Thank you for taking the time to read my submission for the inquiry into allergies and anaphylaxis in Australia.

As a parent of a 10 year old son with severe life threatening allergies to dairy products and nuts, I wish to make some suggestions relevant to the terms of reference which may help improve quality of life for those suffering from allergies in Australia.

To provide you with a bit of background information, my son was born by emergency caesarean section in a small rural hospital. He was transferred by ambulance to a special care nursery in a city hospital as he had the umbilical cord wrapped around his neck and nearly died at birth. He was given IV antibiotics and formula fed for the first 2 days as there were no free hospital beds for myself, his mother, so I remained in the rural hospital until a bed became available. Upon my arrival at the city hospital 2 days later he was able to be breast fed and was discharged in a week.

For the next 7 months he had atopic dermatitis/eczema of unknown cause. Steroid creams and moisturisers had little effect.
At 7 months he was given cows milk for the first time since a newborn, in the form of yoghurt. His face became swollen and red and he became very itchy. Having a background as a veterinarian, I recognised his symptoms as being those of an allergic reaction and rushed him to the GP. They gave him adrenaline and he recovered.

There was a very long waiting list for an appointment at the childrens' hospital – he was 18 months old before we could get an appointment to see a paediatric allergist. Skin prick testing and IgE blood tests showed he had dairy, egg and multiple nut allergies.

At that time, I was told to avoid dairy products, eggs and nuts and it has been a steep uphill learning curve since then in learning what foods he could and could not eat and how to ensure he had a balanced diet with sufficient calcium in particular without dairy products.

I wish to highlight the difficulty of managing dairy allergies (and egg allergies – my son has since outgrown the egg allergy).
One problem is a lack of education in the general community about allergies. Many people are sceptical that allergies really exist. Most people confuse dairy allergy with lactose intolerance, which while unpleasant is not fatal, unlike dairy allergy.

Dairy and eggs are very hidden and in so many foods that they are very difficult to avoid. Dairy is found in milk, cheese, yoghurt, cream, icecream, most bakery products, bread, gravy, sauces, chocolate, delicatessen products, processed meats, museli bars, some cereals, pastry etc. There seems to be much better awareness of nut allergy in the community as it is well publicised. Nuts are also much more visible in food.

Allergies impact our daily quality of life – eating out in restaurants is something we rarely do due to the risks and the difficulty in finding meals that don't contain dairy.

School camps and cooking classes at school are difficult. Birthday parties are challenging. We have to pack food from home with us before almost every outing.

Children with allergies often feel different or excluded – eg at parties or hot food days at school where they can't join in with others. Children often feel anxious about eating food that is not prepared at home. There is an ever-present fear that if they eat the wrong thing and make a mistake, they can die.

1. **The potential and known causes, prevalence, impacts and costs of anaphylaxis in Australia;**
   More research would be very beneficial in identifying causes. There is no cure so identifying cause(s) would be wonderful. The prevalence is high and increasing. 1/10 children have food allergies now. As well as genetics, I believe there is an environmental association. I often wonder if there is a link with the rising number of caesarean births in Australia and a similar increase in the prevalence of food allergy over the same time scale. Babies born by caesarean are not exposed to the same bacteria at birth as those born vaginally. Anecdotally, my eldest son was born by caesarean and given IV antibiotics at birth and has severe food allergies. My 2 younger sons were not born by caesarean, did not receive any antibiotics and have no food allergies.
2. **The adequacy of food and drug safety process and food and drug allergy management, auditing and compliance (including food allergen labelling by manufacturers and food service providers);**
   I would like to see mandatory labelling of allergens, not just on processed foods, but in bakeries, delicatessens, on restaurant/café menus, prescription medicines and toiletries. For example, I have discovered many liquid soaps contain milk protein and this is often not clearly labelled. "Tooth mousse" from the dentist contains dairy milk protein and is also not clearly labelled. This labelling would allow consumers to make an informed choice.
   Some restaurants now have codes such as DF=dairy free, NF=nut free etc on menus which is fantastic. If all menus listed the 10 common allergens in this manner, patients with allergies would be able to eat many more meals out safely.
   Currently, food service staff have compulsory training in food hygiene. It would be great to incorporate mandatory food allergy education into this training to make it safer for customers.
3. **The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis;**

I think the more education people are given in allergies, the safer the world will be for those with allergies.

I think Epipen training courses are great at showing the method of giving an Epipen, but in my experience more emphasis needs to be placed on recognising the *symptoms* of anaphylaxis. Many people are confused as to when to give the Epipen and how to recognise anaphylaxis. They often hesitate, not being sure whether to give the Epipen or not. Also, there needs to be more emphasis on making sure patients are lying down not sitting/standing when having an allergic reaction. In addition, many people are unaware that there can be biphasic reactions where patients start showing symptoms when the adrenaline from the Epipen has worn off, so calling 000 and observation at hospital for 4 hours is critical. Even doctors discharge patients prematurely at times.

We have found a lack of education in food allergies in the hospital system. When my son was a patient in hospital, it was difficult to obtain dairy free meals. It would be great if all hospitals had systems in place to communicate food allergens to kitchen staff so they are able to cater for patients with allergens. It is very stressful as a parent of a child in hospital and not have access to safe meals.

I believe an education campaign, such as advertisements about allergies on television or on the internet would be great to help the general community understand and realise that people are allergic to lots of things, not just nuts. It could explain how common allergies are, list the common allergens and explain what to do if someone is having an allergic reaction.

4. Access to and cost of services, including diagnosis, testing, management, treatment and support;

The costs to allergy sufferers and parents are enormous, including GP and specialist allergist visits, medications - Epipens, anti-histamines, Ventolin, eczema creams, moisturisers, special/alternative/substitute foods (much more expensive than regular food), travel to see a specialist, dietician appointments etc. We travel 170km each time we see a paediatric allergist. We waited 11 months to see an allergy specialist intiially – the waiting lists are enormous. Providing incentives for doctors to specialise in allergies would help reduce this waiting list.

In conjunction with allergist appointments, a visit to a dietician and/or psychologist would be helpful. When excluding whole food groups from a child's diet, it is important to know what to feed in terms of substitute foods. Also, the psychological impact of allergies and the anxiety/fear of death/feelings of exclusion/being different from others etc mustn't be underestimated.

It would be really great if patents could access 3 Epipens/script not 2. In our situation, my son has 1 Epipen at school and 1 at home. If a mistake is made in giving the Epipen, or a second dose is needed, there is no back up one, unless you purchase it over the counter, which costs >$100. Epipens last usually only 12 months at most before expiring.

5. **Developments in research into allergy and anaphylaxis including prevention, causes, treatment and emerging treatments (such as oral immunotherapy);**

It would be wonderful if Australians could access oral immunotherapy treatments that are available overseas and showing promising results.