STANDING COMMITTEE ON HEALTH, AGED CARE AND SPORT

Allergies and anaphylaxis

(Public)

TUESDAY, 18 FEBRUARY 2020

BRISBANE

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Terms of Reference for the Inquiry:

To inquire into and report on:

Inquiry into allergies and anaphylaxis

The House of Representatives Standing Committee on Health, Aged Care and Sport will inquire into and report on:

1. The potential and known causes, prevalence, impacts and costs of anaphylaxis in Australia;
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);
3. The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis;
4. Access to and cost of services, including diagnosis, testing, management, treatment and support;
5. Developments in research into allergy and anaphylaxis including prevention, causes, treatment and emerging treatments (such as oral immunotherapy);
6. Unscientific diagnosis and treatments being recommended and used by some consumers; and
7. The impact of unnecessary drug avoidance due to unconfirmed drug allergies and its management, such as drug allergy 'de-labelling'.

Members in attendance: Ms Bell, Mr Dick, Dr Freelander, Dr Martin, Mr Zappia, Mr Zimmerman.
WITNESSES

CLIFF, Dr Cynthia, Director, Knowledge Transfer and Partnership Development, Faculty of Health, Queensland University of Technology ................................................................. 32

CROSBY, Ms Raphaella Kathryn, Founder and Chair of the Organising Committee, Migraine Australia ................................................................................................................. 50

CULLEY, Ms Markeeta, Private capacity .................................................................................................................. 1

DAVIES, Professor Janet, Head, Allergy Research Group, School of Biomedical Sciences and Institute of Health and Medical Innovation, Queensland University of Technology .......................................................... 32

FUNK, Ms Melanie, Managing Director and Founder, Eczema Support Australia ........................................... 26

GRAY, Mrs Sarah, President and Founder, ausEE Inc ........................................................................................................... 20

GRAY, Ms Bella, Member, ausEE Inc ............................................................................................................................ 20

GRINTER, Ms Kirsten, President and Director, The Allergen Bureau Ltd .............................................................. 42

LACIS-LEE, Ms Jasmine, Secretary and Director, The Allergen Bureau Ltd .......................................................... 42

LAYTON, Ms Victoria, Volunteer, Eczema Support Australia ................................................................................. 26

MARCHAND, Dr Birgit, Paediatric Allergist and Immunologist, Queensland Allergy Service .............................. 11

MARRON, Ms Loretta, Chief Executive Officer, Friends of Science in Medicine .................................................. 46

MULCAHY, Dr Andrew Mulcahy, Representative, Australian Society of Anaesthetists ........................................ 37

NEVARD, Ms Jacqueline, Founder, My Food Allergy Friends ................................................................................. 55

NIELSEN, Mrs Teresa, Private capacity .................................................................................................................. 1

SCOLARO, Dr Richard, Chairman, Australian and New Zealand Anaesthetic Allergy Group ............................. 37

SLY, Mrs Catherine, Private capacity .................................................................................................................... 1

SMITH, Professor Peter, Director, Allergy Medical Group; and Allergist ............................................................... 11

THOMSON, Ms Jody, Nurse Practitioner, Allergy Medical Group ........................................................................ 11

VICTOR JOHN, Ms Jacintha, Policy Manager, Australian Society of Anaesthetists .............................................. 37
CULLEY, Ms Markeeta, Private capacity

NIELSEN, Mrs Teresa, Private capacity

SLY, Mrs Catherine, Private capacity

Committee met at 09:25

CHAIR (Mr Zimmerman): I declare open this public hearing of the Standing Committee on Health, Aged Care and Sport's inquiry into allergy and anaphylaxis. Thank you all very much for joining us this morning. For our first witnesses here, I imagine this is probably the first time you have ever appeared before a parliamentary committee so don't be daunted; we don't bite unless requested to do so. So be relaxed and calm. I am required to let you know that these are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter. Your evidence attracts parliamentary privilege. All three of you have been kind enough to provide written submissions. Would you all like to now make a short opening statement?

Mrs Nielsen: Thank you for the opportunity to be here today. I am the mother of two young children with food allergies and risk of anaphylaxis. My son, who is almost five, is allergic to egg, milk and certain species of fish; and my daughter, who has just turned one, is allergic to egg, cashew and pistachios. As you are aware, life with food allergy is challenging, time-consuming, expensive and at times incredibly distressing. I would like to use my short time here today to advocate for two things: firstly, the continued research into the causes of food allergy. As I mentioned in my submission, it came as a huge shock to realise that my children have life-threatening food allergies, and my family experience has led me to seriously consider what may have caused my children to develop these allergies and if there were additional preventative steps that we could have taken. I acknowledge that there are already a set of recommendations designed to reduce allergies; however, I feel it is an area of public health that warrants ongoing attention to assist future generations to avoid the burden of living with allergic disease.

Secondly, I would like to advocate for the continuing research and funding into allergy treatments. My family has been living with severe food allergy for five years and it is likely that this will be our reality for the foreseeable future unless treatments become available. I follow with interest the treatment and prevention studies currently noted on the Centre for Food and Allergy Research website, and we hope that some of these treatments currently on trial may become available in a clinical setting. As you know, strict allergen avoidance is the only management option currently available in Australia, and I feel strongly that the introduction of treatments could greatly increase my children's quality of life and minimise the anxiety that we feel daily. I understand that there have been no significant trials of oral immunotherapy in Australia to date and I hope that an outcome of this inquiry would be the commencement of large-scale trials.

My son often has severe allergic reactions when dairy products touch his skin. Something as simple as my son playing with a child who has recently eaten cheese-flavoured chips, for example, can result in my son having severe facial swelling with welts and hives which usually cover his face, chest and back. As you can imagine, it is heartbreaking to see my son reacting this way, and we hope that oral immunotherapy or similar treatments may reduce his immune response to this kind of incidental exposure. I'd also like to mention the importance of oral food challenges and the positive effect this has had on our family. My son recently undertook a bake-day challenge and he is now able to tolerate a small amount of egg and baked goods. We feel that this ongoing exposure will assist my son to eventually grow out of this particular allergy.

Lastly, I'd like to thank the committee for undertaking this inquiry. Living with allergic disease can at times feel isolating and overwhelming, and this inquiry is bringing attention and understanding to this important area of public health.

CHAIR: Thank you, Teresa. Markeeta.

Ms Culley: Thank you for the opportunity to speak today. My son is eight years old and has suffered from severe allergies since birth. He remained undiagnosed for a very traumatic 13 months of his life despite countless visits to GPs, paediatricians and nurses, where I was repeatedly told I was being an overly concerned first-time mother. He is at risk of anaphylaxis to 15 allergens—dairy, wheat, eggs, peanuts, sesame seeds, kiwi fruit, shellfish, cashews, salmon and pistachios to name a few—as well as chemical sensitivities to many products. Allergies have had a considerable impact on our lives. We had a very successful kindy year, when he was four, with understanding and compassionate staff. This was followed by the complete opposite in the school setting where, despite the same child-staff ratios, there is a completely different attitude to allergy management. As a result, I now homeschool my son and was forced to resign from my much loved position in local government to educate my son and keep him safe.
Allergy management within schools is a huge issue. Despite the fact that we have Queensland guidelines for state schools here, many schools do not follow them. In our experience, 95 per cent of the issues we encountered were covered in the guidelines. We were constantly made to feel like a burden and an inconvenience by the school staff. There needs to be legislated policies nationwide that schools are required to abide by.

The financial burden on our family is immense. Cooking everything from scratch, making household products from washing powder—wipes, sunscreen, insect repellent and dishwashing liquids—and the constant cleaning and management involved with my son’s allergies takes up many hours a day on top of our homeschooling. Despite the care my son receives, I’m not eligible for any sort of carers allowance or payment. Financial support is required for the management of allergies in families, including out-of-pocket expenses for specialist medications and equipment and, in particular, everyday living costs such as specialised food. The extreme cost of this food results in my grocery bill exceeding my mortgage repayment each week.

We have an urgent need for a competitor to EpiPen in Australia. The annual shortages we’ve endured for the last three years continue to this very month. It is simply unacceptable that we do not have alternative life-saving medication in Australia and are forced to choose expired or contaminated stock when our children’s lives are at stake. Mylan has had a monopoly here in Australia for far too long, and there is a lack of transparency about what competitors are not in the Australian marketplace. As parents we’ve tried to rally companies such as Auvit-Q and Emerade to Australia, yet we’re having no success when contacting government local members and the companies themselves. This must be remedied. Are we going to wait until someone has died as a result of the shortages before something is done? We need to take action to ensure that we have a choice of autoinjectors immediately. In addition, four autoinjectors need to be included on the PBS instead of two. Allergies need to be recognised under Australia’s disability law just like other conditions including diabetes and autism. I feel this is a vital way to have the community, institutions and businesses realise the seriousness and implications of allergies and anaphylaxis, and better protect and support sufferers of allergic disease.

I personally believe that the gut microbiome accounts for the increase in allergies and holds the potential for a cure. My son and I have both had positive results by working on our microbiome health. We’ve gone back to basics—close to how my grandparents used to eat and live—to try and undo some of the detrimental effects of our modern lifestyle. I’m heartened to see the advances in microbiome studies—in particular, research published in October last year that identified the species of bacteria in the human gut that protect against food allergies and found that giving an oral formulation of species of bacteria protected against food allergies and even reversed established disease. More funding needs to be directed into this sort of research.

Thank you for your time and consideration of the points I’ve raised. I’m hopeful this inquiry can bring about positive change and improve quality of life for allergy sufferers.

CHAIR: Thanks, Marketa. Catherine.

Mrs Sly: Good morning, and thank you for giving me the opportunity to share my story today. I can honestly say that food based OIT is the best thing we have ever done for my daughter Zahlia and for our family. We have freedom now. We can go out to a restaurant or order takeaway safely. We can go to a playground and not worry whether someone's peanut-buttery hands have touched a swing or a slide. Everything is easier and more relaxed now. We're living a great life, and have been doing so since we got back from America. I'm quite a shy person and it would have been very easy for me to come back and just quietly enjoy this wonderful new life, but, as much as I wanted to do that, I couldn't just sit back and not try to change things here. I know what our life used to be like and I know that there are so many people still living like that now. I need to do my best to change that for them.

Zahlia's OIT journey has been smooth sailing. In the whole nine months since she started, the only symptom she has had at all was a mild stomach-ache which lasted for about 15 minutes after dosing for about three days while we were in America. That was only because she was going faster than normal since we were trying to fit in as much as we could in the short time we were over there. Our doctor adjusted her dosing and it stopped happening. Since we've been back in Australia, she's had absolutely no reactions to dosing at all.

You would have read in my submission that, in all the years we were seeing allergy specialists, no-one ever mentioned that OIT existed. Whether that was because they didn't know about it or because they disagreed with it, I'm not sure, but I really don't understand the reluctance Australian specialists have to even look at this treatment. It is proven to work. There are so many people who have undertaken successful OIT, usually in America, Canada or Singapore. There is research showing that it works. The fact that the research is from overseas doesn't bother us. Allergy parents don't care whether the research originates in Australia. American proof is just as good as Australian proof. They don't care whose name is on the paper or who received funding for yet another clinical trial. They care that there's an option out there that could be keeping their child safe, but they're missing out on it...
because they can't access it in Australia. Research is definitely an important part of any medical treatment, but there comes a time when that research needs to be put into practice. I'm sure that in the future there will be improvements in OIT—everything is improved over time—but that's not a reason to not offer it now.

Zahlia's treatment is purely food based. She doesn't take any sorts of probiotics or supplements. I buy the peanuts from Coles and they cost a couple of dollars. From all the research and articles I read, it seems that a lot of medical professionals are trying to put a pharmaceutical spin on OIT, but it doesn't need a spin; it's amazing exactly the way it is, as the American and Canadian private practice doctors are offering it, using food. Their version of OIT works because it's not standard; it's tailored specifically for each individual patient, taking into account age, size, allergy severity and current health. They get great results because they don't have a blanket approach; they treat each patient as an individual. And they are willing to train our doctors in their methods.

Dr Ruchir Agrawal, the amazing OIT doctor that we saw, is willing to share his knowledge with any doctors who are interested. Dr Douglas Jones, another wonderful American OIT doctor, has told me that he would love to be involved in providing OIT in Australia. He's already in the process of being registered as a doctor in Australia, so I would suggest that he would be the perfect person to be involved in the set-up of an Australian OIT clinic and the training of our doctors should the committee recommend that an OIT clinic be opened in Australia. Please consider that. OIT is the best thing that we've ever done. I cannot convey that strongly enough. I sincerely hope that all Australians can soon have access to the freedom which my family now has. Thank you.

CHAIR: Well done. That wasn't too bad, was it? We haven't been through our questions yet! I'll kick off with a few questions. Catherine, what allergies does your daughter have?

Mrs Sly: Based on what the Australian specialists told us, milk, eggs and peanuts. I asked to do a milk challenge two years ago because I know a lot of people grow out of it and I thought she might be there. Our specialist said, 'No. Based on her skin-prick results, it's definitely too dangerous. We can't do it. We'll try again in another year.' That's what they told me the year before that as well. So we went over to treat all three. She did an egg challenge once we got there and she passed the challenge. She didn't need to treat for egg. She went through milk really quickly and they said that, despite her IgE level being 12, which was quite high, it wasn't an actual allergy to the milk. So she is fine with milk. The only thing that we're now treating is peanuts.

CHAIR: I'll ask all of you this, although, Teresa, I know your eldest is four, so he wouldn't have enrolled in school yet—or has he?

Mrs Nielsen: He's almost five.

CHAIR: This is the point that Markeeta made about experience with the education system here. One of the things we found is that it does vary enormously between states. Markeeta, it's interesting because your experience, I assume, was with the government education system.

Ms Culley: Yes.

CHAIR: You had a disappointing experience. I find that, for example, in schools in my electorate in Sydney there are so many children who have allergies that the schools are quite experienced now in supporting children with allergies, although your case might be a little bit more complex. Catherine or Teresa, I'm wondering whether you've had similar reservations or experiences.

Mrs Sly: Our school has been okay. I wouldn't say they've gone out of their way to be helpful but I would speak directly with her teachers each year and they were really good about not letting other children share their birthday cakes or anything like that, and about washing hands and sitting separately and things like that. So they've been okay, but it still leaves her quite isolated when she's told—before OIT—'You can't have this cake,' or 'You can't be involved in this science experiment,' making bread or whatever it was. But it is definitely not as bad as what others here had.

CHAIR: Did you find the awareness among other parents is better now? Or is it nonexistent?

Mrs Sly: No. There are a handful of people out there who are amazing, who get it and who really try hard. There are far more people who just don't care, who say: 'My kid's fine. It's not my problem. If my kid wants peanut butter, I'll send it to school. That's your problem.' So, no, I don't think there's a lot of widespread caring or awareness of how bad it actually is.

CHAIR: Do you want to add to your comments about your experience in the schools?

Ms Culley: Sure. So I went in quite prepared because I knew the guidelines and we'd been to kindy and they were so supportive and we'd had lots of meetings and things. I worked in the education system too—I used to be a teacher aide—so I knew how things worked. I went to 16 schools the year before. Out of those 16, we were only accepted to two. I even got in writing that we weren't accepted due to allergies. Then, of those two, I thought this
one sounded the best and it turned out it was a lot of lip service and no delivery. We had everything in place, including risk management plans—that was my doing; I sort of pushed for that. They didn't even know about the guidelines. We had things in place for if a relief teacher came in. There was a folder that so she would know who the children with allergies were, where the EpiPens were, and things like that. That just didn't happen. He was sent to the toilet by himself at five years old when he had a reaction. He was sent without his EpiPens endlessly. Everything was in place so that none of this would happen. Everything that happened, we had already discussed prior to him starting, to make sure there management things were in place. But it just didn't happen. In the end, you try and communicate—I was always calm and I was always trying to be nice. You never want to put people off, but they made it quite clear that we were not welcome really and it was a big inconvenience that we were there.

CHAIR: Teresa, you're obviously just starting that journey with your boy. Have you got any feedback at this stage?

Mrs Nielsen: Yes. We did something similar. I made sure I read the guidelines. We had a really successful year at a community kindy prior. I met with the principal late last year, just because I felt quite anxious about him starting, and also prep at his school is not separate from the main school so, with primary school kids, no-one's sitting there neatly eating their food. It's been okay so far. I picked him up yesterday and he was crying. He was having an allergic reaction. His face was blowing up and he had welts. I don't know how long that had been happening for but I had to give him the Claratyne that I keep in my purse. So I already think there was a little bit of a breakdown of procedure.

CHAIR: What kind of reaction do you think it was?

Mrs Nielsen: I think it was just touch. I mean, it happened at 2.30 or so in the afternoon, so it was quite some time after the kids had lunch. As you know, it's part of the guidelines that, if you have a child at risk of anaphylaxis, they must wash their hands. Is that happening? But again we want to have a really positive year with the school and we don't want to feel like it's an inconvenience, because it's my child's life.

CHAIR: Yes. Catherine, with your OIT experience, do you have an allergist in Brisbane?

Mrs Sly: No. I haven't been back to the person that we previously were seeing once a year for skin prick tests.

CHAIR: Okay. There obviously is some debate about how effective OIT is. From the experience you had with the American doctors, did they recognise that for some people it's going to work more effectively than for others and that it may not be a solution for everybody and every allergy?

Mrs Sly: They have a very high percentage of people it does work for. The way the treatment happens is what they vary. So some people can go a lot faster. As they do their up-doses, they can do them closer together and for a bigger amount each time, so they'll fly through in a couple of months. Some people need to really spread that out and go a lot slower. Every time they increase it needs to be a smaller increase. So they do acknowledge that not everyone flies through it really quickly and has the best possible experience. But they say that most people get there eventually. Some people will still have mild reactions. Maybe their mouth will tingle and their throat will tingle, things like that. They might feel a little bit sick. So people do get small reactions like that. Xahlia has been quite lucky that she hasn't. As of last year, at the time that we went to our doctor, he had given 4,000 up doses in his clinic and not once had to use an EpiPen. So it's not that everybody has a major reaction and needs an EpiPen. That's not the reality of the doctor that we saw, or Dr Jones either.

CHAIR: Markeeta, you mentioned that you were trialling something both for yourself and for the child. I presume it's through diet.

Ms Culley: Mainly diet. Because of his chemical sensitivities that's eliminated a lot of household cleaners, soaps and things like that, which has benefited us. We've seen positive changes. He has allergic rhinitis and was on a steroid spray for three years and has eczema. He has had no eczema in four years and he has been off the spray for four years. He probably hasn't even caught a cold in over 2½ years—even if I brought one home. He is so healthy. I caught a virus that put me in hospital nine times five years ago and ended up with asthma, out of the blue, and couldn't breathe without a preventer. I'm now without that preventer completely. I never use a reliever—nothing. We are on no medications at all. We see it in our health in lots of ways. It's mainly diet.

CHAIR: What are the changes that you have made to your diet?

Ms Culley: We do organic and spray-free food and we do high fibre. We try to eat a huge range of vegetables, in particular, and organic meat—so that there's no antibiotics in there. We also took sugar out of our diet. That was unintentional; it just happened. That made a big difference. We also make and eat fermented food.
Ms Culley: The Sunshine Coast.

Mrs Nielsen: Brisbane.

Mrs Sly: Brisbane.

Dr FREELANDER: Thank you very much for giving us your personal stories. Clearly, you’ve all had pretty complex histories. Have any of you had to use an EpiPen or an adrenalin injection?

Ms Culley: Just last month.

Dr FREELANDER: What was that for?

Ms Culley: We think it was cross-contamination in a ham that we bought. The facility is adjacent to a bakery that had air-locked doors, but apparently there might be a chance of some wheat getting in there. That happened a month ago.

Dr FREELANDER: So you gave him the EpiPen.

Ms Culley: Yes.

Dr FREELANDER: Then what happened?

Ms Culley: Then we took him to hospital. We've had a few close calls and a few anaphylaxis episodes. He was taken to hospital. They tried to release us early but I insisted that we stay for four hours.

Dr FREELANDER: Did you have difficulty replacing the EpiPen?

Ms Culley: No, but I have had friends who are having trouble with the adult EpiPen now. I know the junior was stopped. I was able to get one that lasts only eight months.

Dr FREELANDER: So you have to replace it after eight months?

Ms Culley: Yes.

Dr FREELANDER: Catherine, you said that you have had to use it.

Mrs Sly: Throughout the year, Zoe has had four anaphylaxis episodes where she has needed an EpiPen. Because the last was four years ago, we didn't at that point have any problems getting junior pens. We still carry them just in case. This last time, she had to have an adult EpiPen because they didn't have any juniors and they said her weight was just on the border, so she could get the adult pen now.

Dr FREELANDER: Did you take her to hospital each time after you've used the EpiPen?

Mrs Sly: We called an ambulance; so the ambulance did, yes.

Dr FREELANDER: Teresa?

Mrs Nielsen: We've been fortunate that we've never had to use an EpiPen. My child didn't go to childcare, and he has had a fairly sheltered existence. We rarely eat out and we generally take our own food. We do occasionally go to some places that we trust. But now that my son is in school he is at higher risk. I would just note that two of the EpiPens that we do have are from the contaminated batch, unfortunately.

Dr FREELANDER: Has it been difficult getting them replaced?

Mrs Nielsen: Yes, it was. We had to wait awhile. Our pens expired in November of 2019 and we had a month when we were using the expired pens into December.

Dr FREELANDER: Because you couldn't get—

Mrs Nielsen: That's right. I think there was a limit on what could be dispensed—one EpiPen per person. My son and daughter each had one and then a second one on back order because they both require two based on the severity of their allergies. So they each have one that's not from the contaminated batch and in date, and another one that's in date but from the contaminated batch.

Dr FREELANDER: And do you see a regular allergy team or a private allergist?

Mrs Nielsen: We do. We see a private allergist-immunologist. We did start the journey at a GP based clinic, but we've now moved to an allergist-immunologist who we see once or twice a year.

Dr FREELANDER: Have they spoken to you about things like food challenges?

Mrs Nielsen: Yes. I think about November last year, my son undertook the baked egg challenge. Even though his skin prick test hadn't improved at all—it was still very huge to egg—my doctor thought it was worth a try.

Dr FREELANDER: And was he okay?

Mrs Nielsen: He passed in a way that he can tolerate a small amount—so not the full amount that they would generally classify as a pass, but certainly he's able to have some, which we think is a great step forward.
Dr FREELANDER: Did you have to wait a long time, or was the challenge done in a private setting?
Mrs Nielsen: It was done privately, but we did book it around six months in advance because that was the time my doctor suggested that we have the challenge, so we didn't have to wait.

Dr FREELANDER: Was that expensive?
Mrs Nielsen: It was. My daughter had her first appointment on the same day with the same doctor, and I think for the time that we were there, just for that morning, I was at least $500 out of pocket for the doctor's appointment and my son's challenge.

Dr FREELANDER: Markeeta, are you seen regularly at a clinic or by a private allergist?
Ms Culley: Private again—we always pay privately just to get in quicker. We were seeing Professor Pete Smith on the Gold Coast, but we now have immunology here in Brisbane which we come down annually for. They're a bit more generous now—we used to be $200 or $300 out of pocket and they've limited it a bit, so it's probably just under $200 out of pocket now.

Dr FREELANDER: Have they suggested challenges to you or anything?
Ms Culley: Not really. His allergies are quite extreme, so it's not something I'd be comfortable with seeing how easily he reacts against touch and everything.

Dr FREELANDER: Presumably your GP manages things like prescriptions for EpiPen.
Ms Culley: He says, 'You tell me what to do now,' because he knows that I know more about it than he does. I went in just the other day and said: 'This is what I'd like from you.' He said, 'okay,' because he's the one who misdiagnosed him for an awfully long time.

Dr FREELANDER: You said there was a bit of a difficulty in infancy—
Ms Culley: It was terrible, it was horrendous—how they missed it is beyond me.

Dr FREELANDER: Catherine, do you see anyone regularly?
Mrs Sly: We were seeing an allergist in Brisbane privately, but since we've gone to America I haven't been back. I think I will, at some point, just to say, 'I told you so.' The only thing that they ever did was a skin prick test each year and say: 'Nothing's changed, come back in a year, maybe things will be better.' I didn't feel that there was any benefit. I asked for food challenges, and they just flat out said no. There wasn't really anything they were doing for us. My GP wrote the EpiPen scripts for us whenever we needed them.

Dr FREELANDER: Do you still see your GP and rely on him for the scripts?
Mrs Sly: Yes.

Dr FREELANDER: Could any of you give me some idea of the financial and emotional costs of having child with severe allergies like these?
Ms Culley: I had to give up my job to homeschool my son because of his allergies, and because of that I've had to draw on my superannuation for the last two years and will again this year—it's a financial difficulty.

Dr FREELANDER: Have you been allowed to do that?
Ms Culley: Yes, you can—if you're in financial hardship, but only a limited amount per year. I'm lucky that I knew how to save before so I lived off my savings and I have my own home, so that's okay. But it's not doable long term. I do wonder what I'm going to do in the next couple of years, because my expenses alone—just for my mortgage and food—are more than I'm getting from my payments from the government.

Dr FREELANDER: And is there pressure on your relationships?
Ms Culley: With family, in particular—just the lack of understanding that I've found. Even our immediate family sometimes still don't get the gravity of allergies. I'm a single mother, so I don't have anyone to care for him usually as well. It can be really straining.

Dr FREELANDER: And you don't get any government support at all?
Ms Culley: No—just the jobseeker Newstart allowance.

Dr FREELANDER: Cath?
Mrs Sly: Emotionally, it was very, very hard. Because of our experiences with ambulances and with meeting special-care ambulances on the side of the road on the way to hospital, if I see an ambulance with its lights on go past me now, I still get shivers, and that really affects me. It was very, very traumatic each time she had a reaction.

Dr FREELANDER: How much did it cost to go to America and have the oral immunotherapy?
Mrs Sly: Just over $20,000 for everything: the accommodation, the flights, the transport while we were there and the doctor's fee.

Dr FREELANDER: How much did the doctors charge?

Mrs Sly: In Australian dollars, it was roughly $5,500 at the time, just to see him.

Dr FREELANDER: Just to see him?

Mrs Sly: Well, for all of his treatments—

Chair: Was that the six-week treatment?

Mrs Sly: Yes. It ended up only having to be four weeks, not six. And now we've got access to him. There's no ongoing cost or anything. If I need to talk to him, I just call him or Skype him, and he'll let us know whatever we need.

Dr FREELANDER: And you don't get any government support at all?

Mrs Sly: No.

Dr FREELANDER: Teresa?

Mrs Nielsen: There's obviously a financial component, but I think it's mostly emotional. It's anxiety inducing. You're sending your child off, and you have to trust other people, particularly in a school setting. We've only been there for a few weeks, as I said, but it is a big leap of faith to put your child in the hands of others and also, in a school, with hundreds of kids. We've been really lucky that our families have really understood the severity, because most of them have witnessed my son having reactions. We've been really lucky that we do have a good support network. But it can be quite isolating because, as soon as you're invited to anything, then you have to start a conversation about, 'Will there be food?' and you then have to go and make something similar so your child doesn't feel left out. Occasionally he can eat what's provided, but then you think, 'Is the worry worth it?' when you're sitting there, watching.

Chair: One of you talked in your submission about having to sneak food into venues and things like that because they wouldn't let you bring it in.

Dr Martin: Teresa, my question is directed to you. Is it your son that has just started prep?

Mrs Nielsen: That's right.

Dr Martin: During the orientation process, what sorts of discussions or plans did you enter into? I'm assuming there is something in place.

Mrs Nielsen: We completed all the paperwork and sent through action plans et cetera, and then, around November, we hadn't really heard—I don't know what I was expecting—so I emailed the principal directly and asked to have a conversation with her, just to—

Dr Martin: When you say you filled in the paperwork, was that just the forms—

Mrs Nielsen: They were enrolment forms.

Dr Martin: Just standard forms?

Mrs Nielsen: Yes. Also we alerted them to his medical conditions straightaway, and then I had a meeting with the principal in November, which was a really positive one. She was incredibly on board and wanted to hear our thoughts. Then she explained the school's policy and we touched on the Queensland state government policy. Then, from there, I was introduced to his classroom teacher. This was late last year. So I felt that we have everything in place, so that if something happens—

Dr Martin: What's the strategy?

Mrs Nielsen: I haven't seen their risk management plan. I know from the policy that they should have one. From my son's reaction yesterday, I'm curious to make sure that they do have one, even though it was only a very minor reaction. At my school, all the EpiPens and the asthma medication is stored in the office in a central place. They have this policy that, for example, if my son was taken ill to the sick bay, he wouldn't be left alone and unsupervised. I feel relatively confident that all of those things that are in the policy are in place. They have things like alert lists. Any child with a medical condition is on this alert list, so that all the teachers in the playground know. It's not just his prep teacher that knows who he is, but also relief teachers. These are all the things that we spoke about, to have them in place. I do have a relatively high level of confidence.

Dr Martin: Do they talk about ongoing reviews and meetings throughout the school year?
Mrs Nielsen: No, but it's something that I will initiate myself—just to touch base. Depending on how he goes in the first term, I'll see if there are things that we need to refine. But it's certainly something that I would initiate on my own, just to feel confident.

Mr ZAPPIA: I thank all three of you for presenting to the committee. You've all got fascinating stories that are very interesting. Dr Freelander pretty much covered the questions I would have asked, but I want to ask this: how did you find out about the American treatment?

Mrs Sly: It was just research. I eventually found a Facebook page from another Australian boy, Oliver, who had seen Dr Jones in America. I think he had been there for about a year and he was doing really well. I thought, 'Hey, I didn't even know that was a thing,' and I started investigating it. We couldn't afford, timewise or moneywise, to be over there for that long so I kept looking and found a doctor who had an international protocol, and that was exactly what we did. You're there from between four to six weeks and they just write out a whole plan. So we have a plan: 'If she's sick, we do this. This is how you up-dose and this is how often et cetera.'

Mr ZAPPIA: I think you said in your introductory comments that the doctor who treated your child is happy to do OIT here in Australia. Given that you had to pay for it yourself, even if it weren't covered by Medicare in any way, what's stopping your doctor from doing it?

Mrs Sly: It wasn't our doctor, it was another one, who is just as awesome!

CHAIR: A US doctor.

Mr ZAPPIA: Another doctor—yes. A US doctor.

Mrs Sly: He's another American doctor who does that. I believe it's something to do with the registration; he's an American registered doctor and he needs to be registered as an Australian, which he's in the process of doing.

Mr ZAPPIA: That's what I'm trying to get to: why are no Australian doctors, separate to the fact that they won't get reimbursed from Medicare, still prepared to say, 'I'm prepared to have a go and offer you this treatment, but you've got to pay for it'? Maybe it's a question Dr Freelander might be able to answer for me later on.

Mrs Sly: I don't know. I think the collective medical opinion is that it needs more research and it's dangerous. They just don't look at what's actually happening in real life in America. There's a Canadian clinic which was actually partially funded by parents like us, who just said, 'We need it here.' Australians don't seem to look at that research for some reason; they want to do their own research. That's what's taking the time.

Dr FREELANDER: With respect, I don't think that's necessarily true. I think there's lots of research that occurs overseas that the Australian medical 'establishment', if you like, is happy to accept. I just don't think that the research that has been done on oral desensitisation has been definitive and that some of these treatments can be dangerous.

Mrs Sly: I agree that it could be dangerous. To me, the difference seems to be the trial research versus the actual, real-life private practice research. In the private practice, where they can alter it based on changing it that day for that child, who might have a cold or whatever the situation is, there is a lot more flexibility. So I believe they have better results with that rather than in a clinical trial, where it's a lot stricter. There is a definite, 'You've got to do this and this,' and I think that's why people have more reactions in that scenario.

CHAIR: This is an obvious question, and my language might be wrong, but I think from previous evidence it's a non-approved therapy in Australia outside the clinical trial setting—

Mrs Sly: I believe that insurance may have something to do with that as well, because it's—

CHAIR: I'm not quite sure about the prohibitions, but I don't think you could offer it legally in a general setting.

Mrs Sly: I'm not sure on all of the technical reasons why.

Ms BELL: It does appear that it's different in every state across the country, and that's one of the most difficult things to overcome in these instances. But I want to go back to your experience with the schools. I'm just looking at the Education Queensland website, which says:

Queensland state schools are required to have sufficient staff who have completed:

- the online Australasian Society of Clinical Immunology and Allergy (ASCIA) anaphylaxis e-training course for schools and childcare (Queensland version)
- practical training in the use of adrenaline auto-injectors (e.g. EpiPen®)
- current first aid training (which includes cardiopulmonary resuscitation (CPR) and the administration of emergency asthma medication - as anaphylaxis and asthma are often linked).

It also goes on to say:
Schools will determine how many staff need to be trained by considering the health needs of their student population. My question is: schools are required to do that; was that your experience in the schools that you went to?

**Ms Culley:** I had to request that they do it. They weren't even aware of it. They didn't even know about it. I had to point it out. That last sentence says that they will determine who needs to do it. There were many times I walked into the class and there was no-one there who had that training, and I was supposed to leave him with those people, knowing that they had not been trained. That was my point to them: why can't we? It's only an hour and a half quick training, I think. It's really comprehensive. It's wonderful. I think it should be essential for every school staff member.

**Ms BELL:** The schools are actually required to do it.

**Ms Culley:** Yes. Even his kindy did it. Anyone can do it. Part of my family did it, just for their own peace of mind and so they could educate themselves. But the school were not keen. I got his teacher and teacher aide to do it, and that was about the extent of it.

**Mrs Nielsen:** My son goes to the local state school and, to my knowledge, all of the teachers undertake that training, including the office staff—the sick bay is directly in their proximity. To my knowledge, they are meeting that requirement.

**Ms BELL:** So perhaps it's the proactivity of the school in this space as to whether they provide that.

**CHAIR:** It shouldn't be hit-and-miss.

**Ms Culley:** It would be great if it was across the board. Then there is no argument.

**Ms BELL:** Of course. Did you have any comments, Catherine?

**Mrs Sly:** I'm not aware of who, at our school, was trained, but I know that there were people in the office and then I would always just talk to her actual teacher for the year and was confident. I always stressed: 'Just call an ambulance.' I would rather rely on an ambulance to help her than some teacher who may or may not have had all of the training.

**CHAIR:** What type of support have you had from allergy support groups? I think, Teresa, in your submission, you indicated you had good support from Allergy & Anaphylaxis Australia. Markeeta, you had some different comments.

**Ms Culley:** I did, very different!

**CHAIR:** Whether it's that organisation or others, have you had help and support from other organisations?

**Mrs Nielsen:** I haven't had direct support. I haven't had any direct contact.

**CHAIR:** But you've used their resources online?

**Mrs Nielsen:** I have. I was acknowledging their resources on the website in terms of getting ready for kindy, getting ready for school—the fact sheets and checklists that were just prompts for me for things that I need to check. That was helpful to me. But we haven't sought any help from any organisation.

**CHAIR:** Markeeta, have you had any support groups that you've—

**Ms Culley:** I have a friend who's here speaking today, and we all live on the coast, so we started our own Facebook closed group and met up with other allergy families. That's been the best support of all, I think, just making our own groups.

**CHAIR:** One of the things that we've heard previously is that, with some of the social media networks—and a local group like that probably wouldn't fall into this—they can be very useful but they can also be a source of bad advice. Are you ever concerned about that?

**Ms Culley:** Not with our local group. It's more like: 'Here's something that's local that's relevant to allergies.' But you're right: I follow other groups and I see things like that. I just don't get involved, don't comment, don't do anything on those sorts of groups. This is more like 'Look at this research we've just found' posts. And it's nice just to meet up and have like-minded people around you.

**CHAIR:** And know you're not alone.

**Ms Culley:** Exactly, yes.

**CHAIR:** Catherine?

**Mrs Sly:** The Allergy & Anaphylaxis Australia site hasn't been of any help to me. It's more other parents, and I wouldn't necessarily just go off their advice, but it's nice to have that idea which you can then research yourself and then make your decision or speak to that doctor—not just take their word for it. But it's more been other parents who are all helping each other who have been helpful for me.
CHAIR: Thank you very much for your time this morning. All three of you have been exceptionally eloquent advocates for your children. As I've noted before, it's always the mums who come to this committee. I won't ask you to comment on why that's the case! Thank you for your evidence. We will send you a transcript of this morning and, if you see any errors or want to make any corrections, you can do that through our committee secretariat staff. We really value your time. We can talk to lots of medical experts, which is important, but it's actually hearing the lived experience which is the most important in many ways. Thank you for being here.
MARCHAND, Dr Birgit, Paediatric Allergist and Immunologist, Queensland Allergy Service  

SMITH, Professor Peter, Director, Allergy Medical Group; and Allergist  

THOMSON, Ms Jody, Nurse Practitioner, Allergy Medical Group  

[10:10]  

CHAIR: Thank you very much for joining us. I'm required to remind you that these are formal proceedings of the parliament and the giving of false or misleading evidence is a serious matter. Today's proceedings are being recorded by Hansard and do attract parliamentary privilege, not that it's an invitation to defame anyone, particularly your employer.

Thank you for your recent submissions. I invite you—maybe starting with you, Dr Marchand—to give an opening statement, before we move on to questions. Would you like to go first?

Dr Marchand: I can go first. Or you could go first?

Prof. Smith: Birgit said she's anxious about this. I guess we all are. I'm very happy to go, if that breaks the ice. But thank you very much. It's an honour and privilege to have this— I recognise it as a once-in-a-generation opportunity to give feedback to the government.

CHAIR: No pressure on us, thanks!

Prof. Smith: It's an engagement, which is why we're having this discussion. I'd like to specify, first, that food allergy and the care of food allergy and anaphylaxis is a complex care condition and, as such, many allergists will engage a lot of one-three-two consultations. We will appear outside the normal. As one-three-two consultations, in private practice—if you are doing nine or 10 consultations we are really the top 20th percentile.

Dr FREELANDER: What's a one-three-two consultation?

Prof. Smith: One-three-two is a complex care involving two organ systems. We'll have patients, for example, with food allergy and anaphylaxis who may have airway disease, allergic rhinitis, allergic conjunctivitis, asthma or eczema. As part of that care, they've often had a diagnosis of asthma and have never had a lung-function test done.

Prof. Smith: Could you also explain if it's a much larger Medicare rebate?

CHAIR: So one-three-two is a Medicare schedule item?

Dr FREELANDER: Could you also explain if it's a much larger Medicare rebate?

Prof. Smith: Yes. Hence, we're under the watch as well of that service. It's a pressure we need to have. There needs to be cost containment but, again, we wish to practise in quality. Actually, the one-three-two doesn't cover this. Birgit and I both employ nurses to make the care about an hour or an hour and a half, and we have a nurse practitioner there. I'd like to stress that there's also a challenge, as a result. We see a couple of thousand patients a year compared to our hospital colleagues who may be seeing several hundred patients per year. As such a challenge, procedure is part of our practice for both drugs and food. Hence, that is very difficult and something that is underfunded. I would reinforce ASCIA's request for a challenge item to be done. Many of the challenges can be done, in rooms, in hospital challenges. Currently, I have a nine-month wait for that, and we're going to see an increase in adults who need food allergy challenges, as we have that growth of 700 per cent of children who develop food allergy becoming adults.

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I'd also like to raise attention to the respiratory review in Medicare practices. We have patients with complex respiratory disease who we manage. As such, the respiratory review cut items for physicians to manage respiratory disease and limited the money to respiratory physicians. With an expertise in rhinology, our ability to measure upper airway function is only limited to respiratory physicians. Doing a lung function test, which sometimes hasn't been done, takes an extra 20 minutes and is rebated at $35. If a GP has done it in the last 12 months and you are needing to assess that, it is a $17 rebate of Medicare. If we have complex patients with severe asthma we need to be able to do that repeatedly and be funded for that.

I would challenge the respiratory review committee that a physician with our experience and training knows how to read a lung function test better than a GP—a standard GP rate. Having only respiratory physicians be involved in that care is inappropriate. We look after patients with severe respiratory disease who are on immunological drugs, for which a monitoring tool is FeNO, which is expired nitric oxide. We are not allowed to claim that. They've ring-fenced that to respiratory physicians only in respiratory labs. We don't have respiratory labs, but we have methodologies, and getting a FeNO machine is quite important for managing our patients better. A FeNO predicts risk of hospitalisation. It is a very useful, modern tool, and we are seeing it used in primary care in the UK.
The Therapeutic Goods Administration, I'd like to say, is creating problems for us in private practice. We have just recently been asked to put in annual ethics committee approvals to obtain skin-prick-test reactions. This is easily done from hospital; you just go to the ethics committee and they write it. In private practice we have to go to a local hospital, and for each company it has to be an annual ethics approval. That is ridiculous in that it's not ethically different from one year to another. For a fully trained allergist and member to put that in each year, and for the TGA to approve that, it becomes onerous and time wasting. Five to 10 years would be reasonable, or as a one-off.

I'd like to congratulate the government on SAS C for drugs like ketotifen, which, for off-label use, we now can now fast-track without having to do TGA approvals. I'd also like to congratulate them on some of the biologicals that have been approved, as they are expensive. I would also reinforce that, with respiratory care, immunotherapy has now become a method of getting people off some of these biologicals that allergists are experts in. To be able to get patients off those, we need adequate measuring of their lung function and the tools to do that. The European Academy of Allergy and Clinical Immunology has said this is a new category where we should initiate immunotherapy as way of turning off people's allergies.

I would also like to make a point about labelling. I very much reinforce the idea that 'may contain' is dangerous and frustrating. I've bought some European products that just brightly say what the ingredients are. It is legible and it's in bold. Yes, it's French or German, but it raises the point that the foods that are in there are clearly and legibly labelled in bold. Often it's in six-point font, and parents in their late 30s and early 40s, having visual denial about needing glasses, are not reading it. So it's very easily oversought and can change the price.

Putting my allergy and medical hat on, I would say that a lot of care can be given in general practice clinic with appropriately trained GPs. I set up Allergy Medical in 2001 because there was a plethora of alternative health practitioners, including naturopaths and holistic doctors. There was even a white-witch service offering to treat allergies, and there was an advanced elimination clinic rubbing a stick up somebody's back to treat their allergies; it was $85 a session, and multiple sessions were required. They got deregistered. It appeared on Today Tonight—a complete scandal. They were open again within a week, under a different name. So we set this up to get people seen, screened and sorted. I had an 18 month waiting list to see patients properly. We set the process up to get people seen, screened, safe, sorted and sustained in ongoing care. We are very proud of the service. We cannot do the depth of care that a specialist can, but we've got flags and alerts. I have some documents which summarise the pressures on a service, what the service can provide, the limitations for review and why patients need more frequent review. I've also got some of those flags.

We do challenges at Allergy Medical. We've got doctors, nurse practitioners, dietitians and psychologists for food allergy anxiety now. We have two doctors there. There's a doctor there every week. We train the doctors up, and all doctors are encouraged to be part of the Westmead course and members ASCIA. Through our service we see 4,000 patients a year. A challenge in that service costs the patients about $250, after expenses, so half the price of what I just heard of. I'll close there and give others the opportunity to speak.

CHAIR: Thank you very much. We'll have to get some formal advice about whether we can eat evidence presented to the committee. Dr Marchand?

Dr Marchand: Thank you for the honour. I really am here to pledge support for our patients. My big request is for a code for food and drug challenges. Food challenges remain the gold standard for establishing the presence or absence of a food allergy. They also give us the opportunity to assess the development of tolerance in children with potentially transient food allergies. This particularly pertains to dairy, egg, wheat and soy.

We've just heard from families about how all-consuming it is to have a child with a food allergy. Food challenges are a step in the right direction. They can improve quality of life and allow for inclusivity—for example, when the child attends a birthday party and is allowed to have at least a cupcake with some dairy or egg in it—and yet they remain underused. Food challenges are resource intensive. They are inadequately reimbursed, and there's always the risk and concern of anaphylaxis. Currently most food challenges are provided by public hospitals only. This limits allergists and immunologists in private practice, as there is no code. That puts an extra load on the public system and removes a very valuable tool for us, and therefore patients do not get the quality of care they need. That's a big issue for me—to have the ability, availability and support to allow my patients to have food challenges—as well as drug delabelling. It's very simple to always say, 'You've had a reaction to penicillin,' but that label sticks for the rest of their life. We have a lot of adults who now need challenges, because they've got that label. A properly reimbursed drug challenge gives me that opportunity to delabel a patient in a safe environment. And I stress that our environment is safe. We do it as an outpatient within our practice, but we are within a hospital environment.
The next point—and you would've heard this from our patients—is that these are complex patients; they need a lot of support. They need help. I bring you back to the 132 code. Just to have one of those a year, and two 20-minute 133s, is simply not enough. These are patients that need extra help and support. Professor Smith has mentioned some of the respiratory-issuue codes. Patients might only get one code for a spirometry a year, or one Medicare rebate a year. It is our tool to assess a severe asthmatic and to assess how desensitisation immunotherapy works. We need to do rhinoscopies. These are patients who are plagued and almost disabled by severe allergic rhinitis. We need assistance in assessing our patients to the best of our ability.

CHAIR: Thank you very much. Ms Thomson?

Ms Thomson: I'll be very brief. Thank you for this opportunity; it's amazing. To listen to those parents that were here before makes me feel like I'm at work. When we have parents that come in, they are extremely concerned about their children and they are very isolated by their allergies, concerns and chronic health issues. As a nurse practitioner, I'm very privileged to be able to help them navigate through that system, because I have very few time restraints put on me by my very generous employer. So if I need to spend 55 minutes or 75 minutes there are no questions asked. And some of these people will need multiple appointments. They may need to have assistance with wet wrapping their eczema because their wounds are so severe that they're weeping and sticking to the clinic furniture, so you can't do that in five minutes. I talk to those parents about the food allergies and their grave concerns. Because the children's force field is down and they can't protect themselves, the parents are trying to protect them and the system is trying to protect them. It's just a beautiful thing to see those children come in pale, floppy and afflicted, and then for them to bounce in a couple of years later to say they've just been on their first school camp and have had sleepovers and they're playing cricket now because their grass allergy is controlled and their eczema has gone away.

We see babies to adults. My eldest patient at the moment undergoing immunotherapy is 85 years old. I also have a lady with a severe milk allergy, she's 83—not quite my eldest lady—and she has a 22 millimetre skin prep test to cow's milk protein, which she hasn't eaten since 1992. She's terrified of going out and having meals with her friends just in case somebody may slip up and she receives contaminated food.

I like to think my role is also about interpreting and supporting people regarding information. There's a lot of information out there—there's the wonderful World Wide Web—and sometimes people just need a little bit of a sit down, so we talk about what they found. They bring me information. As the professor said, there are all sorts of treatment modalities out there, and we like to think that we have a very good research and clinically-proven methodology at Allergy Medical that's always changing. We participate in research. We're participating in international research, which is improving in leaps and bounds our progress with food allergy.

We do clinical assessments. The biggest thing we do is we're there with the patients, so we're in there for the journey. It's not just a quick tick and flick. As the professor said, we screen people, we make sure they're safe and we get their conditions sorted, and we're in there for that support too, for the long-term. So thank you again.

Dr FREELANDER: Thanks for coming along today. I've got a lot of questions. First of all, we've had evidence from other places about the supposed need for an item number for food challenges. I wanted to get from all three of you: what do you think the cost of that would be per challenge? Have you given any thought to the actual costs for that procedure?

Prof. Smith: Within Allergy Medical, our structure is one of doing it with a doctor and nurse practitioner, and overall the cost is close to $400. I understand, with an admission to hospital, it can be close to $1,000 for that service, including the greater-than-four-hours short-stay admission. I haven't given too much thought to it. There are different models of support as well. There might be a smaller fee. I know that there's the opportunity some clinics will have with specialised care—some have a funded nurse or part-time nurse in their practice as part of diabetic care, under special programs, to help facilitate that. Then, there might be a reduced item if you had an extra care. So there's various models for that to occur under.

Dr FREELANDER: There's more than one model?

Prof. Smith: Yes, there's more than one model. But the cost, I think, is several hundred dollars. It's more than $200, but it shouldn't be $1,000—everybody does not need admitting for a challenge.

Dr FREELANDER: Because that's what we've been told, that the cost would be $1,000 to $1,200.

Dr Marchand: May add something? It obviously also then depends on how the patient reacts—if there's an anaphylaxis and it takes the entire day to ensure the patient has adequately recovered—so it's complex.

Dr FREELANDER: Indeed, it is complex.
Dr Marchand: It might just be a quick four-hour challenge and everything goes well and they go home, but it is more complicated than that.

Dr FREELANDER: In your clinic do you ever use a 10 item number?

Prof. Smith: Yes.

Dr FREELANDER: What percentage of patients would be seen for a 132 compared to a 110?

Prof. Smith: In my experience probably about 80 to 85 per cent are 132s. You might get somebody coming in with, say, a penicillin allergy and no other urgent morbidities. You may get somebody coming in with wasp allergy or bee allergy and no other comorbidities. If you've got food allergy 90 per cent will have eczema.

Dr FREELANDER: Do you bulk-bill for those consultations?

Prof. Smith: No, I'm in private. The bulk-billing rebate does not cover the expense of running the practice.

Dr FREELANDER: What is your standard fee then for a 132 initial?

Prof. Smith: Currently my gap is about $262.70, which is about $100 less than the AMA recommended amount.

Dr FREELANDER: So that's the gap?

Prof. Smith: That's the gap yes.

Dr FREELANDER: The total fee is—

Prof. Smith: About $490.

Dr FREELANDER: So 500 bucks.

Prof. Smith: That allows me to employ a practice nurse with that. I don't want a barn-door service, a wrong door service. I want qualitative care, depth of care. If somebody is on a health care card the gap is about $170 out of pocket.

Dr FREELANDER: Do you do any work in the public hospital system?

Prof. Smith: There is limited public health. When I came back to Australia—I did my training in Australia and went to London for three years—they had no allergy positions here in Queensland. They've established one subsequently which now is the Queensland Children's Hospital. But that's in Brisbane and I mainly work on the Gold Coast.

Dr FREELANDER: So effectively it's all private practice?

Prof. Smith: It's all private, yes.

Dr FREELANDER: What about yourself, Dr Marchand?

Dr Marchand: Same. Our patient demographic on the Gold Coast ranges from Coffs Harbour to rural New South Wales and all the way to Cairns.

Prof. Smith: Vanuatu and New Caledonia.

Dr FREELANDER: Sure. I appreciate it's a huge area. Let me put something to you. You've already given evidence, and we've had lots of evidence, about the complexity of allergic disease, and I would say it's even more complex in children. Wouldn't you agree that the best way to manage these patients is in a non-transactional, multidisciplinary clinic rather than separating each visit into different item numbers? Would you agree that that would be the best model of care, or the best practice?

Prof. Smith: Getting your ducks in a row is very hard to do. We've tried to do that. We have a dietician in our clinic and we try and link those up when possible. We have a nurse in our clinic. In the allergy medical model we have nurses, nurse practitioners, dieticians, psychologists. They get booked out. You can't get them. Yes, we can have case conferences with difficult patients but not every patient needs the multicare and it would be very cost ineffective to run it that way. Yes, it would be great if it was not transactional. There are increased pressures of a several year Medicare freeze as well that have been passed on to the patients. We've tried to buffer that. We have not gone up with CPI. Yes, it would be great. It would be great if the hospital services could see patients quickly. Again, part of setting up Allergy Medical Group was to get people seen and re-screened. If somebody has a peanut allergy they go to the hospital and they get seen. If they develop a cashew allergy and they want to get seen again they've got to wait the extra period. With Allergy Medical Group we can get people seen within two to three weeks.

Dr FREELANDER: Thanks very much.
Ms BELL: Great to see you here from the Southport, from the great electorate of Moncrieff which I represent. I'm pleased to know that we have this service on the Gold Coast and that it's so broad and far-reaching. My question is to, Dr Marchand, and the others here, around de labelling. If you're a patient and you go through the process of the allergy—what's the terminology—

Dr Marchand: De-labelling?

Ms BELL: The actual tests. You're going in to hospital. There are a couple of us here who are allergic to penicillin and have been labelled as penicillin allergic. We go through the tests and the drug challenge and then let's say we are de-labelled. We are then left with the problem in the health system of removing that label through, in my case, over 40 years of medical history. Do you have any suggestions about how that process could be undertaken? I understand that we are going to the digital age, and records are going digital. But in the short-to-medium term it seems to me there are millions of medical records or hundreds of thousands medical records that would have to be de-labelled so that the patient isn't then refused that drug at a later stage once they have been de-labelled. Do you have any thoughts on that? Could you break it down, the problem that we are left with?

Dr Marchand: One is that obviously the GP who referred the patient gets a letter. I think it is a very good idea if you would have worn a medic-alert bracelet saying that you are penicillin allergic to maybe wearing one that said 'de-labelled, all drugs in use'. But I think Australia is moving towards the digital age with the My Health Record.

Ms BELL: I can see that, moving forward, that would be a good opportunity.

Dr Marchand: It is not there yet. Where this would be an acute situation is if a patient were to arrive in hospital in a serious condition. Maybe letting the various hospitals know the patient had been de-labelled by putting it onto their record so if there is an accident—hopefully not—the hospital, the casualty, will be aware and have records on patients saying 'I have been de-labelled; I can use penicillin'.

Ms BELL: In the case of perhaps somebody travelling, not being near the hospital or their GP, they have had many GPs or they had moved from one country to another, I can see a hole with there being able to properly de-label. It is a little bit like removing misinformation, isn't it, from the internet—it takes some time. I am just getting my head around how that would actually work with so many manual records around the country.

Dr Marchand: How would they know you were penicillin allergic? There are clear medic-alert bracelets. I think that may be one option.

Ms BELL: My understanding is that it would be on every single medical record that you may have had in different states. When you go to a new GP, they ask you about allergies and you write, 'I am allergic to penicillin,' and that would appear, follow you around the country, I suppose, in your medical records. Then one day you are de-labelled because of this process and you would have that history and, depending on which state you are in or which facility you went to, they would have differing records.

Dr Marchand: Unless you didn't have a voice to say, 'I have been de-labelled,' a medic-alert bracelet stating that you have been de-labelled might be the only other option until we have moved forward to one health record.

Prof. Smith: I was going to make the comment that if I do label a food or a drug, the patient receives a copy of the letter in a PDF form that they can have electronic access to. So if they are in hospital situation and they need to show they haven't got that, they've got that record available.

Dr MARTIN: Following on from what you were just talking about, we heard yesterday that people can be de-labelled but that doesn't necessarily mean that they don't still change their behaviour. The interesting thing about de-labelling is that it doesn't necessarily take away the fear of the risk associated, even though there is some proof or evidence that they are no longer technically allergic. Obviously managing allergies whether they be food, drugs or environmental—we heard yesterday of insects, latex and what have you—is complex and requires multidisciplinary teams of specialists who work together collaboratively to develop treatment plans. I build on from what Dr Freelandor said: it seems to be very necessary to take a multidisciplinary approach. What I am concerned about is what you were mentioning before in relation to non-health-registered health professionals who are providing services and how we might be best able to manage that as a government. With organisations and authorities like AHPRA, how do we protect patients or potential patients from people who are providing services and claiming to be treating allergies, when in fact they are not registered health professionals or using evidence-based treatment approaches? What do you suggest?

Prof. Smith: The first thing is that it's very difficult to deregister somebody who's not registered with AHPRA. It is around the $400 mark to see somebody in allergy medical. That gets people an hour, or an our hour and half, service with a doctors and a nurse—that should be their normal procedure. It undercuts many of these alternative practitioners who are charging $500 or $600. The gap is still similar to what specialists have. We've set
that up as a model to try and not undervalue the specialist but provide accessibility and re-accessibility. With the people who are fraudsters, I think that needs to be pursued actively by the health authorities. If they are misrepresenting themselves, I think there needs to be legislation saying that people cannot fraudulently treat people and make claims.

**Dr Martin:** Would it be helpful to provide to parents information statements that are endorsed by an authority as such, which outlines the various disciplines involved in the treatment of allergies and discusses their roles and responsibilities perhaps in the multidisciplinary complex nature of the treatment so that we're advocating for professionals who have qualifications rather than not educating potential patients—for example, a list of things to consider when choosing a health professional to treat or a list of things to consider when seeking treatment for allergies. Does that already exist?

**Prof. Smith:** I think GPs and patients are very smart and aware. Some people would choose their own options. Some people will want to have naturopath-driven treatments. I don't know, if you published something, where that would be visible and the cost of that relative to other improvements we can do in the medical system and the allergy field.

**Dr Martin:** In the field of autism, for example, what was then called the Autism Association, at the time, used to educate parents about professionals to seek assistance from and provided a list of questions to consider. I think that really helped parents who were just at that early stage after a diagnosis to guide them and to assist them with making informed decisions about the types of treatments that they could engage. I think that was helpful. I wonder if it could also be used by perhaps a national allergy body in this space to help educate parents about best practice and the sorts of health professionals to engage so that we can avoid unnecessary death and so that we make sure patients, Australians, are getting access to evidence based treatment.

**Prof. Smith:** I think you make a very good point. ASCIA, our professional peak body, is involved, and I think Allergy and Anaphylaxis Australia do fill part of that role. I think they could have specific information about that. One of the points I would like to make, and you've somewhat raised it with anxiety, is the term that is used in the psychological food allergy literature is 'living with fear'. These patients live with fear and they want to do everything and immediately. Part of the pressure to seek alternative access is the lack of specialist accessibility. If somebody has got a six to twelve or eighteen month wait, they're going to go and look elsewhere where people make promises to help them.

**Dr Martin:** And that is my concern.

**Mr Zappia:** Did you make a submission to the respiratory review committee with respect to the MBS rebate?

**Prof. Smith:** With that committee? No, I was not aware the review was going on.

**Mr Zappia:** I'm not sure if the review process is finished, but, regardless of that, have you considered putting in a submission of some sort or writing—

**Prof. Smith:** I thought I would raise it at this opportunity, but if there is another opportunity and you recommend I do that, I'm more than happy to contact them and talk about the inequalities or the overlooking of the fact that we share these patients and how we have an opportunity to make these patients better and get them off some of these expensive biologicals, which don't have any end date in the current circumstances.

**Mr Zappia:** If I heard you correctly, you said that your waitlist for someone to see you was about nine months.

**Prof. Smith:** The waitlist for a challenge is nine months. I think my waitlist is about 18 months.

**Mr Zappia:** 18 months? The alternative, obviously, for someone who can't see you is to go to a public hospital.

**Prof. Smith:** Yes.

**Mr Zappia:** Do you know what the waitlist in a public hospital would be?

**Prof. Smith:** My understanding is it varies somewhere between nine months and two years.

**Mr Zappia:** If a family thought—and I'm referring to a family with children—their child needed to see someone more urgently, what do they do?

**Prof. Smith:** We do triage referrals. We have Dr Marchand, who has joined my practice, and we have another allergist who joined us a couple of weeks ago. We're trying to keep the capacity up. They can be seen as adult patients shortly, but with a child who is failing to thrive, they're having unknown anaphylaxis, we screen those and try to get those in within a couple of weeks. We also have Allergy Medical Group there to get people seen...
and their screening sorted. If they need an EpiPen, the doctor contacts me and says, 'It is appropriate,' and we arrange that to occur.

**Dr Marchand:** I have slots exactly for those urgent patients. I cannot deny an infant or a young child care, so I do have emergency slots.

**Mr ZAPPIA:** You may or may not wish to comment on this, but in evidence yesterday it was suggested to us that a lot of GPs could do with some training themselves with respect to allergies and allergy treatment, and that the system isn't set up to give them sufficient training to deal with issues. Would you agree or disagree with that observation?

**Prof. Smith:** I had 15 minutes of allergy training at medical school—15 minutes. It was in a pathology lecture, and then we went to type 2 reactions. It doesn't prepare us for what's out there, which is why all of our doctors who work only in allergy in the GP model have at least two years experience—some have five or six years experience—in the service and have got ongoing education and training, practise days and training days, peer reviews and are involved in education on an ongoing basis. For the majority of GPs, yes, they need to understand allergy a lot better.

**Mr ZAPPIA:** How would the GP having a better understanding improve the treatment? What would be the benefits of that? My simplistic mind says, 'Well, the GP doesn't understand, so therefore they refer to someone like you and therefore, from day one, the patient is actually in better hands because they've been referred to a specialist.' What would be the advantages of the GP having a better understanding?

**Prof. Smith:** There are costs to the patient and having appropriate diagnosis, having appropriate testing. They can do tests which have false positives. Wheat is a very common false positive. If somebody is off wheat, it costs them between $1,200 and $4,000, because the whole family goes off it. That is an extra food cost. If it's a common false positive, it's a grass. Many patients are grass allergic; it will come up on a skin or blood test. So tests need to be done in an appropriate context and have an appropriate diagnosis. It's about doing appropriate tests and not doing IgG testing, which costs several hundred dollars and wastes money.

It's about identifying patterns of drug allergy. If somebody has a reaction within 30 minutes of having a drug, gets rashes and it disappears quickly then, yes, it's likely to be penicillin. Having a rash two weeks later, after you've had a drug, without ulceration and fever is not going to be a true allergy or any of the rare syndromes, such as Stevens-Johnson or DRESS, which are more severe, but they don't have a penicillin allergy either. But GPs just say, 'Oh, yes, it's a drug allergy; don't have it again.' If they knew flags and patents better, I think we'd actually not label people. In the first place, not waste patients money and get appropriate referrals—and then we wouldn't have to de-label people.

**CHAIR:** I'll ask a general question that we ask occasionally: why are allergies on the rise in Australia? It's the million dollar question!

**Prof. Smith:** It's probably more than that, with respect! It's a multitude of forces coming together; it's not one answer. We feel that part of the hygiene hypothesis has got strength. We're living too cleanly. We did make mistakes with the suggestion of not introducing early foods, and the window of time for introducing foods is no longer years.

We are eating foods that look like danger signals—I published a paper on this in *JACI* in February 2017. We have foods that look like damaged tissue. When we microwave meat, we dehydrate and reheat it, also when we fry foods. When we have sugar—particularly fructose-rich sugar, which has gone up 700 per cent in the last 20 years.

If we're not having enough dietary fibre in our foods—the type of fibre and the variety of fibre is important to our microbiota, which then tells our body that everything's okay. We've just had a paper suggesting that of these slurpee juices that children have, 60 per cent of them have an acid pH under four, which is known to damage the epithelium. So if you're sucking back these slurpees, they're damaging the lining. Then, when you're eating the food, the body's going to say, 'Danger.' The other factor is vitamin D: our 'slipping, slopping and slapping' and getting low vitamin D does seem to be a risk factor for developing allergies. There are about five main reasons.

**Dr Marchand:** And it's a lot to do with epigenetics. With the industrial revolution and our vehicular pollution, we have switched on certain genes and that gets transferred from generation to generation. We see that each generation has become more allergic. There are certain genes that are just activated that program the body to a more allergic state.

**Prof. Smith:** You would see that, for example, with the grandparents smoking there is the risk of their grandchild having an allergic disease, so you're absolutely correct there. And we can deacetylate some of those—
CHAIR: But some of those environmental factors would be more profound in parts of the world where allergies haven't increased, wouldn't they? For example, you're talking atmospheric pollution. We know that allergies have increased most dramatically in the developed world, but if you took atmospheric pollution then it would be worse in countries that don't have higher emission standards, for example.

Prof. Smith: We're seeing a rise in respiratory allergies in those countries. In China, in the current generations, we're starting to see the rise of food allergies; they're starting to approach our figures in places like Singapore. We have had the bushfires, I expect us to see a massive rise in [inaudible] post bushfires. The small DEPs, the small particles that are two to 10 microns in size are going to irritate the airways, and, with the pollutants on top of that, we're going to become more sensitised from that. I think we're going to have an increase in airway allergic disease in the next one to two years.

CHAIR: I suppose the thing I'm thinking though is—you mentioned smoking, for example. Smoking rates were obviously higher 100 years ago than they are today.

Prof. Smith: Yes, but what Birgit is saying—

CHAIR: We're seeing the effects several generations later.

Prof. Smith: Yes, the sins of our fathers. We've seen the genes change, and then they reproduce. Those changed genes are then transmitted. We can clean some of our genes with healthy living and exercise as well, so there are some lifestyle options that can—

CHAIR: I don't think I've asked this before: the increase in the preponderance of allergies, is it across the board or is it primarily in food allergies where there's been the biggest increase? For example, susceptibility, and I notice that you've got a particular interest in insect allergies, are we seeing an increase in the incidences of insect allergies within a population do you think?

Prof. Smith: I haven't seen that increase. We've seen chronic urticaria increase slightly, where people are actually—and the data that has come out in the last two or three years is that this is a condition where patients actually make allergic antibodies to themselves. So, we're seeing a rise in this condition, which we're very grateful for the opportunity to have Xolair when patients—

CHAIR: So most of the increase in allergies is in food allergies?

Prof. Smith: Definitely it's increasing in food, and it is in the young. A paper on that came out in JAMA in America on 20 January last year suggested that half of adults with allergies develop their new allergies in adulthood. So we're seeing this growth, but also assessing that we're not ready to manage this tsunami of children allergies that have increased 700 per cent from the early nineties.

Dr MARTIN: I'm wanting to know if there is a relationship between childhood allergies and autoimmune disease in later adulthood?

Prof. Smith: We tend to see a protective effect: if somebody's got food allergy, there are lower rates of diabetes and lower rates of rheumatoid arthritis—they are the two autoimmune diseases that I'm aware of. It depends on the regulatory mechanisms. We've got something called regulatory T cells. They can regulate the direction as to whether you go allergic or self-attack. We have chronic urticaria, which is a self-attacking allergic mechanism, but generally there's a dissociation of those. There are cases were it occurs, but its real risk, I understand, is lower.

Dr FREELANDER: Dr Marchand, in paediatrics we're certainly seeing diseases that we really never saw before—or, if they were there, we didn't recognise them—things like eosinophilic enteritis. One of our mums was talking today about the gut microbiome, which of course is developed in infancy from the time of birth. I saw a recent paper that described the increase of incidences of things like eosinophilic enteritis with the rapid increase of the use of antibiotics during labour for group B strep et cetera. So would you agreed that we need to be looking more at these sorts of issues—the gut microbiome and infancy—if we're going to get an answer to these questions?

Dr Marchand: There is a lot of research going into exactly that area. Those are all very valid points.

Dr FREELANDER: I've been around for a while but I cannot remember 20 or 30 years ago ever seeing a child with eosinophilic enteritis, yet it's not uncommon now.

Dr Marchand: Non-IgE mediated food allergies is a huge area which we deal with. They're even more complex than IgE mediated.

Prof. Smith: Gastroenterologists need to be aware of allergic conditions a lot more. We reported that 20 per cent of our patients with EoE will have a history of severe food allergy. In general clinics it's between five and 10 per cent, but in private practice they may refer differential referrals but many of them will have a history of severe
food allergy. We also find that patients need many scopes, repeated scopes, to diagnose if a food is involved, so, again, an awareness of the MBS items—if somebody is doing four scopes to try and identify if someone's food allergic they may be worried about over-servicing when it's actually very appropriate servicing. We have the difficulty of drugs that are also being used off-label, like swallowed steroids, which I have to write privately even though they are best practice because there isn't PBS recognition.

Dr FREELANDER: I don't know if you're willing to admit to this, but do you ever prescribe for, say, asthma if you're using it for eosinophilic enteritis to reduce costs for the patients?

Prof. Smith: No. They very much have an awareness of that, and we can get the Pulmicort for $37 from a discount chemist, which is actually cheaper than the PBS schedule. But for somebody on a healthcare card it is an issue. Within hospital systems many of them will get it prescribed in the hospital system but again we need the TGA to be aware of best practice and we need to be sheltered and protected for the best practice to stop disease occurring by treating EoE properly.

CHAIR: Thank you very much for your time this morning. It has been very helpful. We will send you a transcript from Hansard of today's proceedings. If there are any errors or corrections, could you let the committee secretariat know by 29 February. Thank you again for participating. We very much appreciate it.

Proceedings suspended from 10:58 to 11:15
GRAY, Ms Bella, Member, ausEE Inc
GRAY, Mrs Sarah, President and Founder, ausEE Inc

CHAIR: Welcome. Thank you both very much for joining us this morning. I do need to remind you that these are formal proceedings of the parliament, and giving false or misleading evidence is a serious matter. Today's proceedings will be recorded by Hansard and attract parliamentary privilege. Thank you for your submission. I invite you to also make an opening statement.

Mrs Gray: Firstly I want to say thank you to the committee for this opportunity to raise issues faced by those living with allergic disease and what our focus is on, which is eosinophilic gastrointestinal disorders, or EGID, which I'll use for short here. I speak from my role as president of ausEE, the peak national support and patient advocacy organisation representing Australians living with an EGID, including eosinophilic oesophagitis, or EoE.

My journey with allergic disease started soon after my daughter Bella was born, and I'm proud to have her representing ausEE with me today. Bella, like many others with EGID, also lives with multiple allergic diseases, including food allergies with risk of anaphylaxis, rhinitis, asthma and eczema. Bella was diagnosed with EoE in 2005, when she was 18 months old, but her symptoms started when she was just four months old. After a long road to receive a diagnosis—and I want to acknowledge here that hers was short compared with what many others endure—and the years that followed, I was feeling very overwhelmed, isolated and frustrated at the lack of information and support available in Australia, so I set out to create it in 2009; ausEE is a volunteer-run Australia-wide charity. For me, it's been a labour of love for over 10 years, balanced with my part-time employment.

EoE is the most common EGID, which now has an estimated prevalence of one in 2,000 people. I say 'now' because when ausEE was founded and when Bella was diagnosed, 15 years ago, the prevalence was estimated at one in 10,000. So, there has been a significant increase over these years, and demand for our services has grown. Whilst I covered many key issues and recommendations in our submission to this inquiry, today I will focus on five key issues.

First, there is no defined referral diagnosis pathway for EGIDs, so a journey to receive a diagnosis varies greatly. A pathway can reduce unnecessary tests and strain on healthcare services and improve the timeliness of a diagnosis, which may result in less need for invasive treatments. Second, with no standards of care guidelines in place, there are many inconsistencies in the care people receive in managing their EGID day to day and through emergency care, and this varies from hospital to hospital and from clinician to clinician. Third, regarding providing individuals, families and healthcare professionals with quality, evidence-based information, before ausEE there was no information available in Australia on EGIDs. We've collaborated with our medical advisory board, international specialists and stakeholders and provide these free of charge, but our limited resources impact our capacity. Fourth is extending the reach of our support networks, as living with an EGID greatly impacts on quality of life—physically, socially and mentally. As the only patient support organisation for EGIDs in Australia, we play an important role in providing support to improve wellbeing, and it breaks my heart that we aren't reaching as many as we could because we just don't have the capacity to extend our reach further. Fifth is increasing the awareness of EGIDs through community outreach to help people recognise the symptoms of EGIDs so that they can seek appropriate medical advice to receive a diagnosis and to provide the community with an understanding of the impact on families and individuals; ausEE is also actively raising awareness for those with feeding tubes, as an EGID is one condition where someone may require a feeding tube. Bella herself had a gastrostomy tube from ages seven to 12 years.

Additionally, we are advocating for PBS coverage for Alimentum formula to not be limited to patients under the age of 18, as adults with EoE are currently being disadvantaged; multidisciplinary team healthcare EoE clinics in key Australian hospitals; an increase in the number of subsidised allied health service visits; increased availability of carer payments, allowance and eligibility for a healthcare card; addressing and reducing the waiting lists for treating specialists hospitals; the need for EGID patient registries; and PBS approved medications for EoE.

To say that our journey has been overwhelming is an understatement. We are just one story. Some people are just starting their journey. Some, like us, have been riding the rollercoaster for a long time. The impact that EGIDs and allergic disease can have, not just on the individual but on the whole family unit, in every aspect of life, is huge. Today we hope we are representing them all well in bringing to your attention these key issues and providing recommendations to the government, where, with your support, we can all help to provide a better future for Australians living with EGIDs. Thank you.

CHAIR: Thank you very much. Bella, do you want to add anything at this stage?

Ms Gray: No, I'm good.
CHAIR: I'll ask you a question, to start off with. Firstly, how old are you now, Bella?
Ms Gray: I'm sixteen.
CHAIR: Do you want to share with the committee your own experience, how your life's been affected by your condition, how it is now and what's worked well for you and what hasn't?
Ms Gray: I was diagnosed quite young. I was 18 months old. I had a big, rough patch when I was younger and I'm in remission at the moment. I'm at a really good stage right now. I'm at the stage where I know what I can tolerate and what I can't tolerate. I know what to avoid. But while I was in school it was really hard having all that sort of stuff, and making friends was also really hard—people just not understanding. I'm hoping that is going to get better, in the future, and people will know about that stuff.
CHAIR: Do you find it better now?
Ms Gray: Yes. I have left school and am doing full-time TAFE now. I really feel I fit in there and am happy to move on to that stage of my life.
CHAIR: This is for either of you. For those of us who are familiar with the disorder, when you say you're in remission is that because you're managing it yourself?
Ms Gray: Yes. I'm taking my medication and my eosinophil count is at a normal level.
Mrs Gray: She had a very active disease state for a long time—a feeding tube and stuff—due to the issues with the multiple allergies that she's had and some food-avoidance things that happen when you are fearful of eating food. It's a magnitude of things. But now, because of the regime change, which is diet related plus some treatment, the last couple of scopes have been zero eosinophils, which is great. But she has to keep that up. It's the sort of disease where, if you were to stop taking your treatments and stop having the diet, it would just come back. So it's important that people continue to follow their management. She'll have endoscopies now, probably, every two years.
CHAIR: You mentioned it was difficult because it was hard to make friends, because they didn't understand. You're in remission now so it's obviously a lot easier, but did you find that as you got older and your peers were more mature it got easier or not really?
Ms Gray: Yes. When I was younger people just didn't understand. They really had no idea what it was and there were a lot of questions. People just didn't know. I suffer from anaphylactic allergies as well. That is a more complicated part as well that I have to deal with, on top of that, dealing with contamination and food allergies and stuff like that.
CHAIR: The first two points you mentioned were the diagnosis pathway and the standards of care. I don't know the answer to this question, and I'm not sure whether you do. Dr Freelander might know. Who within government or the health sector sets those things, and are they normally done nationally or are they normally done state by state?
Mrs Gray: What we are looking at wanting to do is something similar. We have had discussions with Crohn's and Colitis Australia about their IBD standards. Something similar to that would work for EoE. That's separate to the diagnosis bit, because there are two parts to that. It can be diagnosed through a gastroenterologist, which is through having biopsies. With a referral pathway, it's knowing the signs to get an earlier diagnosis. We see people that are being diagnosed in their 50s and 60s. Some are younger than that. We did a survey where the earliest was six months, which is quite young. I would say they're mostly from around 12 months to where there's a person in our group who said they had been diagnosed at age 66. These people have said they'd had symptoms for many years and, the thing is, they weren't even necessarily looking, in the emergency ward—when they remove an impaction, especially in adults, this can be one of the first red flags, that this might be what it is. So a lot of awareness raising is really important to the medical community about it as well.
Dr Freelander: You're right. It's a multidisciplinary clinic, where you can go along and see—
Mrs Gray: That's right. That's why we'd like to see an EoE clinic that has, at a minimum, a gastroenterologist, allergist and diettian support, which is really important, and then—
Dr Freelander: As far as I'm aware, there are none that exist in Australia.
Mrs Gray: They have been setting up some, but they're not official clinics. For example, the Queensland Children's Hospital here in Brisbane has started to set one up with the gastroenterologist and an allergist. We've been trying to advocate to have them have a dietitian join that as well, which I think will be happening. The waiting list again is an issue to even get in to get diagnosed to begin with.
CHAIR: You mentioned the increased incidence—one in 2,000, I think, you said it now was. From your research, what do you think has caused the increase?

Mrs Gray: It's hard to say, but it could be awareness. Looking for increased diagnosis—if people are looking for it it goes in hand with what we're talking about. All allergy diseases are increasing—it is an allergic disease so that could be part of it as well. It's hard to say plus they're only just working on the study for the prevalence in Australia to say that figure. It's in line with America. They have a lot of the world leaders that field. They've talked about it as being one in 10,000 as well. It's just grown, and we don't know the reasons why. I think it's a bit of everything to be honest.

Dr MARTIN: I was just wondering about mental health and wellbeing and whether or not you've engaged in—if you're comfortable in disclosing—any psychological services over the years both for you and Bella and also Sarah for things such as living with fear and anxiety related symptoms.

Mrs Gray: Very much so. Right from when she was in prep she started seeing a psychologist for the first time. She saw a psychiatrist for many years. We don't like the stigma around mental health so Bella was on medication for her mental health before she had the feeding tube. That was obviously a very anxious time. She might want to talk more about some of those things. We weaned her off that medication about two years ago, which was a really big battle in itself, so I'm really proud of what she's been through to be honest. I could talk for an hour just on some of the mental health stuff we've had to go through.

Dr MARTIN: Bella, what do you think? Has it been helpful over the years to have that kind of psychological intervention; and do you think it would be helpful for other people living with those symptoms and anxiety related to your condition?

Ms Gray: It's been really beneficial for me. Everyone's different in what they feel comfortable doing. It's really whatever people want to do. For me, I love going there and I feel like it's made a big impact and helps my life. I'm really grateful that I could do that from an early age and that I was introduced to it then so that I feel more comfortable doing it now. I still really enjoy going there, and it makes me feel safe. It's a good thing to be able to do.

Mrs Gray: The 10 visits aren't really enough though. She was using up her 10, and then we'd just start paying for them. She also has food related anxiety, which is also something we need to address, but it doesn't fit into the category of a typical eating disorder case even though some of it is. We just pay privately for extra visits.

Dr MARTIN: How much do you think you've spent out of pocket over time on that?

Mrs Gray: It's hard to say because when she was seeing a psychiatrist for all those years it was like $265 a visit—thousands; I can't put a price on it. I just pay and go: 'Let's not add that up.' It's just a need and you just have to. We do utilise public health. For a period of time she was in CYMHS—Child and Youth Mental Health Service. We tried to go back there to help with some of the eating issues, but they said she wasn't a clinical enough case for that, which was good. We're just working with headspace at the moment.

Dr MARTIN: I think it's wonderful that you're willing to share that because it's really important for us in guiding future decisions. Thank you very much for sharing.

Dr FREELANDER: Thanks very much, Sarah and Bella, for coming in. I think your family must be very proud of you, Bella. I think you're obviously a very mature young lady, and it's great that you could come in and talk to us. I'll just ask Sarah a couple of questions first. How difficult was it to get the diagnosis?

Mrs Gray: Bella's system started failing to thrive when she was four months old, and I think we went through three GPs and three paediatricians. It was the third paediatrician that suspected that maybe it was coeliac disease and referred us to the then Royal Children's Hospital to a gastroenterologist, and that's when they found this—

Dr FREELANDER: Were there long waiting times?

Mrs Gray: I can't remember because she was young and she was failing to thrive, hence we ended up with a feeding tube.

Dr FREELANDER: She was tube fed from four months?

Mrs Gray: No. She was diagnosed at 18 months old and then put on alimental formula. She did drink that orally and just never drank enough of it, hence the decision when she was seven—and it was her decision as well—

Dr FREELANDER: For that long, too?

Mrs Gray: No. She kept drinking the formula and she was just tapering. She just wasn't growing enough on the percentiles. She wasn't thriving, but she was just getting by. We were worried about some of the issues that
might come, mentally, even from having a feeding tube. Again, that's an issue that there's just not enough information about: feeding tubes and what's involved. That's why we set out to create that too, just as an extra thing, because we lived that as well.

Dr FREELANDER: She had a feeding tube from what age?

Mrs Gray: From age seven, and she had that removed when she was 12. Then she started drinking the formula again.

Dr FREELANDER: Did she have a gastrostomy, or was—

Mrs Gray: Yes, she had a gastrostomy. She never did the nasogastric tube because they knew it would be long term for her. It was her pure willpower when she was 12 to want to have the tube out, and she started drinking the formula again.

I will say that she did eat some food all along as well. She had a limited diet due to her allergies: she is anaphylactic to milk, egg, fish and chicken, and then she also had wheat, corn and other things.

Dr FREELANDER: There must've been a lot of doctor visits and things in that time.

Mrs Gray: Yes.

Dr FREELANDER: Did that affect your ability to work?

Mrs Gray: I went to part-time to start this charity, so I've stayed working the whole way through. I still work three days a week. I was lucky I had good family support from my mother, who lived on the Sunshine Coast as well.

CHAIR: By the way, Sarah and Bella, you can set the boundaries of how much of your own personal stories you want to tell.

Dr FREELANDER: Yes.

CHAIR: So feel free to say, 'Let's not discuss that.'

Mrs Gray: Most people know about what we think, due to the support group, but yes.

Dr FREELANDER: Did you have difficulty accessing carer allowance or anything like that?

Mrs Gray: Yes. When we found out about it, it was a fair way on in the journey. But we did have it for a period of time. Obviously, now that she's 16 we don't have that.

Dr FREELANDER: Was it difficult to get the carer allowance?

Mrs Gray: We hear all the time about how people do find it difficult. So, yes, it's not easy. But for the period of time that we did have it, when Bella was younger, it was a bit of a different system. Yes, there are a lot of problems with that. We didn't have to go down the NDIS path at all, because Bella doesn't have a feeding tube anymore and things like that. So we just paid. But she does have a healthcare card herself, which does help with her medications.

Dr FREELANDER: And with the medications, is there still a significant cost because they're prescribed off-label?

Mrs Gray: Yes. Bella is not on those particular medications anyway, but that's because they're not covered for the indication of EoE. And even though it's not a medication, that's why I put about alimental formula in there particularly. Although there is only a small number of adult patients who would require it and do want to have it—if they've tried every other treatment and those haven't worked, and they're prepared to go down that route—they don't even have that option. I do know some who are spending thousands of dollars every year—I think one person reported $12,000 a year—buying the formula themselves. Bella's case study was shared in my submission, showing how much it costs to have that alimental formula. Obviously, no-one wants to be on it if they don't have to be on it, so it's unfair. It stops when people turn 18. I know some kids who are at an age similar to Bella's and when they turn 18 they still have to supplement their formula, and then they're not covered or they have to start paying for it.

Dr FREELANDER: Bella, it must have been absolutely painful sitting in pediatricians' waiting rooms and things. What was the worst part of it all—having this illness and gastrostomy feeds?

Ms Gray: I'm not sure—

Mrs Gray: Managing at school, do you think? It did make managing at school hard.

Ms Gray: Yes, that was hard.

Dr FREELANDER: What was that, sorry?
CHAIR: Managing at school.

Ms Gray: Managing my life with allergies and stuff, and also trying to have a social life on top of that was really hard.

Dr FREELANDER: Did you have to feed yourself at school, or was it—

Ms Gray: Yes, I did. I had a teacher aide with me and I got fed during lunch breaks and stuff. My classmates knew about it. They didn't really understand what it was and bullying and all that sort of stuff did happen because of that. It was people not understanding and discriminating because of it. Yes, that did happen and that was a struggle in school.

Dr FREELANDER: So, school was an issue.

Ms Gray: Yes.

Dr FREELANDER: How could we have made things better—for both of you, really—in terms of the diagnosis and management?

Mrs Gray: That's why we're really keen to be able to help. I want to help the government. I want to help put through things like these guidelines, just because the standard of care will set out things like the right to see a dietitian and the right to see an allergist. We have people who have reported that they have EoE and they're being refused a referral to an allergist, because skin prick tests and those typical things will not show up what the EoE triggers are, but there are many allergists who are specialists in the field of EoE, so they can give good advice and guidance. Working with dietitians and things like that are really important. And it varies very much state by state as to who will lead. In some states it will seem that an allergist is more the leader of the treatment journey with the patient, because it's very specific from patient to patient. So, it's not as though you get a diagnosis and then are told, 'This is what you do.' It is very much patient-specific, to work through what's best out of the options.

Dr FREELANDER: It would be best if you had a dietitian, allergists, gastroenterologists—

Mrs Gray: Yes, and paediatricians. Obviously that's often the case. And GP awareness: we just want to raise awareness that it even exists.

Dr FREELANDER: In the same clinic?

Mrs Gray: I think psychologists definitely—to be offered—especially because a lot of these kids do end up with issues around food, because food causes fear in them to eat, including swallowing difficulties. Bella had a bit of both, and she's not alone there, having the anaphylaxis allergies as well. She did experience anaphylaxis a couple of times. It's hard to say which was which—

Dr FREELANDER: Has that been a bit of an issue for you, Bella, the anxiety about food?

Ms Gray: Yes, very much so. I feel that's something that follows you along in life. As long as you have an allergy, there's always that fear and you are always being very careful and cautious, because something so small can really affect you and cause an anaphylactic reaction. I had an anaphylactic reaction two years ago, and that was a pretty traumatic experience for me, especially with the ambulance officers not really understanding, or not having the needed education. They made me walk after I had an EpiPen injection, which is the No. 1 thing to not do.

CHAIR: So, they made you walk.

Ms Gray: Yes. We were at an apartment block, and they said they couldn't—

Mrs Gray: They couldn't bring the stretcher up. They had to walk down the flights of stairs. It was suggested that I put in a—well, not a complaint—and I did fill out the form. I said that it wasn't a complaint, because I felt that they helped save my daughter's life. But they investigated and said they did everything following protocol, even though I sent them the link to the ASCIA medical resources—that list of things such as that you shouldn't be walking after you've had an EpiPen.

Dr FREELANDER: Do you carry your EpiPen with you?

Ms Gray: Yes, I do. I carry it everywhere I go.

Dr FREELANDER: How many times have you had to use it?

Ms Gray: I've only had to administer it once, but I had close calls when I was a little girl.

Mrs Gray: She had three anaphylaxis reactions, but the other two were dealt with by the ambulance as the first line.

Dr FREELANDER: Thank you very much, and thanks to both of you for your time here. Your story is very important.
Ms BELL: Thank you so much for coming today. I think I speak on behalf of all of us when I say, Bella, that you're an inspiration for coming here today, and for what you've been through—and Sarah, as her mother. It must have been very difficult, and I'm sure you've done a great job taking care of Bella and her general wellbeing. In your submission you say that EoE sufferers use alternative unproven therapies to help their condition. So I want to ask about perhaps some of the stories of your members using alternative therapies to try to help their condition. Perhaps you could just share a couple of anonymous stories with us.

Mrs Gray: I was just answering the terms of reference—so, anecdotally. Yes, they do use IgG testing, because there is no testing, so they will maybe try that. Some say they have benefit, from seeing a naturopath and things like that.

Ms BELL: IgG testing—I'm not aware of that—

Mrs Gray: Is Professor Pete Smith still in the room? No, he's not. IgE testing is like the IG media test—like a skin prick test—and then IgG is more like testing for tolerance. So you would get a test done and, if Bella had it, it would probably say she's allergic to a hundred things.

Dr FREELANDER: You could do a blood test to test for IgE antibodies to specific things. It is often negative.

Mrs Gray: I guess they are just frustrated. Waiting lists are an issue as well, for the time taken. I think when you asked that question before I didn't get to finish. When Bella was diagnosed we then had to wait 18 months for her to be seen by an allergist. So I feel that time probably contributed to her being more reliant on the formula. People having to wait so long do then resort to trying to find other answers before they've reached the diagnosis. That's probably the main thing, but it's hard to say—there are so many different ones. There is a good resource, which we do share on the ASCIA website, about unorthodox testing, just to let people be aware about the sorts of tests that are being offered, like hair analysis tests and things like that. There is a good explanation of why they're not beneficial. I do share that resource.

Mr ZAPPIA: Thanks both of you for coming along today. It's been very interesting. I've not heard of this condition before, until reading your submission. From your submission, I get the impression that it is not a condition that is very well understood and dealt with. What's your observation of gastroenterologists generally? Do you believe that they understand it well enough or not?

Mrs Gray: I think, yes, good gastroenterologists understand it. As part of our advocacy work, I go to the gastro conferences as well, and we've also been part of stakeholder groups for certain things. So, yes, I believe they are aware of it, but not so much with emergency care. We've heard of multiple issues, especially in rural and regional areas, with a lack of understanding—and I did share one patient's story in our case study of an incident that happened. So it's getting those gastroenterologists to be more aware. There is obviously something going on that some people are taking that long to be diagnosed with something.

Mr ZAPPIA: You also comment on the TGA process in your submission and about the fact that you can't get access to certain medications. I'm just curious as to why the medical profession itself isn't making submissions to the TGA to have those medications listed earlier.

Mrs Gray: I think part of it is that we're just a small number compared to what the main medication is used for. There are some medications that are happening in the pipeline that we hope will, at some stage, be put to the PBAC to be approved. We're closely following what happens over in the UK and in the States. We're not the first country to get clinical trials, but I do know some that are happening and I'm exited to see that they do progress through, because that's something that has been certainly lacking. But there was no FDA approval in America either—they were still using them off-label in America as well. This is an issue where basically the disease came in, probably, and you saw a rapid increase, then they started working with medications that were already there and then were using them off-label. Obviously, as the number of people with it has grown, the amount of usage has grown. For a lot of these medications, it's just all catch-up time now.

CHAIR: Can I thank both for your evidence today. It's been really useful in shining a light on this issue, and your detailed submission was fantastic as well. We'll provide you with a transcript of today's proceedings, and if you wish to make any corrections please do so by 29 February.
FUNK, Ms Melanie, Managing Director and Founder, Eczema Support Australia

LAYTON, Ms Victoria, Volunteer, Eczema Support Australia

[11:44]

CHAIR: Thank you very much for joining us this morning. I need to remind you that these are formal proceedings of the federal parliament. The giving of false or misleading evidence is a serious matter. Your evidence today is being recorded by Hansard and does attract parliamentary privilege. Thank you for your written submission. Can I invite you to make an opening statement, before we move onto questions.

Ms Funk: First of all, thank you for inviting me here today to represent the many members of Eczema Support Australia, a support network that I co-founded four years ago. I want to start by saying thank you for the work that you're doing through the allergies and anaphylaxis inquiry. It is tremendously important. Australians living with severe eczema are in desperate need of help. They've been suffering in silence for far too long. Today, I want to give them a voice and outline some practical things that need to be done to help them.

First, the problem. Severe eczema is underrecognised and undersupported and requires significant investment by government. Severe atopic eczema is not just an itch. It is painful, relentless and debilitating, and it drives people to actively plan suicide. It is more than a skin condition. It is an inflammatory autoimmune disorder that often coexists with other allergic inflammatory diseases such as asthma, food allergies and allergic rhinitis. As a mum of twin 10-year-old boys with eczema, I know how debilitating severe eczema is, watching those you love tear their skin to pieces. They also have many comorbidities. It isn't just a childhood condition. It can be lifelong and incredibly severe.

With me today, I have Vicki Layton, a brave and amazing lady who is volunteering with Eczema Support Australia to help build the psychosocial support for our community. I say 'brave and amazing' because Vicki is also battling a daily health crisis with her own severe eczema. I'm sure she would be happy to answer any questions you may have today for an adult with eczema.

Imagine operating on three to four hours of broken sleep a night, for years. Imagine the struggle to survive, never mind work—the broken skin, the skin infections and the pain that drives people to breaking point. This is a pain suffered by children and adults with eczema, and there is also an enormous impact on families and relationships. I know how little support is available. That's what drove me to found Eczema Support Australia. However, we are entirely volunteer based, and the support required is great. Thousands of Australians are suffering right now, but their suffering is invisible. One mum told us: 'My son attempted suicide when he was 18 as a direct result of his eczema. He does not believe there is any hope for him and his condition.' Depression and suicide are, sadly, common for people with severe eczema. This is backed up by research. A major meta-analysis in the journal JAMA Dermatology revealed that people with eczema are 44 per cent more likely to contemplate suicide and 36 per cent more likely to attempt suicide than people without the condition. We hear repeatedly about suicidal ideation among our members, and even about actual suicide within families of our members.

So—what needs to be done?

In a nutshell, there needs to be more practical support and improved treatment access for people suffering with severe eczema and their carers. Whether the person with eczema is a baby, a young child or an adult struggling with life and coping with depression early intervention is a must. Practical support and treatment needs to occur well before the person is driven to breaking point. The gold standard of care should be available to all so people don't fall through the gap between dermatologists, immunologists and primary care. Financial support needs to be available so people with eczema aren't thousands of dollars out of pocket due to daily eczema management regimes. For example, moisturising isn't a choice for us; it's a medical necessity. Then there are the additional costs of other medical topical applications and related management costs.

Eczema Support Australia receives no government funding which limits how much we can do. We need investment from the federal government for support services to ensure we are meeting the needs of members with severe eczema.

I know you've already heard from Professor Connie Katelaris and other doctors about the urgent need to make new biologic medicine available in Australia. Dupixent has been publicly funded in the UK since 2018 but Australians have to pay thousands of dollars a year for it. This means for many Australian's with severe eczema they cannot afford it.

The Pharmaceutical Benefits Advisory Committee will consider Dupixent for the third time in March. Three-thousand people have signed a change.org petition for this medicine to be added to the PBS. I want to read you some of their comments. Julie-Ann says:
As a nurse I have seen patients suffer terrible torment with this condition. I would love to see relief provided at a reasonable cost.

Emma says:

Eczema is a debilitating and torturous disease that has stopped me enjoying much of my life. Having this disease makes every day tasks … nearly impossible. Effective treatment would mean normality for me and thousands of other Australians …

Parney says: 'I am an eczema sufferer and I will kill myself if I don't get relief.'

We recognise the federal government's commitment to making life-changing medicines available, but we are concerned that severe eczema may be overlooked amongst other budget priorities. We appeal to you that severe eczema is a condition that destroys all semblance of normal life. It makes people question whether life is worth living. Early intervention and funding for support and treatments are urgently needed. We need government to set aside some funding for new biologic therapies so it can be added to the PBS as soon as possible, as we've outlined in our pre-budget submission to the government.

Before we take questions, I want to tell you about our SOS save us from eczema campaign, which we've recently launched to draw attention to the severity of eczema. We chose the name SOS to draw attention to the distress and agony of eczema. The response to our campaign has been overwhelming, from all ages and all corners of Australia.

Our members are sending SOS postcards to their federal members of parliament and I just want to read three of them to you. A mum says: 'I'm sending an SOS because my 22-year-old son has suffered from severe eczema all his life and nearly died of sepsis. I find it incomprehensible that he's been forced to move overseas to access medicine that isn't available through PBS.' I've actually met this mother's son. It is a tragedy that we're losing him and he has to leave his family and friends and restart his life away from his home, Australia. Another one, Brooke, who is 32-years-old wrote: 'I'm sending an SOS because it's taken a huge toll on my life. I've been hospitalised with infections. I've had depression and anxiety since I was 14. I finally found relief through Dupixent. If it isn't PBS listed it will absolutely destroy me.'

I've also met with others face-to-face who are currently on Dupixent and have said very similar things. Caitlin 23 states: 'I'm sending an SOS because eczema is agony. I wouldn't wish eczema upon my worst enemy.'

To sum up, a few hours of broken sleep a night, torture, depression, suicide— Australians with severe eczema need your help. We appeal to the committee to recommend that the government provide funding for practical support services for Australians with severe eczema and urgently subsidise biologic therapy that is already funded overseas. We are seeking immediate relief where this is possible, through life-changing treatments as well as some longer term support for our Australian eczema community, for the young families and the teenagers as well as the long-suffering adults with eczema. Thank you. We welcome questions—or if Vicki would like to add something.

Ms Layton: Thanks for having me. I will briefly tell you my story. I got eczema for the first time when I was 32. I literally woke up one day covered in this rash and it's just—

CHAIR: Is it unusual to have such late onset?

Ms Layton: I guess so. I always had a little bit of hayfever, or little allergies to things I could wash off, but absolutely not eczema or anything I ever needed to get medical help for. I literally just woke up covered in this rash. I didn't know what it was. GPs didn't really know what it was and I had no idea about the next 10 years of my life and what that would entail. The eczema has taken away a little piece of every part of my life. Things have developed along. I haven't responded to the treatments that are available in Australia. Then in November last year I developed idiopathic anaphylaxis and it has been a tough journey.

CHAIR: Thank you. And thanks, Melanie, for your evidence. I know that was hard. What strikes me about this and so many other health inquiries is that so much of the support that is given is through parents like you taking the initiative, not just worrying about your own kids but worrying about other kids in the same circumstances and actually trying to make a difference for people across Australia. You should be very proud of what you're doing in that regard. Dr Freelander.

Ms Funk: Thank you.

Dr FREELANDER: I found your submission very moving. I think everyone here did. I would like to say firstly that your voice is being heard. Connie Katelaris has presented to this committee, and on her instigation I have written to the minister for health asking for dupilumab to be made available for people with severe eczema—funded through the PBS—because it is clearly life-changing for people with severe eczema. We run a
severe eczema clinic at my hospital, and Connie is head of that. We have a trial at the moment that is incredibly effective and life-changing.

I thank you both for your submissions. I found them very moving. Some of my patients have a really incredibly distressing time with severe eczema. I think what you say is right. Because people with severe eczema tend to cover themselves, they're not immediately obvious to someone walking down the street. But I've seen what it can do to kids, from babies and adolescence through to adult life. I think we need to make people aware of how severe eczema can be and how life affecting it can be and what it can also do to families. There are better treatments available. So we need to really put the pressure on now to ramp up the availability of these newer medications.

I want to briefly ask you about the financial costs involved. Having twins is bad enough, I know, in terms of cost and time. But having twins with severe eczema must have been extremely financially difficult as well as time consuming. Can you give us an idea of the costs involved?

Ms Funk: Extremely. It's very difficult to put a monetary figure on it. I titled my submission, 'It started with eczema'. That was a bit of a personal submission, because my boys presented with the skin barrier defect really from birth, and we have asthma and hayfever in our family but I have no food allergies.

Dr FREELANDER: I didn't mean to be horrible about twins. My son has twins and we are always glad to see them but we are also very glad when they go home.

Ms Funk: One thing I'm thankful for is that, with both of my boys having the severe eczema, multiple food allergies and the asthma, they do get each other. So they've got their own little support network together from birth, which is wonderful. But putting a figure on it is difficult. I made a note here that for us it's meant a big list of things: things not to do and things to do. And there are huge pharmaceutical bills. Our local chemist must love us. There are constant applications of creams and ointments and bleach baths and wound dressings and specialist appointments. They all add up. But they also had to be withdrawn very quickly from mainstream school environments; because of their comorbidities, the school environment wasn't compatible and our specialist told us to get them out and home school them. So we've been home schooling for five years. But, prior to that, I had to give up my career, my job as HR manager. That happened even before we started school, because they got so severe they needed 24-7 in-home assistance. I'm very lucky I have a registered nurse living at home—that is, my mum. So we've been able to manage things well with a lot of communication with multiple specialists, dermatologists, pediatric allergists, GP, pediatrician. The costs involved, you can't put a figure on it. Financially the costs are huge. They are completely life-changingly huge. But they're very difficult to add up.

Dr FREELANDER: For you, Victoria, have there been big costs involved?

Ms Funk: Big costs. I think my costs are probably a bit easier to quantify. I can say definitely the first three years of diagnosis was a $50,000 input. At the time I was diagnosed I was living in a regional area so I didn't have access to doctors. So you do fall into the trap of trying everything, every promise. As foolish as I feel now—you are so desperate to keep yourself alive and keep yourself going through the day. So there is a lot of financial debt. I had to sell my house to pay for the electricity bills, the pharmacy bills, the creams, all of these sorts of things. I also had to step down from my career. I was a registered nurse in an acute setting and I just physically could not do that anymore. So financially my costs went up and my income went down. Yes, it's a big loss. It was definitely $50,000, I can say. It could be $100,000, I don't want to say. But it was enough to change your life and change the course of your life for years to come.

Ms Layton: And they're just some of the direct costs.

Ms Funk: Yes. The financial cost.

Ms Funk: I think the support out there for people dealing with eczema and the comorbidities that often go with that is lacking. As a support organisation we're not there to provide medical guidance. We point to the evidence based medical authorities on that. But we are there to help reduce that isolation and provide access to things like psychology services. We actually pay for psychology services for our members where we can and general information school kits—which is ironic since my children aren't in the school system—and support group meetings. There is that. But those other areas of support really need to be boosted as well as the treatment options. Ideally, if we've got better treatment options, we can reduce the need for support because we're not going to be having as many issues. But, until people get things under control, it's going to be an uphill battle. Unless you live with it or you're very close to it as a medical professional, the problem is severe eczema is not recognised as a need.

Dr FREELANDER: Thank you both for coming along and for your very powerful submission.

Dr MARTIN: Thank you for coming along today and thank you also for sharing the information about the mental health impact that people with eczema experience. It is very high—the research that you quoted, 44 per
cent. I wasn't aware of that. Obviously, a lot of people reach out for help through your organisation, Eczema Support Australia. I am just wondering if you have a way of communicating to people who might be members or who are contacting you for the first time, who are experiencing mental health problems? Do you have a mechanism by which you can communicate to them where to get help, for example? Do you have on all your communication contact details for Lifeline and for mental health services across the country?

Ms Funk: That is something we are wanting to build at the moment. We have developed a partnership with clinical psychologists in Brisbane, who are providing our members with consultations either by Skype or telephone. One of the things we want to do is to be able to induct, educate other mental health practitioners and allied health practitioners about the impact of allergies and eczema. We have done it with one group. We've only been going four years. We were only renamed Eczema Support Australia last May. Before that we were Hands to Hold—allergies and eczema support. So, yes, we are. We are providing lifelong contacts on certain posts that we put out but there is a lot more that we would like to do in that area. It was probably our No. 1 priority, first project—support groups and then psychology consultations—to get people to reach out for that support and to break down the barriers. So we don't require a GP referral initially and we pay for the consultations to make sure that people know that (a) they deserve the support, (b) they need the support and it is available.

Dr MARTIN: I would recommend, given the high incidence of mental health issues for people with eczema, that the information is on all your correspondence so that there is access to help because Lifeline, headspace and other organisations—ReachOut—

Ms Funk: We want to develop more partnerships and connections there. We are going through a big learning curve ourselves. I have never run a charity before. There has been a lot of big change over the last 12 months in our charity, positive changes and focus, so certainly any support and guidance from the committee elsewhere would be very much appreciated.

Dr MARTIN: Of course we will take away that number as well, that 44 per cent, because that is very high.

Ms Funk: And that is part of recent research that has come through.

Mr ZAPPIA: Thank you very much for coming along today and for sharing your two individual stories. I think, like with so many other people that this committee listens to, we don't always have an appreciation of just how serious issues are until we actually hear firsthand from people like yourself, so thank you for that. And thank you for arranging to come to Parliament House on Thursday week, where perhaps some more of our colleagues will be able to attend and hear some of the statistics and issues that you are confronted with. I really only have a couple of questions and one is to do with the TGA process and the fact that that there are medications overseas being used that have had some degree of success and why are they not being used here. Do you know whether any of the manufacturers of those medicines or creams have actually applied for PBS listing?

Ms Funk: Yes. There is the injectable biologic Dupixent, dupilumab, which has TGA approval, I understand, for adolescents and adults. For the adults, I believe it is going for the third round of review by the Pharmaceutical Benefits Advisory Committee next month. As for other ones overseas—I know we are calling it the 'era of eczema'—there are new treatments coming through the system, but I believe the only one TGA approved in Australia is Dupixent. A lot of our members have been on the trial and had compassionate access to it, so that is the one we almost aware of.

Mr ZAPPIA: Can they access that right now?

Ms Funk: Yes, you can access it on private script for about $1,600 a month. And there are a number of people who were on the trial and have compassionate access to it, I believe, through the pharmaceutical company.

CHAIR: Have you been able to use it with your boys?

Ms Funk: Not yet. They are 10; so they have not been able to access it as yet. But, given their comorbidities and their skin, they are well controlled at the moment, but it would only take two days for them to get out of control again. I imagine that, by the time they are teenagers or young adults and out of the bubble environment that they are in now with home-schooling, they will probably need something like that.

Dr FREELANDER: It's only approved from 12 upwards.

Mr ZAPPIA: In your presentation today you referred to people becoming suicidal. Are you aware of anyone who has actually lost their life as a result of it?

Ms Layton: I can speak to that. My father also had eczema later in life. He lived in a rural area and didn't have access to treatment. The day that he went to the doctor and was told that there was no further treatment is the day we lost him to suicide. I do not blame his doctors for what happened—they didn't know any better. That's a big loss.
Ms Funk: Through a lack of hope and despair.

Ms Layton: Yes, and, I guess, that lack of recognition and understanding even with health professionals. When you say that you are suffering, people don't get it. We don't see that adults have that intensity of the disease and the relentlessness. When that builds over years and years of not being treated and when it is not recognised you don't get that emotional support. After my dad died we found that he actually had exposed bone where he had scratched through. But that wasn't looked at when he went to the doctor—because they didn't know that it could be that bad. This was somebody who had suffered for many, many years without access to treatment and with no awareness in the community. It was a loss that could have been avoided.

Mr ZAPPIA: Lastly, is it food and perhaps other chemical products that make contact with the person that trigger the eczema, or is it even emotional conditions?

Ms Funk: It is a very, very complex condition. I think Professor Smith said earlier that, of his patients, 90 per cent have eczema. Of the people who have eczema many don't have food allergies—many do; many don't. This is where I think in the communication between dermatologists and immunologists the patient or the parent gets stuck in the middle. The triggers for eczema are varied and many, which makes it even harder to control. That is why with something like a biologic it doesn't matter what the trigger is, it turns off those receptors. The triggers could be heat, stress, cold, food, grasses, dust mites or pets. I know—particularly through this SOS campaigns and a lot of the stories that came through—that it tends to get turned on a lot in adulthood with stress. It could be one incident in life that just flicks on that switch. It is so varied and complex, which is why we need better treatment options. A topical treatment is just going to fix part of—or not even fix part of it—and it's not always a long-term solution for people. And avoidance is sometimes impossible, and sometimes you can't avoid stress in life, either.

Mr ZAPPIA: Thank you very much.

Ms BELL: I have one final question. Victoria, I am sorry for the loss of your father. It's always difficult when you lose a loved one. My question is around dupilumab. Have you actually seen the direct difference that this drug makes in the lives of people with eczema?

Ms Funk: Yes.

Ms BELL: How does the drug work—in layman's terms and for the sake of Hansard—and what's the difference in the quality of life of someone who is able to access it at that $1,600 a month and someone who is not able to access it?

Ms Funk: We can only talk anecdotally from the experience we've had with members, what they've told us and what we've seen with our members. The first person I met who was on dupilumab was almost bouncing off the walls with joy and wanting to shout from the rooftops. For him personally, he couldn't access a trial because he had so many other comorbidities and health issues that he couldn't go through the washout phase. But he did access it through compassionate access later on and he said within two weeks he was a different person. He is in his mid- to late 40s. All his life he has suffered terribly. And now he has to remember to put moisturiser on, for example; he forgets that he still has the dry skin, but he doesn't have the symptoms at all. And that, for him, occurred within the first two weeks of commencing on dupilumab.

Ms BELL: Is that a tablet form?

Ms Funk: Injectable.

Ms BELL: A subcutaneous injection?

Ms Funk: Yes.

Ms Layton: I think it is an intramuscular injection.

Ms BELL: Every two weeks?

Ms Funk: Another member was the same in that he was on a trial and had had that rapid change, and he didn't realise what having a life actually meant until he was—

Ms BELL: Does it completely disappear? Is it held at bay for a percentage?

Ms Funk: I think it varies. From the statistics I have seen and read, it can vary somewhat over a period of time. For the ones I have spoken with, their symptoms have 90 to 100 per cent gone.

Ms Layton: For the people I have spoken to, the debilitating aspect of the disease is taken away. One of the people used a tiny bit of steroids once in a six-month period. Certainly, it reduces it to where you are not disabled or limited by the disease by any means.
Ms Funk: We've heard from some members whose comorbidities such as asthma and hayfever have also improved.

Dr FREELANDER: They said it was very good for hayfever

Ms Funk: Yes.

Ms BELL: Does anyone know whether there are any long-term side effects from taking that drug for a long period of time?

Dr FREELANDER: It seems to be extremely safe. Some people get a bit of gastrointestinal upset and nausea, but the vast majority of people get very few side effects. You have to remember that the treatments they're on, like topical steroids and sometimes chemotherapy type drugs—methotrexate and cyclosporine—cause major side effects. This is a dramatic new treatment because it doesn't cause the side effects the current treatment cause. My understanding—and Connie Katelaris is the best one to ask—is that at least 80 per cent of people get a dramatic response.

Ms Funk: One of our members was on cyclosporine, methotrexate—the works. He had to stop because he was having organ failure—liver problems. The only side effect he has had is conjunctivitis—dry eye—which they are managing better earlier to try and minimise that common side effect. Everyone we've spoken to who had that side effect has said they would rather live with dry-eye syndrome every day of the week than go back to what they were like before.

CHAIR: So the long and short of it is that your understanding is that the PBAC is considering it in March?

Ms Funk: Yes.

Dr FREELANDER: I did write to Greg Hunt about it.

CHAIR: When you are down in Canberra are you seeing Greg Hunt while you are there?

Ms Funk: I would love to. I believe he has another meeting on at that time. I would love to meet with Greg Hunt. I'm hoping Sam Develin will be coming to our event, and we welcome anyone else to come along. We're going to have a number of patients there. We'll have the College of Dermatology there. The Australian Dermatology Nurses Association will be represented there as well. There will be a good all-round network of people to talk to. Allergy and Anaphylaxis, through the National Allergy Strategy, will be there at some point. We would love to have many people come along to that. I have requested a meeting with Greg Hunt. I know that he is extremely busy. As a said, this submission is about making eczema seen and heard. We feel it is often the lowest priority in the pile. We need a voice there as well.

CHAIR: Okay. I undertake to try and help arrange that meeting.

Ms Funk: I do have some hard copies of some invitations I am happy to leave with you should you like to spread them around.

CHAIR: I thank you for being here today and, more importantly, for everything you are doing more broadly. We will see you in Canberra. Hopefully, there is some good news from PBAC in March. Thank you for your time today. We will send you a transcript of the proceedings. If you want to make any corrections or additions, you can come back to the committee secretariat by 29 February. You've both been very powerful advocates, so thank you.

Ms Funk: Thank you.

Ms Layton: Thank you.
so the timely and relevant allergy diagnosis and. There are over 100 standardised allergen extracts available commercially, but not widely adopted in clinical practice in Australia. This may be because of cost, reimbursement policies and also clinical education needs. Such diagnostic precision could be applied with great benefit if we had the right locally relevant allergens for Australian environments, if they were standardised and effective. They could be more specific, quantitative and accessible. Importantly, these types of tests could allow us to identify thresholds of sensitisation which may be associated with disease progression and the risk of severe events, such as anaphylaxis or thunderstorm asthma events. Also, further than that, allergen-specific IgE tests that are point-of-care based could enable us to set up models of virtual care, where clinical specialists support healthcare providers in rural and remote communities and support in clinical decision management for the patients in rural regions.

Allergen sensitisation can also be tested by blood tests that measure IgE, which is the main antibody that mediates allergy. Most allergy tests are based on whole extracts. The content of allergen in an extract will vary from batch to batch and between suppliers, and this affects consistency. We could, instead, use purified standardised allergen components as the active target of allergy testing. There are over 100 standardised allergen component tests available commercially, but not widely adopted in clinical practice in Australia. This may be because of cost, reimbursement policies and also clinical education needs. Such diagnostic precision could be applied with great benefit if we had the right locally relevant allergens for Australian environments, if they were standardised and effective. They could be more specific, quantitative and accessible. Importantly, these types of tests could allow us to identify thresholds of sensitisation which may be associated with disease progression and the risk of severe events, such as anaphylaxis or thunderstorm asthma events. Also, further than that, allergen-specific IgE tests that are point-of-care based could enable us to set up models of virtual care, where clinical specialists support healthcare providers in rural and remote communities and support in clinical decision management for the patients in rural regions.

Australia has a very strong track record in allergy research and allergen innovations, including my own lab, which has developed specific tests that could be translated for grass pollens. But most of these innovations which are protected by patents have not been commercially developed, for various reasons. This means that, despite the clinical importance and the socioeconomic impact of allergic diseases on the Australian community, we haven't yet realised the potential to transform and improve how we do allergy diagnosis and management. Hayfever is the most common of allergic diseases. It's associated with asthma and Sinusitis. It's associated with dental malformation and sleep apnoea. It's associated with eosinophilic oesophagitis, eczema, and mental health and anxiety. It follows on from food allergy and can progress to asthma.

The harm that allergy to grass pollen can cause became tragically apparent during the Melbourne 2016 thunderstorm asthma epidemic. It's important to note that all of the Australians affected by any of the 10 thunderstorm asthma events that are reported in Australia all had grass pollen allergy and hayfever, but as few as 40 per cent of them had diagnosed or known asthma. So there are people in our community who think they have a trivial condition when they are actually at risk of very severe consequences. We could better manage those
patients, particularly those with severe and moderate allergic rhinitis, using available and efficacious allergen-specific immunotherapy. I think it would be useful for the patients with very severe allergic rhinitis to have available to them, through the PBS, that kind of allergen-specific immunotherapy treatment. I also think that we really need to have integrated care pathways. Currently, allergic rhinitis, if it's managed by a clinician, is under the auspice of clinical immunologists, or allergists, whereas asthma is managed by respiratory, thoracic, physicians. We don't have good integrated care pathways between these two medical disciplines to effectively manage people with asthma who have also got allergic rhinitis.

The last thing I want to talk to you about is the AusPollen aeroallergy network. Australia has one of the highest frequencies of allergic respiratory diseases worldwide. Understanding exposure to local current pollen levels helps clinicians diagnose and identify triggers for allergic disease, helps patients identify when they are at risk of experiencing symptoms and allows them to better manage their exposure to reduce their symptoms. Until recently, Australia has not been well served with pollen monitoring services. In contrast, Europe has 600 pollen monitoring stations and the US has 87 pollen monitoring stations that are managed by the peak professional bodies.

Since the inception of the NHMRC AusPollen partnership, we've grown the Australia network to up to 25 pollen monitoring stations. A team of very dedicated academic researchers like myself and others have all developed an interim standard, protocols and quality control systems, including audits and certification of counters, sophisticated forecast models rapidly in response to that thunderstorm asthma event in Melbourne and dissemination pathways.

Pollen monitoring has been supported thus far in ad hoc ways through competitive NHMRC ARC projects, as well as student stipends and other small competitive grants. However, funding for all of those grants will currently cease mid-2020. There is no further support at the state or federal level, including direct or indirect competitive research grants, for continuing this pollen monitoring for Australia.

To continue to meet the needs of over three million Australians with pollen allergies, there is an urgent need for resources to allow us to sustain and improve the coverage of the AusPollen network. I am here as an advocate for the researchers who undertake that service to the community and I am here as a person who has always suffered from allergic rhinitis. That really severely impacted me as a teenager. It is teenagers who are most severely affected by pollen allergies.

**CHAIR:** I will start with some questions. Firstly, on the pollen monitoring stations, in layman's terms can you give us the elevator pitch as to why they are important to our ability to treat pollen related conditions.

**Prof. Davies:** They are the indicators to tell people and clinicians what's in the air—when are the allergens peaking?

**CHAIR:** It's weather forecasting for pollens?

**Prof. Davies:** That's exactly what we are doing, yes. We are taking evidence at ground level by going to a site and using an instrument to collect an air sample. We come back to the lab and then put that sample onto a slide. We stain it, we sit there and then we count it. We then take information on the weather from the Bureau of Meteorology—on temperature and rainfall. We use satellite remote sensing information on ground cover—where is grass and what's the amplitude change in greenness?—to inform a forecast that we then disseminate through apps to the community. The clinicians rely on knowing what allergens are present in the air. It helps them to understand the exposure of patients and what might be part of that clinical history and what is triggering allergies.

**CHAIR:** It could act as a warning system if there is going to be an unusual event?

**Prof. Davies:** Yes, absolutely. What we are doing now is a short-term daily pollen forecast. We have good efficacy for predictions for one to three days. What we haven't been implementing yet and what we are doing at a research level at the moment through this four-year project is looking at, 'Can we predict seasonal severity?' This is a new area that our current forecast is not able to do, but it is important to be able to understand when the season is going to start and how bad it is going to be this year in Sydney, Canberra, Perth or Brisbane, for instance.

**CHAIR:** On the funding you have received to date, the NHMRC had three-yearly funding—

**Prof. Davies:** For a four-year project.

**CHAIR:** Did you apply again and it was unsuccessful?

**Prof. Davies:** I will apply again now. We have been—

**CHAIR:** To understand the process, you have to apply—

**Prof. Davies:** You have to apply for competitive research funding.
CHAIR: Did you apply last year for the coming four years?

Prof. Davies: No. I will apply now. The project finishes in September.

CHAIR: So you can't apply until, effectively—

Prof. Davies: I could be applying now. We will be wanting to apply now. I have applied for ARC funding, so I've been successful in completing and getting further funding through ARC. So, in a way, our resources have been overly stretched. We got that grant initiated two months before that thunderstorm asthma episode, so I guess that drew attention, energies and resources towards the need for a very acute, immediate response. So, we have been in the implementation phase, in the scale-up phase, setting up the standards, setting up the processes, being able to deliver and evaluate the benefit of that forecast system, yes.

CHAIR: You say that the funding runs out this year. That's a statement of fact. But it's not accentuated by the fact that you've applied and been rejected? You still have the opportunity to be funded?

Prof. Davies: I did have the opportunity to continue to apply.

CHAIR: But you'd prefer ongoing funding rather than ad hoc funding?

Prof. Davies: As the minimum ongoing, sustainable support for the infrastructure, for the basic service, I feel that the research grant funding scheme is highly competitive. You've got only a nine per cent chance of success. It's also very politically motivated, and motivated by what's currently important at the moment. So, I would suspect that current competitive funding is likely to go and support bushfire research next—which is also important, and obviously there is an intersection between air quality exposure and allergen exposure. If we are only able to rely on competitive grant funding for this kind of national infrastructure and service, then there is a risk that it won't be maintained. I think competitive research grant money should be used for the additional research that should be bolted onto and supported around a minimum service delivery.

CHAIR: That gives rise to an interesting question—and I've never really thought about how this is conducted, but presumably we have a network across Australia of air quality monitoring stations—

Prof. Davies: Yes.

CHAIR: I don't know who runs that.

Prof. Davies: They're state based, and they come under the jurisdiction, in Queensland, for instance, of the Department of Environment and Science.

CHAIR: So, EPAs would normally—

Prof. Davies: The EPA in Victoria, yes. That's correct.

CHAIR: Wouldn't the best option be for all those air quality monitoring stations to be also monitoring pollen?

Prof. Davies: Yes, in future. We have two of our pollen monitoring stations supported by and located on the air quality monitoring stations of the Department of Environment and Science here in Queensland, and two of our stations in New South Wales are similarly supported. But our system, although we've developed the standard, is based on antiquated technology, from the 1950s. It requires a lot of—

CHAIR: The pollen, or the air quality?

Prof. Davies: I have to personally go to the site daily and collect the sample—or my team does. We come back to the lab. It takes us about an hour and a half to take that sample, load it onto microscope slides, stain it and count it and then impute the forecasts. What we need in future, alongside that minimum service, is innovation. We can't go on forever counting in an antiquated way. We did not get funding. We sought funding under the ARC large infrastructure and equipment grant to trial a Swiss automated pollen counter that cost about 157,000 Swiss francs, to bring that here and test it alongside what we are calling our standard pollen monitoring, so that in future we would have an automated network that could be managed by the air quality monitoring stations. But that I'd say would be a five- to 10-year transition, until we could move that into that kind of level—absolutely; it's a great direction to head in.

Dr MARTIN: Thank you very much for contributing. It's very insightful and very helpful for our committee. I think if anything you've reinforced the need for multidisciplinary specialist teams in treating allergies and anaphylaxis, and in particular in your case it's the respiratory focus—and the need for cross-referral collaboration and consultation between specialists. So, I'm going to ask you: how best can we do this? What do you think? How can we provide these multidisciplinary specialists to hubs for people at risk of or currently being treated for allergies and anaphylaxis?

Prof. Davies: Increase support to the public health service so that there is a multidisciplinary allergy clinic where patients can come. In the same clinic you could have respiratory physicians as well as clinical
immunologists and supported research or clinical nurses who are able to do the testing. Multidisciplinary clinical teams have been implemented in public hospital and health services for cancer care, for instance. Another way to do that would be to encourage joint symposia between the clinical immunology society and the Thoracic Society of Australia and New Zealand, for instance. I think there are a number of ways where we might influence those professional communities to come together. But I think there are models now in hospital and health services that are effective at having multidisciplinary care teams for particular clinical purposes like this.

**Dr MARTIN:** There seem to be quite a range of disciplines involved: dieticians, psychologists, immunologists, paediatric respiratory specialists—and it goes on.

**Prof. Davies:** Absolutely.

**Dr MARTIN:** So there are a lot of professions involved.

**Prof. Davies:** That's correct, yes.

**Dr FREELANDER:** I'm fascinated by this, and pardon my ignorance. I'm interested in the role that you mentioned of the pollen counts and the thunderstorm asthma events, of which there have been a few. Can you explain the mechanism to me?

**Prof. Davies:** Yes, I can explain that to you. We have a current ARC discovery project where we're looking at exploring it in more detail at a molecular level. The hypothesis that's widely accepted—but it is still a hypothesis—is that during springtime all of the thunderstorm asthma events have occurred in the spring grass pollen season. They have occurred in temperate regions of eastern Australia—not just Melbourne but throughout rural parts of Victoria and New South Wales. They always occur on high or extreme days with high levels of grass pollen, and they occur with particular types of thunderstorms where there are severe gust fronts and change of direction in the wind. So you would have a body of wind passing over a rural area collecting or sweeping up, if you like, grass pollen that is then uplifted into a cloud base. Then it's transformed, most likely—and it's been shown experimentally—by osmotic shock due to water, but it may also be exposed to electrical activity, nitric oxide and other chemicals in the air that change the allergenicity of the pollen. The pollen grains essentially burst open. In one pollen grain you could have hundreds, up to thousands of tiny starch granules that carry the allergen particle, so that then becomes much smaller. A pollen grain itself is about 40 microns, but these little allergen packages are about a half to two microns. That means they can readily be breathed deep into the air and elicit an allergic response, not just in the nose, which is hayfever, but deep into the lungs. So you've got this potentiation, if you like, because of the weather conditions.

**Dr FREELANDER:** You looked at that severe Victorian event and found that the majority of people who were hospitalised or who died had evidence of—

**Prof. Davies:** Yes. There was some research done by the clinical community in Melbourne: Professor Jo Douglass at the Royal Melbourne Hospital, Professor Robyn O'Hehir at the Alfred Hospital and Dr Michael Sutherland at Eastern Health. They have actually had a look at subsets of the patients and tested their sensitivity to grasses. They found that there was an elevated concentration and level of reactivity to rye-grass, in particular—which is the temperate grass in Victoria—in those patients who were more severely affected and admitted to hospital.

**Dr FREELANDER:** Taking what you said about Australia having one of the highest incidents of asthma and allergic rhinitis in the world, and that's certainly true, have we looked at Australian native plant pollens in that regard?

**Prof. Davies:** Most of the allergenic pollens are exotic introduced species. We are very concerned, with climate change, about the increase in the distribution of subtropical types of grasses such as johnson, bahia, bermuda, but also *Chloris*. A lot of these were introduced by the New South Wales Department of Primary Industries in the fifties for agricultural purposes, but they're very well naturalised. A lot of the Australian native grasses, like *Cynodon*, are also allergenic. Their distribution is quite widespread. We often think that it's just ryegrass, but actually, if you look at data on the distribution of different types of grasses, most of Australia is co-exposed to the subtropical and the temperate grasses. An issue for allergen-specific diagnosis and immunotherapy is that most of that comes from Europe, developed by European companies; it's either uniquely Timothy grass, which we almost don't have in Australia, or it's a combination including ryegrass. None of the subtropical grasses are standardised for tests and treatments.

**Dr FREELANDER:** But you're suggesting that's what we should be doing?

**Prof. Davies:** Yes. Our research would suggest that that is a necessary testing that should be done in Australia to better manage our allergic rhinitis now and into the future.
Dr FREELANDER: Am I right in saying that, in terms of research, what you would be looking for is longer-term research grants? Is that correct?

Prof. Davies: Yes, and also minimum service provision for the pollen monitoring network and then opportunity, for instance, for targeted calls for research or centres for research excellence. That would give us a much higher quantum of research money and a longer-term period where we can build up and sustain these kinds of research programs. Again, I would be using this multidisciplinary and intersectoral partnership model where we bring in pharmacists and clinicians as well as scientists who know about the remote sensing and develop the innovative tests for diagnosis along with the provision of service. So you not only marry up 'What are you exposed to?' but have the ability to test the patient as well and be confident that the exposure is linked to what they're specifically allergic to. So a whole integrated approach would be good.

CHAIR: I thank you for your evidence today. It's been very helpful. We will give you a transcript of today's proceedings. If you have any corrections of errors, if you could let the committee secretariat know by the end of the month that would be very much appreciated.

Prof. Davies: Sure. Can I make a concluding remark?

CHAIR: You may.

Prof. Davies: In the interests of time I will jump to the last part: I think what we really need is that sustainability of the research and the service infrastructure. What that will deliver for us is better patient outcomes and better health service provision at a reduced cost, with lower lengths of stay and lower costs per patient, allowing us to better manage patients in primary health care and keep them out of hospital ED settings.

CHAIR: Thank you.

Proceedings suspended from 12:47 to 13:56
MULCAHY, Dr Andrew Mulcahy, Representative, Australian Society of Anaesthetists

SCOLARO, Dr Richard, Chairman, Australian and New Zealand Anaesthetic Allergy Group

VICTOR JOHN, Ms Jacintha, Policy Manager, Australian Society of Anaesthetists

CHAIR: Thank you very much for joining us here today, and thank you for your written submission. Would one of you like to make an opening statement before we move on to questions? Thank you, Dr Scolaro.

Dr Scolaro: It is a pleasure to have this opportunity to represent ANZAAG, the Australian and New Zealand Anaesthetic Allergy Group, at this public hearing for the parliamentary inquiry into allergies and anaphylaxis, and we thank the federal government for this opportunity.

Anaphylaxis is the cause of seven deaths annually in Australia. Half of these are the result of anaphylaxis. Perioperative anaphylaxis, those episodes of anaphylaxis associated with an operation or procedure, make up a third of all cases of anaphylaxis admitted to intensive care units. Approximately 400 patients develop anaphylaxis annually in Australia.

ANZAAG is comprised of anaesthetists, immunologists, pathologists, allergists and scientists. Its aim is to develop best practice in the areas of prevention, treatment and investigation of perioperative anaphylaxis. ANZAAG developed the perioperative anaphylaxis management guidelines and worked with the Australian and New Zealand College of Anaesthetists to develop a perioperative anaphylaxis online learning module. ANZAAG has produced guidelines to standardise investigation of perioperative anaphylaxis. Our written submission contains four points, and I would like to expand on these today.

Firstly, ANZAAG wants patients to have timely and appropriate investigation of their perioperative anaphylaxis. Patients are exposed to multiple agents during an operation. These may include drugs to produce unconsciousness, neuromuscular-blocking drugs—drugs that are used to paralyse muscles—multiple painkillers, antibiotics, antiseptics and blood products. Following an episode of perioperative anaphylaxis the patient is investigated to elucidate the cause, although one might not be found. A plan is developed for future anaesthesia, giving recommendations as to what agents are likely to be safe and which agents to avoid in the future.

Dr Mulcahy is going to speak to the effect that removal of MBS item No. 21981 has on the ability of patients to access allergy testing. In addition to item No. 21981, the current model is used for public health funding of allergy testing and needs to be altered to encourage hospitals to support specialists in this activity.

Secondly, ANZAAG aims to reduce the number of episodes of perioperative anaphylaxis. In addition to appropriate and timely investigation, improved labelling of chlorhexidine products and its appropriate use will reduce perioperative anaphylaxis. Chlorhexidine is an excellent antimicrobial agent used widely in hospitals. The TGA currently lists 145 products containing chlorhexidine. Chlorhexidine caused 10 per cent of all episodes of perioperative anaphylaxis in the sixth national audit project conducted in the United Kingdom in 2016, the largest ever audit of perioperative anaphylaxis. It is essential that the presence of chlorhexidine in any product is clearly labelled; currently, this is not the case. This issue is made more difficult as chlorhexidine is found in unexpected places such as within the lubricant used to place urinary catheters and within the coating of central lines. Health departments must ensure that an evidence-based approach and broad consultation be used prior to mandating the use of chlorhexidine-containing products. Chlorhexidine has been mandated for applications where chlorhexidine is not superior to other products. This increases the likelihood of chlorhexidine exposure in the chlorhexidine-allergic patient and may result in the development of chlorhexidine allergy in the previously non-allergic patient.

ANZAAG would like to see pholcodine, an ingredient found in more than 50 over-the-counter medications used to reduce cough, be restricted to sale by prescription only. ANZAAG believes that pholcodine use is associated with increased incidence of allergy to neuromuscular blocking drugs. ANZAAG has previously approached the TGA about this issue. The TGA stated there would need to be conclusive evidence that pholcodine consumption is definitely the cause of anaphylactic reactions before it could take any regulatory action regarding its availability in the Australian market. ANZAAG respects this decision but it may not be possible to prove this theory conclusively. ANZAAG will continue to encourage more research in this field. An Australian paper, currently unpublished, provides evidence for this link. Following its application, ANZAAG will approach the TGA again on this issue.

Thirdly, ANZAAG is seeking federal funding to develop and maintain a database. We are currently uncertain of the number of cases of perioperative anaphylaxis that occur each year in Australia and which agents are causing these reactions. We want to know what treatments for anaphylaxis are most effective and if any are detrimental. We want to improve allergy testing methods. We want to know if community exposure to particular
agents is associated with an increased risk of perioperative anaphylaxis. A database will help to answer these questions.

In conclusion, we believe that ANZAAG with the support of the federal government can reduce the frequency of perioperative anaphylaxis, and improve its treatment and investigation.

Dr Mulcahy: Again, thank you for this opportunity to present to the committee. Just briefly, the ASA is one of the two major organisations that represents the interests of anaesthesia in this country along with the Australia New Zealand College of Anaesthetists. Amongst our objectives is improving anaesthesia and ensuring safety and education of anaesthetists in Australia. I wish to talk about the Medicare funding for anaesthesia allergy testing. Unfortunately in November 2018, the Medicare item mentioned by Richard, 21981, was deleted, and the service was provisionally replaced by a different item in a different section of the schedule. The impact of that has been a reduction in funding of over 50 per cent. I do believe it was unintentional. It was recommended as part of the review of the Medicare Benefits Schedule. The Medicare MBS Review Taskforce oversaw that and one of the committees that was not an anaesthetic committee, the dermatology, allergy and immunology committee, in its deliberations relating to allergy testing, believed it would be sensible to have the item covered in its section of the Medicare schedule. Unfortunately, without consultation with the anaesthesia committee or any of the representative organisations, it went ahead and recommended—and it was implemented—the deletion of 21981. Due to the way the fees are represented in the published Medicare Benefits Schedule, it appears that the fee is a certain amount and that fee was replicated in the new item but, unfortunately, the actual fee is more than double what appears in the schedule. I can explain that more if you wish me to. The fee represented in the schedule does not include the time allocation.

Dr FREELANDER: Can you tell us in dollar terms with the difference is?

Dr Mulcahy: The total funding for this service for a year, in the last four years before the item was deleted, was $13,000 for all of Australia, total funding. That has been reduced. The data we have shows us about a 55 to 60 per cent reduction in funding. As I said, I believe it was a mistake.

Dr FREELANDER: It's just there weren't many episodes of testing.

Dr Mulcahy: Through the Medicare system, it varies from year to year. Looking at the last 10 years, you expected around 100 cases a year. We know that there are around 400 cases of anaesthetic allergy or anaphylaxis during anaesthesia or the perioperative period, so clearly, by definition, that's a life-threatening situation. They all need to be tested to ensure that they can have safe anaesthesia for the future. Our concern is that this reduction in funding by the deletion of this item will lead to either a reduction in access to that service—and I think that is what will happen—or a reduction in the affordability of the service, due to the fact that, to cover the service, there'll have to be some patient out-of-pocket expense incurred. The actual testing usually takes three hours also, and the fee at the moment is $80. So we would like to see the item reinstated to allow that service to continue to be provided in the private sector.

There's a concern that this may inadvertently have a greater impact in rural and regional areas. The major public hospitals in the metropolitan areas will continue to have a unit or a service that provides testing for anaesthesia agent anaphylaxis. But, in rural and remote areas, where it may have been possible to do it in a private setting with Medicare funding, with the reduction in funding, that may no longer be possible. And those patients will then be told, 'You'll need to go to the major centre for testing.' There'll be issues of waiting times and issues of consideration of travel, and it may be that some of those patients—and we see these in everyday practice—who've had an episode of collapse and cardiovascular collapse but haven't been tested may end up not being tested or may have a significant delay. So we believe it was an error that that funding was reduced, and it could simply be reinstated by reinstating that item.

CHAIR: Just by way of background, if you have an allergic reaction to an anaesthetic, in 99.9 per cent of cases, that's going to appear when you're on the operating table for the first time, isn't it?

Dr Scolaro: Yes—or in the recovery room, immediately after the operation.

CHAIR: And your point in relation to the MBS item is that you can actually alter the composition of an anaesthetic once you've identified which agent within an anaesthetic is causing the allergy?

Dr Mulcahy: That's exactly right. We know which are the most common agents, but, without testing, you don't know, obviously, the specific agent in this particular patient. When you have testing, the opportunity is taken to test all the commonly used anaesthetic agents, and, frequently, a patient allergic to one that precipitated the event will actually also be allergic to some other agents that they haven't yet been exposed to. So they will be given a bracelet or a card to say, 'I must never have rocuronium,' or cefazolin or whatever the drug is. They will
carry that around, it'll be in their medical file and they can be safely anaesthetised for their appendix or broken arm next week and avoid those drugs.

CHAIR: As an anaesthetist, do you actually construct, mix or prepare the anaesthetic yourself, or do you actually then go back to the supplier and say, 'We need a product that is minus'—

Dr Mulcahy: With anaesthesia, there's a plan of management that entails amongst other things a cocktail, if you like, of medications. Medications are given for a variety of reasons. Sometimes it's antibiotics to fight infection. There'll be pain-relieving medication, there'll be drugs to induce loss of consciousness, there'll be drugs to induce muscle relaxation and there'll be a number of other drugs. So we don't go back to the manufacturer, but we know, if you're allergic to this drug or that drug, that we'll use an alternative drug to provide the same effect.

Dr Scolaro: And we need to work out which of those alternative drugs may or may not be safe, as well, because sometimes people who haven't been exposed to that agent before then may develop anaphylaxis to similar agents.

CHAIR: Did you say 40 per cent of all admissions for anaphylactic attacks are during—

Dr Scolaro: One-third of all cases that are admitted to the intensive care unit with a diagnosis of anaphylaxis are perioperative cases of anaphylaxis.

CHAIR: You have proposed a register for perioperative cases of anaphylaxis. Isn't there a case for having a national register of anaphylactic attacks, of which this would be a subset, rather than creating a separate database just for perioperative instances?

Dr Scolaro: I can't say as to what would be the best structure for that.

CHAIR: We have had the suggestion that there should be a national database of all anaphylactic episodes.

Dr Scolaro: Yes. There are things that are specific to perioperative anaphylaxis. In an episode of perioperative anaphylaxis it's a situation where we know that patients are exposed and then those patients are immediately treated, whereas patients in the community will not necessarily receive treatment straightaway. We also want to be able to see what happens with that treatment, what works in particular with that treatment. Then, with regard to testing those patients, there are a number of patients for whom, despite their having had a severe allergic reaction, we can't find the cause of that allergic reaction, and we know they've had an allergic reaction. Hopefully, a database from a perioperative point of view would enable us to be more sensitive with our testing so we can pick up the cause more frequently.

Dr FREELANDER: Thanks for making us aware of this problem. What you're saying is that perioperative anaphylaxis is quite common—if, as you say, it's in the hundreds—yet testing is rare?

Dr Scolaro: No, testing is not rare. From data to hand, there have been at least 400 patients who have been tested in the last year for perioperative anaphylaxis in Australia.

Dr Mulcahy: Medicare will fund those who are tested through the private system. That will be either in a private hospital, in a private allergy testing unit; or just under the care of a private specialist in a private hospital; or in a public hospital but with the patient admitted as an outpatient and billed through Medicare. So about 25 per cent of the total testing is directly through Medicare.

Dr FREELANDER: And the others we don't really know; is that right?

Dr Scolaro: The others are funded through—
Dr Mulcahy: Public hospitals.

Dr Scolaro: the public hospital system.

Dr FREELANDER: But there's no effective register, at the present time, of all those cases?

Dr Scolaro: No.

Dr FREELANDER: Do you, to your colleagues, publish a list of the likely agents?

Dr Mulcahy: It's absolutely well-known in anaesthesia which are the likely agents.

Dr FREELANDER: Can you tell us some of them?

Dr Scolaro: ANZAAG have been around for the last 10 years and we've progressively tried to do different things. One of the things we're trying to move to is recognising throughout Australia what agents are the cause. We've had a lot of difficulty with this issue because of privacy concerns about sharing information. But in the last year, with the data that I have to hand at the moment—it's not complete—in Australia and New Zealand, because that's where it's based, we have had 420 positive tests of episodes of anaphylaxis. That will include, probably, the majority of patients throughout Australia and New Zealand.
Dr FREELANDER: You think but you're not sure?

Dr Scolaro: It's the majority of patients who have been tested by someone who's with ANZAAG. It's the patients who have recognised the fact that they've had an episode of some sort of life-threatening event in theatre and that it could have been anaphylaxis, who have then referred it on to one of us. So not all episodes of anaphylaxis will actually get tested. But the Australian medical community is much more aware of us, so the number of cases referred to us is increasing, even for more minor things that maybe would have been missed in the past. We've had about 400 people test positive in that time period. From the larger centres, it would appear that only around 60 per cent of the patients that are actually referred to a service will test positive.

Dr FREELANDER: Right. And 40 per cent go the other way.

Dr Scolaro: With 40 per cent we test but we don't end up finding a cause. They're the most difficult patients, because then you have to work out how you're actually going to anaesthetise them the next time round, while not being sure what caused it last time.

Dr FREELANDER: Is it correct to say that anaesthetic anaphylaxis is really in the severe group of anaphylaxis?

Dr Scolaro: The main issue with perioperative anaphylaxis is that these agents have been given intravenously. If you give a drug intravenously it is presented to the body at a very high concentration and produces a profound effect in someone who may already be under the influence of anaesthetic drugs, which will already have an influence on their cardiovascular system.

Dr FREELANDER: And it is very likely, as you pointed out before, to require intensive care.

Dr Scolaro: Yes.

Dr FREELANDER: Are there any statistics on deaths?

Dr Scolaro: At this stage, about three per annum die from what's definitely anaphylaxis in Australia. It's hard to exactly say what that number is, because most deaths in the operating theatre are going to be a cardiac event or a respiratory event, and those events can occur for a whole number of reasons. Testing can only be done on patients who have survived the episode. So you can't be absolutely certain that anaphylaxis was the cause, and people might not recognise anaphylaxis as being the cause at the time. So it is hard to say. But we know definitely that there are about three per annum.

Dr Mulcahy: Dr Freelander, you asked about which drugs. Unfortunately, the drugs that are most implicated are ones that we use pretty much every day. But we have to remember the denominator. The denominator of the number of people anaesthetised in Australia is over three million a year. Every anaesthetist is trained in the management of anaphylaxis and almost all anaesthetists will personally see a case in one of their patients. It is still a rare event, but if you anaesthetise enough patients you will see it.

Dr FREELANDER: We do have a dearth of information in terms of the real statistics of what is happening and the pathways.

Dr Scolaro: We're trying to develop that at the moment. With regard to drugs, the neuromuscular blocking drugs and antibiotics would be the two major drugs. Then there is patent blue, which is a dye that we inject into people when they are having surgery to look for where the cancer may have spread to, and chlorhexidine. Those are the four major ones at the moment. Patent blue is not used as frequently as all these other agents. So it is overrepresented, really, in that group.

Dr FREELANDER: I'm also interested in the chlorhexidine issue, because it's in just about everything that you would use in an operating theatre and hospital ward.

Dr Scolaro: Yes.

Dr FREELANDER: What is the answer to that—finding an alternative?

Dr Scolaro: There are alternatives. One of the issues is that health departments have mandated the use of chlorhexidine. They have done that sometimes based on research that doesn't directly address the question they are trying to answer. Chlorhexidine is mandated in the NHMRC guidelines for the placing of an intravenous cannula, for example. But it's not necessarily any better for a short-term cannula than just using alcohol, because both of them will destroy the organisms over a period of time. We use needleless injection sites—so, when you've got a drip in and then you've got a line attached to that, there are little plastic ports that you can inject the drugs into. They should be cleaned just with alcohol, because it's one-off thing.

But generally in hospitals now all you can obtain at any time is chlorhexidine. Sometimes it is beautifully labelled and sometimes you don't even know it's in there—it's really hard to see. I've investigated a patient who
had anaphylaxis simply from a bung being wiped with chlorhexidine and then something else injected through it, and he almost succumbed. So it is an issue. It needs to be clearly labelled and we need to have guidelines on when chlorhexidine should be used and when it's safe to use other agents. Hospitals do things like only have chlorhexidine wipes, because their knowledge is that the NHMRC guidelines say only to use chlorhexidine, when other products would be as good in particular situations.

**Dr FREELANDER:** Thank you very much.

**CHAIR:** I have a question on the removal of that MBS item. What was the impact? Was it more in a regional or rural area that you found that people just wouldn't be able to afford that? Was there any evidence or feedback that you got about that? It just seems to be a bit of an oversight here—for $13,000.

**Dr Mulcahy:** That's the total funding. It's less than that to restore it. We don't have specific data on the locations. That's not available to us. We've had some anecdotal feedback from Western Australia, where there was a reduction in the service outside of Perth and the patients were going to be referred to the major hospital in the city. But it's relatively early days yet. It was in November 2018. So we just don't have access to the data for the location. There were only around a hundred claims a year—sometimes less, sometimes more—so it's a very small number of claims to observe. You'll have to wait and see.

**CHAIR:** Thank you for presenting to us today. It's been a very useful discussion, because as we keep going we find that there are more and more areas that we need to examine. We'll give you a transcript of today's proceedings in due course. If there are any corrections you want to make, if you could do so through our committee secretariat by the end of the month that would be much appreciated. Thank you for your time today.
GRINTER, Ms Kirsten, President and Director, The Allergen Bureau Ltd
LACIS-LEE, Ms Jasmine, Secretary and Director, The Allergen Bureau Ltd

[14:21]

CHAIR: I need to remind you that these are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter. Today's proceedings will be recorded by Hansard, and your evidence attracts parliamentary privilege. Thank you very much for your written submission. Would you like to make an opening statement?

Ms Grinter: The Allergen Bureau welcomes the opportunity to appear at this public hearing of the inquiry into allergies and anaphylaxis. The overall objective of The Allergen Bureau is to share information and experience on the management of food allergens within the food industry. Our key driver is to ensure consumers receive relevant, consistent and easy to understand information on food allergens. As the peak industry body representing the food industry in allergen management in both Australia and New Zealand, our written submission addressed those aspects of the inquiry terms of reference we consider to be of most relevance in providing safe food for the food allergic consumer.

There are three main areas in our submission that we would like to briefly emphasise today. These are: current best practice allergen management initiatives developed by the food industry, such as The Allergen Bureau's VITAL Program; the research of the VITAL Scientific Expert Panel in providing internationally recognised food allergen reference doses or thresholds; and the benefits for the food allergic consumer through improved education and training over the food industry.

On the current best practice allergen management initiatives, such as VITAL, the Australian food industry devotes a significant amount of time and resources implementing robust allergen management to ensure the allergen status of their products is understood and so consumers can rely on and trust food allergen labelling. The Allergen Bureau has developed and provides key best practice allergen management and labelling guidance for the food industry. In particular, our voluntary incidental trace allergen labelling, or VITAL Program, provides a standardised allergen risk assessment for the food industry. The VITAL Program is widely recognised as a world-leading initiative in food allergen management and labelling. The VITAL Program aims to ensure consumers receive relevant, consistent and easy to understand information on food allergens.

It is our understanding that organisations such as the Australian Food and Grocery Council and the consumer organisation Allergy & Anaphylaxis Australia have already recommended the benefits of the VITAL Program to the committee in previous hearings. As the owners and developers of this voluntary industry initiative, The Allergen Bureau welcomes this opportunity to provide the committee with further detail on the VITAL Program.

The VITAL Scientific Expert Panel reference doses: the panel is an international collaboration between The Allergen Bureau, the Food Allergy Research and Resource Program from the University of Nebraska, and the Netherlands' Organisation for Applied Scientific Research. The panel is chaired by the US based professor, Steve Taylor, from the Food Allergy Research and Resource Program from the University of Nebraska.

Based on local and international clinical data, this panel of food allergen world experts has developed the most robust and scientifically credible food allergen reference doses available. These 2019 reference doses were represented in our written submission. They provide the scientific basis of The Allergen Bureau's VITAL Program and its precautionary allergen labelling outcomes.

We understand that this inquiry into allergies and anaphylaxis has available to it the knowledge and expertise of Professor Katie Allen. Prior to her election to the Australian parliament, Professor Allen was a member of the VITAL Scientific Expert Panel for approximately eight years. The Allergen Bureau encourages the committee to utilise Professor Allen's understanding of the VITAL Scientific Expert Panel reference doses should they wish to know more about it, the allergen research involved in it and its use in scientifically robust precautionary allergen labelling.

I will now move on to address improved education and training for the food industry. Greater knowledge of food allergy and food allergen management through improved education and training for the food industry will lead to improved food safety outcomes for the allergic consumer. We consider that there are current gaps in institutional education for food manufacturing professionals. Many of the current TAFE and university courses, from general manufacturing workers through to food science graduates, do not adequately address food allergens and their management. The Allergen Bureau considers that a full review of educational gaps in educational institutes providing education and training for the food industry would ultimately benefit the food allergic
consumer with improved food safety outcomes. The gap analysis should include education and training, not only in food manufacturing but also in catering and food service certificate qualifications as well.

The National Allergy Strategy has developed food service training, and we recognise this work is highly valuable in reaching a sector of the industry where allergen management training is paramount to enable strong food safety outcomes. In considering their recommendations, we urge the committee to recognise the needs of the food industry for improved resourcing of education and training in food allergy and allergen management.

Thank you for the opportunity to introduce The Allergen Bureau. We look forward to the recommendations of this inquiry, and we welcome any questions that you may have.

CHAIR: Thank you very much. I just want to clarify: the bureau is effectively a voluntary industry collaboration?

Ms Grinter: We're an industry not-for-profit, yes.

CHAIR: Okay. In relation to the VITAL scheme, it's voluntary. What is the current take-up of VITAL amongst food—is it international, or just in Australia?

Ms Grinter: There is a lot of international interest in VITAL, and there are organisations internationally that have taken it up.

CHAIR: How do you measure its penetration in Australia?

Ms Grinter: Do you want to say something?

Ms Lacis-Lee: It's a good question. From an Allergen Bureau perspective, we have metrics that we measure internally based on the number of member organisations that subscribe to the actual Allergen Bureau, and also measure the number of VITAL online calculator subscriptions, which is the tool that's required as part of the risk assessment process. We have year-on-year measurement, and I guess we can share the uptake of that program. But a percentage against the food industry as a whole, from a manufacturing perspective? We wouldn't be able to give that data off the cuff.

CHAIR: Why shouldn't it be mandatory?

Ms Grinter: Precautionary allergy labelling or the use of VITAL?

CHAIR: VITAL, yes.

Ms Grinter: I think there will be a time when precautionary allergen labelling may be a regulation in legislation. As a not-for-profit our mandate and our priority are to build tools and to have evidence based tools for the industry so that they're doing good quantitative risk assessment right from the beginning. We've been really advocating for that since 2005, when our industry not-for-profit was developed.

Ms Lacis-Lee: I agree with Kirsten: there will come a time when precautionary labelling or recommendations around precautionary labelling will be mandated, for sure. We need to be conscious though that mandating it will not necessarily move the food industry in its entirety to applying a quantitative risk assessment approach, which is what The Allergen Bureau would be advising is the critical step around ensuring that precautionary labelling is done in an adequate fashion to actually protect the allergic consumer.

Ms Grinter: There is also some work happening internationally, within Codex. They're looking at the allergens that are in the Codex standard now and also the science behind precautionary allergen labelling. But as a not-for-profit and representing the food industry, quantitative risk review is our mandate. That's why we wanted to really build the science so that it is underpinned by a good evidence base, and so that would be our priority and that's how we speak to our members as well.

Ms Lacis-Lee: It's also important to highlight, as part of that quantitative risk assessment, what manufacturers are encouraged to do, as part of the part of the implication of the VITAL Program. It's important to acknowledge that the actual crux of that entire risk review and risk assessment process is about manufacturers actually moving towards eliminating and reducing the allergen risk within their facilities before precautionary labelling is actually used. That's actually the last step of the entire process of that quantitative risk assessment. It's all about the encouragement of eliminating and reducing the risk in your facility to avoid having to have a precautionary allergen statement; therefore, it's only used when it's actually really intended, based on that scientific evidence. That's underpinned by the work done by the VITAL Scientific Expert Panel.

CHAIR: Two of the most common issues that have been raised are, firstly, the adequacy of existing labelling in terms of full descriptors of content and, secondly, the issue of food that's reconstituted so that it has a new formula, which can confuse a consumer. This can happen because they've been buying the same product for 10 years and suddenly there's an allergen introduced that can then make trouble. Firstly, in relation to full contents,
have you looked at whether it might be possible to mandate the use of a QR code that people could just scan on their handheld device? Secondly, have you looked at all at the issue of reconstitution of existing products?

Ms Grinter: QR codes: yes, you could definitely get that information from your label. We—so when I say 'we', I work for Nestle as well—have some experience with QR codes. It wasn't really a device that was heavily utilised by consumers, so it's no longer across our packs. In terms of the differentiation piece: if you've changed an allergen or added an allergen or taken one away, we have addressed that in the Food industry guide for allergen management and labelling. That's a collaboration between The Allergen Bureau and AFGC.

CHAIR: So have you addressed it?

Ms Grinter: Yes; we've got a guide in there, what the principles are and what you should look for and how you should potentially call out on pack. It's a guidance document, but it actually gives you some guidelines and principles that you should adhere to for best practice.

CHAIR: To make it simple: what would be wrong with having, if you reconstitute an existing product, a period of time—12 months or something like that—simply putting on the label something that stands out and says, 'New contents,' or something like that. We've heard the tragic example of someone who actually died because they bought the same product—they thought they were buying the same product, but it wasn't.

Ms Grinter: Yes, that's possibly a place to go; I could see that you could potentially do that. There is a lot of complexity in managing stock in and out of supermarkets and managing labels and managing that complexity.

CHAIR: That's exactly the problem: you could have two identical packages on the shelf, one which may have an allergen and one which may not.

Ms Grinter: Yes, you can.

CHAIR: So this is actually a simple solution, I would have thought, for that problem.

Ms Grinter: Yes, potentially.

CHAIR: Sorry, I'm putting you on the spot!

Ms Grinter: Yes, you are!

Ms BELL: With regard to the QR codes, I've had some experience in that area as well. I see Simplot is on one of the lists that we were just looking at.

Ms Grinter: This one?

Ms BELL: Yes. I used to work for Simplot, actually. We also found that consumers didn't really take up advertising messages through QR codes; however, do you think that QR codes would be a good solution for people who are specifically looking for contents because of their allergies? Do you think there would be a better take-up of a QR code for that use, as opposed to a competition use on labelling, which is what it has been used for in the past on supermarket shelves?

Ms Grinter: There's potential, and it would be something that could be investigated. When I think of any scanning that we've done in that digital space—this is an Allergen Bureau perspective—while the allergen information, nutrition information and details about a product were available, we still didn't have great uptake across consumers. So, it could be something that's looked at, but in our experience it wasn't something that consumers utilised at that time.

Ms BELL: What other vehicle do you think could be used not only on consumer products but also on food service products to clearly outline every ingredient? It's quite a comprehensive list in some products, isn't it?

Ms Grinter: Do you mean unlabelled product?

Ms BELL: I guess in the food service sector you've got larger portions being delivered in different kinds of packaging, because it's wholesale packaging as opposed to retail packaging.

Ms Grinter: So, it might be on a specification document or a sale document rather than on a label?

Ms BELL: Well, if we're talking about labelling on food, so that consumers know what they're eating, that includes food service outlets that have food delivered that may not have all the ingredients on their food, so therefore they don't know exactly what's in the food that they're serving, for example. So, if there was a retail QR
code, I suppose, for those products, where consumers would buy the product and take it home and use it, and there was a QR code on food service products, that would also give the venues an opportunity to scan their food that's being delivered, with a full list of ingredients, so that they could determine which foods have allergens in them and which don't. Does that make sense?

Ms Grinter: Yes.

Ms BELL: Is that potentially a scenario that could work?

Ms Grinter: It's definitely something to be investigated. I mean, if you're purchasing food to use within your food service establishment, you should know the allergens in your food. You should be asking for that information, because otherwise you can't provide the information with any credibility to the allergic consumer.

Ms Lacis-Lee: Which is also a current requirement as part of the food standards code—that any consumer, allergic or not, should be able to walk into a food service facility and ask for the ingredients and/or the allergens that are present in that food. That's a requirement already. So, to Kirsten's point, one would hope that the information is already accessible and available, at the end of the day. With any system that we're going to have, whether that's packaged food, which currently bears a label with the ingredient listing, and/or a precautionary statement or not, or whether it's information supplied from a front-of-house person in the food service establishment, I think we're still back to the reliability around the information at the grass roots, really, around making sure the information that's within that product, supplied by their suppliers and so on throughout that whole traceability supply chain, is actually accurate. There's one thing to be said about the information that's available to the consumer, but there's obviously a whole chain of information that needs to be gathered, I guess, to ensure that the initial information given to the consumer is accurate. You're still relying on the information being accurate, whether it's on a QR code or whether it's on the label.

Ms Grinter: And some of the training developed by the National Allergy Strategy talks to that front-of-house and back-of-house aspect and getting the right food to the allergic consumer, getting the right dish to them, and the management behind the scenes—how to get the information from the supplier, what to ask for, having a matrix, such as an allergen matrix, that's there for the kitchen staff. It was a great piece of work and I think something that needs to be utilised more and taken up more. And it's really about that relationship, that shared responsibility, between the allergic consumer and the person serving the food—being open about your food allergy and then the person taking the information and relaying it back, and the process of getting the right dish back to the consumer.

Ms BELL: It sounds very complex in that sort of food service environment.

Ms Lacis-Lee: It is, exceptionally, and with the members we work with and in my experience in my other role, outside of The Allergen Bureau—although there is a lot of discussion around on-pack labelling around allergens, by all means, there's still also quite a considerable risk within that food service space. A lot of the Australian manufacturers are currently aware of the Food Standards Code requirements and all the great tools that already exist, from a guidance perspective; whereas there does seem to be more of a gap within that food service space, without being able to obtain that information appropriately.

Ms Grinter: The information should be supplied by the supplier. Whoever's purchasing any kind of food and that information is mandated, you need to provide that information. It needs to be clear and it needs to have all of the allergen information.

Mr DICK: The full members, associate members and global members are some pretty heavy players in the marketplace and on the world stage. Is there any evidence or can you provide information on which countries are leading by example, which countries are getting this right? You might need to take this on notice. Some of these members would be across all continents. Australia is trying, but are there any—

Ms Grinter: To be honest, I think we're at the head of the game. We're also speaking internationally about the work that we've done, and we've collaborated internationally, because we didn't have all the expertise locally and we needed to go bigger. We needed to have that collaboration to give us that power, the science, that underpins the work that we've done. I would say we are really quite leading, here, and open to sharing all that we have to get a really great international result. That's always been our mandate, not just about Australia and New Zealand but about internationally as well.

CHAIR: If there are no other questions, I thank you for your evidence today. We'll provide you with a transcript of today's hearing and if you have any corrections please provide them by the end of the month to our committee secretariat. Thank you for your evidence and your submission. We very much appreciate it.
MARRON, Ms Loretta, Chief Executive Officer, Friends of Science in Medicine

[14:42]

CHAIR: Welcome. I'm required to let you know that these are formal proceedings of the parliament and the giving of false or misleading evidence is a serious matter. Today's proceedings are being recorded by Hansard and do attract parliamentary privilege. Thank you very much for your written submission. Would you like to make an opening statement?

Ms MARRON: Yes, I would.

CHAIR: Tell us a bit about the Friends of Science in Medicine.

Ms MARRON: Friends of Science in Medicine is a not-for-profit organisation, co-founded by four professors and myself, and we're about promoting sound health care.

CHAIR: Do you know of any enemies of Friends of Science in Medicine?

Ms MARRON: Pretty well everybody in the complementary and alternative medicine field and most alternative medicine practitioners.

CHAIR: Please proceed with your opening statement.

Ms MARRON: I have a Bachelor of Science in physics and maths but I spent most of my career as a computer professional. I have an interest in computerised so-called energy medicine devices, including the bioresonance device. This story goes back to 1991 when a group of allergists looked at the VEGA device, which is a bioresonance device, and decided that it was an unorthodox device that was not scientifically tested or based and that it was going to be a problem in cost to the community and to patients.

Wind the calendar up to 2010, where I documented over 220 websites making false and misleading claims for bioresonance and other sorts of energy-measuring devices. I'm not an allergist, so I contacted two groups—the ASCIA, who I believe addressed this group in November last year, and Professor Connie Katelaris. Professor Katelaris was one of the co-authors of that article that was published in the Medical Journal of Australia back in 1991. I have two statements from these organisations. The ASCIA is the Australasian Society of Clinical Immunology and Allergy. They said: 'I have had the guidance of ASCIA for my work challenging unproven and disproven interventions that target patients with allergies.' Also: 'I have had the guidance and support of Professor Connie Katelaris AM—allergy clinical immunology, paediatric and adult patients—for my work challenging unproven and disproven interventions that target patients with allergies.' There were these reports, and the 220 websites were sent to the various complaints authorities in each state. Within months, some of the devices were cancelled by the TGA, including the VEGA, which was very high profile at that time, and a number of other devices. But the BICOM—that's another brand—was not. The second device that is mentioned in our first submission is CyberScan. That was not listed until 2012.

Moving time forward to 2018, on 1 July 2018 the TGA took over handling complaints processing for health advertising. In September-October, FSM sent them over 200 complaints about false and misleading advertising, which we believe breached the Therapeutic Goods Administration Act. Ten months later they closed all the cases and sent them all back to me. They also put on their website a statement about bioresonance which particularly mentions allergies and food intolerances—warning people about them. They then stated they were going to run an investigation and they were going to undertake an education campaign. That was August last year, and I didn't hear a lot after that, but I kept looking at the BICOM and whether it was still listed. Quickly, the BIOCOM costs over $34,000 and practitioners are told they can earn $151,000 a year. In January, the device disappeared off the register, so I contacted the TGA and asked them what was happening. They said that a number of the sponsors had cancelled the devices following the completion of their investigation, and they were still undertaking an education campaign. They also said that they were going to cancel a number of other devices at the end of this month. That made our first submission redundant in that it requested that both the BICOM and CyberScan be cancelled.

The second submission is more about educating our practitioners, which follows on from the TGA's education campaign but widens it somewhat. Thank you.

CHAIR: Thank you very much. So the TGA promised action last August. Have you had any follow-up with them as to why they haven't progressed as expeditiously as you would like?

Ms MARRON: I understand it takes time because they have to give the sponsors the opportunity to provide evidence. Sometimes they have to give an extra month or months to do that. I think their deadline has changed several times, but their investigation was completed in December and I do believe they're actually cancelling the devices. I'm quite confident.
CHAIR: So they're cancelling all bioresonance devices or just for certain conditions?

Ms MARRON: No. There were quite a number of devices they were cancelling over a number of sponsors. They looked at a wide range of energy type devices, not just bioresonance. There were a lot of other devices that had light therapy that cured you based on the colour of your chakras and things like that.

CHAIR: I can see where the enemies of science are coming from! Do the bioresonance devices, as a class, have TGA approval for treating any conditions at the present time?

Ms MARRON: The bioresonance people, in their wisdom, called them biofeedback devices, which have a legitimate place. It was only when we challenged that it wasn't true—that it was not biofeedback—that we had a response from the TGA.

Dr FREELANDER: I'll play devil's advocate. I don't disagree with you in any way. Do these devices do any harm?

Ms MARRON: I think the three harms that they do are: financial harm to the patient—

Dr FREELANDER: I accept that.

Ms MARRON: and there's the harm of disappointment when the treatment doesn't work, and there is harm in the delay of proper treatment and diagnosis as well.

Dr FREELANDER: We accept other things that have very poor evidence. People are entitled to seek out other treatments that many of us might not necessarily believe work. Isn't the ultimate test whether they do any physical or psychological harm?

Ms MARRON: I think they do harm, particularly financial harm. I think if a parent of a child goes to these practitioners month after month and there is no benefit—that is a harm to the parent as well when they could be getting real, proven treatment.

Dr FREELANDER: But people do seek out alternative treatments. They go to iridologists, for example, or to naturopaths or, dare I say it, to osteopaths. People are entitled to seek treatments that are alternative.

Ms MARRON: They certainly are. But I think they're entitled to make an informed choice and know that the evidence is not there. When you look at things like Cochrane reviews, there is no robust evidence for clinically significant outcomes for acupuncture, Chinese medicine or homeopathy for any disease or disorder. Providing they know that, it's buyer beware—and providing the government is not funding it—I think that's important as well—and also providing they're not teaching it in universities or colleges, and they actually are.

Dr FREELANDER: That's true also. So what should our overall response be?

Ms MARRON: The problem with the TGA is that they run out when the advertising stops. You'll notice, in appendix B, that there's a BICOM course being run in Adelaide next month. I've noticed a couple of the websites are saying: 'We use the BICOM. Call us to find out what we have to offer.' I think we have a serious problem in that we've got the allergies people on one side—appendix A gives a great long list of unproven, unorthodox, disproven treatments—and on the other side we have no effective way of stopping practitioners from offering those treatments to patients, to your patients.

Dr FREELANDER: Thanks very much.

Mr ZAPPIA: Can I get something clear for my own mind: before any of these products are allowed to be used by a practitioner, does the product have to be approved by the TGA?

Ms MARRON: There's a problem with devices in that the TGA, by law, have to accept any device from Europe that has the correct certification. All that means is that they're not going to electrocute the person. It usually means that the sponsor is meant to hold the evidence. Once they come into this country they are not approved by the TGA; they are accepted by the TGA. But once they get on the register it is incredibly difficult—incredibly difficult—to get rid of them.

Mr ZAPPIA: To get rid of them.

Ms MARRON: That's right. In fact, it was impossible. I heard that in 2010 it was the first time in the history of the TGA that they had cancelled devices other than for non-payment. The reason I sent these reports to the individual state authorities—health complaints authorities—was that I had no confidence that the TGA would do anything. I figured they could ignore me, but they may not be able to ignore the states, and they didn't.

Mr ZAPPIA: What kinds of reasons does the TGA need to deregister these devices so that they can't be used?

Ms MARRON: Usually harm. If someone gets electrocuted, they'll do it. When it comes to registered products, I have no problem with the TGA; they do a great job there. It's the so-called AustL products that are a problem, because they consider them safe. They'll keep talking about harm. But they forget that there are 10,000...
naturopaths and 4,000 Chinese medicine practitioners, and I'm pretty sure that most of them will be available to help patients with their allergies. These treatments are just not effective.

**Mr ZAPPIA:** I ask these questions because the TGA has to approve medicines after they have been market tested and proven to be safe, and also do what they claim to do. Yet they don't apply the same standard, obviously, to any of these electronic pieces of equipment that others claim will then do the same as medicines do.

**Ms MARRON:** This applies to complementary medicines as well, where the sponsor is meant to hold the evidence. If you have a complementary medicine or one of these devices, you go to the computer, tick a few boxes, state that you hold the evidence and then you get a number—and Bob's your uncle; you can go out and start treating patients.

**CHAIR:** Doesn't the TGA require disclosure? You can't put on the side of a bottle of vitamin C that it's going to cure your cold.

**Ms MARRON:** If you do that, people like myself and my organisation have to put complaints in and it may take six months before that claim is gone; it is that slow. And even if that claim is gone, the sponsor has put a few new bottles out with new labels making the same claim and you have to wait another six months. Before 2010, every time I sent in a huge report with a truckload of evidence, I got the same letter back putting complaints against advertising. They seem to think that once the advertising is gone—this may be true—that their role is done. That for us is not appropriate. We believe that more training should be done in consultation with the ASCI, for example. Appendix 8 gives the full list of treatments that are being offered to patients. There is a second one there which is live blood analysis. I had a letter from the head haematologist from the Alfred hospital, Professor Hatem Salem, saying in no uncertain terms—colourful terms, actually—that it didn't work. The TGA took over that on 1 July 2010. I could not put in a complaint for four years and four months because the TGA had to give the sponsor three years to apply for a listing, to provide their evidence. The TGA then gave them another year and then took them four months to process that. I am very patient. I waited four years and four months before sending in quite a few complaints against that device. That device is made locally here at Health World Pty Ltd, the sponsors of Ethical Nutrients and Inner Health Plus.

**Mr DICK:** How long has Friends of Science and Medicine existed? How many members are there? How do you join? Are you a membership based organisation, business organisation or interested-in-defending-science organisation?

**Ms MARRON:** Four professors and I set it up in 2011. We then called out for friends and ended up with about a thousand friends including two Nobel laureates and Australian scientists. You will find names like Ian Fraser on our list. They are not required to pay any membership but if I ever need someone to talk to media about iridology, I look through my thousand professors on the list and find someone who is an ophthalmologist and they will talk to the media.

We see ourselves as the go-to place for anything to do with complementary and alternative medicine and we are very much evidence based. We pride ourselves in that whereas, the alternative practitioners, their response when you ask them for evidence is to try to discredit us. They put out false facts, which they did recently when they denied that some products were adulterated and we had to provide information for that. That is our role. We have changed heads a few time because some of our professors are turning 80 but they are now consultants so they will hopefully never leave the organisation. It is not just complementary and alternative medicine; there are medical doctors who are doing some rather dodgy things as well and we take that on. We were slightly overwhelmed for the first eight years with chiropractors dangling babies upside down and osteopaths messaging heads claiming they could cure all sorts of things.

**Mr ZAPPIA:** Getting back to the TGA, to any of these practitioners that use these devices ever claim ‘this is TGA approved’ as part of their promotion?

**Ms MARRON:** There are many. In fact, some of our complaints are around websites that claim that things are TGA approved because they do not approve any of these devices. But that is very convincing to a parent of a child that has an allergy.

**CHAIR:** Thank you for your evidence. I hope during the course of my public life I never have cause to come up against you because I think that would be quite formidable. Thank you for the work that you are doing on behalf of science and for what you are trying to achieve. It is obviously an important issue because we do know from what we have heard that there are lots of snake oil salesman out there. We will give you a transcript of the proceedings in due course and if there are any corrections please feel free to make them.

**Ms MARRON:** One final comment: it has been 30 years to this time before this meeting. I hope we don't have to wait much longer before there can be a change.
Proceedings suspended from 14:59 to 15:20
CROSBY, Ms Raphaella Kathryn, Founder and Chair of the Organising Committee, Migraine Australia

CHAIR: Thank you for coming and appearing before the committee this afternoon. Because this is an official hearing I need to remind you that these are formal proceedings of the federal parliament. The giving of false or misleading evidence is a serious matter. Today's proceedings are being recorded by Hansard and do attract parliamentary privilege. We're grateful that you've made your time available and also for your written submission. Would you like to make an opening statement?

Ms Crosby: Just a brief one: thank you very much for holding this inquiry into allergy and anaphylaxis. Allergy is one of our friends in terms of conditions that are not well understood. Migraine Australia is very new, and we wouldn't have had the capacity to even form an organisation or advocate for ourselves in any way except for new medications that became available 18 months ago. The first one in particular, Aimovig, which I am on, dramatically changed my life, as well as those of about half the original organising committee. We went from completely disabled to functional, and being able speak for ourselves is a very powerful thing for our community.

I understand, from listening to other evidence given to this committee and from people I know in the allergy community, that allergy is just as disabling in that it is invisible, it is often not believed and you end up spending most of your life dealing with it. About two-thirds of people who live with migraine also live with allergy, so there is a very significant overlap in the communities. The difference is that migraine can become so consuming that you stop using the language of allergy and you start using the language of migraine, which is when you're talking about triggers and you're talking about ending up in migraine attack as opposed to having a reaction.

That's probably the most important thing I want to get across—that we do have very significant overlap—but that other third of people with migraine are still going to use allergy services. They have to go through a process of figuring out their triggers. That necessarily involves figuring out whether they have food or dust or pollen or any of those other things that trigger their migraine. My main aim, in submitting to this committee and coming to speak to you today, is to make sure you understand that all 4.9 million Australians that live with migraine are also going to tax the allergy services that exist for people with very significant allergy.

CHAIR: Thank you very much. Do you have any specific recommendations for us as things we should include in our report? Have you thought about that?

Ms Crosby: The biggest one, I think, is around food labelling: simplifying that and making it uniform and consistent. That was in the written submission. That's probably the biggest one that can help both communities, because then we don't need to think and we can plan our lives with a lot less anxiety. Anxiety around triggering migraine attacks is huge. One study put it at 60 per cent of people with migraine also have clinical anxiety; another one put it at 80 per cent. There are some arguments that everybody with migraine has some level of anxiety, and I'm sure it's the same for the allergy community.

CHAIR: The medication that you mentioned is obviously for people who suffer regular and severe migraines. What percentage of the population is that assisting who have severe migraines?

Ms Crosby: In Australia there are about 400,000 with what we call chronic migraine—which I hate; I want to eradicate the words 'chronic' and 'episodic' from the discourse of migraine entirely. Migraine is a genetic condition; therefore it's always chronic. You've always had it. What it actually means is chronic migraine attacks, which is more than eight migraine attacks a month. Basically half of your life is gone to migraine. That's 400,000 people in and of itself.

CHAIR: And the medication works with everyone who suffers from chronic migraines?

Ms Crosby: No, everything with migraine is 'most but not all'. Because there are over 40-odd genes already identified, and still counting—that work is actually being done here at QUT—there is no one-size-fits-all solution. CTRP antagonists, which is a group of new medications, have massively changed the world of migraine. We have gone from accepting a 50 per cent reduction in attacks and severity of attack as the best that we could get and that was usually a combination of drugs, lifestyle management, being on an elimination diet and all of those kinds of things—that kind of reduction we thought was great—now we have set the bar as acceptable, normal, standard response to therapy is 50 per cent reduction. I am a super responder to Aimovig; I have literally gone to zero migraine attacks a month in six months. So the capacity for these drugs to massively change people's lives really can't be understated. At the moment, we have a problem with PBAC. They don't think that it is better than Botox. We are sitting there, pulling our hair out, asking, 'What are you thinking? What are you even talking about? Come and see our lives.' But that is where we are at. I should also note—

CHAIR: So it is not PBAC listed yet?
Ms Crosby: No. The one that I am on, by Novartis, they withdrew it from the PBAC process because they thought PBAC were playing silly games, and we wholeheartedly concur. There is something really weird going on. Aimovig was rejected twice. The last rejection basically indicated that PBAC didn't think it was worthwhile spending taxpayers' money on migraine. I can assure you that you are spending taxpayer money on migraine; you are just doing it through every other service because we do drain everything.

Dr FREELANDER: The issue was the cost that Novartis was being asked to reduce to and they thought it was not worth their while.

Ms Crosby: From my conversations with Novartis, the point that PBAC wouldn't accept was that it was not superior to Botox. That was their main breaking point and they decided to walk away from the process. Emgality, which is the second one in the process, has been recommended by PBAC but with an unworkable condition that they fitted under the existing Botox cap, which translates to 'no more new taxpayers' money on migraine'.

Dr FREELANDER: I still think that the issue with Novartis is cost.

Ms Crosby: Partially, yes. But these are very cheap biologics. You heard evidence here already about biologics that are $1,600 a month; these are $800 a month. They are very cheap biologics. We also have 13 more additional migraine medications coming down the pipeline in the next 18 months and that is because there has been a very significant shift in the way that we think about and treat migraine. So there is a whole pile of new drugs, both acute and preventative, coming onto the market. They will work for different people; you have to try them. These first ones are obviously going to be a little bit more expensive because they did a bit more in the research. That's okay. They are allowing a whole lot of people to try them for free; I am one of those people. Emgality is available to everyone for the first two months for free. You don't even need to go to a neurologist; you can get it from your GP. So the drug companies are being incredibly generous with the migraine community.

Dr FREELANDER: I am not so sure about that.

Ms Crosby: Well, Novartis have given away Aimovig for over 18 months. At $10,000 a year for a couple of thousand patients, that is a lot of money. And they've made nothing back and they are not going to make anything back out of this.

Dr FREELANDER: I am a migraine sufferer myself and I actually get hemiplegic migraine—

Ms Crosby: Me too.

Dr FREELANDER: though these days not so frequently. What other treatments have you been on in the past? Can you describe the side-effects of some of those medications?

Ms Crosby: I am not sure we have time to go through the entire list. I did try Botox. I had a very severe negative reaction to Botox, and ended up basically in and out of hospital, unable to function, unable to get out of bed for five months. Botox works for some people. I am not going to sit here and say it is a demon drug; it is not. I was on Topamax for very long time. It reduced the severity but not the frequency. It was the only thing out of everything that worked. So I did basically every available treatment short of having a nerve stimulator put in my brain and that is where I was at when I decided to stop, and then Aimovig became available six months later.

Dr FREELANDER: Has the migraine affected your ability to find work or maintain—

Ms Crosby: I have been on DSP since 2014.

Dr FREELANDER: Was that because of migraine?

Ms Crosby: It was because of migraine. I was on income protection for two years before that. So I haven't worked at all since 2012.

Dr FREELANDER: Wow.

Ms Crosby: I am now here and functional. I drove myself here and I haven't driven for seven years. I cannot say how much this has—

CHAIR: Excuse us if we don't get a lift with you to the airport.

Ms Crosby: I am going to the Gold Coast. I take almost no pain killers anymore, not even Panadol or Nurofen; I just don't. I used to walk around with wallets of everything up to Tramadol, occasionally an opiate patch, not to mention a lot of antiemetics. I would never go anywhere without them and I would very rarely leave the house. I have completely changed my life.

Dr FREELANDER: It's been put to me that people with severe migraine often give up seeking treatment.

Ms Crosby: Well, until recently, they were told that was it; that there was nothing else you could do. The extent to which we need to retrain the entire medical profession is really quite true. What we know about migraine has significantly changed. The entirety of the migraine classifications in the ICHD-3, the International
Classification of Headache Disorders, was changed in 2016. Migraine infarction is now included in that. So we now accept and recognise the fact that migraine can kill.

So the extent to which we need to retrain everyone in even little things like ‘They're not migraines; they're migraine attacks’—we live with migraine and we have migraine attacks. Instead of, 'I have migraines. Migraines are something that go away and then you are completely healed.' That's not the reality, just as it is not the reality of living with allergy. Just because you're not having a reaction right now doesn't mean that you don't still have that allergy. Just because you're not having an attack right now doesn't mean you still don't have migraine.

**Dr FREELANDER:** So education is one thing.

**Ms Crosby:** Yes.

**Dr FREELANDER:** What else can we do?

**Ms Crosby:** For migraine or the relationship between migraine and allergy?

**Dr FREELANDER:** For the migraine community.

**Ms Crosby:** The really big thing, our No. 1 on the to-do list, is we want to prepare a white paper for discussion and then, from that, lead to the development of a holistic migraine management plan. We're calling it the migraine MAP—the management and action plan. That is to manage everybody from the second that you first get diagnosed with migraine—the same as you would with asthma. You get a plan and you're told, 'If this happens, take your puffer,' and 'If this happens, go to the hospital.' We need the same kind of thing for migraine. It's very, very important, because, when you are in the middle of a migraine attack, your brain doesn't work and you can't think straight. So you do actually need written down instructions to do this, do that, try this and, if that doesn't work go to emergency. That's very important. The US has already started to work on that. That is the action plan bit. But we need to do holistic prevention as well. That's managing food, managing the environment and making sure that your workplace is supportive or your school is supportive—all the way through to, 'Are you getting enough exercise?' and 'Is your family understanding and supportive of what's necessary to manage migraine?'

That's a very big task, obviously, which is why we wanted to start with the white paper and get everything on the table. We don't even have solid prevalence rates in Australia. We don't have any information to start the conversation. We have the Deloitte white paper that was funded by Novartis at the end of 2018 and that's it—and a lot of those numbers are very, very soft, particularly the prevalence rate, which they have put at, I think, 20.5 per cent or one in five. Globally the WHO puts it at one in seven, 14 per cent. It's probably somewhere between the two. We do know that migraine is more prevalent in Caucasian people than in people of colour. So in countries like the US, the UK, Australia and Canada you have a slightly higher rate than some other countries.

**Dr FREELANDER:** Thank you very much.

**Ms BELL:** I have a question, and you seem to be a veritable encyclopaedia on migraine. Thank you for coming today.

**CHAIR:** Wikipedia, this century.

**Ms BELL:** Wikipedia. I have people in my family who have suffered with migraine for years. I want to ask a question about current research based on why.

**Ms Crosby:** There's lots going on. There's genetic research, as I mentioned, going on here at QUT. There's research into the link with hormones, which is really important, happening at the University of Newcastle. That's really interesting research, because there is a very big gender gap, with 75 per cent of people that have active migraine, currently having migraine attacks, are women. And it most dramatically affects women between the ages of 35 and 55. So you're talking about taking a huge chunk—45 per cent of women between 35 and 55—out of the workforce or down from what they would normally be able to do, because they have to manage their migraine. That's huge, So we need to understand the hormonal basis that's going on. That work is happening at Newcastle.

The University of Wollongong has an incredibly long and rich tradition of studying migraine. I'm not sure exactly what projects are going on there at the moment, but the entire work that led to triptans, which are the abortive drugs that we had, that then led on to this work on CGRP antagonists all happened at the University of Wollongong. The University of Melbourne is doing research into finding different chemical pathways and proteins that work with CGRP. So there's a lot of work, and that's all happening in Australia. Dr Peter Goadsby is obviously the world-leading kind of expert. He was significantly involved in the identification of CGRP as being very important in the migraine trigger pathway. He is actually Australian but he spends most of this time bouncing between the UK and the US.
That's what I know off the top of my head. I am happy to get you a better brief, if you—

Ms BELL: I'm just interested in whether it's produced by foods or environment or stress, or something else.

Ms Crosby: All of the above.

Ms BELL: I remember as a kid growing up, my dad went through a period where he thought that oranges brought on a migraine, and then he thought it was eggs—so he went through years of trying not to eat particular foods.

Ms Crosby: And it does change.

Ms BELL: The one food he did not give up, mind you, was West End Draught!

Ms Crosby: That's probably the one he should have given up! So, you do have to have the underlying migraine gene—or gene defect, if you want to use that term—and there are lots of them, and they can combine. So I got allergy from my mum's side of the family and I got migraine from my dad's side of the family and it combined in me to produce really bad migraine. The two do feed off each other somehow. The trigger is different for everybody, and triggers will change throughout your life. Hormone, as I said, is a significant trigger and that's why you see this kind of inverse curve where women get worse in the middle of their life and men get better, and men are usually particularly bad in their teenage years and over the age of 70. So that's a significant trigger in and of itself. And menstrual migraine is a thing: getting migraine with every period or with every ovulation, absolutely, is a thing and it affects a huge number of women. And the other one is that sometimes it's exercise-induced migraine, or relaxation—sometimes it's called Saturday migraine: so you wind down on the weekend and something happens in your brain chemistry and it shifts and it triggers a migraine. So there are a lot of different triggers.

Ms BELL: In your submission you also mention abdominal migraine, which is something I haven't heard of before. Could you explain what that is?

Ms Crosby: Sure. There are a number of different subtypes of migraine. Hemiplegic migraine, which Dr Freelander and I both have, is one that causes stroke-like symptoms. Abdominal migraine is a different presentation. It was previously thought to be limited to children. Basically, it's the same thing going on in the brain—the inflammation of the nerves, the spasm in the blood vessels—but, instead of presenting as a headache, it presents as abdominal cramps and pain, and sometimes diarrhoea, sometimes vomiting—it depends how bad it gets. It's also linked to cyclical vomiting syndrome, which is where you start vomiting and you don't stop.

Ms BELL: Would that mean it's quite difficult to diagnose, with so many gastro symptoms?

Ms Crosby: Yes; it's the persistence of it and the lack of any kind of bug; those kinds of things. It often gets missed. And it often gets dismissed as well: 'Oh yes, it's abdominal migraine; she'll grow out of it'.

Dr FREELANDER: They do respond to anti-migraine treatments, don't they?

Ms Crosby: They do. There are limited migraine treatments available for children, but they do. Once correctly diagnosed, you can put children on a regime, and you can work through an elimination diet to find the food triggers, if it is food triggers—the same kinds of things that you would do for an adult with migraine. It does persist into adulthood. That previously wasn't recognised but is now being increasingly recognised. It's one of the reasons why it was added to the classification in 2016. That classification does actually say it can persist into adulthood, to make that clear to the medical community. We have on our committee somebody with four generations of abdominal migraine. She very rarely presents with headache, but her daughter, in particular, is routinely in hospital for any kind of medical intervention, to either stop her vomiting or to manage her pain. It is incredibly painful, but, because it usually doesn't present with a headache, it is very difficult to diagnose, very common to miss, and—as I said in the submission—very commonly misdiagnosed as IBS.

Mr ZAPPIA: I have to say, it's been fascinating just listening. I've learnt a lot about migraine. I was going to ask about what the triggers are, but that's already been answered.

Ms Crosby: Really, anything can be a trigger, and that's kind of the difficult point—because if relaxing on the weekend is your trigger, how do you explain that? How do you quantify that? How do you find that out? We use these things called migraine diaries, which are awful. Basically, you keep a diary of everything that happens every day—every symptom that you had, everything that you ate or drank, went near—what did you do, the whole thing, all day long. So you spend every minute of every day asking yourself: 'Am I sick?' It's really, really bad for mental health. It's atrociously bad for mental health. PBAC is currently debating whether to make us keep migraine diaries indefinitely in order to stay on the preventative medications. That cannot happen. You simply cannot take a group of people where 80 per cent max are already anxious and 25 per cent have clinical
Mr ZAPPIA: Do the medications just help with the symptoms or do they actually help change the person to the point where the migraines themselves may not occur as often and may fade away?

Ms Crosby: The new ones, the CGRP antagonist? CGRP is calcitonin gene-related peptide, so it's a peptide that exists normally in your body and it does lots of very important things. What the CGPR antagonist does is attach either to the receptor or to the peptide itself and blocks it. We know that, when a migraine attack ramps up, the level of CGRP goes through the roof and, by being able to block that level of CGRP, essentially the migraine just disappears. So you still have migraine, you still live with migraine and you still want to avoid those triggers because obviously you don't want to test the system. I can tell you from my personal experience what happens is I start to get the first little rumblings or I get a bit brain foggy and my speech goes a little wonky and then it's like somebody just dumped a whole pile of chlorine into the pool and the green just fades away; it just disappears. It's not changing your internal chemistry; it just blocking that peptide. We know that manages to break the migraine trigger sequence, which is really amazing and powerful.

Previously, we were trying to block serotonin because we thought that might help, and it did some people. Lifestyle modifications help for some people. We get people posting on our Facebook page all the time saying, 'I just gave up gluten and my migraines are cured.' It's actually a bigger problem dealing with our own community because everybody has their fix. The number of people that are flogging some diet or whatever is enormous. Don't ever put 'migraine diet' or 'migraine cure' into Google. It's sickening to watch how much money is pumped into myths.

CHAIR: You should have been here for our last witness, the Friends of Science in Medicine! Does the new medication help with episodic migraines?

Ms Crosby: Yes. There's actually testing being done—

CHAIR: But is it medicine you can actually take when you feel something coming on, like panadol?

Ms Crosby: One of the new one's called Ubrogepant, which is coming out in the States in the next couple of months, is exactly that—you can take it as a tablet when an attack comes on and it blocks the CGRP. There's a tablet version of a preventative coming out as well. That's what I said about there being 13 new drugs: every company is getting in on it. There's going to be a range of them. Those new ones that come out in tablet form will certainly be much more appropriate for the more episodic patients. The problem that we have is, if we can't get these big monoclonal antibodies through for the worst of our worst, how are we to convince people that having a headache four days a month is not bad enough to warrant being on the PBS. At the moment those people are largely overusing their triptans and other pain relieving medication, which leads to medication overuse headache, which was also mentioned in the submission.

MOH is our biggest problem in terms of managing migraine. There are people that had a bout of migraine in the 20s and don't have attacks anymore and don't think of themselves as still living with migraine. But say they break their leg and they're on opiates for a couple of weeks, they may very well wind up with medication overuse headache and fall into a deadly migraine cycle because they didn't have an MOH plan. A MOH plan is really simple: rotate your meds. If you take an NSAID one day then take panadol the next day, take codeine the third day and take nothing the fourth day. You mix them up so you don't get, basically, an overdose.

CHAIR: Thank you. That has been very instructive. We'll ask Dr Freelander later if his migraines were worse in his teens or in his 70s!

Dr FREELANDER: Now I have what I call a Liberal Party migraine! Pain in the neck!

Ms BELL: Ms Crosby, have you considered doing a PhD in this area?

Ms Crosby: I'm about to finish my PhD on why people vote the way they do. I think one PhD is enough. I think there should be multiple PhDs done in this area. We have also asked for our own inquiry because it's obviously very necessary for us to get as much detail on the table as we can. The problem that we have at the moment is we have no idea what's going on. There are little bits of work being done in corners. Migraine research very rarely gets funding, so it's very important to have that baseline of a white paper and an inquiry so we can build a national strategy.

CHAIR: We'll provide you with a Hansard transcript, which you can put on Wikipedia! If you have any corrections to that, you can let our committee secretariat know. It's been very instructive. Thank you.
NEVARD, Ms Jacqueline, Founder, My Food Allergy Friends

Evidence was taken via teleconference—

[15:46]

CHAIR: Welcome. Thank you for joining the committee this afternoon. We very much appreciate your time and also your submission. I need to remind you that these are formal proceedings of the parliament. The giving of false of misleading evidence is a serious matter. Your testimony today will be recorded by Hansard and does attract parliamentary privilege. I mentioned that we have the written submission from you, but can I invite you to make an opening statement?

Ms Nevard: Certainly. I wish to firstly thank the committee for this inquiry, which is long overdue and something I've been advocating for close to nine years now. It's vital we understand allergic disease and the impact it has on our roles as parents, teachers, educators, and on our children and our community. My Food Allergy Friends was created in 2012 after my own son was diagnosed with seven food allergies. Leaving the GP with little information, given no EpiPen and told just to 'wait and see how bad his reaction was' left me in a place of overwhelm. No education and no support was offered.

After educating myself as much as possible, I went on to educate my son but found no age appropriate material in Australia. I quickly realised it wasn't just him that needed educating, it was everyone that came into contact with him, both children and adults. I founded My Food Allergy Friends and authored a unique series of five children's books; a parent guide; visual education resources, including posters and stickers; and went on to create the Food Allergy SMART Program for schools and childcare centres. Last year I also created an online program for schools and I set up Allergy Masterclass to support and educate families with practical knowledge about everyday challenges they face, along with Simone Albert, a professional counsellor. My programs have had such a huge impact on creating awareness for the younger generation in Australia.

My submission, which I hope you've had the opportunity to read, covers many issues, but I would like to focus on three main areas, all of which fall under education. Firstly, all children need education. Allergy education needs to be taught in every school and every early learning service. Secondly, parents need support in the way of education and counselling. And, lastly, policies need to be standardised across Australia, as currently they are out of date and out of touch with issues arising in schools.

I have listened very carefully to the hearings in both Melbourne and Sydney and lots of vital points have been raised but no-one has really touched on education, especially in our childcare centres and schools.

Education is the key. Food allergies are becoming the norm for the younger generation, with one in 10 infants and one in 20 children now having an allergy. If we educate, we create understanding, empathy and compassion and we create safer places for our children. Through education and awareness, we will prevent many reactions from even occurring. Allergy management, within these services, needs to include student education as part of their allergy management strategy. Currently, the protocols in schools are very reactive. Yet, if we teach children from as young as three not to share food, to look out for our friends and to wash our hands after eating, that becomes part of the school/childcare routine and makes much safer and more inclusive places for everyone.

Parents need education and support. If they are given the knowledge, they will feel empowered and less likely to suffer from anxiety. An anxious parent creates an anxious child. Like driving a car, it's easy when you know how, but you can't be expected to have a safe journey if you don't have the knowledge. Parents need access to allergists, dietitians, counsellors and credible education resources, like those I provide to support children and parents.

I have the solution for education in schools and child care. I am completely self-funded and have approached MPs, education departments and our national charities, yet there hasn't been a leader in government or the education department who has stepped up and realised this is actually the way forward and it's getting results. My program has had amazing reviews from parents, teachers, educators and allergists. In fact, I'm sure many people you've heard from in this inquiry will be familiar with my work. To make real impact, it needs to be rolled out in every school and early learning service. I've done all the hard work. All I need is further support in the way of funding as I cannot do this myself and achieve the same level of impact without backing from education departments.

I'm increasingly frustrated by the lack of support from key organisations and by the fact that funding is always given to the National Allergy Strategy and a small social enterprise like mine gets no support or funding when our goal is all about social community benefit, not personal gain. If we work together, we can create a much greater impact. Surely our goals are the same: to help, support and serve people. I'm afraid any funding will go to the National Allergy Strategy to reinvent what I've already created and is already working and getting results. In the UK, it's mandatory from 2020 to have allergy education, after realising the real need after a fatality happened to a
13-year-old student. The only time real action occurs is when a death happens. I'm working hard to make real
difference. I'm working from a place of preventative care for our children, rather than reactive care. I hope we do
not have to wait for fatalities here for real change and progress to be made. Allergies affect families and our
children on many levels.

Thank you for this opportunity to be heard. Our young children have no say in this. I'm here to speak, and
advocate, for them. Thank you

CHAIR: Thank you very much. With what you're doing at the moment, what is your penetration within the
school sector and amongst young people?

Ms Nevard: I've been doing the live events for about four or five years now and I do over 100 events in
childcare centres and schools a year. But I have three ways that the program can be implemented. Schools and
childcare centres can use the resources—the packs—I provide, and they do the education themselves; I do the
events; and then I've also just produced an online program. In childcare centres, the take-up is pretty good, but, in
schools, the take-up is very low.

CHAIR: I wasn't aware of the UK example you just gave us. You're saying that by 2020—

Ms Nevard: This year—

CHAIR: By the end of this year—

Ms Nevard: Every school has to be teaching students about allergy awareness.

CHAIR: Have you seen the resource material they've produced for that goal? Has it already been done?

Ms Nevard: I haven't, no, because I'm focusing on what I'm doing here which is relevant to Australia.

CHAIR: Usually, governments only consider programs such as those that you're offering if they have a
detailed proposal with costings et cetera. Is that something that you've done and submitted to various state
governments already?

Ms Nevard: Yes, about a year and a half ago, I spoke in Brisbane parliament and I think there were about
seven people in that room. Five of them were personally affected by allergies, so I was definitely heard. Basically,
I feel that there are three barriers, and one of those barriers is that teachers feel that they've got so much to learn in
the curriculum that they can't possibly then start adding another thing. So I was basically sent away to align my
program to the curriculum, so that teachers could see that, by teaching this, they were actually ticking boxes. I've
gone away and done all that work and haven't got anywhere because they won't promote a business. So I went a
further step and did the online program as well.

Ms BELL: Is the All about Allergens course the course that you've created online?

Ms Nevard: No, that's something that the National Allergy Strategy has done. My program is unique in the
fact that it actually teaches children. I teach children as young as three to five and children in school. Prep to
grade 3 is the main area that I teach. Sometimes I do teach whole schools, but the resources are all aimed at
younger children.

Ms BELL: That way the children can learn about their own allergies and take some—but not all, obviously—
responsibility for their awareness of what they're doing? Does it help with their awareness?

Ms Nevard: No, it's not aimed at children with allergies. My resources are used by parents to teach their
children about allergies and ways to stay safe, but my resources are used for all children, because all children
need to understand allergies and understand that, by washing their hands or not sharing food, they're going to keep
their friends safe.

Ms BELL: How do you think an awareness or training program could be successfully incorporated into food
service outlets—basically, across restaurants, venues, hotels, cafes and across the whole gamut of where food is
served? How do you think a training program or a number of training programs could be implemented across
these spaces? It's quite a huge undertaking, I'm sure you would agree.

Ms Nevard: That's what the All about Allergens and the National Allergy Strategy have already created.
There is a course that people working in food service can go to and learn about that. I'm a parent with a child with
allergies, and we constantly eat out. Every time, we have a battle. I don't know even one restaurant that I can go to
and there's not a problem. There is a particular chain that we go to, and they are very well trained in allergies. But,
even the other day when I was ordering, I said, 'My child has egg and milk allergies, so can you make sure you
change your gloves et cetera when you're preparing his food?' I was looking at what he was putting in, because it
comes up; they have something on their register where you can put in the allergens that the customer has. He
actually made the choice not to put the milk allergy in, because he believed that there was no milk in the
kitchen—even though, obviously, they have cheese, mayonnaise et cetera. The All about Allergens course is there. It's a brilliant course. But, unless it's mandatory, then obviously people working in cafes and restaurants are not all doing it, and everybody needs to be doing it. My focus is in childcare centres and schools.

**Mr ZAPPIA:** Getting back to trying to get through to the schools, I have two suggestions. Have you tried, firstly, seeing if you can get even one school—or two or three—as a pilot school to run the program and then use that as a basis to justify why it works? Secondly, have you tried working through one of the private school organisations and, again, getting them to either adopt the program or, at least, trial it for you? I say that because I recently had an experience with someone who had a different kind of program on a different matter. He went to the private schools, and I think he had pretty good success.

**Ms Nevard:** There are schools—in fact, the school that I've literally just come from did have my programs three years ago. Because I teach prep to grade 3, obviously, they've now moved into the higher school, so they've actually asked me back again to present to prep to grade 3. So there are schools that are using the program, and I do have reviews, but one of the other barriers that exists is the lack of understanding from teachers and principals. Everybody has their EpiPen training, but that's very reactive. They don't understand the seriousness of allergies. To give an example, on Sunday, I met a parent who said, 'My school has just put in hand sanitiser to help everybody wash their hands after eating to help with allergy awareness.' They had to tell the school that hand sanitiser doesn't remove allergens. Having EpiPen training is not enough. The teachers and principals need a greater understanding of allergies. I can give you hundreds of examples of things that have gone wrong in schools. I even meet teachers who don't realise that you can have an anaphylactic reaction to milk. So that's another very big barrier.

Often with the schools that I do go into it is because either their systems have been tested and they've had a reaction and they realise how important it is or they have a personal experience. I've even had teachers who have become parents of children with allergies and they've said, 'It wasn't until I had a child with allergies that I realised just how little I knew when I had students in my class with allergies.' So that's the other really big barrier. Like you say, if I could have a pilot school, that could be promoted, but I do have reviews and child-care centres invite me back year after year. But unless somebody in government says, 'This needs to be mandatory,' it's not going to happen and it's certainly not going to happen in the very schools and centres that are doing the wrong thing.

**Mr ZAPPIA:** You said that the National Allergy Strategy might end up running some similar courses to what you are already doing. Have you tried to work together with Allergy & Anaphylaxis Australia—

**Ms Nevard:** Yes; repeatedly. I have asked Maria Said to work with me to make Thai & Rbbie the educational tool for the whole of Australia and so the whole of the world can use Thai & Rbbie as the educational tool to teach children about allergies, but they very much do their own thing and they obviously have their medical team. All my resources and programs have been checked by a medical team. When I first started this—because it obviously takes a long time to write six books and produce all this work—I had it all checked because I wanted to very much make sure that we are all giving the same messages about how to stay safe.

**Dr FREELANDER:** Thanks for talking to us. We've had some evidence—and not just today—about a certain amount of resistance within the education system to having another health type program being put upon them. Have you found much resistance in the education system?

**Ms Nevard:** Yes, it's like banging my head against a brick wall. That is how it has felt for the last three years.

**Dr FREELANDER:** Is that across Australia, or is that just in Queensland?

**Ms Nevard:** I've obviously been to Queensland and I have been to New South Wales. In fact, when I went to New South Wales I pointed out that their policies for teachers were, at the time I went, about 10 years out of date and still telling teachers about the AnaPen, which we hadn't had in the country for four years. I've also spoken to Victoria, who actually have amazing policies.

Because I am the contact point for hundreds of parents, I have literally hundreds of parents tell me all these horror stories about what's happening in schools. All schools are different. From the stories that the parents tell me, it is almost like the parents are being bullied because they will try to make change and the schools don't want to know, so they are then classed as a problem parent. On Monday somebody commented on my Facebook page that their child has an allergy to apples. Their school decided that the whole school were going to bring in apples and make apple slinkies. If the school were doing proper risk assessments on the activities that they were doing, they would have realised that there was a child with an allergy to apples and they would have chosen another food, because it wouldn't have made any difference to the learning that they were going to have. But that didn't happen.
Dr FREELANDER: I don't want to criticise the education system too much, but it seems to me that what we are doing now is not working. How can we better get the education system, and it is not just the public education system, because I know it is in private—

Ms Nevard: It is both public and private. As I said earlier, the EpiPen training is not enough. It's not the teacher's fault or the principal's fault, because they are simply not given the knowledge on how to manage this. Also, there's no point having different policies in each state. I know that's how it works, but I find it incredibly frustrating. It should be that you get a state like Victoria, which has really good policies, and then we roll that out into every state—if that's working it rolls out.

The thing is that some schools will have policies but they are not necessarily carried through. So that's another issue: you might have the policies in place but, just because it's on paper, it doesn't mean it's happening. A big example of this is relief teachers. Relief teachers in most schools would be given a folder to read before they go into the class, and the folder will have details of any medical information they need to know. In my son's case, we had a relief teacher and I said, 'So you know all about his allergies.' She didn't, because she didn't have time to read that folder. So it's about a simple change to policy. If you have students with any kind of medical condition, not just allergies, that folder needs to be read and something needs to be ticked—to say that you've read that folder—before you go in.

Dr FREELANDER: I think there also needs to be some sort of standardised management plan.

Ms Nevard: Yes, exactly.

Dr FREELANDER: It has been noticeably disappointing with the families that we've been talking to who've even gone to the point of having to homeschool their kids, because of the degree of anxiety about interaction with the school system. It just seems to me that we could be doing things a whole lot better. In saying that, we need to support the schools to develop those policies and not be too critical of them, because they do have lots of pressure put on their curriculum; I know that.

Ms Nevard: Yes. I've thought of literally every barrier that I could possibly come up against. With the online program, for example, and teachers not having enough time—I understand that; they are very busy—every student, at some point in the school year, will have a relief teacher. Often, they are not left with work. I've got my program down to 30 minutes. Every relief teacher can teach this in 30 minutes, whether it be through the pack or through the online system, and it's ticking boxes in their curriculum as well.

CHAIR: I thank you for your evidence today—it's been very helpful—and for your submission. Thank you for what you're doing and for not giving up! Many people would have.

Ms Nevard: Yes, they think I'm mad!

CHAIR: You're dedicated not mad. We'll send you a Hansard transcript of your evidence today. If there are any corrections you need to make to that, please get in contact with our committee secretariat. Thank you, again, for what's been an important contribution to our inquiry.

Ms Nevard: Thank you very much for your time today.

Committee adjourned at 16:06