<INSERT FULL NAME>

<INSERT ADDRESS>

The Hon. <INSERT MINISTER NAME>

Minister for Health, <STATE/TERRITORY>

<ADDRESS>

<CITY> <STATE/TERRITORY> <POSTCODE>

<INSERT DATE> February 2024

Dear Minister,

In the light of Rare Disease Day (the 29th of February 2024), I am writing as a member of the Immune Deficiencies Foundation Australia (IDFA) to call for greater consistency across our nation to access timely and accurate diagnosis, access to treatment, health services, and timely support for rare conditions like Primary Immune Deficiencies (PID)s.

Australia is largely failing over two million Australians with rare conditions like PIDs. Many members are not diagnosed until later in life resulting in considerable health impacts. Also, members in the same state or territory receive free immunoglobulin and consumables for fortnightly home infusions and others in different regions pay significant costs. Others travel vast distances for infusions at major hospitals.

Earlier diagnosis and regular infusions are essential as we do not make sufficient immune cells. We have no choice but to manage the inequities for treatment. We come from all walks of life from students to train drivers, to mothers of young children and teachers, and we cannot continue to afford these costs.

In 2020 the Rare Disease Strategy for Australians was launched, which included three key policy areas of: Awareness and Education, Care and Support, and Research and Data.

On behalf of over 2500 Australian IDFA members, I call for clear policy guided by the Rare Disease Strategy to help reduce the inequity and uncertainty experienced by Australians with rare diseases. We support a comprehensive, collaborative, and evidence-based approach built on 3 principles: person-centred, equity of access, and sustainable systems and workforce.

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 also a respected organisation within the medical and patient community supported by their medical advisory panel and national and international relationships.

Our members cannot continue to carry the burden of inequitable access to essential treatment. We need earlier diagnosis, accessible treatment and support, research, and awareness. Our lives depend on it.

Yours faithfully,

<YOUR NAME>