



Press Release

3rd World PI Week unites millions of people fighting for global testing, diagnosis and treatment of primary immunodeficiencies

22nd-29th of April 2013 - marks World PI Week – a week of global action organized by the primary immunodeficiency (PI) community. Now in its third year, World PI Week has grown to become a widely celebrated event focused on increasing awareness and recognition of primary immunodeficiencies as an important disease category.

Throughout an entire week culminating on World Immunology Day on 29th April, the global PI community will be sending a united message to healthcare professionals and health authorities to **'Test. Diagnose. Treat'** this under-recognized condition.

So what are primary immunodeficiencies? Primary immunodeficiency diseases occur in persons born with an immune system that is either absent or hampered in its ability to function. There are over 200 forms of PI, ranging widely in severity. PI often presents itself in the form of "common" infections sometimes leading physicians to treat them while missing the underlying cause, allowing the illnesses to reoccur, and leaving the patient vulnerable to vital organ damage, physical disability, or even death.

Commenting on the need for increased recognition of the disease, Johan Prevot, Executive Director of IPOPI, the International Patient Organisation for Primary Immunodeficiencies, pointed out: 'Being sick all the time does not only affect the person living with this disorder but the whole family. It also brings about important socio-economic repercussions. Early diagnosis will enable people living with a primary immunodeficiency to access life-saving and life-enhancing treatments and to live their lives to the full. Today, a large majority of PI patients still do not have appropriate access to treatment. In order to tackle this issue, increased awareness is essential. This year join us during World PI Week to raise global awareness about primary immunodeficiencies and help us to "Test. Diagnose. Treat"!

Fortunately, with proper medical care, many patients can live full and independent lives but awareness of these conditions amongst physicians and other healthcare professionals is low. Grave inequalities remain across the world in terms of access to early diagnosis and optimal treatment. Indeed, as highlighted in a recent study: 'upper estimates suggest that six million people may be living with a PID worldwide, whereas only 27,000-60,000 have been identified to date (all national registries and the Jeffrey Modell Centers Network, respectively)¹. Awareness is therefore crucial to improve public health policy towards this important disease.

¹ Bousfiha AA, Jeddane L, Ailal F, Benhsaien I, Mahlaoui N, Casanova JL, Abel L. Primary immunodeficiency diseases worldwide: more common than generally thought. J Clin Immunol 2013;33:1-7





Through the many events being organised world-wide on the occasion of World PI Week 2013, the PI community has a unique opportunity to unite in support of increased recognition, prompt diagnosis and appropriate care of primary immunodeficiencies.

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



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NOTE

World PI Week Partners:

ASID, African Society for Immunodeficiencies
CIS, Clinical Immunology Society
CI Society, Canadian Immunodeficiency Society
EFIS, European Federation of Immunological Societies
ESID, European Society for Immunodeficiencies
The Immune Deficiency Foundation (IDF)
INGID, International Nursing Group for Immunodeficiencies
IPOPI, International Patient Organisation for Primary Immunodeficiencies
JMF, Jeffrey Modell Foundation
LASID, Latin American Society for Immunodeficiencies
PPTA, Plasma Protein Therapeutics Associations

The World PI Week Partners thank Baxter and CSL Behring for supporting World PI Week 2013.

