, medications, and appointments, and limited access to 'inclusive' education.

Whilst in kindy, my son would frequently have swollen, red, itchy eyes and an asthmatic cough when I picked him up. Despite the staff being informed of how to manage his allergies and symptoms, they often told me they withheld his antihistamines and treatment because they thought he had an eyelash stuck in his eye. In prep he started being victim to food bullying, with 5 year old children teasing him daily about the contents of his lunch box. I had to pick him up early from school at least once per week due to his reactions. His prep teachers were administering his antihistamines up to two times per day most days of the week. Three weeks into grade 1, we decided to pull him out of school to homeschool him. In those first three weeks we were called to pick him up early from school at least twice per week when his reactions were not responding to antihistamines. He could not tell us what he learnt in class because he spent most of his school time in the sick bay being treated for allergic reactions. Homeschooling him has meant that to ensure his safety I can attend his daily group lessons, activities and play dates, and he can participate in small group classes with leaders and teachers who know exactly how to keep him safe and how to treat his reactions when they arise. We were contemplating enrolling him again in our local state school in the coming years. However when we checked the tuck-shop menu and saw hard boiled egg on offer, we realised he would be extremely unsafe there. In addition to suffering anaphylaxis from ingesting egg, he has had airborne reactions to others eating hard boiled egg.

I will address the Terms of Reference 2, 4, 5, and 6:

2. The adequacy of food and drug safety process, allergy management, auditing and compliance (including food allergy labelling):

Just as there are food labelling laws, we also need urgent medication labelling laws.

My son who has more than ten food allergies and multiple environmental and drug allergies, recently required emergency treatment in hospital for a severe and life threatening viral infection. When the doctor and nurse on duty were about to give my son medication to reduce his 40.3 degree temperature I stopped them and asked if the medications contained any of my son's allergens. They said it was unlikely and they could not find ingredients listings for any of the medications they wanted to use. Before allowing them to give any to my son, I had to use my phone to search online for the product information leaflets for each of the medications and scroll through pages of information to find the ingredients. Of the three medications they wanted to administer, two of them contained at least one of my son's allergens. If these ingredients were listed on the packaging my son could have received the appropriate medication much sooner and could have avoided a potential anaphylactic reaction.

Similarly, in 2016, when questioning a pharmacy sales assistant about which brands of the same medication contained dairy in any form, the sales person informed me they were all identical in their ingredients. When I informed her that they all had the same ACTIVE ingredients as listed on the packaging, but not necessarily the other added ingredients, she continued to argue with me that none of the five brands contained dairy. I refused to buy a medication until I knew all of the ingredients. I spent the next 10-15 minutes in the pharmacy googling the product information leaflets for each of the brands to find lists of all ingredients. Fortunately, I was able to find one brand that had no dairy listed in its ingredients, whilst all of the others had a form of dairy. (My son for whom this medication was prescribed has needed epinephrine, ambulance and in-hospital treatment for ingestion of dairy.) When the pharmacist overheard our conversation, he advised me that by 2017 all medications were required to have all ingredients listed on packaging, just like processed foods. In 2019 I still need to look at the product information leaflets online before making purchases in pharmacies because ingredients are still not listed on medication packaging.

4. Access and cost of services, treatments and management of allergies:

My youngest had his first anaphylactic reaction at 8 months old whilst in Singapore on a family trip. He was referred to a paediatric immunologist there and his appointment was 3 weeks later. Upon returning to Australia we took his Singaporean immunologist report to the GP who gave us a referral to the only public paediatric immunologist in our capital city. We were told he would be on an 18 month wait list (this was around 8 years ago). After returning to Australia to our newly purchased house, our infant son developed a persistent cough (now asthma), eczema and subsequent staphylococcus infections, from which he experienced an anaphylactic reaction to the antibiotics he was prescribed. It took the next six months for us to realise that his cough and eczema were caused by a severe dust mite allergy from the carpets in the home. We accessed funds from our home loan in order to pay for the removal of all the carpet and laying of hard flooring in our home, plus the purchase of dust-mite resistant mattress and pillow protectors, an air purifier to filter dust from his bedroom, as well as other furnishing modifications. The cost of these renovations in addition to the eczema ointments, and other related allergy expenses was unexpected and placed us under financial strain. I applied for Centrelink's Carers Allowance to assist us with the expenses related to caring for our son. Our application was rejected, however he was given a health care card. A few years later when I applied again for Carers Allowance, especially when we had to pull him from school due to persistent allergic symptoms and after spending hundreds of dollars every month on immunotherapy plus asthma and allergy medications, not only was the application rejected a second time but his health care card was cancelled. Apparently his needs were not sufficient to warrant subsidised medications with a health care card. To add insult to injury, Symbicort, the only asthma medication which is effective for him (under supervision of his respiratory specialist) was recently removed from the PBS for children under the age of 12.

In his first few years of life our son experienced four anaphylactic reactions requiring epinephrine and hospital observations and had reactions and positive allergy testing to 16 foods plus reactions to an antibiotic and environmental allergens. We were making all of his 'processed' food by hand (eg., safe breads and meals) and invested in kitchen equipment to make it possible to make all his food.

By this time we were frustrated with the lack of help in the public system and switched to a private paediatric immunologist who advised twice-daily, double dose of antihistamines in order to keep my son's allergies under control. He also started dust mite immunotherapy, requiring an investment of $80/month for access to the solution which is not covered by medicare nor by private health insurance. This course of dust mite immunotherapy has been ongoing for the past three years. Now there are 'safe' products we can buy from the major supermarkets that are free of my son's allergens. However, at $7 for a small loaf of his safe oat bread, $5 for a tin of fish (free of his allergens), and $8 for a small tray of 'safe' meatballs, the cost of purchasing his food exceeds the cost of the rest of the family's weekly food budget.

5. Developments in research and emerging treatments:

Why have immunologists been successfully implementing food oral immunotherapy (OIT) in the United States of America and in Singapore for most of the past decade, and yet in Australia we have not yet moved to the next step of applying the research gathered over the past 10-20 years to clinical practice? I understand that desensitisation through food OIT is not 100% successful in 100% of patients. However, which drug on the market has that rate of success for any other ailment? If food OIT will desensitise even 70% of individuals to their allergen, then I am willing to take that risk if my son agrees to it. But where do I get the tens of thousands of dollars to travel overseas for the treatment, while Australia is still thinking about it?

6. Unscientific diagnosis and treatments

When my infant son was on the 18 month public waitlist to see a paediatric immunologist, we were desperate for answers to what was causing his eczema, hives, asthma, and other allergy symptoms. Our GP at the time did not offer blood tests nor skin prick testing while we waited. So we paid to see a kinesiologist who did questionable muscle impulse testing to ‘diagnose’ my son’s allergies. We also paid hundreds of dollars to have an IgG (not IgE) blood test. The results showed numerous foods that my son would react to. Being skeptical, we used these results as a guide rather than fact until we could get more reliable testing done with an immunologist. But I know of people who eliminate whole food groups from their child’s diet due to the results of these questionable and expensive tests.

Summary

Just as there are food labelling laws, there needs to be strict and thorough medication and pharmaceutical labelling laws in order to keep allergy sufferers safe. The financial burden of allergy management on families is immense and when the government rejects applications for small financial assistance like carers allowance or a health care card it leaves many families struggling. Why is it possible for alternative health practitioners to carry out inaccurate and unreliable ‘allergy’ testing yet not possible for GPs to carry out reliable allergy skin prick testing and IgE blood tests? Finally, let us remove the barriers to rolling out treatments such as food immunotherapy.