September 24, 2019

To the House of Representatives Committee,

I am writing with regards to the inquiry into anaphylaxis in Australia. Our son was diagnosed with multiple severe food allergies when he was 6 months old. The reason I am writing is to draw your attention to the challenges people face who live with food allergies and their immediate family. While this is a small percentage of the population, the proportion is growing faster than the support available to it (Sicherer, 2011; Turner et al 2015).

Some key points are:

- <u>Insufficient labelling of skin creams</u>: Our son suffered from severe eczema, for which we were advised to apply thick creams, such as castor oil. The local chemist's castor oil contained one third peanut oil which was not clearly labelled, but instead labelled as arachis oil which we initially overlooked. Despite applying the oil on his compromised skin as an infant, we were very luck he did not react. We're still wondering if this may have caused the peanut allergy though. One would think that any products related to the immune system should contain better labels of their ingredients, not just food products.
- <u>Elimination diets should only be recommended by qualified allergists</u>: There is a shortage of allergists who have time to treat patients. And immune systems are more plastic in young children, so time is of the essence to help the immune system learn before it gets settled in. The first allergy clinic we landed at that didn't have a year-long wait list was appalling. Despite being a research active clinic that is affiliated with a prestigious research-intensive university, they heretically pushed the elimination diet without taking detailed notes of symptoms or conditions. I say heretically, because virtually everyone else's research indicates that early introduction of foods yielded better results (e.g. LEAP[1]). They seemed more interested in 'proving' their flawed hypothesis, than caring for the wellbeing of patients. As a clinical research site, we were appalled by the lack of attention to keeping detailed records of our son's conditions while the staff dogmatically thrust their elimination diet program upon us. This goes against any code of ethics they should adhere to as researchers and as medical professionals. We tolerated their approach for 6 months, resulting in only setbacks, until we could switch clinics. Setbacks included our son suddenly reacting to foods he previously tolerated (fortunately only vomiting, not anaphylaxis). Thankfully he did not also develop signs of malnutrition or poor dietary habits. However, there is disconcerting evidence that this clinic is dogmatically pushing the wrong agenda, as shown by other local allergists in the area who eventually treat many of their former patients (Gray et al 2013; the heretical clinic's name was not mentioned in this study to avoid defamation lawsuits).

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[1] http://www.leapstudy.co.uk/leap-study-results#.XY1T3egzZhE LEAP is the best known study specific to peanuts, but there are similar studies for other allergens.

- We need better sources or alternatives to EpiPens. Physicians have been trained to write scripts for EpiPens, partially because writing 'epinephrine auto injector' or 'EpiPen or equivalent' takes too much effort to write.[2] The makers of EpiPens, Mylan, are well known for caring solely about their profits and gouging customers.[3] Adding insult to injury, production runs are short and quite often the only pens available on shelves have expirations dates within a few months and won't last a year.

- Authorisation for buying more EpiPens (and equivalents). When children go to school, the school wants a dedicated EpiPen, as does after school care. We need at least one with us at all times, and prefer to have another spare at hand.[4] The 'spare' is usually the one that also goes to holiday care, birthday parties or other situations. Yet, allergy sufferers are only authorised for two pens, after which they pay full price for something that is (i) medically and morally required for themselves, and (ii) legally required by carers.

- Food labelling: We recognise this is a very thorny issue. It seems though that companies are preferring to label everything as 'may contain traces of ..' to legally cover themselves, making it very difficult to figure out which products are safe. See various studies by Prof Katie Allen at Murdoch University, as also featured in SMH (2017). While appropriate labelling is very useful, excessive and paranoid labelling is not. When our son was diagnosed, we spent countless hours reading and re-reading package labels on practically half the items in our local supermarkets. And, manufacturers may quietly change their process and labels, too, requiring us to re-read labels every single time. While I wish 'there's an app for that' I have yet to find one that is designed from the standpoint of prioritising patient wellbeing over supermarket profits.

- Cleaning of schools: Lastly, my son (and I) have severe allergies to dust mites. Anytime he set foot in the sandpit at daycare, you could see his entire body flare up within minutes, requiring a doctor's note to ask staff to prevent him from playing there. Even with heavy steroidal creams, bath oils and more, the itchiness of the flare up would then lead to uncontrollable scratching until he bled, and severe sleep deprivation (for him and the family as he cried). Years later, his eczema is calming down, but he comes home from school with chronic rhinitis almost every day,[5] triggered by dusty carpets in the stair well and classrooms, only somewhat dampened by a morning dose of antihistamines. Daily antihistamines and steroidal creams are costly and are also not a longer-term crutch for the body to rely on. Our climate is unfortunately perfect for such carpets to be breeding grounds for dust mites, too. So, weekends we can get his skin and sinuses to calm down, only for them to flare up again during the week. His daycare had their carpets cleaned regularly, but that's not the case in his school. I had similar issues with my lecture theatre for Chemistry in

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[2] Aside, even with regular antihistamines and eczema medications we have often been locked into one product because the box to permit pharmacists to dispense an equivalent was not ticked on the script.

[3] Just google Mylan and EpiPen for news articles. For example https://www.bloomberg.com/news/articles/2019-03-29/mylan-must-face-narrowed-epipen-class-action-suit-judge-rules

[4] In panic, a dose can be administered improperly and wasted, so an emergency backup is preferred. Also, in case one dose isn't enough because the reaction is so severe or the medication has degraded, then a second dose may be required. Lastly, some EpiPens simply have manufacturing defects https://www.post-gazette.com/business/healthcare-business/2019/08/28/What-s-behind-the-persistent-shortage-of-lifesaving-EpiPens-Mylan-Pfizer-Teva/stories/201908270027

[5] Eczema, allergies and asthma are closely related https://www.nhs.uk/news/medical-practice/how-eczema-might-lead-to-asthma/

uni in the 90s, when few believed I could be so allergic to one venue, all while struggling to concentrate to the lecturer and almost failing that class.

Each of the above issues is entirely addressable from a policy or governance perspective. Even if they are not 'solved,' any improvement would materially affect the lives of those with allergies, their direct families and anyone who cares for them and wants to provide them a nourishing environment (e.g. extended family, friends, nannies, teachers, coaches,..).

Thank you for your consideration of my experience and for the opportunity you are providing for this serious health condition to be reviewed and assessed.

Kind Regards

References

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