



Allergy & Anaphylaxis Australia (A&AA) Annual Report

May 2016 – April 2017

Written by Maria Said (August 2017)

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 (ASCIA) 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 in partnership with ASCIA and in collaboration with many key stakeholder organisations that understand the need to improve allergy care.

A&AA's is proud to say we have a Board of Directors who generously share their time, knowledge and expertise to ultimately improve the quality of life of those with allergic disease. The Allergy & Anaphylaxis Australia Board have had monthly scheduled meetings over this last year and continue to review and improve our remit to support and improve quality of life of Australians with allergy. We continue to consolidate policies and procedures, compliance, finances, sponsorship and sustainability. The Board assists A&AA to uphold the public trust Australians have in the organisation that has now grown over almost 25 years.

A&AA acknowledges Board members, Ms Anna Burke, Ms Kathleen McLean, Mr William Porter, Ms Debra Savage and Associate Professor Richard Loh who work alongside CEO Maria Said and all dedicated office staff. We are grateful to the Board for giving up their time and importantly for sharing their experience and knowledge to assist us in furthering the mission and the goals of the organisation.

Geraldine Batty who joined the organisation as a member, then became volunteer Treasurer of A&AA in 1999 and was then employed by the organisation until she went in to semi-retirement, leaving A&AA in Dec 2016. A&AA was run from Geraldine's home for some years before we moved into office space in Hornsby in 2007. We thank Geraldine for her contributions to the organisation over so many years.

In March of 2017, A&AA employed Karen Wong as Operations Manager in a part time capacity. Health Management Educator, Jody Aiken continues in her part time role as do Vicki Hawkins, our Bookkeeper and Joanne Adams, Office Assistant. At present, the CEO is the only A&AA employee employed full time. Since July 2016, Debra Savage, Director, long term member and volunteer with A&AA now works in the capacity of Health Educator on a casual basis as required.

We continue to receive considerable IT support free of charge thanks to Jason Ross from Ethisec and Clayton Utz remains A&AA's pro bono legal support consultant. We have some trusted, very giving volunteers that assist with A&AA representation in other states, graphic design, Arabic translations and packing of resources when we post out resources to schools.

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

National Progress

Federal Government Funding Support.

A&AA continues to receive funding through the Peak Health Advisory Body Programme. The three-year agreement with the federal government will be up for review in 2019. A&AA continues to provide required reports detailing performance and outcomes to the Department of Health according to the reporting schedule.

Sponsorship

The charity receives sponsorship from several supporters. The work of the organisation could not be progressed without their ongoing support. Whilst we accept funding from private donors and industry sponsors, the mission of the organisation, including resources development progress independent of sponsor input. Sponsors are acknowledged as per individual agreements. Current sponsor logos appear on the A&AA website www.allergyfacts.org.au, the Food Allergy Week website www.foodallergyaware.com.au and/or specific resources developed as per agreement.

A&AA sponsorship policy can be reviewed at <https://allergyfacts.org.au/about/who-supports-us>

National Allergy Strategy

In August 2015, as partners, A&AA and ASCIA – Australasian Society of Clinical Immunology and Allergy (the peak medical body) launched the National Allergy Strategy. See <https://www.nationalallergystrategy.org.au/>

In May 2016, the then federal Minister of Health, Sussan Ley announced funding to progress three specific areas of the National Allergy Strategy, which was launched in August 2015. The projects focus on drug allergy management, improving allergy management for teens and young adults and allergy management in the food service sector.

A&AA has spent considerable time and resources in progressing particularly the food service and teen and young adult projects with Richard Loh and Maria Said as co-chairs and Sandra Vale as the National Allergy Strategy Coordinator. A teen survey and focus groups have assisted us in the creation of resources for teens, by teens. The teen website <https://250k.org.au/> and other resources will be launched in June 2017. The food service training which is to be fast, easy and free for food service staff to complete is planned to be launched in July 2017 at <https://foodallergytraining.org.au/> Both of these projects have required an enormous amount of input. A&AA's knowledge and expertise in both areas has provided the basis for the way forward. A&AA's network of colleagues and members has allowed us to draw on the knowledge and expertise of many.

Alongside the National Allergy Strategy we continue to assist the Australian government in appropriate management of individuals with allergic disease. 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 etc.

Change in membership structure/New website

A&AA changed our model of membership from paid membership to free membership in early 2017. The change has meant a rapid increase in membership, affording us the ability to reach more people with credible, up to date information.

This change coincided with the launch of a new website in Feb 2017. The information dense website houses a "Members only" section which contains newsletters from previous years, free member only resources including a downloadable children's story book A&AA co-authored with The Wiggles and a Dummies publication for those newly diagnosed with food allergy. The Kids Food Allergies for Dummies e-book provides trusted information for parents in the early years of management. Whilst this resource has been placed in our members' only section, membership is free so it is available to all who take the time to join A&AA.

A&AA will continue to increase membership. Members are reminded they can 'opt out' after a five year period. As anticipated, free membership has significantly increased our membership numbers. Members include individuals, parents, extended family members, school and childcare staff, first aid providers, health care professionals, government employees and more. Increased member numbers will provide A&AA with greater opportunities to meet the needs of those living with allergic disease by being able to contact them directly with current and breaking allergy news that has the potential to increase safety and quality of life.

Member newsletter

The final printed version of the A&AA NewsFacts newsletter was sent to members in December 2016. Since that time, an electronic newsletter was sent to members in April 2017 with good response. The plan is for A&AA to send out more frequent shorter newsletters to its increasing number of members.

Australasian Society of Clinical Immunology and Allergy (ASCIA)

Alongside our partnership on the National Allergy Strategy, A&AA has continued to work closely with ASCIA on the development and revision of existing educational resources. We aim to align our messaging (including phone/email support) and educational resources in an effort to decrease confusion on allergic disease and its management. A&AA worked with ASCIA in producing information for the National Prescribing Service MedicineWise Choosing Wisely initiative. We also provided input to ASCIA's infant feeding advice and lupin allergy information to name just two of the resources created with A&AA (representing allergic consumers) input.

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 education staff remain members of several ASCIA working parties/committees.

A&AA was again given a complimentary stand at the ASCIA Scientific Meeting on the Gold Coast in September 2016. A&AA presented two presentations at the ASCIA Allergy Update.

Food Allergy Week (FAW) 14-21 May 2016

A&AA had a very successful 2016 Food Allergy Week with our outreach continuing to increase. Our theme for 2016 remained 'Be Aware, Show you Care.' Information on the success of the week, initiatives and outreach can be found in the 2016 FAW Report <http://www.foodallergyaware.com.au/highlights-of-food-allergy-week-2016/>

[Sponsors of 2016 FAW are acknowledged on the above report.](#)

Coronial investigations

The report on the death of Ronak Warty who died in Dec 2013 after a sip of a drink (imported canned 'Natural Coconut Drink' that was found to contain undeclared cow's milk as an ingredient) was released without inquest in June 2016. A&AA assisted both NSW Food Authority and the coroner with the investigation. Recommendations have been made to increase safety for individuals with food allergy and those that care for and/or about them. The Findings and Recommendations can be found at <https://allergyfacts.org.au/news-alerts/coronial-enquiry>

A&AA has also written to the Coroner in Victoria requesting involvement in the investigation into the death of Louis Tate. A date for the probable coronial inquest has not yet been set. There will be another mention hearing organised once further reports from experts are received.

We are grateful to the families who 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 working group, facilitated by the Australian Food and Grocery Council was established in November 2016 to look at reasoning behind the recall of some 26 coconut products in late 2015 after the death of Ronak Warty in Dec 2013. The Coconut Recall Round Table included regulators, retailers, importers, food analysts, government, A&AA and others. A decision was made to continue the work of this group to assist industry and increase safety moving forward. This working group amongst others is testament to the fact that key organisations in Australia understand the need for food allergy to become part of all food safety practices.

A&AA lodged several submission to Food Standards Australia New Zealand (FSANZ) advocating for the needs of individuals with food allergy. The proposals put forward include discussion on lupin as an allergen and exemptions of some allergens shown to be below the thresholds that trigger allergic reactions.

Allergy & Anaphylaxis Australia also submitted a proposal to the Productivity Commission Review of the Regulation of Agriculture on the need to consider those with wheat allergy as well as individuals with coeliac disease when making a decision on gluten free labelling.

Medication

Therapeutic Goods Administration (TGA)

A&AA has worked with the TGA to share information on use of the word epinephrine which is now the accepted international term rather than use of the terms adrenaline and epinephrine. Whilst the term adrenaline is still the preferred term by healthcare professionals in Australia, documentation must also include the term epinephrine.

After last year's submission to the TGA on inclusion of common food allergens on medication labels we are pleased to announce a decision was made to make this change. A&AA has worked with the TGA to develop suitable materials for both the TGA website and for consumers on the change, which has been welcomed by people with allergies to common food allergens.

In March 2017, A&AA communicated information on the EpiPen recall of devices with an expiry date of April 2017. A&AA also assisted Mylan with the development of information, including film, to communicate the changes in administration of the EpiPen to individuals with allergy, their family, carers, first aid providers and the like.

Research

Whilst A&AA has undertaken very little research we continue to work with researchers nationally and internationally. A&AA took part in an international survey on adrenaline autoinjector availability with findings yet to be published. CEO of A&AA has also been invited to be an associate investigator on several research projects including drug allergy, adrenaline autoinjector carriage and storage in Australia, knowledge and barriers to allergy management in teens, introduction of common allergens to infants at around 6 months and others.

A&AA also reviewed, provided comment and was included as associate investigator on the Centre for Food Allergy and Research (CFAR) National Health and Medical Research Council (NHMRC) Centre of Research Excellence (CRE) application. A&AA's CEO was also invited to CFAR Strategic Planning day for 2016- 2017 as well as other round table discussions including an infant feeding round table which lead to a consensus paper on infant feeding being developed in readiness for the National Allergy Strategy Infant Feeding Implementation Meeting held in March 2017.

Phone 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 are about food allergy management, however, we are getting more enquiries about management of other allergic conditions including eczema, allergic rhinitis, insect and drug allergy.

Many individuals contact us at times of crisis including when there is a communication breakdown, an allergic reaction (mostly severe allergic reaction/anaphylaxis), someone is newly diagnosed, and food needs to be reported to health authorities, delay in getting a specialist appointment and confusion or lack of information about management.

We have a small number of trained staff answering our phone lines and responding to emails in an effort to maintain consistency in our communications. Challenging or more complex calls or emails are forwarded to the CEO who communicates with A&AA Medical Advisory Board when required. Phone support staff attended several professional development sessions to ensure information they share is current. A&AA acknowledges the support Mylan in the USA for unrestricted funds to assist with phone and email support.

Media and social media

A&AA is contacted for media interviews almost daily. Our close working relationship with ASCIA and with consumers with allergic disease means we can be confident our messaging is evidence based, current, consistent and reflects consumer needs/concerns. Media personnel almost always contact A&AA for comment because they have A&AA's CEO listed from previous media stories. This benefits A&AA as we do not have to reach out to media for an awareness raising story.

A&AA has a Facebook following of thirty two thousand individuals/organisations. 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. We often share posts about allergy management and emergency treatment that are sometimes missed or not addressed during a medical consult. 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. A&AA also has an active Twitter platform and Instagram account.

A snapshot of some other important initiatives:

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

- A&AA representation on the Victorian Paediatric Clinical Network, Anaphylaxis Expert Group, which researched management of acute anaphylaxis in Victoria healthcare facilities and provided a report to VIC Chief Medical Officer.
- Updated NSW Food Authority and A&AA booklet titled "Be Prepared. Be Allergy Aware" for food service staff in all NSW food service facilities. The booklet and poster were printed and distributed through local councils.
- Attended National Restaurant Conference and Exhibition in Sydney in May 2016. A&AA CEO presented on food allergy management in food service and an exhibition stand was visited by many working in the food service sector. Free resources were distributed.
- Attended a two day School Nurses Conference that is attended by school nurses along the Australian east coast. Free resource 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 infant feeding at the Murdoch Children's Research Institute in May 2016. At this meeting the National Health Medical Research Council, Dieticians Association of Australia, Australian Breastfeeding Association, ASCIA, A&AA and CFAR met and agreed on guidelines for infant feeding. The new guidelines take into account recent evidence supporting early introduction of allergens such as cooked egg and peanut paste to help decrease the incidence of food allergy. These consensus guidelines are now being used by all organisations and can be found on the ASCIA website.
- Four A&AA staff attended ASCIA Conference on the Gold Coast in Sept 2016. A&AA had a complimentary stand for the duration of the conference where A&AA CEO presented on three different subject areas around food allergy and its management.
- Attended and sometimes presented at several National Allergy Strategy initiatives including the Food Service Forum, Infant Feeding Implementation Meeting, and Penicillin Allergy Meeting.
- NSW Allergy Update: A&AA attended the update for health professionals at Children's Hospital at Westmead. A&AA staff presented and answered queries on resources, support and information we share. Staff attended the ½ day seminar as part of professional development. A&AA resources were also made available to attendees.
- A&AA continues to work with NSW Health on the Kids GPS – Integrated Care Project with a focus on the chronic diseases of allergy and asthma. This project forms part of the Sydney Children's Hospitals Network's commitment to leading change. A&AA is a partner on this project with an aim to improve the patient care journey for children and families presenting to Sydney Children's Hospital Network who require out of hospital care.
A&AA is a member of the Steering Committee at which all partners will contribute to the project strategic direction, governance and major decisions to achieve the best outcome of this initiative.
- A&AA CEO presented at a NSW Food Authority organised Retail Food Service Conference for environmental health officers investigating complaints relating to food allergens.
- A&AA CEO spoke at the launch of Tick induced Allergies Research and Awareness (TiARA) function at Parliament House in NSW.
- A&AA CEO presented at the first Asian Alliance conference organised in Japan in Jan 2017.
- A&AA provided input into a new Hospital Policy for Food Allergy Management for the Princess Margaret Hospital in Perth.

Workshops, presentations, consultation, representation and further outreach

A&AA continues to present on allergy management and anaphylaxis in a variety of settings including schools, workplaces, medical practices, food service facilities, government departments etc.

Presentations/consultations during the report period include:

- A 5 hour interactive workshop with staff at Sydney Academy of Sport (camp facility)
- 5 hour interactive workshop for members of the Australian Camps Association in Victoria and another in NSW.
- Presented a 4 hour masterclass on food allergy, food service, food labelling and investigations to environmental health officers at Environmental Health Australia Conference in Western Australia (WA).
- One hour presentation on food allergy to all delegates at the Environmental Health Australia Conference in WA.
- Organised a workshop on Teens and Management of the risk of Anaphylaxis for the community in WA. Presenters included allergists, a psychologist and A&AA's CEO. The presentations were followed by an interactive panel discussion.
- Presented to ASCIA members at ASCIA dinner in WA
- Organised workshop on Teens and Allergy Management for the community in South Australia. Presenters included two young people with allergic disease, a social worker and A&AA's CEO. The presentations were followed by an interactive panel discussion and included allergists, allergy nurses and allergy dietitian as well as a parent.
- Presented two 3 hour workshops for food service staff at the Lion Hotel in South Australia.
- Organised a community seminar with charity Hands to Hold who focus on eczema on the Gold Coast.
- Presented at Victoria Dairy Food Safety Conference in Victoria.
- Presented at National Institute of First Aid Trainers conference in Victoria. A&AA also had an exhibition stand for the two day initiative.

Resource development and distribution:

- A&AA has distributed more than 70,000 Be-a-MATE brochures and bookmarks free of charge to primary schools to help educate school communities about food allergy management and support. (This initiative was made possible thanks to an independent project grant from GSK).
- Released a 10 minute film on transition of children from preschool to school. This film can be viewed on A&AA YouTube platform <https://www.youtube.com/watch?v=bSKB48sA3f4>
- Distributed 10,000 posters on signs and symptoms of anaphylaxis free of charge to schools(primary and secondary) across Australia
- Shared links to Life Education NSW video A&AA helped produce through social media platforms. This film can be viewed on the Life Education YouTube platform <https://www.youtube.com/watch?v=f974orKeiU>
- Produced e-book Kids Food Allergy for Dummies booklet for those newly diagnosed with food allergy. This is a free downloadable resource for members (membership is free). (This initiative was made possible thanks to an independent project grant from GSK).
- Developed an animation on How to Give an EpiPen which was released during FAW 2016. Throughout the reporting period the animation has been viewed by more than 1.5million people. This film can be viewed on A&AA YouTube platform. It has been updated to reflect the 10 second to 3 second change. <https://www.youtube.com/watch?v=Zmt-cl1ZiYE>
- Adapted short film titled "Take the Kit" with permission from the Anaphylaxis Campaign in the UK for an Australia audience. This film can be viewed on A&AA YouTube platform <https://www.youtube.com/watch?v=9HbXhCcKoto> (This initiative was made possible thanks to an unrestricted educational grant from Mylan).
- A&AA created a flow chart to assist consumers with reporting of foods that trigger allergic reactions. Since creating this resource we have had more people reporting reactions to food in food service <https://allergyfacts.org.au/allergy-management/risk/reporting-an-allergic-reaction>
- A&AA has distributed many materials (brochures, food allergen cards, posters, children's books and more) to members, health professionals, schools and childcare, workplaces, libraries and more free of

charge. (Free distribution of some materials was made possible thanks to an independent project grant from GSK).

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 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 three international conferences. The information learnt is then shared and used to help further promote allergy awareness, management and research in Australia.

Conclusion

As the prevalence and complexity of allergic disease continues to challenge Australians and our society including our health system, we continue our work with all involved in allergy management including individuals, families, government, health professionals, food industry, schools, workplaces, first aid providers and all in the Australian community to improve allergy care and then, quality of life.

A&AA's goal is to be the trusted voice that newly diagnosed patients are referred to on leaving the consultation room. As there is so much information on-line, it is difficult for people to know what information is credible and therefore helpful in the long term. If people are alerted to A&AA, ASCIA and tertiary hospital websites as credible sources of information we will hopefully reduce confusion, promote best practice and have a pathway to support for when people need it. Diagnosis and episodes of severe allergic reactions/exacerbations can be overwhelming and people can be desperate.

Growth of A&AA membership base equates to more people in the community affected by allergic disease accessing timely information and support from an organisation that has strong connections with key stakeholders including, but not limited to, our members and social media followers, health professionals, government, school, childcare, workplaces, food industry, legislators, media, TAFE, universities and researchers. We look forward to improving our communications, progressing project opportunities and increasing the number of dedicated, informed employees to assist us in growing the organisation, therefore improving allergy care of Australians.

A&AA looks forward to working with our members and supporters to build a larger, trusted hub for allergy information, support and advocacy. As we do this we need to improve and diversify our revenue streams to build sustainability. The commitment of our Board, staff and other trusted supporters and loyal members will enable us to achieve this.