



PRESS RELEASE

World PI Week and Rare Disease Day: United to Fight for Increased Awareness

World PI Week lends its support to Rare Disease Day 2013 in calling for international cooperation in the fight against Rare Diseases



28 February 2013 – United to voice the need of over one hundred million people living with rare diseases around the world, World PI Week joins forces with Rare Disease Day to encourage governments across the globe to act for increased awareness of these diseases and to establish comprehensive national plans so that affected patients get the care they need.

Rare Diseases Day annually shines a light on almost 7000 conditions, of which at least 250 conditions are primary immunodeficiencies (PI), representing an important sub group. Previous awareness campaigns increased the number of patients recognized suffering from PID, but still many other patients around the world are not diagnosed and treated accordingly.

Primary Immunodeficiencies (PI) are hereditary and genetic defects in the immune system that cause increased susceptibility to a wide range of unusual, severe and chronic infections affecting different parts of the body. These infections can be persistent and debilitating leading in many cases to early death. Often misdiagnosed for their symptoms rather than their cause, primary immunodeficiencies' main challenge is the need for greater awareness. Rare Disease Day's 2013 theme is ***Rare Disorders without Borders*** and World PI Week joins Rare Diseases Day's call for increased cross border collaboration to take patients out of their isolation and help close the gap in the access to correct diagnosis and appropriate treatment.

While improvements have been made to address rare diseases in Europe, with the adoption of national rare disease plans and the important establishment of a Rare Diseases reference network under the EU Cross border Healthcare Directive, disparities across the world are still hampering the improvement of the quality of life and best treatment options for patients. Awareness is the first step towards better recognition of rare disease patients, and global awareness campaigns such as Rare Disease Day and World PI Week can truly help by promoting the exchange of best practices and expertise and pushing for adequate policies which tackle rare diseases including primary immunodeficiencies. Because of their low frequency and sometimes expensive treatment, rare diseases can be viewed as an easy target for healthcare budget cuts in a difficult economic climate. The true cost saving effect and improved quality of life that comes with early diagnosis and treatment needs to be constantly emphasized.





World PI Week marks this occasion to encourage patients, doctors, researchers, policy makers and industry to work together to remove the barriers for the effective implementation of healthcare policies and strategies at national levels that can benefit rare disease patients and their families and to urge the PI community to sign the Global Call to Action for increased recognition.

Celebrated every year on 22 – 29 April, World PI Week brings together patients, parents, carers, healthcare professionals and politicians and contributes in raising awareness and international cooperation for 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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