



Allergy & Anaphylaxis Australia

Your trusted charity for allergy support

ALLERGY & ANAPHYLAXIS AUSTRALIA ANNUAL REPORT

July 2014 – 30 June 2015

Written by Maria Said

Allergy & Anaphylaxis Australia (A&AA) remains Australia's only national patient support organisation for individuals with any allergic disease. The aim of the organisation is to increase awareness and improve education so as to improve quality of life of all affected by allergic disease. Allergic disease is a community issue with 20% of Australians having a confirmed allergic condition. As the prevalence of allergic disease increases, 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.

A&AA has three directors with two being paid employees and one being a volunteer. We have three other part time employees who each work less than 20 hours a week. We have IT support that is given free of charge and this is a great help to the organisation. Clayton Utz remain our pro bono legal support team and are always willing to assist A&AA.

Further research on the development of a Board has progressed with Directors drafting necessary documentation. It is envisaged that a formal Board will be operational in the next 12 month period. A&AA has a small number of dedicated volunteers with whom we could not do without. Several volunteers are health professionals who lend their time, knowledge and expertise to supporting others with direction from A&AA president. We also have volunteers in a limited number of states who organise support group meetings and connect with others when required.

Our Medical Advisory Board (MAB) consists of five allergists with expertise in both paediatric and adult immunology. All MAB members are Australasian Society of Clinical Immunology and Allergy (ASCI) members. MAB members reside in states across Australia hence this assists us with our goal for a unified national approach to allergy management.

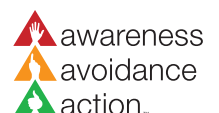
A&AA's membership base remains stable with newly diagnosed people joining the organisation as others, who feel more able to manage allergic disease, not renewing until their next transition stage (i.e. from primary school to high school) or if there is a crisis/sudden need for information and support. Whilst A&AA has a membership base, many who require our services are not members of the organisation. We operate as a service to all Australians needing information and support with allergic disease and its management. When we advocate for those with allergic disease, we advocate for all Australians and not just the minority who pay sixty five dollars membership to A&AA annually.

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NATIONAL PROGRESS

National Allergy Strategy

Allergic diseases have become an increasingly important chronic disease and public health issue in Australia and other developed countries over the last two decades, contributing to increased demand for medical services, significant economic cost of care and reduced quality of life of people with allergic diseases and their carers. Currently affecting more than 4 million Australians, the rapid and continuing rise of allergic diseases is therefore a serious public health issue that requires action by all levels of government and the community.

To address these issues ASCIA and A&AA, as the leading medical and patient organisations for allergy in Australia, have developed the first National Allergy Strategy for Australia, in collaboration with other stakeholder organisations. An important guiding principle is to be patient and consumer focused, and this is reflected in the Mission of the National Allergy Strategy (NAS):

To improve the health and quality of life of Australians with allergic diseases, and minimise the burden of allergic diseases on individuals, their carers, healthcare services and the community.

Goals of the National Allergy Strategy are focussed on:

1. Standards of Care.
2. Access to Care
3. Information, Education and Training
4. Research
5. Prioritise Chronic Disease

More than 50 stakeholder organisations were consulted on the development of the NAS, which is to be implemented in the later part of 2015. After the National Allergy Summit in August 2014, 5 working parties were established to focus on requirements to improve allergy management nationwide. These working parties consisted of A&AA representatives as well as ASCIA members and representatives from key organisations with several opportunities for all stakeholders (including those not on working groups) to review the draft NAS document and provide input.

Whilst key stakeholders worked on producing the NAS framework and live document, A&AA and ASCIA met with members of state and federal government to discuss development and implementation on the National Allergy Strategy.

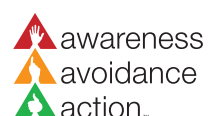
The NAS document will be finalised and launched in August 2015. More on the NAS can be found at www.nationalallergystrategy.org.au

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Australasian Society of Clinical Immunology and Allergy (ASCIA)

A&AA has continued to work closely with ASCIA on the development and revision of existing educational resources. The range of educational materials include helpful information on management of food and insect allergy, allergic rhinitis, immunotherapy, eczema and allergic disease generally. We aim to align our educational resources in an effort to decrease confusion on allergic disease and its management.

A&AA distributes ASCIA information to members and non-members at every opportunity through our quarterly 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 given a complimentary stand at the ASCIA Scientific Meeting in Melbourne in September 2014. Three Directors and a Victorian volunteer attended the conference. A&AA President was part of a panel discussion on a research day organised by the Centre of Food Allergy and Research and also presented on food allergy to dietitians attending the Allergy Update on the last day of the ASCIA Conference.

Food Allergy Week (FAW) 18-23 May 2015

A&AA outreach during FAW continues to increase. Our theme for 2015 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 on the attached 2015 FAW Report.

Fatal allergic reactions

A&AA awaits the handing down of Findings and Recommendations from the Victorian Coronial Inquest into Jack Irvine's death in 2012 where A&AA President was called as an expert witness to assist the Coroner.

In September 2014 A&AA was contacted about an alleged fatal allergic reaction of a 64yr old woman in Victoria after eating food served in a café. A&AA has met with the husband of the deceased to offer support. We also continue to liaise with relatives of those who have lost their lives to anaphylaxis, specifically families that contact us when they lose a family member. There are currently two coronial inquests pending into deaths from anaphylaxis and Clayton Utz have agreed to assist A&AA if they go ahead.

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Food Industry

A&AA has continued to work closely with the food industry including members of the Australian Food and Grocery Council (AFGC), Allergen Bureau, Food Standards Australia New Zealand (FSANZ), Environmental Health Australia and other key stakeholders invited to develop the National Allergy Strategy. We also continue to work with the Allergen Bureau on clearer food labelling with specific attention paid to precautionary statements. A&AA was invited to present at a Precautionary Labelling Round Table facilitated by the Centre for Food Allergy and Research at the Murdoch Children's Research Institute. A&AA and two A&AA Victoria based volunteers attended the round table.

A&AA President was also invited to present at a Food Allergy Management Symposium alongside international speakers. The symposium was attended by food industry, university students, FSANZ, AFGC, scientists and others involved in food science and food allergen management.

The Allergen Collaboration continues to meet (teleconference) at least every 3 months. The Allergen Portal can be found at <http://www.foodstandards.gov.au/consumer/foodallergies/food%20allergen%20portal/Pages/default.aspx>

The portal is a go to place for anyone wanting to find credible information on food allergy management. A&AA has reviewed and provided comment on a short you tube film which is soon to be launched to assist with education of those in the food service sector.

A&AA provided comment on the released Undeclared Allergen Incident and Investigation Protocol developed by the Implementation Sub-Committee for Food Regulation (ISFR). We also provided comment on the Draft Food Labelling Compliance and Enforcement Framework in June 2015. A&AA comment was also provided on the Therapeutic Goods Administration (TGA) Labelling in Medicines Consultation because of foods being an ingredient in some medications.

Allergy & Anaphylaxis Australia forwarded a submission on Proposal P1025, and specifically on Section 1.2.3—4 Mandatory declaration of certain foods or substances in food.

Through our newsletter, website and social media we continue to share information and educate allergic consumers on how to live life with food allergy. We communicate their responsibility to always disclose their allergy when eating out, always read food labels and always have emergency medication and ASCIA Action Plan for Anaphylaxis easily accessible (i.e. with them). Consumers are also encouraged to report reactions to packaged foods that may be improperly labelled and reactions to foods purchased without a label IF they have disclosed their allergy.

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Research

A&AA has been involved in several research studies in the last 12 month period. Involvement varies from advertising research projects/trials/surveys through to conducting studies and assisting with publication of results and review of proposed research surveys. A&AA produced a poster on the Transition to School pilot study that was accepted and presented at the ASCIA Conference. Another poster on removal of tics and mammalian product allergy was presented at the European Academy of Allergy and Clinical Immunology Conference in Europe. A&AA is also involved in international research on availability of adrenaline autoinjectors internationally. Work is also being done to publish data from international research on consumer understanding of threshold levels and precautionary allergen labelling.

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.

Reporting reactions to foods, food recalls - SMS and email alerts

A&AA disseminates information on food recalls to members and non-members via several communication tools including Face Book, twitter, our website, sms and direct bulk email to those on our database. Food Alerts are also listed in our three newsletters each year. If approached by manufacturers, A&AA communicates ingredient and label changes to consumers

A&AA assists consumers with food allergy in reporting reactions to packaged foods and foods they have purchased through food service outlets (i.e. if they have disclosed their allergy). Dietitians, allergists and other health professionals sometimes contact A&AA for assistance in reporting reactions also.

Phone and email support

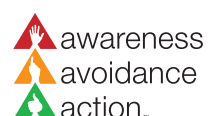
A&AA has a national 1300 support line for anyone wanting/needing to understand more about allergy management. Whilst we do have calls and emails asking about allergic rhinitis, eczema, food and chemical intolerance, most of our calls and emails are in relation to food allergy diagnosis and management,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

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Media, including social media

A&AA share information on a variety of issues through Australian media. In the last year we have written articles for journals and magazines, written fact sheets for distribution to target groups, been involved in TV news items, TV interviews, radio interviews, radio talkback segments, newspaper interviews, online articles and more. Allergy and anaphylaxis remains a topical issue. A&AA was also contacted by journalism students and journalists for indigenous and Chinese populations. We were involved in an hour long TV production on SBS Insight program which generated lots of community discussion.

Many in media, producers/reporters now come to A&AA for comment and guidance on particular stories/issues. We are recognised as the peak consumer body with a focus on allergy and anaphylaxis.

A&AA maintain a Twitter and Facebook account and as of end June 2015 we have more than 900 followers on twitter and more than 15 000 friends on Facebook. Both these channels are great for the sharing of evidence based information, tips on management, food alerts, published research findings, discussion on hot topics and media articles. Both tools are a great avenue for reaching people with and without allergy who need to understand more about management of allergic disease. A&AA closely monitors Facebook so that information shared by the general public is checked and responded to in a timely manner.

National newsletter - NewsFacts

Three A&AA newsletters have been distributed to members. The 28-32 page newsletter is a member only privilege. Currently, newsletters are printed and sent to members via the post however we are developing a member only section on our website and will be moving to the majority of members accessing their newsletters online. The newsletter helps keep readers up to date with changes and best management practices. Doctors sometimes have copies in their waiting rooms to help increase awareness of our organisation and the work we do. Our MAB continues to review and advise A&AA directors and editor on medical information published.

Our newsletter encourages members to write in and provide feedback on our services, as it is important we have ongoing understanding of needs of the people we support.

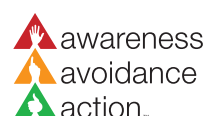
A 4 page Kids Corner is also produced and sent to members. The kids' newsletter has some fun activities for children to do with parents and always has some information on allergy management. We continue to have our popular PenPal club for children with food allergy and importantly for siblings of children with food allergy, who are sometimes forgotten even though, they too, miss out.

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A Snapshot of some other important initiatives:

- 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. Resources were also made available.
- Teen Application –A&AA has been working with MedicineX and ASCIA on the development of a phone application which explains food allergy and anaphylaxis to teens in non-medical language. The free app will be launched later in 2015
- DVD for Primary Schools – A&AA has worked with Kyle Dine from Anaphylaxis Canada in producing a DVD aimed at educating primary school children internationally. With input from Australia, US and the UK it is hoped that the Canadian resource will be a tool to educate children on food allergy management across the globe in a fun way. The resource will be sold through A&AA once it is launched.
- Re –ACT- Redesigning – Allergy Care Together. A&AA, as a consumer representative, amongst other key stakeholders on the RE ACT working group in Western Sydney, have developed a clearer, more efficient pathway to optimal and timelier care for those with food allergy.
- On the success of the RE ACT project, NSW Health have invested in a Kids GPS – Integrated Care Project with a focus on 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.

The project objectives include:

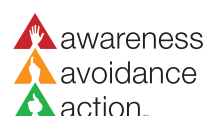
- Improve the experience and health outcomes of patients with chronic conditions
- Improve the experience and capacity building of families
- Provide high quality care in the right locations
- Enhance existing services and develop evidence-based models for the care for patients within a range of chronic conditions.
- In April 2015 A&AA organised a webinar on anxiety and management of the risk of anaphylaxis. We invited an allergist, a psychologist and representatives of Trapeze (an organisation that works directly with teens with chronic conditions) to present during the hour long webinar, which was open to anyone in Australia. The webinar was recorded and now sits on A&AA YouTube platform as a free educational resource.

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- A&AA remains on the TiARA (Tick Induced Anaphylaxis Research and Awareness) Committee and the steering committee assisting with the development of a TiARA Patient Support Group and promoting awareness of tick and mammalian product allergy.
- A&AA also continues to work with Michelle Madden who has set up a Jack Jumper Ant group aiming to make immunotherapy more accessible for all Australians and not only those residing in Tasmania.

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 etc. Presentations during the report period include:

- A 5 hour interactive workshop to more than 100 participants (camp location employees including those who serve food) from the Australian Camps Association and Christian Venues Association in Victoria
- A 2 hour workshop for Aussie Bush camp facility on the NSW north coast.
- Presentation to Allergy Dietitians Special Interest Group

A&AA is a member of the South Australian working party established to investigate adrenaline autoinjectors for general use being placed in SA schools and to improve allergy management at a state-wide level.

- A&AA is a member of Tasmanian Clinical Advisory Group (CAG) to drive for a public allergy service in Tasmania. The CAG is chaired by Dr Malcolm Turner who currently runs the Jack Jumper Ant Immunity project out of the Royal Hobart Hospital.
- A&AA has been part of a review team updating the Crown Copyright 220099VIC Course in First Aid Management of Anaphylaxis.
- A&AA has provided input to an Adrenaline Autoinjector Verification Course that is being developed by Swinburne University in Victoria,
- Presentation at The Australasian Mastocytosis Society national annual conference on emergency management of anaphylaxis.
- 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 children's story books delivered to allergy clinics free of charge. We have also disseminated a form so that allergists can request a pack of several of our flyers and posters free of charge. Many doctors, nurses and dietitians have requested materials to give their patients.

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Travel

A&AA answers many enquiries on travel with food allergy and the risk of anaphylaxis. Enquiries focus on air travel and safety, travel insurance, translation of materials into other languages when visiting non English speaking countries, food law in other countries, overseas school trips and more. A&AA has worked with ASCIA to progress an airline specific ASCIA Action Plan to assist flight crew with online emergencies. This plan will be stored with adrenaline autoinjectors for general use which are now in QANTAS and Virgin airplane medical boxes as well as ampoules of adrenaline to be drawn up and given by medical personnel that might be traveling on the flight. Airline crew on these Australian airlines are being trained on administration of adrenaline via an adrenaline autoinjector (EpiPen®).

A&AA Website and online store

In late 2014 A&AA launched a more user friendly website and online shop. The launch of this new platform has reduced technical enquiries and streamlined online purchasing of resources. A&AA is now investigating a 'member only' section on the A&AA website, where we can also then house a member only forum for member to member discussion on allergy related information, issues and challenges.

School and childcare management

A&AA continues to work with state health and education/childcare departments and ASCIA on the review or development of educational materials to assist with allergy management in the school and childcare setting nationally. The organisation continues to advise, review and inform on current best practice on a state by state basis nation-wide. We have also been involved in the review of the ASCIA Guidelines for the management of allergy and anaphylaxis in schools, pre-schools and childcare services. A&AA Risk Minimisations Strategy discussion paper has now been co-branded with ASCIA and is part of the above mentioned ASCIA guidelines for schools.

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

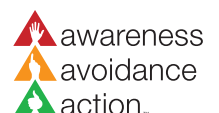
A&AA's president remains a committee member of both the IFAAA and the EAACI Patient Organisation Executive Committee. Both organisations share information on best practice in an effort to improve quality of life of those with allergic disease. A&AA President was sponsored by the American Peanut Council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

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Conclusion

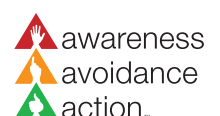
Allergy & Anaphylaxis Australia shares science based information and supports a broad and far reaching number of Australian's managing allergic disease. We work closely with peak bodies in progressing management to improve the quality of life of Australians with allergic disease. We remain the leading consumer support organization in Australia, with our knowledge and expertise also being sought by the food industry, government bodies and the media. Through our outreach and engagement in the National Allergy Strategy and in partnership with the Australasian Society of Clinical Immunology and Allergy, we hope to improve allergy care across Australia by focusing on access and standards of care, education and training, collection of data to further inform and the promotion of further research.

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