

World PI Week 2021 highlights: Thousands worldwide striking a Y for primary immunodeficiency

24 June 2021 – Over 6 million people around the world live with immune system deficiencies resulting from a genetic defect. But promoting early diagnosis, access to treatment and care can help change their lives. The 11th World Primary Immunodeficiency Week campaign placed emphasis on the importance of solidarity, collaboration, awareness and education, political attention as well as research and innovation, showing that together, we can make a difference. Thousands of people worldwide struck a Y from 22-29 April to support the primary immunodeficiency (PID) cause. Find out how and what for.

This year, World PI Week focused on three themes as defects of the immune system have taken a different significance in the COVID-19 context: patient safety and protection with an emphasis on vaccination; plasma availability; and quality of life. The Week was denoted by innovative ways of increasing awareness in the general public and beyond and driving positive change, through community discussions, media interviews and expert conversations, solidarity running competitions and plasma donation campaigns. Over 47 countries marked World PI Week worldwide.

Policymakers stand by the PID community to support policy change

This year, the World Health Organisation (WHO) but also the European Commission represented by Health Commissioner Stella Kyriakides officially gave their voices to the campaign for the first time, committing to continue supporting change for people living with rare diseases such as primary immunodeficiency, including supporting earlier diagnosis, healthcare professionals' education, networks of excellence in care and digitalisation of healthcare.

Personal stories and expert insights to understand what primary immunodeficiency means

Patients from [Argentina](#), [Canada](#), [Russia](#), [Spain](#) and many more shared their stories from testimonial videos, 'real life' photos conveying what living with a PID means, workshops, broadcasts to social media campaigns.

Argentina welcomed the first virtual congress for patients with PID. In [Estonia](#), patient stories outlined how diagnosis and care truly changed lives. "Facts & figures" videos involving specialist doctors were launched in countries such as [Brazil](#), [Ecuador](#) & [Kenya](#) to increase knowledge of the warning signs of PIDs. A webinar series was organised in [India](#) to support greater social understanding of the diseases.

Striking a Y in green to increase awareness and solidarity

Healthcare professionals, patients and families from all around the world participated in the [photo contest #PictureAwareness, striking a Y](#) pose featuring the colours of the campaign; and shared their pictures on social media to draw global attention.

Solidarity runs and mobilisation campaigns in support of patients

[Ireland](#), [China](#) and [France](#) organised solidarity runs to give greater visibility to the disease, which created a sense of togetherness globally, in support of PID. Organisations in Italy and Sweden drew attention to the importance of plasma donations to improve the availability & access to treatment through donation campaigns.

Bringing sustainable improvements

Advocacy does not stop with World PI Week. Policy calls to action were launched on the last day of the campaign to emphasize what the main goals for Governments worldwide should be in terms of patient safety and protection, plasma availability, and quality of life; and help continue drive positive change.

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.

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

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