

Media Release
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Australians Urged to Step Up for Invisible Illness During World PI Week
IDFA Launches “Stride for Primary Immunodeficiency” to Raise Awareness for Hidden Disability

To mark **World Primary Immunodeficiency (PI) Week (April 22–29)**, the Immune Deficiencies Foundation Australia (IDFA) has launched [Stride for Primary Immunodeficiency](#)—a national walking campaign encouraging Australians to take steps in solidarity with those living with this often-invisible condition.

Participants, including IDFA CEO, members, and supporters, are pledging to walk throughout April to raise awareness and support for individuals with PI. The initiative invites the public to “walk in their shoes”—a powerful gesture for a condition that **affects over 6 million people globally**, often without visible signs.

“Primary Immunodeficiencies are invisible, but that doesn’t make them any less real,” says Carolyn Dews, CEO of IDFA. *“This campaign is about giving voice to those who are often unseen and unheard. Every step walked and every dollar raised will go toward education, awareness, and support services that can change lives.”*

Primary immunodeficiency encompasses **more than 400 rare, genetic disorders** that impair the immune system, leaving people vulnerable to chronic infections and complications. Despite their serious impact, these conditions often go undiagnosed or misunderstood.

“People often tell me, ‘You don’t look sick,’” shares Pearl Sims, IDFA member and campaign participant.

“But what they don’t see is the fatigue, the hospital visits, or the daily uncertainty I live with. A hidden disability can be even more challenging than a visible one—some days I have energy, and other days I don’t. The public often assumes you need to have a device or look a certain way to be considered disabled. This campaign gives people like me a chance to be seen, heard, and understood.”

Globally, it’s estimated that 70–90% of people with PI remain undiagnosed, leading to unnecessary suffering and long-term health consequences. The Stride for PI campaign seeks to close this diagnosis gap through public education, healthcare professional training, and community awareness.

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Funds raised during the campaign will directly support resource distribution – ensuring healthcare professionals across Australia have access to vital educational materials. Too many people with PI face delayed diagnoses and inadequate care. By equipping providers with the right information, we can bridge the gap between diagnosis and appropriate treatment.

With generous donations of \$5,000, IDFA will be able to distribute 250 educational packs to healthcare professionals nationwide. By placing these materials directly into the hands of health professionals, we aim to: Reduce the rate of delayed diagnosis; Improve access to timely, effective treatment; Empower healthcare providers with tools to better support their patients; Bridge the knowledge gap that often leaves people with PI feeling misunderstood or overlooked.

“We can’t do this alone,” Dews adds. “Whether you donate, share our message, or join us in walking—even a small step can help bring hidden conditions like PI into the light.”

To get involved, visit <https://www.givenow.com.au/stride-for-primary-immunodeficiencies-2025> and join the movement to support those living with primary immunodeficiency.

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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/>