

***World PI Week 2024 highlights: United towards access to care for all PID patients, everywhere.***

3 July 2024

*Around the world, 80% of people living with primary immunodeficiency (inherited group of diseases resulting in a weakened immune system, leading to increased susceptibility to 'common' infections).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 sometimes shortages of the source material necessary to produce treatments leave individuals and families vulnerable. It's time to shatter these barriers. The 14<sup>th</sup> World Primary Immunodeficiency Week Campaign on 22-29 April mobilised people worldwide around a call for action to lead significant change.*

This year, the campaign emphasized the urgent need for equitable access to healthcare for those living with these genetic diseases. 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. Three key messages were spread during the Week: prioritizing equal access to PID care universally; ensuring every PID patient receives timely diagnosis, quality healthcare, and treatment regardless of their situation - age, gender, or geographic location; advancing awareness, education, and research to bridge knowledge gaps, ultimately enhancing health outcomes and quality of life for patients worldwide.

The campaign received support from two high-level [World PI Week ambassadors](#): Dr.Ruediger Krech, Director of the Department of Health Promotion, World Health Organization (WHO) and Dr. Zhong Liu, Director of the Key Laboratory for Adverse Reactions to Blood Transfusion at the Chinese Academy of Medical Sciences.

**The first-ever World PI Week digital comic book: An Intergalactic Adventure with Immuno-Y**

A new hero emerged during World PI Week 2024 - "Immuno-Y." From 1<sup>st</sup> April to 29<sup>th</sup> April, through a [digital comic book series](#), Immuno-Y embarked on an intergalactic journey, learning about access to treatment and care on Earth. This imaginative approach not only captivated audiences but also sparked conversations about the challenges faced by individuals living with PIDs and opportunities to bring progress.

**A repository of good practices: the World Map of PID Advancements**

The World PI Week [World Map of Advancements](#) served as a window into a variety of inspirational examples and case studies, in awareness raising, advocacy, and significant policy advancements that have contributed to improving access to care for individuals with PID across the world.

#### **#PictureAwareness Contest: Spreading Awareness One Y at a Time**

Across the globe, individuals took part in the #PictureAwareness contest, striking a Y pose to raise awareness for PIDs and show support. This grassroots movement, received very interesting submissions from the Philippines, truly showcasing solidarity and welcomed new participation from countries like Honduras, highlighting our growing PID community signalling that once again brought the community together in solidarity, raised awareness, sparking conversations in communities far and wide.

#### **World PI Week in Action: Spotlight on Some Inspirational Success Stories at Local Level**

In [Canada](#), mayors of 13 cities offered their official support to the World PI Week.

[Spain](#) organized solidarity walks, while France saw a unique one-week bike tour across major cities to project a documentary film about the realities of living with PIDs. This tour, led by the [French](#) patient organization, offered at each stop, the opportunity of a public debate convened by the President of the national patient organization.

[Malaysia](#) hosted a comprehensive three-day event featuring educational meetings, exhibition booths, webinars for medical professionals, and blood collection stands. [Japan's](#) themed patient and family meetings, titled "What are people doing?" provided a platform for the community to connect and share their experiences. In [China](#), a first ever awareness day at a medical university campus was convened to bring medical students closer to the field of PIDs. In [Tunisia, children were](#) directly part of World PI Week celebrations through laboratory visits and animated presentations about PIDs.

On a more poetic tone, [Colombia](#) celebrated World PI Week with a symbolic butterfly release while in [Turkey](#), a novel tree-planting initiative organised in several cities raised awareness and support for the PID cause, adding a green touch to the global efforts.

These varied and impactful activities underscore the global commitment to raising awareness about PIDs, fostering collaborations, and advocating for better healthcare policies and support systems for those affected by primary immunodeficiencies. Many more highlights of this year's campaign, celebrated in over **54** countries, are covered in this year's [report](#).

Together, bringing about change for primary immunodeficiency patients worldwide.

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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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