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World PI Week 2023: Turning real-world data into knowledge for better PID care

Brussels, 21 April 2023 – Robust, quality health data is critical to enhance disease knowledge, healthcare delivery, medical research and innovation, support policy and regulatory decisions; and ultimately benefit patients as well as societies. In rare diseases like primary immunodeficiencies (PID), data is all the more vital to provide more efficient, higher quality, safer and more personalised care.

This year, World Primary Immunodeficiency (PI) Week (22-29 April) puts a spotlight on the value of real-world data in improving diagnosis, treatment and care for patients with PID.

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 2023](#) aims to encourage global collaboration in data collection, sharing and use to turn real-world data into healthcare advances for the benefit of patients. Leveraging real-world data including patient-reported outcomes data can inform priorities for research, care pathways, regulatory and policy decisions, as well as drive a better future and enhanced quality of life for those living with PID. It can change lives.

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 2023 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!

