



Draft Press Release

4th World PI Week: It is not just another cold

Seven days of global action to take primary immunodeficiencies out of the shadow

22nd-29th of April 2014 – For the fourth consecutive year the primary immunodeficiencies (PI) community joins forces to celebrate World Primary Immunodeficiency week (WPIW). On this occasion patients, healthcare professionals, and the general public gather together for seven days to call for increased awareness of this devastating condition and mobilize to take it out of the shadow through concerted global action.

Under the slogan ***Test. Diagnose. Treat.*** World PI week unites, empowers and engages all global stakeholders in the PI cause. Patients, nurses, physicians, scientists, allied health professionals, and industry will together advocate for testing, optimal care and the best possible treatment for a disease that although classified as rare, affects more than six million people¹ worldwide, with no gender, age or geographical boundaries.

Primary immunodeficiency (PI) diseases occur in persons born with an immune system that is either absent or deficient in its ability to function. PI often present in the form of "common" infections, sometimes leading physicians to 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.

One in 1200² people are suspected to live with a genetic primary immunodeficiency that significantly affects their health. However lack of awareness means that between 70 to 90% of PI sufferers remain undiagnosed, with their healthcare practitioners treating PI related infections as common flus. With early diagnosis, proper care and optimal treatment the disease is manageable and can save patients from lifelong disabilities, unnecessary vaccinations and lengthy hospital visits. Detecting the disease early can improve patients' conditions offering them all the opportunity to live full and rewarding lives.

During the 4th edition of WPIW, we will address this awareness deficit with walkathons, educational initiatives, social media outreach, lectures in schools, hospital symposia and media events across the globe.

¹ Ahmed Aziz Bousfiha & Leïla Jeddane & Fatima Ailal & Ibtihal Benhsaien & Nizar Mahlaoui & Jean-Laurent Casanova & Laurent Abel, Primary Immunodeficiency Diseases Worldwide: More Common than Generally Thought, *Journal of Clinical Immunology* 2013;33: 1-7

² J.M Boyle, R.H. Buckley - Population Prevalence of Diagnosed Primary Immunodeficiency Diseases in the United States; *Journal of Clinical Immunology* (2007) 27:497–502



Listen and Learn – Test. Diagnose. Treat!

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
EFIS, European Federation of Immunological Societies
ESID, European Society for Immunodeficiencies
Immunodeficiency Canada
IDF, 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 2014.