

Patient centricity – turning a vision into action during World PI Week 2019

Brussels, 8th August 2019 – *The wellbeing of patients is what health care is all about. But in reality, how often are patients placed at the heart of the healthcare systems? In a hectic everyday clinical environment, this can sometimes be forgotten. This is why the 9th World Primary Immunodeficiency Week campaign put the focus on patient-centred care. Throwback to a week of awareness raising and advocacy with the message that health care be designed and delivered with and for patients.*

In April 2019, national primary immunodeficiency organisations, patients, families, physicians, experts and partners in over 48 countries advocated for considering patients' needs as the driving force behind healthcare. The activities were as diverse as the community itself.

Spreading awareness about what patient centricity in primary immunodeficiency really means

There are over 380 different types of primary immunodeficiencies and over 10 million people are affected worldwide. Patient centricity implies empowering patients and their families, involving them in decisions about their care, helping ensure each patient has a treatment plan that responds to his/her needs and re-structuring services in a way that delivers the best possible outcome for patients.

During World Primary Immunodeficiency Week 2019, many activities focused on information sharing with the general public and the healthcare community: highlighting “the why and how” of [patient-centred care](#). This included educative sessions and discussions on personalised care, treatment options and patient empowerment.

Animating real life stories of children living with the disease

There is no better way of helping understand the value of patient centricity and responding to individual patients' needs than hearing what living with the disease is all about from their perspectives. The [Bubble Foundation UK](#) organised a campaign offering kids the opportunity to have their drawings brought to life through animation, providing a deep dive into the realities of patients' lives and their aspirations.

Rallying the expert “troops” to activate and communicate knowledge across networks

In [Brazil](#), immunologists from different regions gathered to discuss diagnosis and treatment; and activate an awareness raising campaign including videos, interviews and social media activities. Healthcare professionals in [Canada](#), [Ireland](#), Mexico and [El Salvador](#) shared their expertise behind the camera or on TV to spread knowledge. An expert group for the management of primary immunodeficiencies was created in the University Hospital of Canarias (Spain).

Turning calls for action into tangible reality

In countries such as Australia, Belgium, Germany, the Philippines, Senegal, Spain and Uganda, collaboration and engagement with local policy makers, including mayors and national Parliamentarians, or celebrities offered an opportunity to discuss policy change and action; and bring the vision of the primary immunodeficiency community to the attention of the wider public and policy actors.

Other activities in [Belgium](#), [Brazil](#), China, Finland or Malaysia focused on bringing together not only patients, their families, friends and experts, but also medical students, social carers and psychologists to exchange ideas and experiences to progress disease management and care.

Stimulating blood donation to sustain life-saving treatments

Because immunoglobulin replacement therapy, a main treatment for primary immunodeficiency, is made from human plasma, blood donation is a “gift of life” for patients. In countries such as Morocco and Thailand, emphasis was placed on blood donation days and campaigns.

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

World PI Week is over for 2019, but raising awareness never stops. Next year, the campaign will celebrate its 10th anniversary and will continue to help bringing about change so that patients and their families have access to diagnosis, the treatment and care they need.

ABOUT PRIMARY IMMUNODEFICIENCY

Primary Immunodeficiencies (PI) are a large and growing group of more than 350 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!