

Brussels – 29 February 2020

Although Rare, we - the Primary Immunodeficiency Community - are Many, Strong and Proud!

On the occasion of Rare Disease Day 2020 – a special day as it falls on a leap year – the primary immunodeficiency community joins forces with rare disease advocates to promote the spirit of **celebrating ‘Rare’**.

Primary immunodeficiencies, a **group of inherited and genetic defects of the immune system**, are considered rare but still they are estimated to affect over **6 million people worldwide**, with infants and children more commonly having serious forms of the disease.

When living with a primary immunodeficiency, the patient’s immune system is compromised. This can lead to recurring infections as well as autoimmune, autoinflammatory, allergy diseases and cancer. Primary immunodeficiency patients are more susceptible to a wide range of infections, affecting many different parts of the body, which are often chronic and debilitating in nature. Primary immunodeficiency significantly influences patients’ **quality of life, and may limit working ability** and engagement in **physical** and **social** activities.

2020 represents a very unique year for the primary immunodeficiency community, as it honours the 10th anniversary of the World PI week campaign (22-29 April). As such, this year’s theme **is all about celebrations**: celebrating ten years of outstanding collaboration and awareness-raising efforts across the globe to put primary immunodeficiency on the map.

Equity, the theme of the 2020 edition of Rare Disease Day, is inherent to those who live with primary immunodeficiency. The World PI week aspires to fight inequalities in rare diseases which unfortunately persist, to ensure that people living with primary immunodeficiency have the same access to early diagnosis, treatment and care worldwide, as anyone else.

Through this year’s celebration, we will help to spread awareness about what it means to be living with or be affected by a rare disease, such as primary immunodeficiency. This will help the public to better understand the unmet needs of this ‘Rare’ community to ensure no individual with primary immunodeficiency nor any other rare disease is left behind.

Although we still have a long way to go, the 2020 World PI week campaign will take stock of achievements and celebrate life: celebrate the lives of patients and carers, positive research outcomes, an ever-growing understanding of primary immunodeficiencies and aspirations for the future.

Please join us in celebrating Rare Disease Day 2020 and World PI Week 2020 to ensure that the voices of millions of people living with primary immunodeficiency are heard.

For more information on **Rare Diseases Day 2020**: see [here](#)