



**World PI Week and Rare Disease Day:
Day-by-day, hand-in-hand, in support of individuals isolated by rare diseases**

28 February 2015 - World PI Week stands in support of Rare Diseases Day and calls upon the international health community today to recognise the 60 million people who experience the isolation of living with a rare disease every day.

The theme for the 2015 Rare Disease Day is **Living with Rare Diseases**. In a renewed effort to raise awareness through this annual campaign, this year's edition shines a light on the daily lives of families, friends and carers of rare disease patients. Recognising the essential role played by the community around rare diseases patients, World PI Week embraces the campaign's action to mobilise solutions for better care worldwide. Similarly, World PI Week annually raises awareness of the recognition of primary immunodeficiencies, which represent almost 250 of the 7000 known rare conditions affecting 60 million people worldwide.

Primary immunodeficiencies are disorders in which part of the body's immune system is missing or does not function properly. When a defect in the immune system is inherited, it is called primary, or inherited, immune deficiency, ranging widely in severity. PI often presents itself in the form of 'ordinary' infections, this being the main reason for misdiagnosis, inappropriate care, recurring illness and physical disability.

Striving for optimal care and treatment for patients with rare disease has important repercussions for the whole family. Living with a rare disease becomes a daily learning experience for patients and families. How to find a diagnosis, how to access and administer the right treatment, how to identify the right social services or to manage the economic burden of the disease are only some of the challenges that the patient could not face without their support network.

It is fundamental to create a network of solidarity that unites patients, families, caregivers, healthcare professionals, social services, researchers, industry and policy makers. Giving voice to the rare disease patients and their families, the two campaigns share the same goal to improve quality of life of patients and guarantee for them early diagnosis and optimal care.

Celebrated every year on 22–29 April and through the organisation of hundreds of events around the world, World PI Week brings together patients, parents, carers, healthcare professionals and politicians to raise awareness on primary immunodeficiencies.
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For more information on **Rare Diseases Day 2015**: <http://www.rarediseaseday.org/>

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

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