



## PRESS RELEASE

### **World PI Week: United stakeholders raising awareness of Primary Immunodeficiency (PI) worldwide**

Over the period of 22<sup>nd</sup> to 29<sup>th</sup> of April 2017, around the world the Primary Immunodeficiency (PI) community is celebrating “World Primary Immunodeficiency Week” (WPIW). Patients, nurses, physicians, scientists, family carers and industry join forces to hold awareness-raising activities and support events across five continents.

World PI Week was initiated in 2010 with the aim to raise awareness of Primary Immunodeficiency globally, increase understanding of the conditions and ensure that they are prioritised in health policies in all countries to improve the diagnosis, treatment and quality of life of people with PI.

Primary Immunodeficiency diseases are hereditary and genetic disorders of the body's immune system which is partly or totally missing, or does not function properly. These deficiencies lead to increased susceptibility to a wide range of infections affecting different parts of the body including the skin, ears, lungs, intestines, etc. They are often chronic, persistent and debilitating. While antibody deficiencies are the most commonly diagnosed type of PI, over 300 forms exist. A key challenge is in diagnosis because they often present in the form of “common” infections, so practitioners may only treat the infections while un/misdiagnosing the underlying cause. This situation means the infection will reoccur and leaves individuals vulnerable to permanent organ damage, physical disability or even death. However, once recognized, these rare disorders are treatable and in some cases curable.

In 2017, the PI Community is united to ensure that access to life-saving immunoglobulin therapies for people with PI is raised on the agenda of policymakers, health authorities, payers, healthcare professionals; and promoted by the general public. Together, the PI Community calls on all stakeholders to address the barriers that prevent access to the best suited immunoglobulin replacement therapy for each individual with PI.

Over the past six decades, medical research and progress have helped develop life-saving treatments for people with PI. Different treatment now exist, including immunoglobulin replacement therapy, gene therapy or transplantation. Immunoglobulin (Ig) replacement therapy is the most important treatment for a majority of PI<sup>1</sup> and has been highly successful in preventing and managing patients’ susceptibility to infections<sup>2</sup>. It consists in the regular administration of immunoglobulin therapies derived from human

<sup>1</sup> IPOPI (May 2012), Position statement on “Access to Immunoglobulin Therapies for patients living with a Primary Immunodeficiency”

<sup>2</sup> Modell V and alt. (21 September 2011), Global study of primary immunodeficiency diseases (PI)— diagnosis, treatment, and economic impact: an updated report from the Jeffrey Modell Foundation, Immunol Res (2011) 51:61–70 DOI 10.1007/s12026-011-8241-y



**Test. Diagnose. Treat**

Ensuring access to life-saving immunoglobulin therapies for people with primary immunodeficiency

**22nd – 29th April 2017**

Raising Awareness for Diagnosis and Treatment of PI Together!

www.worldpiweek.org  
@WorldPIWeek

**World PI Week**  
Test. Diagnose. Treat.

plasma which provide antibodies to protect individuals against infections. Although Ig therapies are included in the WHO Model List of Essential Medicines<sup>3</sup>, significant disparities exist across the globe in access and availability of treatments, including across countries of a same region. Reimbursement in national health care systems plays a key role in ensuring access to the therapies, but these are not always equally reimbursed in countries, despite evidence of their scientific validity and improved health outcomes and often there is no alternative treatment for qualifying patients. In addition to bringing significant improvements to the quality of life, life expectancy and productivity of people with PI, early diagnosis and the administration of appropriate treatment have a consequent economic impact on the health care systems, as they prevent the occurrence of comorbidities and generate savings for related or avoidable costs of care.

***For the seventh consecutive year, the global PI community gets together to bring about positive changes in healthcare systems and practices worldwide in support of people with PI and their families. Learn more about the activities held in your region or country on [World PI Week website](http://WorldPIWeek.org) and join the seminars, public lectures & info sessions, walks, community initiatives, social media activities, press conferences, media events taking place around you!***

About primary immunodeficiency (PI):

Despite being classified as “rare diseases”, PI is a growing category of more than 300 disorders caused by some form of deficiency of the immune system, increasing one’s susceptibility to infections. It is estimated that PI affects over six million people all over the world.

**Test. Diagnose. Treat!**

For more information on World PI Week: [www.worldpiweek.org](http://www.worldpiweek.org)

- Like World PI Week [Facebook](#) page
- Follow World PI Week on Twitter: [@WorldPIWeek](#)
- Share your pictures

<sup>3</sup> WHO (April 2015, revised November 2015), WHO Model List Of Essential Medicines

