



Allergy & Anaphylaxis Australia (A&AA) Annual Report July 2015 – 30 June 2016

Written by Maria Said

Allergy & Anaphylaxis Australia (A&AA) remains Australia's leading national patient support organisation for individuals with allergic diseases. We have continued with our mission to promote awareness through support, education and research. As advocates for the allergic consumer, we work closely with the peak medical body, the Australasian Society of Clinical Immunology and Allergy (ASCIA). The launch of the National Allergy Strategy in August 2015 has seen ASCIA and A&AA progress optimal care as partners. 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.

During the past year A&AA's three Directors have further developed the Allergy & Anaphylaxis Australia Board which now includes Mr Bill Porter, Ms Kath McLean and Ms Anna Burke. These volunteer members have brought a wealth of knowledge and expertise to A&AA and its members. We are grateful to them for giving up their time and importantly for sharing their experience and their knowledge to assist us all in furthering the mission and the goals of the organisation.

March 2016 marked the employment of a part time (3-4 days/week) Health Management Educator. We now have the equivalent of 3.5 full time staff. An increase in government funding in January 2016 afforded us the opportunity to employ someone with a health science background to assist with education, advocacy, resource development and more.

We are fortunate to have a small number of volunteers continue to assist us in several areas of need including review of educational resources, organizing support group meetings and representation at meetings, including presentations, when required. We continue to receive some IT support free of charge and Clayton Utz remains A&AA's pro bono legal support consultant.

Our Medical Advisory Board (MAB) consists of five allergists with expertise in both paediatric and adult immunology. All MAB members are members of the Australasian Society of Clinical Immunology and Allergy (ASCIA) with some being members of ASCIA Council. MAB members reside in states across Australia hence contributing to A&AA as a lead national consumer support organisation.

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*

National Progress

Federal Government Funding Support.

In August 2015 A&AA applied for funding through the Health Peak Advisory Bodies Programme. In Nov 2015 we were advised of our successful application and in Jan 2016 began receiving funding according to the agreement which will be up for review in 2019. A&AA continues to provide required reports on funding amounts allocated, performance and outcomes to the Department as required in line with our agreement.

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. After more than 18 months of groundwork, and consultation (including face to face, teleconferences and email communication) with more than sixty key stakeholders the National Allergy Strategy was launched. A&AA commitment to the National Allergy Strategy speaks to the aim and objectives of the said Project. Whilst the Strategy was launched in August of 2015, many of the initiatives within it have been work in progress for both organisations over a long period of time.

The symbiotic relationship of ASCIA and A&AA can only benefit Australians with allergic disease and those who care for them. The three priority areas cited in our agreement form the basis of the goals of the National Allergy Strategy.

Goals of the National Allergy Strategy are as follows:

1. **Standards of Care**
Develop standards of care to improve the health and quality of life of people with allergic diseases.
2. **Access to Care**
Ensure timely access to appropriate healthcare management for people with allergic diseases.
3. **Information, Education and Training**
Improve access to best-practice, evidence-based and consistent information, education and training on allergic diseases for health professionals, people with allergic diseases, consumers, carers and the community.
4. **Research**
Promote patient-focused research to prevent the development of allergic diseases and improve the health and quality of life of people with allergic diseases.
5. **Prioritised Chronic Disease**
Recognition of allergic diseases as a prioritised chronic disease and National Health Priority Area.

In May 2016, Minister Sussan Ley announced funding to progress three specific areas of the National Allergy Strategy. The projects focus on drug allergy management, improving allergy management for teens and young adults and allergy management in food service (including the hospital setting).

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*

As we progress the Strategy, we continue to assist the Australian government in appropriate management of those with allergic disease. We continue to make ourselves available as consultants with knowledge and long standing expertise in allergy management. As we represent allergic consumers we aim to improve their quality of life and their contribution to our community, lessening the burden on the healthcare system, workplaces, schools, food industry etc. With ASCIA, we look forward to progressing the said government funded projects and continue to work on other gaps in care as best we can.

Parliamentary Allergy Alliance

Soon after the launch of the National Allergy Strategy A&AA launched the Parliamentary Allergy Alliance (PAA). With Anna Burke, the then MP (ALP) as A&AA's long-time champion ambassador, Senator Richard Di Natale (Greens leader) and Dr Andrew Southcott (representing the Liberal party) as co-chairs. The launch of the PAA signifies leading parliamentary parties coming together to help progress the diagnosis, treatment and management of allergic disease. As Anna Burke and Andrew Southcott have now resigned from their positions A&AA is working to find other parliamentarians with an interest and commitment to allergic disease to help convene the PAA.

Change in membership structure

In April 2016, to reach a wider audience and make a bigger positive difference in the lives of people living with allergic disease, we decided to change our model of membership from paid membership to free membership in early 2017.

Membership numbers have been falling for the last four years. In addition, the changing role of social media and the internet in providing information to our members and the general public has meant that our member services are not seen as being as valuable as they once were. To keep people living with allergic disease up to date with the latest in allergy news A&AA is developing a new website, where our valuable resources can be more easily accessed. Staff, printing and postage costs involved in new member packs and printed newsletters will also be reduced.

At the end of 2016 A&AA will offer free membership to all Australians, with a member only section on the new A&AA website that will be updated with current allergy and anaphylaxis information for the exclusive benefit of members only. In this way A&AA will be able to maintain a database of members whose membership does not expire. It is anticipated that free membership will significantly increase our membership numbers. 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.

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. Our 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

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*

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 President remains a member of several ASCIA working parties/committees.

A&AA was again given a complimentary stand at the ASCIA Scientific Meeting in Adelaide in September 2015. Two Directors and a Victorian volunteer attended the conference.

Food Allergy Week (FAW) 14-21 May 2016

A&AA outreach during FAW continues to increase. Our theme for 2016 remained 'Be Aware, Show you Care.' A&AA, again contracted Bite Communications (PR company) to further develop our campaign. Information on initiatives and outreach can be found in the 2016 FAW Report at <https://www.allergyfacts.org.au/images/pdf/FAW-2016.pdf>

Coronial Findings and Recommendations

The Victorian Coroner released finds and recommendations of two children that died as a result of food anaphylaxis during this reporting period. Jack Irvine's report was released in April 2016 after an inquest was held in Victorian early 2015. The report on the death of Ronak Warty was released without inquest in June 2016. A&AA assisted the coroner in both these investigations where 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 www.allergyfacts.org.au 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

Allergen Collaboration – A&AA sits on the Allergen Collaboration which is a collaboration between Food Standards Australia and New Zealand (FSANZ), retailers, food manufacturers, food service organisations, NSW Food Authority, the Food and Beverage Importers Association, consumer organisations and other bodies which meets to explore non-regulatory measures that can improve the management of food allergens.

Lupin – A&AA made a submission to Food Standards Australia New Zealand (FSANZ) to put forward the views of consumers on Proposal P1026 Lupin as an Allergen, which proposed a change to food labelling legislation to include lupin as an allergen.

FSANZ Allergen Exemptions – A&AA wrote a submission to FSANZ to put forward the views of consumers on Proposal P1031 Allergen Labelling Exemptions. This proposal sought to exclude certain allergens that were below a set threshold from an ingredient list and therefore did not pose a threat to consumers with food allergy.

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*

Medication

Therapeutic Goods Administration (TGA)

1. A&AA has written a submission to the TGA regarding the dangers in the promotion of disassembling the EpiPen® by a first aid provider in Victoria.
2. A&AA also forwarded another submission to the TGA asking that major food allergens (identical to those listed on the Food Standards Code for food labelling) are always declared on labels of medications. A&AA also requested that gelatine be labelled in medication because of the growing number of people with mammalian meat allergy and their need to know what medications (and foods) contain gelatine which is derived from beef.
3. Following a meeting with the TGA, A&AA has informed members of the addition of the word epinephrine on labels where the word adrenaline appears. This change means that where the word adrenaline is stated on medication, the term epinephrine will also be stated in brackets directly after it as the drug is known as epinephrine around the globe and there needs to be consistency. As this is an emergency drug, the representation will remain as such and the drug will not be called epinephrine without mention of adrenaline in Australia. A&AA has communicated this change via email, social media avenues as well as our website and newsletter.

Pharmaceutical Benefits Advisory Committee (PBAC)

A&AA has made two submission to PBAC. One submission regarding a new adrenaline (epinephrine) autoinjector and one regarding inclusion of an immunotherapy on the Pharmaceutical Benefits Scheme (PBS).

Research

A&AA has been involved in several research studies in the last 12 month period. A&AA produced a poster on the Transition to School pilot study that was accepted and presented at the ASCIA Conference in Sept 2016. Using results from this pilot study we secured funding to produce a video to assist parents with the transition of their children with food allergy from preschool to school. This video will be released later in 2016.

A&AA has assisted many researchers with recruitment of candidates or sharing of surveys. We have also assisted university students with survey advertising via our social media channels and email to members.

An important part of A&AA's role is to communicate the real messages to consumers with allergic disease once research articles are released. It is important consumers/patients understand the research findings and its limitations, and we sometimes help, with medical support, to translate research findings into clear messaging.

Phone and email support

A&AA has a national 1300 support line for anyone wanting/needing to understand more about allergy management. Whilst we do have calls and emails asking about allergic rhinitis, eczema, food and chemical intolerance, most of our calls and emails are in relation to food allergy diagnosis and management, including information on emergency treatment. We have a small number of people

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*

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 health professionals within our organization to answer with them, communicating with our Medical Advisory Board where required. Our communication clearly states we are not giving medical advice and that medical advice needs to be sought from a doctor, however we do guide people on accessing medical advice and evidence based information.

Media and social media

A&AA is often approached by media for comments on allergy related stories. We do our best to align ourselves with evidence based medicine seeking assistance from our Medical Advisory Board and/or ASCIA when required. We have a very active media platform with active Facebook, Twitter and Instagram accounts. These sites are used to help educate the general public about allergy management, assist in dissemination of science based information and help dispel myths. 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.

National newsletter – NewsFacts

The A&AA newsletters & Kids Corner issues had many articles relevant to allergic consumers and health practitioners. The hard copy newsletter was sent free of charge to all the paid A&AA members and some allergy clinics. Many have received complimentary electronic copies also.

In 2017 A&AA will be issuing electronic newsletters but will be able to send hard copies to those who have no internet access. This is in part a cost saving measure however as we move to free online membership we hope to increase our membership meaning our electronic newsletter reaches more people in the community who will benefit from it.

A Snapshot of some other important initiatives:

Key successes of our continued outreach have included:

- Our work with the VIC Department of Education and Communities on Ministerial Order 706, development of ASCIA e-training for VIC schools, development of a course to educate Anaphylaxis Supervisors in VIC schools.
- Working with hospital staff/NSW and VIC Health departments and the family of a 13 year old child admitted to hospital with asthma who died in a hospital setting soon after eating a portion of his breakfast.
- Assisting Environmental Health Australia (EHA) and WA Health with the sharing of A&AA resources and expertise to assist in the development of a Food Allergy module for the EHA FoodSafe education program for environmental health officers.
- Representing consumers at a Centre for Food Allergy and Research (CFAR) round table discussion on infant feeding at the Murdoch Children's Research Institute in 2015 and then again 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

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*

help decrease the incidence of food allergy. These consensus guidelines are now to be used by all organisations and can be found on the ASCIA website.

- Met with senior advisor to the TAS Health Minister, with Dr Malcom Turner from Royal Hobart Hospital, to discuss and progress a coordinated allergy service in Tasmania.
- A&AA provided comment on a submission on the National Strategic Framework for Chronic Conditions being developed by the federal government. The Framework will be the overarching policy for the prevention and management of chronic conditions in Australia and therefore improve health outcomes for those with allergic disease.
- Worked with SA Health in developing a report for the SA Health Minister on need for adrenaline autoinjectors for general use in first aid kits of SA schools.
- Presented on the National Allergy Strategy in the US facilitated International Allergy and Anaphylaxis Alliance meeting and then at AllerGen which is a Canadian food allergy research body which operates through McMaster University in Toronto.
- Assisted Medicine X in the development and marketing of an application on food allergy management for teenagers.
- 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, 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 developed a Food Allergen Card for Lupin for consumers and food industry. As an emerging allergen, Lupin is likely to be added to the mandatory list of allergens in Australia by FSANZ it was prudent to develop a Lupin Allergen card. We also provided input to an ASCIA Lupin Allergy Dietary Sheet.
- In early in 2016 a clinic was launched in Victoria to begin the process of Jack Jumper Ant desensitisation. Until 2016 this treatment was only available in Hobart. A&AA has worked alongside parent, Michelle Madden, to make Jack Jumper Ant immunotherapy more accessible for Victorians.
- Princess Margaret Hospital Perth – 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:

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*

- A 5 hour interactive workshop to more than 160 participants (camp location employees including those who serve food) from the Australian Camps Association and Christian Venues Association in Victoria and NSW
- A 5hr workshop for NSW Sport and Recreation camp facility on the NSW coast.
- Presented at KFC state conference in Sydney.
- Participated in a teleconference discussion with Northern Territory Department of Education to assist with revision of a policy on administration of medications in the school setting.
- A&AA had an exhibition stand and presented at the National Restaurant Conference.
- Presented on the management and emergency treatment of severe allergy at Medicare, Australian Taxation Office, Centrelink, and other workplaces that have employees at risk of anaphylaxis.
- Presented at QLD state conference and then national conference of Australian Institute of Hospitality in Health Care.
- Presented at CSIRO and Food Technology Association Seminar in Victoria
- We have made a concerted effort to provide resources to individuals and organisations who need them most. This year, we contacted allergy nurses around Australia and had camp booklets and other resources such as posters and flyers delivered to allergy clinics free of charge. We have also disseminated a form inviting allergists/paediatricians/nurses and dieticians to request a pack of several of our flyers and posters free of charge. Many have requested materials to give their patients.
- Worked with Life Education NSW to produce a video designed to educate students about food allergy and anaphylaxis.

International Associations

International Food Allergy and Anaphylaxis Alliance (IFAAA) and European Academy of Allergy and Clinical Immunology (EAACI)

A&AA's president remains a committee member of both the IFAAA and the EAACI Patient Organisation Executive Committee. Both organisations share information on best practice in an effort to improve quality of life of those with allergic disease. A&AA President was sponsored by the American Peanut Council and Mylan to attend and present at international conferences. The information learnt is then shared and used to help further promote allergy awareness, management and research in Australia.

Activities that support the sharing of information

A&AA has a key focus of keeping allergic consumers up to date with the latest advice and information. A&AA has developed the following resources which have now been disseminated

- **Camp book** <https://www.allergyfacts.org.au/shop/category/13-books>
- **Camp allergy checklist**
<https://www.allergyfacts.org.au/images/pdf/CAMPchecklist516.pdf>
- **Signs and symptoms poster**
<https://www.allergyfacts.org.au/images/pdf/Signsandsymptoms.pdf>
- **Hospital Stays Help Sheet**
<https://www.allergyfacts.org.au/images/pdf/Hospitalstays716.pdf>

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*

- **Hospital Stays Checklist** <https://www.allergyfacts.org.au/images/pdf/checklist-Hospital716-.pdf>
- **Food recall alerts** <https://www.allergyfacts.org.au/news-and-food-alerts/8-food-alerts>
- **Alert sent to members when expired EpiPen®s** were found to be in boxes with a different expiry date. A&AA also sends SMS alerts about food recalls to members who have opted for this notification service.
- **Adrenaline (epinephrine) autoinjector (EpiPen®) administration video** <https://www.youtube.com/watch?v=lb4X1DKJv1A>
- **Take the Kit** video from UK Anaphylaxis Campaign adapted for Australian audience. <https://www.youtube.com/watch?v=WbFYAk7OMyw>

Conclusion

Through ongoing consultation with members and non-members Australia-wide, A&AA remains abreast of the many factors that affect the quality of life of consumers with allergic disease. As the lead consumer/patient support organisation in Australia we continue to listen to and advocate for all with allergic disease. We work with government, health professionals, food industry and many others in the community to share best practise, increase safety and improve health outcomes therefore improving the quality of life of allergy sufferers and those that care for or about them. A&AA continues to actively provide information and advice, and share knowledge to help inform health policy which in turn benefits all. We acknowledge the ongoing support of the volunteers, the A&AA Board, the A&AA Medical Advisory Board, members, non-members, donors, sponsors, fundraisers and all who contribute to make A&AA the trusted charity for allergy support in Australia.

Allergy & Anaphylaxis Australia – *Your trusted charity for allergy support*