

15 August 2023

The Hon Mark Butler MP
Minister for Health and Ageing
Commonwealth of Australia
Email: Mark.Butler.MP@aph.gov.au

Dear Minister Butler,

Re: Implementation of Newborn Screening for Severe Combined Immune Deficiencies

On behalf of the Australasian Society of Clinical Immunology and Allergy (ASCIA), we wish to acknowledge our appreciation but also express our concerns regarding implementation of newborn screening for severe combined immune deficiencies (SCID) in Australia.

As stated in the [ASCIA Immunodeficiency Strategy](#), urgent haematopoietic stem cell transplantation (HSCT), also known as bone marrow transplant (BMT) is required for infants with SCID to survive. Newborn screening for SCID allows early HSCT, with better outcomes in younger infants, before they develop infections that can be life threatening and cause complications.

There has been significant variation in timing of implementation of newborn screening for SCID in different states. At this stage, not all states have commenced screening.

Two of the factors that have delayed implementation are:

- State based technical and logistics issues.
- State government funding issues.

These issues highlight the challenges of state based versus national newborn screening programs. In contrast to the Australian situation, newborn screening for SCID commenced much earlier in New Zealand (in 2017) and has been implemented on a national basis.

Australia's National Immunisation Program is an example of a national program that has transformed the health of Australian children. We believe that a national newborn screening program would result in similar health outcomes.

Without a widespread and comprehensive newborn screening program in Australia, many babies will miss out on a diagnosis which can be lifesaving or life changing. Early diagnosis and treatment can enable children to live healthy and productive lives, instead of living with a permanent disability. This has significant financial implications for the healthcare system and other government programs such as the National Disability Insurance Scheme (NDIS).

We note that the Albanese Government's commitment to a comprehensive newborn screening program was stated on 6 April 2022 and subsequently through social media, that they would deliver a world class national and expanded newborn screening program of 80 diseases. Your [press release on 8 May 2022](#) called on the then Government to match their election commitment.

ASCIA would welcome the expansion of the Australian newborn screening program and implementation on a national basis.

We also welcome the opportunity to meet with you or representatives from the federal health department to discuss this further.

Yours sincerely,

A/Professor Theresa Cole
ASCIA President

Jill Smith
ASCIA CEO

Australasian Society of Clinical Immunology and Allergy (ASCIA)

Correspondence: email jill@allergy.org.au or phone 0425216402