



australasian society of clinical immunology and allergy

## NATIONAL IMMUNODEFICIENCY STRATEGY PROPOSAL

ASCIA is seeking expressions of interest for funding via unrestricted educational grants to progress the development of the first National Immunodeficiency Strategy for Australia.

The first stage will involve hosting a face to face meeting in early March 2019 (subject to funding) to progress development of the Strategy, beyond the draft Mission and Goals. Our intention is to involve representatives from:

- Clinical Immunologists and Immunology Nurses (e.g. ASCIA members)
- Patient organisations (e.g. AusPIPS, IDFA, IDFNZ, HAE Australasia)
- Relevant foundations (e.g. Jeffrey Modell)
- Regulatory bodies (e.g. National Blood Authority, Jurisdictional Blood Committee).
- Supply channels (e.g. Australian Red Cross Blood Service, Pharmacists)
- Allied health professions (e.g. Dietitians, Physiotherapists, Occupational Therapists)

### BACKGROUND

Meetings to discuss issues concerning the care of patients with primary immunodeficiencies have been held in 2018 with Australian government representatives. These meetings have involved Prof Jo Douglass (ASCIA past President) and Jackie Murphy (AusPIPS President). Prof Jo Douglass, Dr Melanie Wong (ASCIA past President), Jackie Murphy and Jill Smith (ASCIA CEO) had an informal meeting during the ASCIA 2018 Conference to discuss the possibility of progressing this further, by developing a National Immunodeficiency Strategy.

A/Prof Richard Loh (National Allergy Strategy co-chair, ASCIA past President) first suggested developing a National Immunodeficiency Strategy at a TAPID (Transplantation and Primary Immunodeficiency) meeting in May 2017. A/Prof Loh has since encouraged this to progress, following the success of the National Allergy Strategy.

### MISSION (draft)

The National Immunodeficiency Strategy mission is to improve the health and quality of life for Australians with primary immunodeficiencies and minimise the burden on individuals, carers, healthcare services and community.

### GOALS (draft)

1. Develop expert centres throughout Australia to provide early and appropriate diagnosis of primary immunodeficiencies, including newborn screening and genomic diagnosis.
2. Improve access to appropriate medical and nursing specialist care and training for patients (adults and children) with primary immunodeficiencies.
3. Recognise complexity of care required for primary immunodeficiencies in hospital care priorities, funding models, e-health and coding.
4. Improve access to comprehensive multidisciplinary care, including dietitians, physiotherapists and occupational therapists for patients (adults and children) with primary immunodeficiencies.
5. Ensure sufficient supply of Immunoglobulin Replacement Therapy (IRT) and Hereditary Angioedema (HAE) treatments for patients (adults and children) with primary immunodeficiencies.
6. Ensure appropriately supported and funded choices of IRT, including subcutaneous or intravenous immunoglobulin (SCIG or IVIG) and HAE treatments for patients (adults and children) with primary immunodeficiencies.

For register your expression of interest please email [education@allergy.org.au](mailto:education@allergy.org.au) by 15 October 2018.

---

ASCIA is the peak professional body of clinical immunology and allergy specialists in Australia and New Zealand  
Website: [www.allergy.org.au](http://www.allergy.org.au) ABN: 45 615 521 452 ACN: 608 798 241

Postal address: PO Box 450 Balgowlah NSW 2093 Australia  
Office address: Suite 238, 117 Old Pittwater Road, Brookvale NSW 2100 Australia