



Connecting the worldwide rare disease community with three months to Rare Disease Day



28 November 2020, Paris

Today marks the launch of the global awareness campaign for the **over 300 million people living with a rare disease worldwide** - three months ahead of Rare Disease Day which will take place on 28 February 2021.

EURORDIS-Rare Diseases Europe and [over 60 National Alliance patient organisation partners](#) invite **everyone** to join us digitally in bringing the entire rare disease community together to launch the messaging, adaptable materials and the key milestones for this upcoming 14th edition.

Rare is many.

Rare is strong.

Rare is proud.

This **redefining of the word Rare**, representing the **over 6000 rare diseases** and **6 continents**, is highlighted by the individual stories of people living with a rare disease. Today [we introduce the first 6 individual and family stories](#) of Harvey, Syafiq, Angelina, Tristan, Regina and Jon-Kristian who share their experiences, from across the globe, to show that while each rare diseases is rare, as a community we share a lot.

In light of the current global pandemic, for many, we launch what might be **the first-ever all-digital Rare Disease Day**. We are proud to announce that the first batch of high-quality, passionate and engaging [digital promotional materials](#) are coming soon for 2021. These materials will be adaptable for all **languages**, allowing the global patient community to relay patient stories from around the world across diseases, borders and cultures.

Every year this global, patient-led awareness campaign brings together millions worldwide in solidarity with the **300 million people living with a rare disease worldwide**. In 2020, thousands of events took place in **over 100 countries**, mobilising people living with a rare disease and their families, healthcare professionals, policy and decision makers, and industry and company representatives. We hope that this will grow even more in 2021!

*"Everyone can participate in Rare Disease Day and show how as a global community we are stronger together, even during the COVID-19 global pandemic", says **Simona Bellagambi**, Member of the EURORDIS Board of Directors.*

'As part of the planning for Rare Disease Day 2021, the National Alliance international partners have been working together to develop a suite of high quality, high impact digital materials to effectively tell the story of Rare Disease patients. We're delighted to launch the first set of materials for 2021 and we look forward to watching the worldwide Rare Disease Community participate.'

There are many ways to get involved!

- [Adaptable materials coming soon](#) - add your story, your pictures and share them with your networks! Remember to use **#RareDiseaseDay**.
- [Plan an event or a digital event](#) and post the information on rarediseasday.org
- [Share your story](#) with the rare disease community on our website.
- Illuminate buildings in your area [using our toolkit](#).
- Call on policy makers and partner with a local patient organisation to make the patient voice heard!

Visit rarediseasday.org for the full set of information and details on how to participate.

[Shape History](#) is the marketing agency that has produced the creative and adaptable materials for the campaign.

###

Contact

Lara Chappell, Strategic Communications and Marketing Director, Head of Awareness, Public Engagement and Events, EURORDIS-Rare Diseases Europe

lara.chappell@eurordis.org

About Rare Disease Day

A patient-led campaign, [Rare Disease Day](#) was launched by EURORDIS and its Council of National Alliances in 2008 and brings together millions of people in solidarity. EURORDIS coordinates the global community in organising Rare Disease Day, which takes place on the last day of February each year to raise awareness of the impact that rare diseases have on over 300 million people around the world. #RareDiseaseDay

EURORDIS-Rare Diseases Europe and the over 60 National Alliance patient organisation partners

EURORDIS-Rare Diseases Europe organises the international patient community and produces the campaign elements for Rare Disease Day with over [60 National Alliance patient organisation partners](#). EURORDIS is a unique, non-profit alliance of over 800 rare disease patient organisations from 70+ countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information visit eurordis.org.

About rare diseases

The European Union considers a disease as rare when it affects **less than 1 in 2,000** citizens. **Over 6,000 different rare diseases** have been identified to date affecting an estimated **30 million people in Europe** and **300 million worldwide**. **72% of rare diseases are genetic** whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. **70% of those genetic rare diseases start in childhood**.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.