



Rare Disease Day: Primary Immunodeficiency Community calls for increased research on PI diseases

Brussels – 28 February 2017

Today, the rare disease community all over the world celebrates Rare Disease Day. As the theme of this year's edition is research, so as to highlight its fundamental role in improving treatment, cure or care for people with rare diseases, the PI Community underlines the need for greater research on Primary Immunodeficiency (PI).

On the occasion of Rare Disease Day 2017, the Primary Immunodeficiency Community - united under the "World PI Week" campaign - is calling for increased research on Primary Immunodeficiency (PI), to improve understanding of PI diseases but also support the development of new innovative treatments for people with PI, in line with the theme of the World PI Week Campaign 2017: *"ensuring access to life-saving immunoglobulin therapies for people with primary immunodeficiency"*.

Over six million people live with a Primary Immunodeficiency worldwide. PI accounts for more than 250 of the 6,000 recognised rare conditions. PI diseases are hereditary disorders in which part of the body's immune system is missing or does not function properly and can, if not treated, be chronic, and even fatal. Primary immunodeficiencies challenge the daily lives of people with these conditions, similarly to other orphan diseases. While there have been significant research and medical progress over the past decades making the condition manageable, the commonalities between PI symptoms and other recurrent infections lead to difficulty for practitioners and healthcare professionals to appropriately and early diagnose the diseases. Many people with PI are undiagnosed, under-diagnosed, or misdiagnosed.

This is why today, the PI community - including patients, nurses physicians, scientists, family carers and industry - reaffirms its support to the broader rare disease community, with a joint objective to continue raising awareness of rare conditions and strengthen research. Together, PI advocates call for a coordinated approach on PI diseases, cooperation in research and scientific knowledge sharing, as well as greater patient engagement in research processes.

From the 22nd to 29th April 2017, the PI community will raise voices and actions to inform about Primary Immunodeficiency and aim to improve access to life-saving immunoglobulin therapies for people with these rare, chronic conditions. Such treatments exist for people with PI, but access to them can vary significantly across continents and countries of a same region. The World PI Week wishes to help drive change and equal access to quality treatment for patients at all levels.

For more information on **Rare Diseases Day 2017**: www.rarediseaseday.org

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

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