



Allergy & Anaphylaxis Australia (A&AA) Annual Report

May 2018 – April 2019

Written by Maria Said

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

We continue to progress the National Allergy Strategy (NAS) in partnership with ASCIA and in collaboration with many key stakeholder organisations.

A&AA has a dedicated Board of Directors who generously share their time, knowledge and expertise to progress our mission and vision. The dedicated Allergy & Anaphylaxis Australia Board continue to have regular meetings to optimise governance and provide strategic advice.

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 (ASCIA) with some being members of the ASCIA Council.

A&AA has the equivalent of 4.4 full time staff members with the CEO being the only fulltime employee. We have five part time and two casual staff members. We continue to receive considerable IT support free of charge from EthiSEC and website support from Impagination. Clayton Utz generously continues to be A&AA's pro bono legal support consultant. We have a small number of dedicated, very capable volunteers that assist A&AA with various projects.

A&AA continues to draw information from our members, our social media followers, its 1300 helpline, and website and email communication to engage and then compile feedback on matters that inform our consultations with the Australian Government and development of resources. We continue to work toward optimal care of individuals living with allergic conditions including atopic dermatitis, allergic rhinitis, allergic asthma, food, insect and medication allergy. We also continue to pursue improved food allergen labelling, access to in-date adrenaline autoinjectors and other priority needs.

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 was extended with no increase (including no consumer price index [CPI] increase) for another three years and will begin from 1 July 2019. A&AA has continued 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. A&AA CEO is co-chair of the National Allergy Strategy, providing consumer driven direction for this Department of Health funded project. Several consumer representatives are on the NAS Steering Committee and A&AA consumer representatives' co lead/deputy lead the various projects.

In August 2018 the pilot Food Allergy Prevention Project was launched in Western Australia. An [inviting website](#) and engaging campaign were developed to help Australians "Nip Allergies in the Bub". With information for both consumers and health professionals, the website has been well utilised even during this pilot phase. A&AA, through the NAS, have presented this food allergy prevention project to both health professionals and consumers. The project encourages the early introduction of common food allergens and optimal eczema care. It is based on research which shows that these two strategies can help to prevent development of food allergy in infants. We have also distributed posters and bookmarks promoting the project to healthcare facilities who provide information to consumers across Australia. A&AA hosts the infant feeding 1300 66 13 12 consumer and health professionals help line and responds to emails from the Nip Allergies in the Bub website. This is in addition to the general 1300 728 000 A&AA support line.

A NAS Food Allergen Forum brought key food service organisations together to assist us in determining what further resources on food allergy management were needed by back of house food service staff. This meeting and then a round table half day meeting with a group of eight chefs helped us progress 'Food Allergen Training, the next steps for cooks and chefs' which is planned to be launched in July 2019. Online training for cooks and chefs in general food service establishments will be launched as well as a separate training program for those working in food service in camp facilities.

A NAS national anaphylaxis register/ data capture meeting was held in Melbourne in March 2019. State health representatives, A&AA, ASCIA members and other key stakeholders met to discuss the potential of a data capturing system that would allow us to improve knowledge of severe allergic reactions and fatalities, help us learn how to increase safety, improve quality of life and importantly reduce risk of preventable deaths in Australia. The reporting system that was legislated in Victoria and began in November 2018 was discussed at length.

A meeting to discuss a shared care model for medical management of people with allergic disease was progressed in December 2018. The meeting, part of a scoping project funded by the Australian Government Department of Health, engaged many key stakeholders including but not limited to

organisations such as the Royal Australian College of General Practitioners (RACGP), Australian Paediatric Society and consumers with allergic disease from both rural and remote areas.

The first NAS 250K youth camp was held in Western Sydney at Yarramundi in January 2019. The camp aimed to bring teens and young adults with severe allergy together to learn from experts and each other. As project lead, A&AA CEO joined 30 campers, aged from 11-23, on the camp alongside 9 National Allergy Strategy staff and volunteers. This was the first face to face meeting of some members of the 250K Youth Advisory Team. Despite the scorching temperatures (45°C!) campers participated in all of the planned fun activities including a learning session on food allergy management lead by a clinical immunology and allergy specialist, an allergy nurse and an allergy dietitian. Seventeen meal times over the duration of the three night camp and a total of 21 different food allergies were catered for without incident.

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

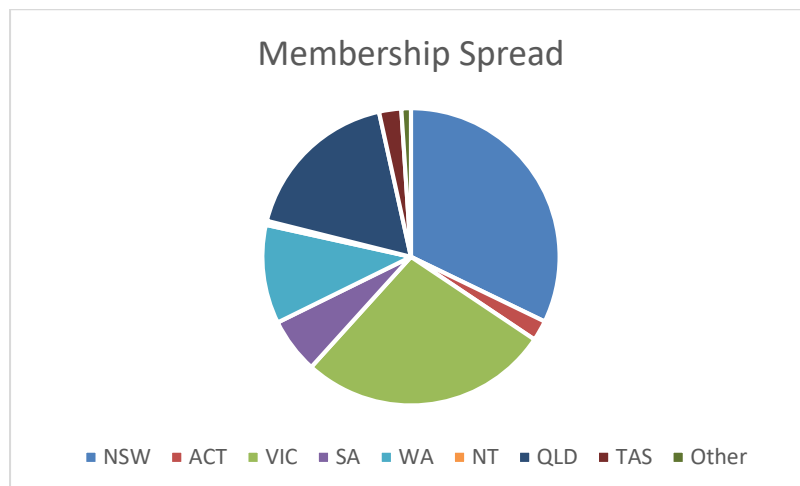
- Drug allergy
- Food service in Hospitals
- Progress with a Clinical Care Standard for the management of anaphylaxis in health facilities.
- My Health Record (MHR) - we continue to work with the Digital Health Agency to make MHR the document of truth for food and drug allergy.

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.

More information on the work and outcomes of the National Allergy Strategy is available on the [website](#).

Membership growth

As anticipated, making membership free has continued to significantly increase our membership numbers with membership increasing by approximately 40% during this reporting period. As of 30th April 2019 A&AA's membership was 4,509.



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 news items, research, important updates, new resource information, member stories, recipes and more. The open rate for our emailed member newsletters during this period averaged 35-40%.

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 for 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 e-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 in September 2018 as part of their professional development.

A&AA was given a complimentary stand at the ASCIA Scientific Meeting in Canberra in September 2018. A&AA CEO presented on the National Allergy Strategy and the work of A&AA at the conference and the Allergy Update for nurses working in the allergic disease space.

Food Allergy Week (FAW) 13-19 May 2018

A&AA had a very successful Food Allergy Week in 2018 with continued increase in our outreach. Through our theme BE AWARE SHOW YOU CARE we were successful in increasing awareness through 306 FAW media stories with more than 21 million Australians having the opportunity to read information on food allergy. We gained 299 new members and had 1,143 new Facebook followers through FAW. A 36% increase in FAW website users compared to 2017 shows more people are accessing our credible information and resources.

Coronial investigations

A&AA was asked to provide three separate reports on three coronial investigations in Victoria. The requested reports answered a series of questions asked by the coroners after three fatal allergic reactions, two as a result of food purchased in the food service sector and one as a result of a packaged food. A&AA is recognised as a credible, evidence based organisation and therefore asked for expert information, opinion and advice when attempts are made to understand fatalities as a result of anaphylaxis.

Food Industry

A&AA continues to advocate for Australians with food allergy and works to improve food labelling and increase safer food choices. We also work to improve consumer education around safer practises when eating away from home and continue to share information and develop resources to assist the food service industry. We do this by representation on working groups, face to face and

online presentation opportunities and development of resources to assist consumers, compliance officers, food service staff and anyone needing to manage food safety around food allergy.

A&AA lodged a submission to FSANZ on Plain English Allergen Labelling (P 1044) in May 2018. A member survey assisted A&AA with our responses to questions asked. See submission [here](#). We also reviewed the Australian Food and Grocery Council and Allergen Bureau [Food Industry Guide to Allergen Management and Labelling](#) and assisted the Allergen Bureau with information on a [risk anomaly associated with dark chocolate](#). Many consumers believe that dark chocolate does not contain cow's milk however, reactions have occurred because of the difficulty in cleaning manufacturing lines when making dark chocolate after milk chocolate. A&AA supported the suggested inclusion of milk as a last ingredient on dark chocolate rather than a precautionary allergen statement which many consumers now ignore.

A&AA continues to alert consumers with food allergies of food recalls. In this reporting period there were 37 allergen related food recalls that included removal of some 70 products from the Australian market place. These food recalls were communicated to all A&AA members and social media followers in a timely manner via A&AA's social media platforms, website placement as a Food Alert and email to all registered members in a timely manner.

A&AA represents consumers on the Allergen Collaboration, which is a collaboration between Food Standards Australia New Zealand (FSANZ), retailers, food manufacturers, food service organisations, NSW Food Authority, the Allergen Bureau, the Food and Beverage Importers Association, consumer organisations and other bodies. It meets to explore non-regulatory measures that can improve the management of food allergens and help direct Australians to credible online resources. A&AA is consulted on issues specific to food allergen labelling and food allergy management in food service. A&AA attended a face to face meeting as well as teleconferences during this period.

A&AA forwarded a submission to CODEX Alimentarius asking that they expedite investigation and global advice on precautionary allergen labelling i.e. May contain warning statements. The international alliance (International Food Allergy and Anaphylaxis Alliance) also forwarded a co-signed submission from almost twenty countries.

Mandatory Reporting in Victoria

A&AA welcomed the launch of legislation requiring mandatory reporting of anaphylaxis presentations to hospital emergency departments through the Victorian state government anaphylaxis notification scheme. The reporting system came into effect in November 2018 as a result of food containing an undeclared food allergen being in the market place for some 6 weeks after causing the fatal anaphylaxis of a 10 year old Victorian child in December 2013. The food was not recalled until A&AA was made aware of the death, contacted the distraught family and reported the imported coconut drink. The investigation process did not begin until weeks after the child's death when it should have begun when the child presented with anaphylaxis to the hospital emergency department. See here for [more information about the Victorian Anaphylaxis Notifications Scheme](#).

Medication

EpiPen®

A&AA continues to share information, educate and support people prescribed adrenaline autoinjectors in Australia. The only available brand in Australia is EpiPen®. We share information on signs and symptoms of anaphylaxis, the ASCIA Action Plan and use of the EpiPen® widely through email, website, social media, presentations and almost all activities when speaking about severe allergy management and risk of anaphylaxis. We use any and every opportunity to demonstrate administration of the device according to instruction on the ASCIA Action Plan as we continue to advocate for adrenaline autoinjectors for general use in public places such as clubs, hotels, schools, children's services, camp/sporting facilities and more.

A&AA worked with Mylan Australia, the distributor of EpiPen®, the Australasian Society for Clinical Immunology and Allergy (ASCIA), the Therapeutic Goods Administration (TGA) and others to keep consumers informed about the ongoing shortage of EpiPen®.

The shortage of EpiPen® 300mcg from November 2017 through to approximately June 2018 greatly impacted individuals at risk of anaphylaxis. A&AA regularly shared information on the shortage to keep Australians informed of supply progress. We also worked closely with ASCIA, the TGA, Mylan Australia, pharmacists and others to improve communication on the shortage and the processes put in place to access EpiPen®s. A one off shipment of Emerade under a TGA section 19A approval did not proceed because Mylan Australia then communicated supply shortage was lifted.

A&AA and ASCIA met with Bausch and Lomb to discuss launch of the already registered Emerade® in Australia. A&AA also communicated with Pfizer Australia about EpiPen® shortages and Kaleo, who distribute Auvi-Q® in the United States.

New legislation requiring companies to report medication shortages of reportable medicines was introduced in early 2019. A&AA had forwarded a submission to the TGA about this issue on the eve of this reporting period in April 2018.

Research

A&AA has conducted A&AA member and social media follower research into eating out with food allergy to gain insights into member experiences, on subject areas for webinars and food allergen labelling. Findings of the research surveys assist A&AA with project development to ultimately help improve the quality of life of Australians with allergic disease.

A&AA often shares information on ongoing research and published research, conducted predominantly by researchers through the Centre for Food Allergy and Research (CFAR), to benefit our membership and social media followers. A&AA has also shared information on research studies conducted by allergists and other researchers and continues to assist with patient recruitment.

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 research project journey in the development phase.

A&AA staff also attended the annual Centre for Food and Allergy Research (CFAR) retreat in February 2019. The topic was Food Allergy Prevention – beyond early exposure. The A&AA CEO participated in several panel discussions.

A&AA CEO is supervising a PhD student at the University of Western Australia who is doing research of anaphylaxis registers globally.

Phone, social media private message and email support

A&AA continues to provide support for people that make contact either via phone, email, social media or face to face. On average we receive 1,100 requests for support per month (emails, phone calls, private messages via social media). All requests for information and support are 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.

Media and social media

A&AA, alongside phone and email support, continues to provide evidence based, best practise advice and information on living with allergic disease primarily through the website and social media platforms - Instagram, Twitter and Facebook. At the end of the reporting period A&AA had over 47,000 followers on social media.

A&AA CEO has had at least 120 media interviews in this reporting period. As the lead patient support organisation in allergic disease, A&AA is often called on for comment on news items/articles related to allergic conditions. These include TV, radio, print and online media for the community, health professionals, food industry and others.

A Snapshot of some other important initiatives:

A&AA has worked with pharmaceutical company Bayer to notify consumers about the Novalac Allergy infant formula shortage (a rice based formula given to babies with cow's milk allergy) and has advocated for improved access to the formula for those in need.

A&AA attended a workshop on a new treatment for those with food allergy, which is anticipated to be coming to Australia in the near future. As we are the hub for credible information on allergy management, we (health professionals within A&AA) need to be upskilled on new treatments for food allergy.

A&AA CEO was invited to be on an Allergic Rhinitis expert panel alongside respiratory and ear nose and throat specialists to help increase the awareness of allergic rhinitis diagnosis and management in the community. A&AA then participated in an allergic rhinitis campaign to help communicate the need for doctor diagnosis rather than over the counter medication without medical advice/formal diagnosis.

A&AA conducted an awareness campaign to educate consumers about atopic dermatitis/eczema. This campaign encouraged those with difficult to manage atopic dermatitis to see a dermatologist and make contact with A&AA for support and information on management.

A&AA conducted a webinar held on 13 March 2019 on “Food Allergy Treatments – where are we at?” This webinar was presented by Dr Paxton Loke, an allergist from the Royal Children’s Hospital in Melbourne. Participants were given an opportunity to ask questions after the webinar presentation. Dr Loke then developed a Q&A for consumers on the topic, which is housed with the webinar as an ongoing resource on the A&AA website here: <https://allergyfacts.org.au/resources/webinars/food-allergy-treatments>

A&AA, with the NAS, presented at a ‘Managing Food Allergy and Eczema’ consumer information evening at the Perth Children’s Hospital in March 2019. Two teens (who attended the NAS 250K youth camp) and their parents were part of a panel discussion on teens and food allergy management.

A&AA had an information and resources stand at the Children’s Hospital at Westmead and also attended the annual Paediatric Allergy Update at the hospital as part of professional development in September 2018.

A&AA shared information on A&AA and NAS resources with nurses in attendance at the ASCIA conference in September 2018.

A&AA continued to encourage uptake of the Allergy Pal application to assist individuals and families with food/insect allergy management and emergency treatment. The Allergy Pal app has now been downloaded by more than 10 000 users. We continue to work with MCRI to improve usability and increase downloads of the application.

A&AA attended WA School Canteen conference to promote A&AA membership and resources available to school canteens.

ASCIA and A&AA CEOs met with ACECQA (Australian Children’s Education and Care Quality Authority) to discuss food allergy management in childcare settings after numerous reported anaphylactic reactions in childcare where children were given the food they were allergic to.

A&AA lodged a submission to the Pharmaceutical Benefits Advisory Committee (PBAC) on Pharmaceutical Benefits Scheme (PBS) listing of Dupilumab for adults with severe atopic dermatitis whose lives are greatly impacted. This new medication used on compassionate grounds in Australia is making a significant difference to the lives of many.

A&AA CEO attended PharmAus day at Parliament House in Canberra and then joined the Medicine’s Australia breakfast the following morning.

Meetings commenced in preparation for a new Allergy Show and co-located Free From Show in Melbourne and Sydney 2019. The shows aim to bring together product and service providers and consumers under one roof and to promote credible brands serving the allergy community. As the platinum sponsor for 2019 A&AA is managing the Learning Centre where we will invite allergists,

legislators and other to present on hot topics to help promote accurate information, dispel myths and promote best practice.

Workshops, presentations, consultation, representation and further outreach

- A&AA presented on challenges of living with food allergy to the Australian Paediatric Society Allergy Masterclass held 16 February 2019 – 80 paediatricians in attendance.
- A&AA presented at two NSW Food Authority, Food Regulation Partnership Retail and Food Service Information Sessions. One event for food businesses was held in Griffith and the other in Camden.
- A&AA, through the NAS provided pilot face to face training in food service allergen management to cooks and chefs at Melbourne Convention Centre and Mitcham Private Hospital.
- A&AA CEO presented in Japan to the Asian Alliance on Food Allergy and Anaphylaxis on allergen management in food service and food allergy prevention in April 2019 - 75 attendees.
- A&AA, through the NAS, conducted an education session for cooks and chefs working in aged care facilities in Melbourne.
- A&AA CEO was the consumer representative invited to present to a worldwide audience (numbers unknown) on a World Allergy Organisation webinar held during World Allergy Week (12 April 2019). The webinar covered the topics of food allergy, allergy prevention, treatment and accurate diagnosis. The World Allergy Organisation is a world federation of allergy, asthma and clinical immunology societies. See <https://www.worldallergy.org/resources/world-allergy/2019>.
- A&AA staff attended the Centre for Food and Allergy Research day and ASCIA conference in Canberra in September 2018 to continue to maintain current knowledge of allergy research and best practice.
- A&AA presented and had a stand at the National Institute of First Aid Trainers conference in Sydney (August 2018).
- A&AA CEO presented to 30 health professionals on “Living with peanut allergy: the patient and care-giver’s perspective in Australia” at DBV Technologies dinner in September 2018.
- A&AA CEO presented on the National Allergy Strategy at Centre for Food Allergy and Research conference in Canberra. 120 health professional attendees. CEO sat on numerous panels during the conference day in September 2018.
- A&AA CEO presented on food allergy management in food service and 250K teen project to 30 health professionals that attended ASCIA dinner meeting in November 2018.
- A&AA was involved in and presented at two allergen education workshops at Mondelez. Audience: staff, production, management, marketing, regulatory and safety etc.
- Through the NAS, A&AA conducted training of food service staff and camp staff at Yarramundi YMCA camp site. Two workshops were conducted and others from surrounding camp facilities attended in December 2018

Resource development and distribution:

A&AA has created and distributed many resources throughout the 12 month period. Resources created include:

Home alone help sheet <https://allergyfacts.org.au/allergy-management/emergency/alone-anaphylaxis>

Our hard copy “Preparing for camp with food allergies” was updated and converted to an e-book <https://allergyfacts.org.au/resources/e-books/preparing-for-camp-with-food-allergies>

Atopic dermatitis brochure – <https://allergyfacts.org.au/allergy-anaphylaxis/eczema-atopic-dermatitis>

Halloween posters and help sheet <https://allergyfacts.org.au/resources/posters/halloween-food-allergy-friendly>

Food for a long haul flight help sheet
https://allergyfacts.org.au/images/pdf/Food_for_a_long_haul_flight_with_allergies.pdf

Urticaria – e-brochure https://allergyfacts.org.au/images/pdf/Urticaria_Hives_Brochure_2018.pdf

Urticaria information for the A&AA website <https://allergyfacts.org.au/allergy-anaphylaxis/urticaria-hives>

Conclusion

Allergy & Anaphylaxis Australia has succeeded in continued growth and extended outreach to support those living with allergies. We advocate for 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 allergy management helps to reduce the burden of allergic disease on individuals and their families, on the healthcare system, workplaces, schools, food industry and more.