Inquiry into allergies and anaphylasis,

To the committee,

Thank you for the opportunity to be able to submit my story.

My submission comes as I have a now eight year old boy who was dianosed with allergies and anaphylaxis from the age of 15 months old. My son is currently anaphylatic to all seafood, and peanuts. He also has quite bad allergies to all grass, pollen and dust mites. On top of that my son also suffers from exczema and asthma. The last 6 years my son has been on a medical journey that no child at his age should have to go through. This submission brings me hope that there may be possible changes that the government are willing to make my son's future a little more easier. As mother of my son and his protector I want him to happy, healthy and safe life.

I submit the following to the committee:

Terms of reference 2: The adequacy of food and drug safety process and food and drug allergy management , auditing and compliance (including food allergen labelling by manufactures and food service providers)

The changing of food labels: Instead of saying, "May contain traces of ………." Or "Manufactured in a facility which also processes…………" These label needs to be changed to say definitively what ingredients are used. There needs to be standed wording that all manufactures can use to make the so-called precautionary warning less confusing for all consumers. Quite often the print on these label are too small and package food continues to be recalled at an alarming rate within the food indusrty. There has been cases in Australia where there are no warnings at all on packaging which has then lead to anaphylaxis and serious risk of life.

Eg. My son purchased slime from a toy shop (not food related) but that slime ended up contaning seafood ingredients. While the slime was never purchase with the intention to eat my child definatley brought the slime to play with. Within minutes of paying with the slime he was in hives due to the seafood ingredients. There was no list of ingredients on this purchased product and it was only after much dective work via goggling did I discover what was placed into theis slime made in China.

While the wider community is becoming anaphyalxis and allergy aware – slowly. The current labels makes it very hard for people within non anaphylaxis and allergy children to understand the differnce in the wording. Quite often it has been easier fo me to take "safe" foods to a child's birthday party for my son instead of relying on another parent to ensure my child's safety when food is provided.

Terms of reference 3: The adequacy and consistency of prfessional education, training management/treatment standards and patient record system for allergies and anaphylaxis.

Registry of children with allergies or anaphylaxis: I currently work in an early years setting where I encounter many children each year diagnised with allergies and anaphylaxis. If a child is diagnosed as allergic or anaphylatic to an item then there should be a registry and the patient should then be required to seek follow up appoinments at least every two years. While some childen's diagosis can and will be life long, for some children they can out gow their allergy and we are finding that <u>some</u> parents are trying to prolong their child's diagnosis from either fear or lack of knowledge/understanding. A registry will not only help guide the medical profrressional responible for diagnosis to gain a better understanding of each patients needs, but it could ensure that each patient is recieveing the required treatment and follow up as required. This will also assist people who move interstate or choose not to see a regular GP.

<u>Primary school in QLD and Austarlia:</u> It saddens me know know there is such a huge difference in policy and regulations amongst the different education department depending on what state you live within in Australia. In Queensland, it is not mandtory for schools to have communications plans in place with theirs families regarding their child's allergies and anaphalxis while in Victoria this is a requirment. When it come to life threating situations I honstley believe that all states should be guided by the same policies and regulations that the government sets into place. Most inportantly a parents voice is the lodest voice when speaking for a child and should be heard particualry when entering into a school environment.

<u>Professional education and training</u>: It should be mandatory that all required medical staff in any medical facility across Australia should have minimum training for anaphylaxis and asthma. I have been persoanally shocked to discover that in major hospitals within Australia that staff are not trained in the signs and sysmptoms of anaphylaxis let alone how to use an Epipen.

I have had my son's epipen taken off me during hospital stays as it is medication that needs to be kept in a locked facility even though the nurses on duty were not trained in the use of Epipen or aware of the signs and symptoms. I understand the policies an dguidlines that hospitals have to work under but from a parents perpective it leaves me with no trust for my sons care. Like the early years sector there should be mandatory training at least once a year.

All staff in a food service should have mandatory training in understanding the simple things like reading food labels, understanding the implications of cross cotamination and knowing what is in their food being prepared in their food service.

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

<u>Cost</u>: For me persoanlly I would spend approximatley $450 a year on Epipens for my son. That does not include the cost for antihistmines, doctoros appointment, specialist appintments or skin prick testing. We pay full price for the Epipen that we are require to supply my sons school each year. We pay full price for the Epipen that we provide the after school care that my son attends. We pay full price for an

Epipen so my son's grandparents can have with them and then we get two epipens each year at the reduced price that we keep with us at all times.

We are also a familiy that keeps our expired Epipens as there has been times when we have been unable to access Epipens due to shortages. I still do not know why as a 1st world country we do not have medical scientist who are able to create another form/version of an Epipen that can be made and distributed within our own country. Why are we having to rely on America for life saving medication.

Waiting times: Hospital waiting times are ridculous. We have had to go through a privatley owned company and pay $380 for my sons skin prick testing and check up for each visit. We did not have the time to wait on a wiaitng list and we needed immedicate clarification on my sons medical condition when we become aware of his condition. I personally feel sorry for families in Australia they have no choice but to go on these massive waiting list as they do not have the means to be able to afford to go private. These waiting list could meant the difference between life and death.

Terms of reference 6: Unscientific diagosis and treatment being recommend and used by some consumers

Working in a mangement role in the Child Care sector, I am sadden by the lack of professional standards from companies that provide families with diagnosis of allergies and anaphylaxis. Recently in the last year it has come to my attention how easy it is for parents to take their child to a specalist company that provides diagnosis and these companies will hand over letters to families without any testing or follow up on the child's previous medical diagnosis or parent concern.

We are discovering children's parents are self diagnosing their child's condition and then seeking the "right" company to provide them with the documentaion needed to ensure the child can be excluded from a particular food group. The standard within the sector needs to be improved and a minimum expectation expected when a child/patient is seeking specalist treatment in this field. I would also like to note that majority of companies operating, providing diagonsis and helping to treat children with allergies and anaphylaxis are fantastic at what they do and do act professionally. There needs to be consistency across all companies and states and territories.

I would like to thank the committee for the opportunity to provide a voice for not only myself but for my son on all of the above matters. I really look forward to hearing the outcomes from this inquiry.