

World PI Week 2024: Access to care for all PID patients, everywhere.”

Brussels, 21 April 2024 – Around the world, 80% of primary immunodeficiency patients do not yet have access to adequate care. Lack of knowledge around PIDs, gaps in the availability and accessibility of diagnosis and treatments, lack of specialists & multidisciplinary care or shortages of the source material necessary to produce treatments leave individuals and families vulnerable. It's time to shatter these barriers. Let's make universal access to early diagnosis & quality treatment a reality for all those living with PIDs.

This year, World Primary Immunodeficiency (PI) Week (22-29 April) is rallying a call to action that would make a significant impact: “Access to care for all PID patients, everywhere. *Let's make early diagnosis & timely access to quality treatment a reality worldwide.*”

Primary immunodeficiencies occur when a person's immune system is absent or does not function properly, which leaves individuals more prone than other people to infections and predispose them to auto-immunity, allergy, malignancy, or inflammation. There are more than 430 different types of primary immunodeficiencies (PIDs), affecting over 6 million people worldwide and around 70-90% of them go undiagnosed. For this very reason, collecting & sharing data on PID can support greater knowledge about the disease, facilitate testing and early diagnosis, improve personalised care, support patient's early access to treatment and reduce disparities across regions.

[World PI Week 2024](#) underscores the urgent need for equitable healthcare for individuals with Primary Immunodeficiency Disorders (PIDs). Despite the World Health Organization's vision of Universal Health Coverage, discrepancies persist in the level of care available globally, particularly for those with rare diseases like PIDs. It's imperative to dismantle these barriers. Three pivotal areas emerge: first, prioritizing equal access to PID care universally; second, ensuring every PID patient receives timely diagnosis, quality healthcare, and treatment regardless of their demographics or geographic location; and finally, advancing awareness, education, and research to bridge knowledge gaps, ultimately enhancing health outcomes and quality of life for PID patients worldwide.

Thousands of people worldwide will gather for a week of awareness and advocacy, striking a Y to show their support to the cause and helping to increase knowledge, drive investment and action at all levels.

World PI Week is for everyone. Join the many patients, policymakers, healthcare professionals, researchers, journalists, pharmaceutical companies and other partners that come together on 22-29 April to shine the light on what living with a PID means; and how data can deliver change. There are many ways you can bring attention to PID and [mark the campaign](#) – from spreading the word around you or online, to getting involved in an activity organised around you or by donating plasma.

Celebrate World PI Week 2024 and help make a difference for patients and their families around the world.

More information about World PI Week: www.worldpiweek.org

ABOUT PRIMARY IMMUNODEFICIENCY

Primary Immunodeficiencies (PI) are a large and growing group of more than 430 disorders caused by some form of deficiency of the immune system, increasing one's susceptibility to infections and predisposition to auto-immunity, allergy, malignancy, or auto-inflammation. Primary immunodeficiencies are generally recognised as rare disorders but some are more common than others, and it is estimated that six million people worldwide live with a PI. When left undiagnosed or misdiagnosed, the immune system remains defective, leaving the patient vulnerable to illness, physical disability, vital and permanent organ damage, or even death. Learn more information about primary immunodeficiencies and World PI Week efforts [here](#).

ABOUT WORLD PRIMARY IMMUNODEFICIENCY WEEK

World PI Week is a global movement to raise awareness of primary immunodeficiency and related challenges; promote quality of life for people with primary immunodeficiency, early diagnosis, availability and access to treatment and care worldwide; and stimulate communication and advocacy around primary immunodeficiency.

For more information, please visit www.worldpiweek.org, follow us on Twitter @WorldPIWeek.

World PI Week thanks the sponsors including Takeda (gold sponsor) for supporting and making our campaign possible!

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Together, bringing about change for primary immunodeficiency patients worldwide!



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