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Crisis in the Care of Allergic Patients in Australia

- Australia has among the highest allergy rates in the world\(^1\)
- Life threatening food allergy rates have doubled in ten years\(^2\)
- Allergy deaths have increased by 42% over six years\(^2\)
- Australia has a shortage of allergy specialists and health professionals with allergy expertise, particularly in rural or remote areas
- Children are being sent home from health facilities inadequately treated after severe allergic reactions (anaphylaxis)
- In one state alone there have been close to 1000 cases of anaphylaxis since November 2018\(^3\)

“We are talking about young people dying and going into emergency departments, in most cases due to anaphylaxis that could have been avoided,” claims Associate Professor Richard Loh, a leading children’s allergy specialist. “And the irony is that allergy specialists, GPs, families and consumers who live with allergy have developed a comprehensive solution. It just needs the political will and commitment from all parties, and at all levels of the health care system, to provide leadership to implement the strategy. We must also have adequate funding or else we will progress slowly or not at all and Australians will continue to be at risk.”

“The National Allergy Strategy was developed using the best available evidence and aligned with the experience of consumers,” says Maria Said, CEO of Allergy & Anaphylaxis Australia and a parent of a young adult with severe allergies who has been advocating for people with allergic disease for more than 25 years. “Families living with a child or young adult with food allergy, live life being fearful. They don’t trust food labels and they don’t trust the health care system to do the right thing, and that’s just food allergy. There are many thousands of people who are unsure whether they have a drug allergy, who can either be wrongly denied medication or be given it unknowingly.”

“The increased allergy rates amongst children and adults have put an enormous burden on the health care system. Many doctors have not had enough support or allergy training,” says Associate Professor Loh. “This means that allergy specialists like me see young people who should be managed by their GP, and could be, if GPs felt more confident. Others who should see an allergy specialist for severe allergies are left to manage themselves leaving them at even greater risk. Many people in rural and regional areas are travelling unacceptable, costly distances for health care at huge costs to both the family and the health system.”

“With relatively small investments we could take a ‘whole of health’ approach from the ground up, because it needs comprehensive action to avoid delays in accurate diagnosis and best practice treatment,” says Maria Said, who is also a registered nurse. “People can either have unnecessary food restrictions or insufficient restrictions because they are poorly diagnosed.”

“On top of that, patients are put at risk because we do not have standards of care for anaphylaxis in Australia – these need to be developed and implemented. When children have a severe allergic reaction, many don’t receive the right emergency care and are often sent home without self-injectable adrenaline. These people need food to sustain their life but without appropriate care and ongoing management it could be food that actually kills them. It is not a lifestyle choice,” continued Ms Said.

“The National Allergy Strategy calls for a top to bottom approach,” says Associate Professor Loh. “That includes a system such as an anaphylaxis register or notification scheme, which collects better data on things such as unsafe foods which don’t have accurate ingredient labels. It also includes
training of health professionals and food service providers so that more people can receive quality care, better training in the food service industry, better access to emerging treatments for food allergies, immunotherapy for insect sting allergy, better diagnosis of drug allergies, and much more."

"While there is no cure for food allergy, continued funding to help prevent allergies is critical, such as implementing infant feeding guidelines," continued Associate Professor Loh.

"All political parties have publicly endorsed their commitment to the strategy, but serious funding is required to do what needs to be done. An investment of just $20 million would go a long way to getting some of this off the ground," says Maria Said.

"That's less than the cost of some of the cancer medications that have been approved in recent years. We applaud those approvals and hope that political parties also provide funding to prevent the development of allergic diseases and to improve care of those with allergic diseases. Allergic disease is one of the fastest growing chronic diseases in Australia and must not be the poor cousin. The impact on quality of life is greater than that of diabetes or rheumatoid arthritis," finished Ms Said.

How will the National Allergy Strategy address these issues?
The National Allergy Strategy is asking for 20 million dollars in funding over five years to allow implementation of the following important projects:

- A Shared Care Model (‘whole of health’ approach) for allergic diseases to improve timely access to quality care for all Australians living with chronic allergic conditions – ensuring the patient gets the right care, by the right health professional, at the right time in the right place.
- A comprehensive approach to drug allergy management so that patients are not incorrectly diagnosed as having a drug allergy and that patients with severe drug allergies are not incorrectly given the drug that they are allergic to.
- A comprehensive, consistent approach to food allergy management in all food service (e.g. restaurants, schools, education and care services, hospitals, aged care facilities, airlines etc), expanding on the initial work that has been undertaken.
- Working with teens and young adults (at highest risk of fatal anaphylaxis) to help them to manage their severe allergies, particularly food allergies.
- Expansion of allergy prevention strategies to help avoid the development of allergic diseases including food allergy and some forms of asthma.
- Implementation of an anaphylaxis register/reporting system that meets the needs of all Australian states and territories to allow collection of nationally representative de-identified data to better understand the gaps in knowledge regarding anaphylaxis, and to allow for rapid removal of incorrectly labelled foods from the marketplace and allows prompt investigation of food service facilities when an individual disclosed their allergy before ordering food - this only exists in Victoria.
- Access to new allergy treatments that will be available in the next few years - we need time and resources to ensure that we can deliver these treatments.
- Expansion of existing education and support resources for health professionals and the community.

ENDS


Media case studies available upon request.

About the National Allergy Strategy

The National Allergy Strategy aims to improve the health and quality of life of Australians with allergic diseases and minimise the burden of allergic diseases on individuals, carers, healthcare services and the community.

The National Allergy Strategy is a partnership led by the Australasian Society of Clinical Immunology and Allergy (ASCIA) and Allergy & Anaphylaxis Australia (A&AA), the leading medical and patient organisations for allergy in Australia. www.nationalallergystrategy.org.au
NOTES FOR EDITORS

National Allergy Strategy petition and World Allergy Week 2019

World Allergy Week is a global campaign of the World Allergy Organisation (WAO) which aims to raise awareness of the impact of allergy in our communities. World Allergy Week 2019 runs from 7-13 April and the focus area is food allergy.

In the lead up to World Allergy Week 2019, we encourage anyone who is affected by allergy to support the National Allergy Strategy's $20 million election plea to all major political parties, by signing a petition and sharing it with family and friends. https://nationalallergystrategy.org.au/news/nas-election-platform

The core issues in allergy management revolve around effective prevention and accurate and prompt diagnosis - being treated by the right level of health professional at the right time, including support and education for families. Delays in diagnosis and management can result in:

- unnecessary dietary restrictions and impaired quality of life,
- suboptimal follow up after anaphylaxis affecting ongoing management and risk of further potentially life threatening allergic reactions,
- potentially preventable hospitalisations,
- development of further allergic disease states (e.g. poorly managed allergic rhinitis can contribute to development of asthma)
- risk of severe adverse events, and
- patients seeking advice from alternative/unorthodox practitioners.

Patients are put at risk because health professionals need better education and resources and standards of care for anaphylaxis need to be developed and implemented.

One study reviewed anaphylaxis management in eight Australian emergency departments and found that:

- 27% of reactions consistent with anaphylaxis were NOT given adrenaline, which is the first line treatment for anaphylaxis.a
- Less than half of patients with anaphylaxis were provided with a prescription of self-injectable adrenaline (e.g. EpiPen) when discharged.b
- Only one-third of patients experiencing anaphylaxis were referred to an allergy specialist.c

There is inadequate reporting to enable us to understand the size of the problem and respond appropriately. For example, there is currently only an anaphylaxis notification scheme in Victoria, implemented in response to a death. Established in Victorian Emergency Departments late last year there have already been 948 presentations of anaphylaxis since Nov 1, 2018d. Implementing a register in all states and territories would allow the removal of unsafe foods (due to undeclared allergens) from the market place quickly and enable government to better understand the incidence of anaphylaxis to inform public health policy, interventions and research.

More work needs to be done in relation to drug allergies. Many patients are incorrectly labelled as being allergic to an antibiotic when they are not — this means they are not being given the right course of antibiotics when they need it. While others who have life threatening reactions to a drug, are inadvertently being given the drug, causing preventable life-threatening emergencies. We need a whole of health approach to address this.

General Allergy data

- Food allergy induced anaphylaxis has doubled in the last 10 yearsa.
• One in 10 infants now have a food allergy\(^i\) and 1 in 20 children aged 10-14 years of age have a food allergy.\(^{vi}\)
• Hospital admissions for anaphylaxis have increased 5-fold in the last 20 years.\(^{ii}\)
• Deaths from anaphylaxis in Australia have increased by 7% per year (1997-2013).\(^{iv}\)
• Those at risk of anaphylaxis live with the very real daily fear of a life-threatening severe allergic reaction. Individuals at risk of food allergy induced anaphylaxis and their carers have higher than average rates of anxiety.\(^{vi}\)
• Up to 1 in 10 adults with suspected but unconfirmed drug allergy are often unnecessarily treated with more expensive drugs.\(^{vii}\)
• Although 5% of adults may be allergic to one or more drugs, up to 15% believe that they have drug allergy, and therefore are frequently unnecessarily denied treatment with an indicated drug.\(^{viii}\)
• Inappropriately documenting that patients are penicillin allergic can result in the use of more broad-spectrum antibiotics, increasing the risk of antibiotic resistant strains, increased morbidity with more intensive care admissions and longer hospital stays.\(^{ix}\)
• Around 4-8% children (0-5 years)\(^{viii}\), and 2-4% of adults\(^{ix}\) are affected by food allergy.
• Fatalities from food-induced anaphylaxis increase by around 10% each year.\(^{x}\)

\(^{i}\) https://www.mcri.edu.au/research/projects/healthnuts/healthnuts-publications
\(^{ii}\) National Allergy Strategy. 2015. www.nationalallergystrategy.org.au
\(^{ix}\) Tang MLK, Mullins RJ. Food allergy: is prevalence increasing? IMJ. 2017. doi:10.1111/imj.13362