



Press Release

World PI Week: Turning Hope into Action!

Seven days of action to call for early diagnosis and optimal care for patients with primary immunodeficiency

22nd-29th of April 2015 – For the fifth consecutive year the primary immunodeficiency (PI) community joins forces to celebrate World Primary Immunodeficiency week (WPIW). On this occasion patients, families and healthcare professionals work together to call for increased awareness of this devastating condition and mobilise 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. Together patients, nurses, physicians, scientists, allied health professionals, and industry will advocate for testing, optimal care and the best possible treatment – including access to prophylaxis Immunoglobulin (Ig) therapy, antibiotics, antifungal medications, bone marrow transplants, or gene therapy where appropriate. Primary Immunodeficiency is a complex condition requiring a complex therapy; while classified as rare, PI affects more than six million people worldwide, with no gender, age or geographical boundaries.

Primary immunodeficiency (PI) diseases occur in persons 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 1200¹ 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 occurrences. 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.

This year for WPIW, we will address this awareness deficit with walkathons, community initiatives, social media outreach, lectures in schools, hospital symposia and media events including a global balloon launch in which balloons are released simultaneously,

¹ 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



to drive awareness of PI. This year will be the biggest lift off yet – over 110 locations around the world!

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 WPIW 2015.

