

Inquiry into Allergies and Anaphylaxis

30th September, 2019

To the Committee,

I write to the Committee for the Inquiry into Allergies and Anaphylaxis as the parent of a seven year old with a severe anaphylactic allergy to almost all nuts, and the sibling of an adult with a severe nut allergy to peanut, cashew and pistachio. After numerous check ups with our paediatric allergy specialist and Epworth Hospital since my daughter was one year old, we have been advised that she will not grow out of her nut allergy and I base my submission on my experience as an allergy parent, and having grown up with a younger sibling with an anaphylactic nut allergy.

I submit to the committee the following opinions regarding our experience with a child with a severe nut allergy:

Terms of Reference 1: The potential and known causes, prevalence, impacts and costs of anaphylaxis in Australia

Having a child with a nut allergy who has been in child care, community kindergarten, and now primary school including after-school care programs, I implore the committee to reconsider the substantial cost of supplying Epipens to these institutions when patients are limited to two Epipens per calendar year at a reduced cost. With the required Epipen supply at home as being two in the instance that the first Epipen fails, as well as requiring additional Epipens for the school AND for the after-school care program our daughter attends, we incur a total cost of approximately \$260 per year to purchase four Epipens (two on prescription at a reduced cost, and two at full over the counter cost without a prescription). Anaphylaxis management means we have no choice but to purchase this life saving medication. The Epipen prescription allowance per patient needs to be increased to four per year at a reduced cost to allow families to purchase this medication without the financial burden of hundreds of dollars per year, to which there is no way around thanks to school's stringent policies on families supplying one Epipen per child.

Terms of Reference 4: Access to and cost of services, including diagnosis, testing, management, treatment and support

I also implore the committee to allow for both the extensive allergy testing procedures, including the physician consultation, skin prick testing, and all related testing that needs to be undertaken on a yearly regular basis to receive a higher rebate from Medicare, and be claimable through private health insurance, which currently is not the case. With a minimum cost of \$400 per appointment/test and less than half being refunded back to the patient/family, this high cost only further impacts financial strain on families who need to continue with rigorous testing to stay on top of their child's allergy status. Add on to this the cost of having to purchase up to four Epipens per year for home and school, and families are incurring a financial burden of over \$600 per year in some cases, much of which is not rebateable under the current Medicare and private health insurance guidelines. I also want to draw the Committee's attention to the near constant shortage of Epipens available. Why is this medication not manufactured at a higher rate to ensure all patients needing it are able to readily purchase one with a lengthy expiry date? On more than one occasion we have had to purchase an Epipen with less than six months' validity on the expiry date thanks to a nation-wide shortage, meaning we then need to purchase an additional Epipen in another six months during the same calendar year, further adding to the financial cost of managing our

daughter's allergies because we've already used our two yearly prescriptions. This medication and the drug manufacturer need to be held to higher standards of supply and demand to prevent constant shortages in the marketplace OR doctors and specialists need to provide patients prescriptions for a different adrenaline auto-injector that is more readily available with a lower price point to make this life-saving medication available readily across Australia.

Thank you for your consideration of this inquiry submission.