

***World PI Week 2023 highlights: turning real-world data into knowledge for better PID care***

15 June 2023

*Globally, over 6 million people live with primary immunodeficiencies (PID), among which 70 to 90% remain undiagnosed. The 13<sup>th</sup> World Primary Immunodeficiency Week Campaign on 22-29 April brought forth the importance of real-life health data in improving diagnosis and care of the diseases. Thousands of people worldwide showed support for better quality of life of patients.*

This year, the campaign emphasized how real-world data can be turned into knowledge for better PID care. Data can change lives by speeding up diagnosis, improving patient care, and fostering research into new treatments. World PI Week 2023 was celebrated in over 47 countries, bringing together people from across sectors, generations and regions.

World PI Week 2023 counted on the [support](#) of Dr. Ruediger Krech, Director of the Department of Health Promotion, World Health Organization (WHO). The campaign articulated concrete policy recommendations to close the knowledge gap across regions and direct efforts towards improved use of real-world evidence for the benefit of patients.

**First live event “Patient-Clinician Coffee Talk”**

On 21 April, the very first World PI Week “[Patient-Clinician Coffee Talk](#)” happened live from UZ Leuven Hospital, in Belgium. The debate explored a multitude of topics surrounding data and outlined the value of patient registries. It culminated with the release of a new video highlighting the importance of data from the perspectives of organisations from across the world.

**Why does data change lives? Real-life insights from the PID community**

The “[World PI Week Roadshow Series](#)” brought campaigners to 5 destinations, showcasing daily lives of a patient, a carer, a researcher, an industry partner and a nurse across the globe as they speak about the difference which data makes in their lives or that of those around them.

**Some key highlights of World PI Week at local level**

In [Ecuador](#) the Old Cathedral was illuminated with green and blue lights (World PI Week colours) in the city of Cuenca. [France](#) convened a run and Spain organised a hike in the mountains to show support to PID care. The Chinese patient organisation organised a Kite-Flying campaign in 4 cities that combined kite-flying activities with QR codes allowing participants to access a patient survey and support data collection. [Germany](#) held an impressive “Boy in the Bubble” demonstration in

front of the Parliament in Berlin to increase policymakers' awareness of PIDs, while [Mexico](#) launched *"The Ball is in Your Court"* Policy Campaign calling on the Government to act. [Indonesia](#) celebrated World PI Week with the kick-off of a pilot project to launch a national PID registry. [Malaysia](#) promoted awareness of PIDs in collaboration with the Ministry of Health on online portals. Social media awareness-raising activities took place in the majority of participating countries, including [Canada](#) where a new campaign entitled *"Invisible No More"* was launched asking for greater attention to be given to PIDs. Medical seminars for nurses, specialists and medical students took place in many countries including [Argentina](#), [Belarus](#), [Cyprus](#), [Estonia](#), [Iceland](#), [India](#), [Indonesia](#), [Iran](#) and [Japan](#). In Morocco, Malaysia and several other countries, blood donation drives were organised, as plasma-derived medicinal therapies are an important treatment option for many people with PIDs around the world, who rely on the generosity of donors.

These are just some examples of the many activities that happened around the world on behalf of and with PID patients. Many more are covered in this year's [report](#) released this week on the margins of World Blood Donor Day.

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#### 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](http://www.worldpiweek.org), follow us on Twitter @WorldPIWeek.

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