



PRESS RELEASE

World PI Week: 7 days to raise awareness on Primary Immunodeficiency (PI)

From 22-29 April 2016, the global Primary Immunodeficiency community - including patients, nurses physicians, scientists, family carers and industry -- organizes awareness raising activities around the world to celebrate the "World Primary Immunodeficiency Week".

Started in 2010, the World PI Week aims to raise awareness of this devastating condition and to ensure that primary immunodeficiency is taken out of the shadows and into focus as a health priority.

Primary immunodeficiency (PI) diseases occur in people with an immune system that is either absent or deficient in its ability to function. Because PI often presents in the form of "common" infections, physicians can sometimes treat the infections while missing the underlying cause, allowing the illnesses to reoccur, and leaving the patient vulnerable to vital organ damage, physical disability, or even death.

Thanks to research and medical progress over the last 60 years, life-saving treatments have been developed, including immunoglobulin replacement therapies, bone marrow transplantation, gene therapy, antimicrobial and antifungal and prophylactic antibiotics, and emergency medicine.

However, access to these treatments vary significantly across continents and even countries of the same region: access to bone marrow transplantation and gene therapy for severe types of immunodeficiencies is the rule in most countries in North America and Europe, whereas it is available only in a very small number of centers in Latin America, Asia and Africa. Likewise, while national health systems cover treatment with intravenous or subcutaneous immunoglobulin (IgG) in most European countries, these treatments are not always reimbursed in poorer regions of the world despite extensive evidence that early diagnosis and proper treatment are life-saving, life-enhancing and always cost-saving, as they prevent unnecessary co-morbidity for PI patients.

For this reason, in 2016, the PI community raises its voice to call on policymakers, health authorities, payers, healthcare professionals and the general public to put in place the relevant mechanisms to ensure that all PI patients can access the care they are entitled to in order to live normal and productive lives.



Hospital symposia, info sessions, walks, community initiatives, social media outreach, lectures in schools and media events and more will be organized around the world this week. Please check World PI Week website (www.worldpiweek.org) for more information on the activities in your country!

About primary immunodeficiency:

Despite being referred to as “rare diseases”, primary immunodeficiency (PI) is a growing category of 300 different disorders resulting from some form of deficiency of the immune system. Primary immunodeficiency is said to affect more than six million people worldwide.

Test. Diagnose. Treat!

For more information on World PI Week: www.worldpiweek.org



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