

The Importance of Rare Disease Day

by Nicole Shen

Patients around the world will mark the tenth annual Rare Disease Day on Tuesday, February 28th. A rare disease, also referred to as an orphan disease, is any disease that affects a small percentage of the population. Most rare diseases are genetic, and thus are present throughout the person's entire life, even if symptoms do not immediately appear. Many rare diseases appear early in life, and about 30 percent of children with rare diseases will die before reaching their fifth birthday. [Global Genes](#) have estimated that more than 300 million people worldwide are living with one of the 7,000 diseases they define as "rare" in the United States. Over the last 10 years, Rare Disease Day has become iconic as the global campaign for raising awareness of rare diseases among politicians, clinicians, researchers, and pharmaceutical companies. Rare Disease Day is a patient-led campaign that EURORDIS-Rare Diseases Europe and its Council of National Alliances launched in 2008. Since then, thousands of patient organizations in over 100 countries and regions have held tens of thousands of events. Rare Disease Day brings together millions of patients, families, caregivers, medical professionals, policy makers, and members of the public in solidarity - everyone can get involved! Organizations in over 80 countries and regions are participating in Rare Disease Day 2017, by holding local events. Rare disease research needs more attention and more funding. We need to shout loudly to make sure all researchers, universities, doctors, and companies know that we need a huge commitment from everyone involved to do more research. Through research, we can ensure that more patients get the answers they need about their diseases. The Rare Disease Day 2017 theme is Research and slogan, "With research, possibilities are limitless."

Rare disease research is crucial to providing patients with the solutions they need, whether it is a treatment, cure, or improved care. The tenth edition of Rare Disease Day will see people from all over the world come together to advocate for more research on rare diseases. Over the last few decades, funds dedicated to rare disease research have increased. But it must not stop there. Rare Disease Day 2017 is the opportunity to call upon all to come together for this cause.