

Show Your Rare for Rare Disease Day 2019

[#RareDiseaseDay](#) [#ShowYourRare](#)

1 February 2019, Paris - The countdown has begun to [Rare Disease Day 2019](#) on 28 February. People around the world are joining the global movement for rare diseases by taking part in the [#ShowYourRare campaign](#), holding events and raising awareness.

There are over 6,000 rare diseases. 30 million people are living with a rare disease in Europe and over 300 million worldwide. Medical expertise and knowledge on rare diseases is scarce and scattered across borders. People often wait years for a diagnosis and struggle to access the medicines or care they need.



This year's theme is '[Bridging health and social care](#)'; Rare Disease Day 2019 is an opportunity to be part of a global call on policy makers, healthcare professionals, and care services to better coordinate all aspects of care for rare disease patients and families.

Rare Disease Day is for **everyone** - individuals and families directly affected by rare diseases, caregivers, medical professionals, policy makers, companies, researchers and members of the general public can all [get involved](#) to show their support for the global rare disease community.

Rare Disease Day 2019 official videos

Out today – watch and share this year's [#ShowYourRare video](#)! In the coming weeks, three new videos telling the stories of [Filip](#) from Romania who is living with achondroplasia, [Karlo](#) from Croatia who is living with neurofibromatosis type 1, and [Lorena](#) from Spain who is living with Phelan-McDermid syndrome, will be launched via [rarediseaseday.org/videos](#).

Get involved throughout the month of February!

- [Show Your Rare, Show You Care](#) - paint your face and/or hold up [this board](#), take a selfie or photo and share on social media.
- [Organise an event and post it to rarediseaseday.org](#) to be part of the global community! Thousands of events take place in over **90 countries around the world**.
- [Download the official Rare Disease Day 2019 poster and logo](#) to put up in your workplace or home and for use at your events.
- Companies, organisations, caregivers and researchers can [Become a Friend of Rare Disease Day!](#)
- Upload the [Facebook frame](#) or [Twibbon](#) to your social media profile pictures
- [Shop Rare Disease Day](#) – buy official Rare Disease Day products for your events including bags and t-shirts.

EURORDIS marks the occasion of Rare Disease Day

EURORDIS-Rare Diseases Europe is holding a series of events throughout the month of February to mark the occasion of Rare Disease Day 2019:

- The **EURORDIS Black Pearl Awards** (12 February, Brussels), an annual event held to recognise the outstanding achievements and exceptional work of people making a difference for the rare disease community. [Attend](#) or [watch online](#).
- The **3rd EURORDIS Multi-Stakeholder Symposium on Improving Patients' Access to Rare Disease Therapies** (13 – 14 February, Brussels). [Attend](#) or [watch online](#).
- **Rare Disease Day Policy Event at the United Nations, Second High-Level Event of the NGO Committee for Rare Diseases** (21 February, UN Headquarters, New York). [Join online](#).

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 leads 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.



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EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe 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.

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. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering 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.

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