



PRESS RELEASE

World PI Week and Rare Disease Day: United to fight sufferers' isolation

World PI Week supports Rare Disease Day 2014

28 February 2014 - Embarking on its 4th Edition, **World PI Week**, supports **Rare Diseases Day** calling for collaboration for better care and encouraging the rare disease community to mobilise necessary resources to improve lives of those who feel isolated by their condition.

The theme for Rare Disease Day 2014's is **Join for Better Care**. Although rare conditions differ enormously, they commonly mark patients' struggle for care and isolation. World PI Week embraces the campaign's action to mobilise solutions for better care worldwide. World PI Week annually raises awareness on the recognition of primary immunodeficiencies, which represent between 200 and 250 of the 7000 known rare conditions affecting nearly 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 a 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 inappropriate care, recurring illness and physical disability.

Striving for optimal care underpins a cross border effort that brings together scattered knowledge and advancement in research, regardless the world's different levels of rare diseases' care. While these conditions in Europe have recently benefited from the introduction of policies to improve treatment, the establishment of dedicated national plans and of EU expert groups supporting public authorities, there are still many patients in many areas of the world that do not focus efforts on prompt diagnosis and optimal treatment. Raising awareness amongst physicians, healthcare professionals and public authorities becomes crucial to give visibility to the many facets of rare diseases.

World PI Week and Rare Disease Day join forces today to give voices to rare disease's sufferers and to create a network of solidarity with the goal of ending the isolation of these patients. Giving voice to the rare disease patients, 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 organization of many events in the world, World PI Week brings together patients, parents, carers, healthcare professionals and politicians to raise awareness on primary immunodeficiencies.

For more information on **Rare Diseases Day 2013**: <http://www.rarediseaseday.org/>

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



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