



## Allergy & Anaphylaxis Australia (A&AA) Annual Report May 2017 – April 2018

Allergy & Anaphylaxis Australia (A&AA) is Australia's leading national patient support organisation for individuals with allergic diseases. As advocates for the allergic consumer, we work closely with the peak medical body, the Australasian Society of Clinical Immunology and Allergy (ASCI) to share up-to-date, evidence-based information to all Australians managing allergic conditions.

Over the last 12 months we have continued to progress the National Allergy Strategy (NAS) in partnership with ASCIA and in collaboration with many key stakeholder organisations that understand and are wanting to work with the National Allergy Strategy to improve allergy care.

A&AA has a passionate Board of Directors who generously share their time, knowledge and expertise. The dedicated Allergy & Anaphylaxis Australia Board continue to have regular meetings to provide governance and strategic advice. Together, we continue to progress our mission: *The trusted charity for allergy support. We listen, guide and educate Australians living with allergic disease. We advocate on their behalf to ensure their voice is heard.*

A&AA has the equivalent of 3.5 full time staff members with the CEO being the only fulltime staff member. We have four part time staff and two casual staff members. We continue to receive considerable IT support free of charge thanks to Jason Ross from EthisEC; website support from Impagination and Clayton Utz remains A&AA's pro bono legal support consultant. We have a small number of volunteers that assist A&AA with graphic design, communications including social media advertising, Arabic translations and packing of resources when we post out resources to schools and child care services.

Our Medical Advisory Board (MAB) consists of seven allergists from across Australia with expertise in both paediatric and adult allergy and immunology. All on the MAB are members of the Australasian Society of Clinical Immunology and Allergy (ASCI) with some being members of the ASCIA Council.

### **National Progress**

#### **Federal Government Funding Support.**

A&AA continues to receive funding through the Health Peak Advisory Body Programme. The three year agreement with the federal government will be up for review in mid-2019. A&AA continues to

provide required reports detailing performance and outcomes to the Department of Health and Ageing according to the reporting schedule.

### **National Allergy Strategy (NAS)**

A&AA and ASCIA continue to progress the National Allergy Strategy, which was launched in 2015. See [www.nationalallergystrategy.org.au](http://www.nationalallergystrategy.org.au)

In June and July of 2017 two new NAS resources were launched.

- 250K website for the two hundred and fifty thousand young people with severe allergy. See [www.250K.org.au](http://www.250K.org.au). This website was developed by teens and young adults between the ages of 12 and 24 years. A Youth Advisory Team was formed after focus groups were held to determine the needs and wants of young people living with severe allergy. Young people communicated they wanted their friends to know about their allergy but they did not want to be the ones educating them about it. They wanted a single go to place for credible information on management of severe allergy. The quirky avatars serve to help young people share their information in an unidentified way with the capacity for animations of signs and symptoms of an allergic reaction and how to give an EpiPen® to be shared with friends. A launch was organised in Sydney where Minister David Gillespie launched the project. Two young people spoke of their experience of living with severe food allergy.
- All About Allergens – free online training for food service staff. After many months of collaboration, a fast, easy and free online training too was developed for food service businesses. This project was launched in July 2017 and the number of people trained to date, and feedback have been great. This e-training is a first step in free education of food service staff with many businesses now mandating the training for all staff. See [www.foodallergytraining.org.au](http://www.foodallergytraining.org.au)

With further funding received in June 2017, the NAS progressed work on a West Australian pilot project to help prevent development of food allergy in childhood. In the lead up to implementation of the pilot project in July 2018 a suite of resources were developed. With engagement of a media company with a focus on health and behavioural change, several focus groups of both parents and health professionals were organised. Based on outcomes from a NAS Infant Feeding Implementation meeting and the focus groups NAS worked on message content and delivery with the plan to roll out the Food Allergy Prevention Project – “Nip Allergies in the Bub” across Australia with further funding the following year. A&AA staff have had an integral role in developing website content, simple messaging, resources etc. A&AA will house a national phone support line to assist parents and health professionals with introducing common allergens before the age of 12 months whilst optimising eczema management.

A&AA has also helped with development of a GP initiated SMS program to share information on introducing food allergens before the first year of life and then monitor for possible allergic reactions. This system is based on the SmartStart information and monitoring system GPs use for vaccinations.

A&AA has also continued to contribute to other NAS projects including:

- Drug allergy
- Food service in Hospitals
- Review of free All about Allergens online training
- Model of Care pilot project in Broome
- The need for a Clinical Care Standard for the management of anaphylaxis in health facilities. The Australian Commission for Quality and Safety in Healthcare have now confirmed this clinical care standard will be developed in 2019.
- My Health Record (MHR) - we continue to work with the Digital Health Agency to make MHR the document of truth for food and drug allergy.
- Developing scripts and filming of videos to assist consumers with food label reading, food preparation and food storage in the home, eczema management, wet dressings and bleach baths.

A&AA knowledge and expertise (as advocates for consumers) has provided the basis for the way forward with the NAS keeping the consumer with allergic disease at the centre of everything we do. A&AA's network of members, contacts and colleagues has allowed us to draw on the knowledge, expertise and good will of many.

### **Membership growth**

A&AA membership has continued to grow since the change to free membership in early 2017. The increase in membership means we have an ever increasing number of people we reach through newsletters, news updates and food recalls. Our affiliation with ASCIA, other important key stakeholders and our partnership in the NAS means we share current, breaking, evidence based information with our membership regularly. This assists us in improving quality of life and for some, increases safety.

As anticipated, making membership free has significantly increased our membership numbers with membership quadrupling in the first year.

### **Member newsletter**

A&AA continues to share bi-monthly electronic newsletters with our membership. The newsletters can be found in the Member only section of the website. We include member stories, recipes, research, important updates, news items and more.

### **Australasian Society of Clinical Immunology and Allergy (ASCIA)**

A&AA has continued to work closely with ASCIA with representation on most working parties and committees. Our aim is to align our messaging (including phone/email support) and educational resources in an effort to decrease confusion on allergic disease and its management in the community.

A&AA distributes ASCIA information to members and non-members at every opportunity through our national newsletters, with postal orders and via social media. ASCIA and A&AA continue to communicate regularly on issues surrounding allergy and anaphylaxis management. A&AA Health

Educators are members of ASCIA and attended the ASCIA conference as part of their professional development.

A&AA was given a complimentary stand at the ASCIA Scientific Meeting in New Zealand in September 2017. A&AA CEO presented on the National Allergy Strategy at the symposium of the Centre for Food Allergy and Research and conducted a workshop showcasing A&AA resources for nurses at the ASCIA Allergy Update.

### **Food Allergy Week (FAW) 14-20 May 2017**

A&AA had a very successful Food Allergy Week in 2017 with our outreach continuing to increase. Our theme for 2017 remained 'Be Aware, Show you Care'. We launched a new animation on signs and symptoms of an allergic reaction, which was very well received by the community. Information on the success of the week, initiatives and outreach can be found in the 2017 FAW Report: <https://allergyfacts.org.au/about/food-allergy-awareness>

### **Coronial investigations**

The coronial inquest into the death of Louis Tate was held in Melbourne in December 2017. Represented by Clayton Utz, A&AA CEO Maria Said was invited to assist the coroner by way of researching current policies, guidelines, procedures for management of acute anaphylaxis in healthcare settings and reporting on adequacy and consistency with best practice. A report was prepared and can be found at the end of the Findings from the Louis Tate coronial inquest. See [https://allergyfacts.org.au/images/Finding\\_into\\_Death\\_with\\_Inquest\\_-\\_Louis\\_Oliver\\_Tate\\_08.05.18\\_web2.pdf](https://allergyfacts.org.au/images/Finding_into_Death_with_Inquest_-_Louis_Oliver_Tate_08.05.18_web2.pdf)

We are grateful to the families that have shared their very personal tragedies with us so that we may learn and continue to strive for optimal care for all.

### **Food Industry**

A&AA has continued to work with food manufacturers, Food Standards Australia New Zealand (FSANZ), the Australian Food and Grocery Council, the Allergen Bureau, Dairy Food Safety Victoria, state government food safety departments, Safer Care Victoria and others to promote food safety for individuals with food allergy. We advocate for Australians with food allergy on working parties and work to increase safer food choices. We do this by representation on working groups, presentations to food industry, compliance officers and consumers and through written submissions such as that on Plain English Labelling.

### **Medication**

- **EpiPen®**

A&AA assisted Mylan with a change on holding time of the EpiPen® once the injection was given. The EpiPen® went from being held in-situ for ten seconds to three seconds with no need to massage the injection site. A&AA assisted with the creation of videos and written materials which were disseminated to consumers and health professionals.

The shortage of EpiPen® 300mcg since November 2017 has greatly impacted individuals at risk of anaphylaxis. A&AA has regularly shared information on the shortage to keep Australians informed of supply. We have also worked closely with ASCIA, the Therapeutic Goods Administration (TGA), Mylan Australia, pharmacists and others to improve access to adrenaline autoinjectors. A&AA reached out to Bausch and Lomb to discuss launch of the already registered Emerade® in Australia and we have also communicated with Kaleo, who sponsor the Auvi-Q® in the United States.

- **Therapeutic Goods Administration (TGA)**

After advocating for people with food allergy through a written submission on labelling of common food allergens in medicines, A&AA informed members that new requirements to label medicines with major allergens will come in to force in August 2020. Pharmaceutical companies have a 4-year transition period to comply with new requirements

## **Research**

A&AA has conducted research into eating out with food allergy to gain insights into member experiences. Findings of this research will be used in materials for the pending 2018 FAW in May.

A&AA often shares information on research for researchers progressing projects to benefit our membership. The research surveys we engaged in and shared via social media have included surveys focused on the psychosocial impact of food allergy, atopic dermatitis and allergic rhinitis. A&AA has also shared information on research studies conducted by allergists and other researchers and helped to recruit patients.

A&AA CEO has been asked to be an associate investigator on several research studies with researchers acknowledging the importance of a consumer advocate being involved in each projects research journey.

A&AA CEO was also invited to CFAR Strategic Planning day for 2017- 2018 and a school management round table to discuss state differences and synergies in management of food allergy in schools across Australia

## **Phone, social media private message and email support**

A&AA continues to provide support for an increasing number of people that make contact either via phone, email, social media or face to face. The national 1300 support line is managed by health professionals trained in the management of allergic disease. The majority of our enquiries continue to be focused on food allergy management however we are receiving an increasing number of enquiries on other allergic conditions including eczema, allergic rhinitis, and insect and drug allergy.

Challenging or more complex calls or emails are forwarded to the CEO who communicates with A&AA Medical Advisory Board as required.

## **Training**

- **Productivity Training:**

All staff underwent productivity training in March 2018 with a focus on Office 365 and email management. We continue to receive the support of Tony Hall from Adapt Productivity to embed this training into our work culture.

- **Social Media Training:**

As we use social media, primarily Facebook, as an educational tool, A&AA staff undertook social media training to assist us with greater reach, optimal design and post content, use of social media tools and gathering of data

## **Cost saving**

- **Telephony:**

A&AA conducted a review of its telephony infrastructure during the financial year and implemented a new PABX system in the cloud, with the support of our IT provider EthiSEC. The new infrastructure has enabled greater flexibility for all staff, including an ability to work flexibly and still be able to receive calls from our 1300 number. The software has enabled A&AA to provide a more modern and sophisticated service to those who reach out to us via the telephone, as well as greater transparency and reporting on incoming and outgoing calls. As a result of this new infrastructure and the ability to utilise the NBN, A&AA has been able to drop call costs by close to \$500 per annum. Ongoing savings are expected, as we better utilise the flexibility within the software solution we have implemented.

- **Insurance:**

A&AA implemented a review of all insurances, to ensure comprehensive and appropriate cover was held to ensure cover for all staff, volunteers and directors for the work that we do. As a result of the review, improved cover was implemented with a cost saving of \$2,170.

## **Media and social media**

A&AA continues to be active in the media and is contacted for media interviews at least 3 times per week. Media personnel almost always contact A&AA for comment as we release a limited number of media statements. This benefits A&AA as we have ample opportunities to raise awareness, inform the community and speak for and empower people living with allergic disease.

A&AA has a Facebook following of 36,202 at the end of April 2018. This is an increase of 8,955 followers over the year. The page is active with staff developing content and managing it closely. This educational tool succeeds in getting important information on a balanced approach to management to the people that need it. A&AA is focused on empowering individuals to manage their condition by seeking appropriate diagnosis and care and then aligning themselves with credible organisations they can trust. Food recalls are promptly communicated through Facebook.

A&AA also has a Twitter platform and Instagram account we hope to grow when we have the capacity to do so.

### **A Snapshot of some other important initiatives:**

Key successes of our continued outreach in the past year have included:

- Attended National Restaurant Conference and Exhibition in Sydney in May 2017. A&AA was an exhibitor and was visited by many working in the food service sector. Free resources were distributed.
- Attended two School Nurses Conferences (NSW and VIC). Free resources were distributed and information on school allergy management was shared.
- Represented consumers at a Centre for Food Allergy and Research (CFAR) round table discussion on management of food allergy in the school setting.
- Three A&AA staff attended ASCIA Conference in Auckland New Zealand in September 2017. A&AA had a complimentary stand for the duration of the conference where A&AA CEO presented on the National Allergy Strategy and was involved in a workshop showcasing A&AA resources to nurses.
- NSW Allergy Update. A&AA attended the update for health professionals at Children's Hospital at Westmead. We had A&AA staff present to answer queries on resources, patient support and information we share. Staff attended the half day seminar as part of professional development. A&AA resources were also made available to attendees.
- A&AA CEO and Health Management Educator presented at two NSW Food Authority organised Retail Food Service Conferences for environmental health officers investigating complaints relating to food allergens.
- A&AA CEO presented three presentations at the second Asian Alliance conference organised in Japan in February 2018.

### **Workshops, presentations, consultation, representation and further outreach**

- International adrenaline availability and emergency response plans survey: A&AA participated in this survey conducted by International Food Allergy and Anaphylaxis Alliance (IFAAA) with input from each member country's Medical Advisory Board.
- Journal of AOAC International: A&AA CEO was invited to co-author a journal article on Food Allergen Management in Australia. See more on AOAC International <https://www.aoac.org/>
- Victual Consultancy: A&AA was invited to be a member of a group of consultants that work together to manage food recalls. A&AA CEO attended the launch and helped create short films to inform food manufacturers about food allergy management. See Victual <http://www.victual.com.au/>.
- School Education: A&AA CEO presented at an independent school on Gold Coast Queensland. Two x 3 hour workshops to help educate food service staff, teachers and parents on allergy and risk management were conducted- 35 people attended each of the

workshops. Separate to the workshops A&AA reviewed existing policies and procedures and provided verbal comment as requested.

- Allergen Collaboration meeting in Sydney: A&AA Health Management Educator presented on the consumer perspective of food allergy labelling in Australia – 25 attended. See more about the allergen collaboration here:  
<http://www.foodstandards.gov.au/consumer/foodallergies/collaboration>
- Approaching Teen Years Workshop: Presenters included a psychologist who works with teens, an allergist, a 15 year old and 19 year old who live with food allergy and A&AA CEO. The film of the presentations can be viewed in the Member's Only section of the A&AA website \* Please note this is a members only resource.
- Australasian Mastocytosis conference in Sydney: A&AA CEO presented on anaphylaxis emergency treatment, anxiety surrounding management and National Allergy Strategy progress – approx. 40 people with mastocytosis attended.
- National Institute of Hospitality in Health Care conference in Adelaide: A&AA CEO presented on allergen management. Approximately 200 people working in hospitality in the health care industry attended the conference
- Australian Hotels Association Food Glorious Food state conference in Adelaide: A&AA was part of a panel discussion on aspects of allergen management in food service – approx. 100 people from the food service sector were present.
- Help Sheets translated into Arabic by an Accredited Translator who works in the health space: Five A&AA help sheets were translated into Arabic and placed on the A&AA website. Help sheets translated were: Parent 10 point plan for school; Top entertaining tips when a guest has food allergy; 5 things you should know about food allergy; Trying to make sense of extreme care versus anxiety; Parent 10 point plan for school. See <https://allergyfacts.org.au/resources/translations>.
- Tonic Health media organised a recording of Dr Norman Swan and A&AA CEO for viewing in approximately 4,000 doctors surgeries across Australia. The film can be viewed at <https://allergyfacts.org.au/resources/links/food-allergy-week>
- A&AA presented on a Food Allergen Fundamentals webinar, the first of a series of three webinars organised by the Allergen Bureau and AusIndustry. This webinar's target audience is food manufacturers, regulators, auditors, food analysts and anyone involved in the manufacture and distribution of packaged food. This webinar is available here: <http://allergenbureau.net/resources/conference-presentations/2018-conference-presentations/>
- A&AA presented general community allergy information sessions at Baulkham Hills and Dural libraries.
- A&AA worked with WA School Canteen Association to develop posters and information materials to assist with food allergy management. As this material is freely available online we share links nationwide. <http://www.focis.com.au/resources/>

<https://www.waschoolcanteens.org.au/canteens/foodallergy/>

- Online advertising of opportunities for consumers and health professionals to learn about allergy management e.g. University of South Australia allergy nurse course, Nurses Allergy Update at Children's Hospital at Westmead, Oral Immunotherapy round table at Centre for Food Allergy and Research, recruitment of patients for research studies, sharing of numerous surveys including one on reactions to foods with precautionary allergen labelling

### **Resource development and distribution:**

- A&AA has distributed more than 40,000 250K bookmarks free of charge to secondary schools to help educate teens with severe allergy and their friends about food and insect allergy management. During FAW, we released a Signs and Symptoms animation clearly communicating the signs and symptoms of a mild to moderate allergic reaction and those of a severe allergic reaction/anaphylaxis.
- Distributed 4,000 signs and symptoms posters free of charge to secondary schools across Australia with the 250K bookmarks.
- Created packs as part of NSW Kids GPS project. Those attending low risk food challenges in St George and Sutherland Hospitals were given either pack A or pack B depending on whether their child reacted to or tolerated the food.
- We partnered with Murdoch Children's Research Institute to develop content of an Application titled Allergy Pal. This app can be downloaded by parents of children with food allergy who can then add their child's details and ASCIA Action Plan. The app can then be shared with carers of the child. Parents and carers can also tap on a sign or symptom a child may be displaying and the app directs you to instructions on what to do following instructions on the ASCIA Action Plan. See <https://allergyfacts.org.au/resources/apps>

### **International Associations**

International Food Allergy and Anaphylaxis Alliance (IFAAA) and European Academy of Allergy and Clinical Immunology (EAACI), Asian Alliance Food Allergy & Anaphylaxis (AAFAA)

A&AA's CEO remains a committee member of both the IFAAA and the EAACI Patient Organisation Executive Committee and a Forum member of Asian Alliance of Food Allergy and Anaphylaxis (AAFAA). Organisations share information on best practice in an effort to improve quality of life of those with allergic disease. A&AA CEO was sponsored by the American Peanut Council, the Nippon Foundation and Mylan to attend and present at two international conferences. The information learnt is then shared and used to help further promote allergy awareness, management and research in Australia.

### **Conclusion**

Allergy & Anaphylaxis Australia has succeeded in continued growth and extended outreach to support those living with allergies. We advocate for people with allergic disease in an effort to

improve their quality of life. People living life with often multiple chronic allergic diseases that for the most part, have no cure. These people need access to credible information to assist them in living life with their allergy, rather than for their allergy. The need for ongoing care outside the doctor's consulting room, especially for those with complex or moderate – severe allergy is real. We remain the trusted voice for Australians and progress allergy care and support with many other key partner organisations keeping the health and wellbeing of the consumer as the focus of what we do.

We continue to make ourselves available as consultants and advocates with knowledge and long standing expertise in allergy management. Our work in the allergy management space helps to reduce the burden of allergic disease on individuals and their family, on the healthcare system, workplaces, schools, food industry and more.