

Media Release  
25 June 2024

## *Nationwide Implementation of SCID Newborn Screening Ends Postcode Lottery*

### *International Neonatal Screening Day – June 28*

At only 15 months of age, Severe Combined Immune Deficiency (SCID) took the life of Javeria's first son, Zakariya. Due to being undiagnosed for 13 months and receiving his 12-month vaccinations (fatal in his condition), he never made it to his stem cell transplant date, which was also delayed due to the unavailability of a matched donor. The following year, Javeria had another baby boy, Ismaeel, who was also diagnosed with SCID at birth, and was isolated from the world for the first two years of his life.

This is what life is like for families who receive a SCID diagnosis. Fortunately, due to the advocacy work of patient organisations, patients, and their carers, SCID is now tested for at birth in all states of Australia, during routine newborn screening checks, leading to a higher chance of survival and a better quality of life. In the absence of routine newborn screening, many children with a late SCID diagnosis do not survive their first year of life; surviving babies often live with lifelong secondary consequences caused by the delay in their treatment.

Melanie Wong, Paediatric Immunologist at Westmead Hospital said, "As of May 2024, all states and territories now include SCID into their newborn bloodspot screening test, meaning that all babies in the country will now be tested for SCID. In 2021, Neonatal screening for rare diseases led to the diagnosis of 38,000 babies, this accounts for one baby every fifteen minutes."

The role of the collective voice was pertinent for the implementation of SCID testing Australia wide, with Rare Voices Australia bringing patients and organisations together to advocate for the inclusion into newborn screening. The initial application for inclusion of SCID in newborn screening was lodged by Joh Kelly, who lost her first child due to undiagnosed SCID. For many years, people from the community, including Jenny Tyrell, an IDFA member, were part of the early voices of the campaign, leading national petitions and initial conversations with ministers. Jenny attended local events, asked family members and friends to sign and sent out appropriate state petitions to IDFA members who requested them. Both Joh and Jenny were large contributors to the advocacy work for SCID Newborn Screening, and still are today.

Two years ago, on International Neonatal Screening Day the Hon Mark Butler MP, Minister for Health and Aged Care stated: "In a major milestone, Severe Combined Immunodeficiency (SCID) has been recommended for inclusion in state and territory newborn bloodspot screening programs. Early diagnosis of SCID by newborn screening allows for treatment to be undertaken before infections cause complications." This is the outcome AusPIPS Inc. and IDFA hoped for in advocating for national implementation of SCID NBS.

Australian Primary Immunodeficiency Patient Support (AusPIPS Inc.) and Immune Deficiencies Foundation Australia (IDFA) recognise the efforts of patient organisations, members, and the government for the role they played in getting SCID added to the newborn screening register.

**What happens next – for SCID families.** AusPIPS and IDFA work to ensure that families are supported through their journey. IDFA has worked with SCID families to create and foster a very active and supportive group of people – [SCID Connect](#).

AusPIPS and IDFA would like to recognise and remember the families who have lost a SCID baby, who are living with the crushing grief caused by a fatal condition that should have been detected and treated from birth.

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**About IDFA**

The Immune Deficiencies Foundation Australia (IDFA) is a national not-for-profit and leading peak organisation dedicated to improving the lives of those affected by immunodeficiencies. The organisation provides support and resources to individuals, families, and healthcare professionals and works to raise awareness about these conditions.

<https://www.idfa.org.au/>

**About AusPIPS**

Australian Primary Immunodeficiency Patient Support (AusPIPS Inc.) is an Australian patient led charitable organisation and not-for-profit. The organisation advocates and supports people with primary immunodeficiencies, their families and carers. Working with those affected by Primary Immunodeficiency, alongside healthcare professionals and researchers AusPIPS works to raise awareness of these conditions, to enable better access to healthcare as well as working with government to implement life changing processes across Australia.

<https://www.auspips.org.au/>

**Severe Combined Immune Deficiency (SCID)**

SCID is a life-threatening condition where babies are born without a functioning immune system. The condition gained global recognition in the 1970s due to a young boy called David Vetter, known as a 'bubble boy', who lived his short life inside sterile plastic bubbles to avoid infection. Without treatment, SCID babies are not likely to survive past their second birthday due to their inability to fight even simple infections.