

World PI Week 2022 highlights: a joint call to improve access to quality healthcare for primary immunodeficiency patients worldwide

27 July 2022

Over 10 million people across the globe live with immune system deficiencies caused by a genetic defect, yet this type of rare diseases, called primary immunodeficiencies, still remains widely unknown. The 12th World Primary Immunodeficiency Week Campaign aimed to bring forth greater awareness and advocacy to improve testing, diagnosis, research and access to treatment. Thousands of people worldwide showed support from 22-29 April to improve the quality of life of patients with primary immunodeficiency (PID).

This year, the campaign is about improving access to healthcare for the millions of people living with Primary Immunodeficiency worldwide. Each patient is entitled to the correct diagnosis, quality treatment, and care. It is a matter of saving lives. To that end, the 2022 campaign focused on four themes: early diagnosis & new-born screening, treatment & care, research and preventative medicine. The Week was celebrated by awareness raising campaigns in the general public, media interviews, solidarity running competitions, call to actions and an International congress bringing together experts and patient representatives.

Policy pledge to make access to quality care a reality for all PID patients

Everyone living with a PID worldwide is entitled to correct diagnosis and appropriate treatment and care. This year, World PI Week campaign unified organisations & individuals and called on policymakers to address current challenges in early diagnosis, access to quality care and research. The [policy pledge](#) was signed by 16 organisations worldwide who are committed to making access to quality care a reality for all PID patients.

International Primary Immunodeficiencies Congress bringing together experts and patients

This year the [International Primary Immunodeficiencies Congress](#) (IPIC 5th Edition) was held in Portugal from 27-29 April. The scientific programme of the congress underpinned patient centredness with an international impact featuring key opinion leaders, experts and patient representatives.

Promoting change through the online campaign “Access to Care Matters”

Each PID patient deserve access to quality care no matter where they live, yet this is not the reality for all those living with the disease. Each day of the World PI Week 2022, stories from patients and carers were published to outline the reasons why it is so important to ensure access to quality care. The [campaign](#) focused on eight main issues: early diagnosis, new-born screening, genetic testing, access to specialist doctors, life-saving treatments, immunoglobulin therapy & access to plasma, transplantation and gene therapy.

International support to raise awareness to improve quality of life of patients

Over 37 countries reported participation to World PI Week 2022 through various awareness raising activities. Patients and experts from [Romania](#), [Belarus](#) and many more shared their stories and facts about PIDs. [France](#) resumed the yearly Solidarity Run while [Canada](#) welcomed its first Annual walk for PIDs to bring a sense of togetherness. In [New Zealand](#) put together a World PI Week Quiz and countries such as [Belgium](#), [Bolivia](#), [Netherlands](#) and [Malaysia](#) shared educational content covering various issues surrounding PID care.

[Australia](#) launched a new Immunodeficiency Strategy to improve the health & wellbeing of people living with PIDs and minimise the burden on individuals, carers, health services and the community. [Ecuador](#) “Lit up torches” to commemorate World PI together with the Ministry of Health and called for Immunoglobulin therapies in the city of Cuenca. [Spain](#) provided courses on PIDs for the nursing staff to improve care given to patients.

Strike a Y and share your PI story to show solidarity

Healthcare professionals, patients and families from all around the world participated in the photo contest #PictureAwareness, striking a Y pose and contributed to [#MyPIStory campaign](#) by sharing their pictures on social media to mobilise and drive global attention.

These are just some examples of the many vibrant and engaging activities that happened around the world on behalf of and with PID patients. Many more are covered in this year’s [report](#).

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.

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contact:

World PI Week office: info@worldpiweek.org

