

10 weeks that celebrated 10 years of collaboration and awareness-raising around primary immunodeficiency

Brussels, 9th October 2020 – *In times of a pandemic, solidarity and positiveness are essential. And so is raising awareness of a disease that affects the immune system and has a huge impact on the lives of people affected, without proper diagnosis and treatment. On the occasion of the [International Plasma Awareness Week](#), we release the outcome [report](#) of the World Primary Immunodeficiency (PI) Week 2020. Spotlight on 10 weeks that celebrated a decade of progress and expectations for the future, with the message that the years ahead hold great promise.*

Raising awareness in times of COVID-19 and turning digital

In the light of such special circumstances, World PI Week took place from 22nd April to 1st July 2020. Ten weeks of campaigning that marked the tenth anniversary of the campaign. World PI Week kicked-off with its first-ever webinar, gathering an audience from all continents.

Patient organisations, patients and their families, healthcare professionals, epidemiologists, researchers, and partners across the world found innovative digital solutions to celebrate the Week and spread the word about PI. They participated in the campaign through online educational or 'get together' meetings, awareness videos, virtual walks, radio/TV interviews, social media challenges, in order to stimulate conversations and support knowledge sharing. Digital sessions were convened in many countries to exchange on latest scientific evidence and care models; looking at the links between PI and COVID-19.

Telling the world what it means to live with a compromised immune system

Over 6 million people are affected by primary immunodeficiency worldwide. Most people do not realise or conceive how their life would be if their immune system was not able to protect them from common infections. Paradoxically, the COVID-19 crisis has made this more real for citizens around the world. Recognizing World PI Week this year came with additional meaning.

The majority of campaign supporters have made it a priority to communicate extensively about the disease with personal testimonies. Large numbers of patients and healthcare professionals shared their stories and experiences of living or caring for someone with a primary immunodeficiency during COVID-19; and encouraged the general public to stay home with animated videos, live message boards and other creative initiatives.

In the UK, the Bubble Foundation gave patients a voice with the development of a book compiling messages from PID patients. This is one of many examples.

Plasma donations at the centre of the ten-week effort

Amid COVID-19 and as strains on blood supplies are observed across the globe, many celebrations placed emphasis on the importance of plasma donations. In all countries, participants joined online campaigns encouraging eligible citizens to donate plasma and blood to ensure that people who rely on plasma-derived medicinal products can continue to receive their treatments.

This [World PI Week](#) campaign was very special, but thanks to an amazing and active community, it achieved its objective of helping to improve understanding of diseases of the immune system such as primary immunodeficiency diseases; and prompted efforts encouraging people to protect each other.

ABOUT PRIMARY IMMUNODEFICIENCY

Primary Immunodeficiencies (PI) are a large and growing group of more than 400 disorders caused by some form of deficiency of the immune system, increasing one's susceptibility to infections. 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 underdiagnosed 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 WPIW 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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Together, bringing about change for primary immunodeficiency patients worldwide!