

Media Release

April 2024

It is time to shine a light on 'Hidden Disabilities'

World Primary Immunodeficiency Week, April 22-29 / International Day of Immunology, April 29

In recent times, there has been increased recognition around 'hidden disabilities,' and patient organisations Australian Primary Immunodeficiency Patient Support (AusPIPS Inc.) and Immune Deficiencies Foundation Australia (IDFA) are joining the conversation.

A hidden disability, also known as an invisible disability, is one that is not immediately obvious to others. Conditions can include: neurodivergence, chronic health conditions, intellectual and cognitive disability, conditions affecting mobility, speech, vision, or hearing. Many people in Australia face their daily lives with a hidden disability caused from a compromised immune system.

Primary Immunodeficiencies are often misunderstood and overlooked, yet they affect more than 6 million people globally, the population of Denmark, or New Zealand. It is alarming to note that 70-90% of individuals with Primary Immunodeficiency (PI) remain undiagnosed worldwide.

The International Patient Organisation for Primary Immunodeficiencies (IPOPI) argues that PI causing a heavy burden of disease must always be recognised as a disability and that patients should receive the necessary long-term financial and practical assistance.

"Primary Immunodeficiencies are a group of more than four hundred rare and serious genetic disorders that significantly compromise the immune system's capacity to defend the body against infections and diseases. In Australia (Victoria), research reveals that the average time taken for PI adults to receive a diagnosis after symptom onset is 9 years, with each year of delay in diagnosis resulting in a decrease in life expectancy, said Emily Edwards, AusPIPS Inc. Vice President, and PI medical researcher at Monash University.

Earlier diagnoses and more timely access to efficacious treatment, can slow disease progression, be curative in patients receiving stem cell transplantation or gene therapy, improve patient quality of life and increase life expectancy. Furthermore, this will reduce the number of hospitalisations per patient dramatically reducing costs to the healthcare system," added Edwards.

To highlight the need for support for those living with an immunodeficiency, IDFA partnered with Wollongong local organisation, Taylor Made Outcomes, to develop a resource '[Immunodeficiencies and Applying for the NDIS](#)' to launch during World PI Week, to assist people applying to access government support from the NDIS.

"World PI Week is a pivotal moment for raising awareness and advocating for those with immunodeficiencies," said Carolyn Dews, IDFA CEO. "Our collaboration has allowed us to create a valuable resource that empowers our members to live their best lives despite the challenges of immunodeficiency."

Taylor Made Outcomes, a leading provider of tailored support services for individuals with disabilities, brings expertise in creating accessible and user-friendly resources. The resource booklet includes tools, how to access the NDIS, and advice to ensure that it meets the diverse needs of the immunodeficiency community.

"We know the processes of securing NDIS funding is challenging, and we want to make sure that those in need, and eligible for the NDIS, receive the support they deserve" noted Mandy Drain, Director, and Specialist Support Coordinator at Taylor Made Outcomes. "Our goal with this booklet is to shine a light on these hidden conditions and provide practical strategies for improving quality of life."

The launch of the resource booklet coincides with World PI Week, a global campaign dedicated to raising awareness about primary immunodeficiencies and advocating for better access to diagnosis and treatment, and International Day of Immunology.

AusPIPS and IDFA are focused on achieving early diagnosis, timely treatment, and equitable access to specialised care for individuals with primary immunodeficiency disorders, regardless of their location.

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Contact:

Danae Pikkat, Communications Officer
Immune Deficiencies Foundation Australia
0498 070 226
danae@idfa.org.au

NOTES FOR MEDIA:

Available for interview:

- Carolyn Dews (NSW), CEO of Immune Deficiencies Foundation Australia (IDFA)
- Mandy Drain, Director, and Specialist Support Coordinator at Taylor Made Outcomes
- Emily Edwards, Vice President at AusPIPS Inc., Senior Research Fellow at Monash University and Member of the Jeffrey Modell Diagnostic and Research Centre for Primary Immunodeficiencies in Melbourne
- Case Study (IDFA Member)

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

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/>

About Taylor Made Outcomes

Taylor Made Outcomes is a registered NDIS provider of Plan Management, Support Coordination including Specialist and Psychosocial Recovery Coaching. Social Work is available to plan and self-managed participants.

<https://taylormadeoutcomes.com.au/>