



Primary Immunodeficiency Community Supports Rare Disease Day

Brussels – 29 February 2016

Accounting for about 250 of the 6,000 recognised rare conditions, Primary Immunodeficiency (PI) affects more than six million people worldwide. United under the “World PI Week” banner, the PI community, from patients to healthcare providers and family carers, expresses its affinity with the broader rare disease community today, to continue raising awareness about orphan diseases. Alongside the Rare Disease community, PI advocates call for a coordinated approach, research cooperation and scientific knowledge sharing around these diseases towards improved therapeutic and diagnostic processes.

As with other rare diseases, daily life for patients diagnosed with PI is fraught with challenges. Primary immunodeficiencies are disorders in which part of the body's immune system is missing or does not function properly and can, if not treated, be chronic, serious and even fatal. Thanks to research and medical progress over the last decades, most of these conditions are now manageable, yet because symptoms are those of common and recurrent infections, PI often remains undiagnosed, misdiagnosed, or late-diagnosed.

The theme of this year's Rare Disease Day is “Patient Voice”, recognising the crucial role that patients play in voicing their needs and in initiating change that improves their lives and the lives of their families and carers. Just like World PI Week, Rare Disease Day amplifies the voice of orphan disease patients to a collective that it is heard all over the world.

In line with Rare Disease Day, patients, parents, carers, healthcare professionals and politicians will organize hundreds of events around the world on 22–29 April to raise awareness on Primary Immunodeficiency and how to improve its diagnosis and treatment.

By bringing patients' lives into the spotlight, the rare disease community hopes to contribute to bringing about change and achieve equal access to quality treatment and care at local, national and European levels for patients – a goal that is equally high for PI patients and advocates as illustrated by WPIW 2016 theme “Improving Access to Care for patients with Primary Immunodeficiency”. Indeed, despite life-saving treatments having been developed for patients affected with PI, access to care can vary significantly across continents and even countries of the same region.

For more information on **Rare Diseases Day 2016**: www.rarediseaseday.org

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

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