



Press Release

World PI Week, a global awareness campaign to save the life of millions of people.

22 April – Despite the fact that this disorder affects 10 million people worldwide, most people do not know what primary immunodeficiencies are.

Celebrating its second annual awareness campaign on 22-29 April, with a focus this year on "**access to appropriate treatment**", World PI Week aims to reverse this lack of understanding by raising awareness of primary immunodeficiencies.

Primary Immunodeficiencies are genetic defects in the immune system, most

of which are hereditary. They cause increased susceptibility to a wide range of infections, affecting the skin, the ears, the lungs, the intestines and other parts of the body. What we may mistake as repeated bad flu, ear infections, sinus infections, intestinal problems etc., may in fact well hide a deficiency in the immune system. In practice, many doctors will treat these infections with repeated prescriptions of antibiotics with little effect, and instead miss the underlying cause. The consequences can lead to vital organ damage or even be fatal in some cases. Meanwhile, this also means for healthcare systems unnecessary associated costs due to the extensive use of medication to treat the symptoms and high rates of hospitalisation. For children it also means many missed days of school and for adults missed days of work.

Speaking about her own experience, Gabrielle, who lives in Johannesburg South Africa, said "at the age of 34, I have finally reached a point of independence in managing my illness. With the support of family and a team of professionals through dedication, attention, trial and error, I now am able to live a more full and free life. Free from lengthy hospital visits, free from being sick in bed, free to work, free to have a great life and lifestyle. This illness is manageable with an accurate diagnosis and proper treatment and the freedom that accompanies that, is a gift that I wish for anyone who is still suffering in the fear of the unknown".

Awareness is therefore crucial, and "the upcoming World PI Week is an excellent opportunity to further achieve our goal of educating the medical and general community about PIs. Their awareness will increase prompt diagnosis and better access to appropriate treatment of children





and adults whose past prognoses were very poor" stressed Prof Ricardo Sorensen, founding partner of World PI Week.

Last year multiple events took place across the globe, led by patient organisations, physicians and nurses. This year WPIW hopes to repeat the successful launch of its campaign to drive a global movement around PI and call upon countries across the world to take heed of these devastating and under-diagnosed diseases by developing national strategies that address primary immunodeficiencies. - END

The World PI Week Partners thanks Baxter and CSL Behring for supporting the second World PI Week

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Note -

World PI Week Partners include the following organisations:

ASID, African Society for Immunodeficiencies
CIS, Clinical Immunology Society
EFIS, European Federation of Immunological Societies
ESID, European Society for Immunodeficiencies
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 Association

