

## **Actions speak louder than words: 8 days of recognition of Primary Immunodeficiency (PI) around the world**

*Brussels, 14<sup>th</sup> of June 2018 (World Blood Donor Day) – Imagine living with a rare disease that prevents your immune system from fighting common infections – it would dramatically impact your life. But early testing and diagnosis as well as appropriate treatment could change this reality and allow you to lead a healthy and productive life. This was the takeaway message of the many grass-roots actions that took place during the eight days of April that marked the 8<sup>th</sup> [World Primary Immunodeficiency Week \(WPIW\)](#).*

70-90% of people living with Primary Immunodeficiency (PI) worldwide still remain undiagnosed. However, responding to the PI diagnostic challenge can change lives. Fighting for early testing and diagnosis of PI was the key message of the PI community during the campaign week which ran from the 22<sup>nd</sup> to 29<sup>th</sup> of April. National PI organisations, patients, families, physicians, experts and partners in over 40 countries generated campaigns, patient-specialist meetings, educational conferences, public lectures, TV and radio interviews to put the spotlight on the importance of early recognition of PI, under the theme “*My future starts with early testing and diagnosis of PI*”.

**Telling the world about what it is like living with PI:** ‘Have you ever wondered how your life would be without a fully functioning immune system?’ In many countries that engaged in World PI Week, the focus was on storytelling, to raise awareness of how an early testing and diagnosis of the disease makes a world of difference for patients with PI. Many patients and their carers invited people to enter their worlds via video clips in [Estonia](#), [Malaysia](#), and with ‘screenlife’ messages in [New Zealand](#) and [Russia](#).

**There is no health without knowledge - enhancing knowledge on PI diagnosis and treatment:** World PI Week was the occasion to inform patients and healthcare professionals, from medical students, primary care doctors to nurses, immunologists and other specialised professionals on the latest advances in PI to leverage expertise, education, and diagnosis early-on. Patient-expert dialogues took place in all participating countries, particularly in the context of international conferences on PI. The 8<sup>th</sup> National Conference of Patients with PI in Belarus built on the active support and participation of the Ministry of Health. The 6<sup>th</sup> Symposium on PI - Paediatric Immunology in Greece allowed discussions on newborn screening, vaccination and registries for PI and aligned with the International Day of Immunology on 29<sup>th</sup> of April. In Venezuela, meetings with national health authorities were convened on the sidelines of the national PI patients meeting.

**Empowering patients:** Meetings including exchanges with experts, legal and psychological support were convened in more than half of the countries that joined the campaign. For the first time, a national conference of PI patients was held in Romania, and a free hotline to consult with immunologists was made available in Russia.

**Connecting the dots:** Several countries organised ‘get connected’ sessions between blood donors and patients, since people with PI rely on the generosity and commitment of plasma and blood donors, and these donations are an essential gift to develop life-saving immunoglobulin treatments and other plasma-derived medicinal products. Blood donation days in Malaysia and Morocco reached high donation rates.

**Meaningful efforts were placed on raising public awareness:** Press conferences, TV reports and TV interviews with specialists in immunology were organised in all regions of the world, from Bolivia, Mexico, Canada to Germany, Belarus and Iran. Radio shows and interviews on PI were live on national radio channels in several countries, and national PI webcasts ran in Canada, as a learning opportunity for physicians and the general public. In Russia, live TV-ads were broadcast on national TV, while for the first time awareness-raising activities were conducted at the workplace to spread the word about PI “without borders”, in partnership with third party businesses and private companies.

The successful World PI Week initiatives were diverse (read the [report](#)), but raising awareness of PI and driving public and political action is a never-ending process, and in the lead up to the 2019 World PI Week campaign, the PI community will continue to stimulate understanding and advocate for a better diagnosis, treatment, care and quality of life for the estimated 6 million people living with PI worldwide, and their families.

### About Primary Immunodeficiencies:

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. PI 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 PI and WPIW efforts here.](#)

## Test. Diagnose. Treat!

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