< INSERT FULL NAME >

 < INSERT ADDRESS >

The Hon. Amber-Jade Sanderson
Minister for Health

5th Floor, Dummas House

2 Havelock Street,

West Perth, 6005

<INSERT DATE> September, 2022

Dear Minister,

I am urgently writing as a concerned member of the Immune Deficiencies Foundation Australia (IDFA) in relation to needing a start date for Severe Combined Immune Deficiency (SCID) newborn screening in Western Australia.

It is hard to understand why our parents cannot access critical SCID screening to avoid the death and disability of their baby, while parents in QLD, NSW, ACT and VIC can do so. Whilst I welcomed the recent Federal announcement by The Hon. Mark Butler in 28th June to roll out SCID screening, I am very concerned Western Australia has not announced a pilot start date.

SCID is a life-threatening condition that can be diagnosed early using the existing newborn screening test (Guthrie test). Without it, most undiagnosed babies will die before the age of two. If tested and treated within the first few months these babies can be saved from death and disability.

Together with other peak bodies, IDFA has worked hard to make sure states and territories do not repeat the devastating experiences of many parents with SCID babies. IDFA is a national not-for-profit and leading peak body supporting over 2,500 Australians living with a primary or secondary immunodeficiency through education, advocacy and awareness to improve patient outcomes and quality of life. IDFA is a respected organisation within the medical and patient community supported by their medical advisory panel and national and international relationships.

Our babies and parents in Western Australia cannot keep waiting and it may be already too late for some babies who have been left undiagnosed. I urgently request you to announce a start date to ensure Western Australian families and their babies are no longer being left behind.

Yours faithfully,

<INSERT NAME>