PO Box 742, Wollongong, NSW 2520

Media Release
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Calls for Earlier Diagnosis as Canberra Mother Shares Rare Disease Journey

Nearly a decade for answers highlights the urgent need for earlier detection

To mark World Primary Immunodeficiency (PI) Week (April 22–29), the Immune Deficiencies Foundation Australia (IDFA) is highlighting the critical role healthcare professionals play in recognising and managing primary immunodeficiencies, and the urgent need for earlier diagnosis of these complex conditions impacting more than 6 million people worldwide.

Primary immunodeficiency (PI) refers to more than 400 rare, genetic disorders that impair the immune system, leaving people vulnerable to chronic and recurrent infections. Despite their significant impact, PI is often under-recognised, with an estimated 70–90% of people globally still undiagnosed, leading to prolonged illness, misdiagnosis and long-term health consequences.

A Canberra mother of two is sharing her story this World PI Week, highlighting the importance of healthcare professionals in improving recognition and care. Working full-time at the Australian War Memorial, Lauren Hewitt spent nearly a decade seeking answers after years of recurring infections — from frequent tonsillitis and respiratory illness in childhood to ongoing skin infections, cellulitis and multiple bouts of pneumonia in adulthood. It wasn't until her mid-30s, shortly after the birth of her daughter, that she was finally diagnosed with Common Variable Immunodeficiency (CVID), following years of misdiagnosis and uncertainty.

Now managing her condition with home-based Subcutaneous Immunoglobulin (SCIg) Therapy, Lauren says the support of dedicated healthcare professionals has been life-changing. "The healthcare professionals who guided me through my treatment have made all the difference," she said. "They gave me the confidence to manage my condition and helped me get back to a more normal life."

"It's important to recognise the hard work and dedication of the SCIg nurses, Lisa and Selin, at Canberra Hospital (TCH)," she said. "Because of their support, people like me can continue our daily lives with minimal disruption. They taught me everything about my treatment and guided me through my first infusions, making the whole process feel manageable and seamless."

The TCH subcutaneous immunoglobulin replacement program continues to expand, and within the next few weeks, they will support 100 clients.

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SCIg Nurse Lisa said supporting patients through treatment is a privilege. "We're just doing our jobs, supporting people to take control of their treatment is at the heart of the program, and it's incredibly rewarding to know we can make a real difference in helping people regain confidence and stability in their daily lives," she said.

IDFA CEO Carolyn Dews emphasised that closing the diagnosis gap remains a key priority.

"Too many Australians are facing delayed diagnosis of immunodeficiencies, which can have a significant impact on their health and quality of life. By improving awareness and equipping healthcare professionals with practical tools, we can support earlier diagnosis and better outcomes for patients," added Ms Dews.

Collaboration is key

On Wednesday, 29 April, IDFA will bring together immunologists, SCIg nurses, patients and university academics and partners for a collaborative meeting focused on improving awareness and education around immunodeficiencies.

The event will also mark the launch of the 'Think PI Sooner' resource — a practical graphic designed to help healthcare professionals consider immunodeficiency in everyday clinical practice. IDFA will also highlight its 'Distribute Resources' initiative, which provides free, accessible materials to support healthcare professionals and patients navigating diagnosis and care.

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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.

Interview Opportunities

Immune Deficiency Foundation Australia CEO – Carolyn Dews
Canberra local with immunodeficiency – Lauren Hewitt