



Rare Disease Day 2020 to take place on 29 February



25 January 2019, Paris - With only five weeks until 29 February, people in **100+ countries around the world** are finalising preparations for Rare Disease Day 2020. The campaign is open to **everyone** - people living with a rare disease, their families and carers, policy makers, public authorities, researchers, industry representatives, health professionals and the general public.

Rare Disease Day aims to raise awareness for people living with a rare disease and their families. In 2020, the message for this patient-led campaign is:

Rare is many. Rare is over 300 million people around the world.

Rare is strong. The rare disease community is connected across borders and diseases to raise awareness and advocate for equity.

Rare is proud. Show your support for the rare disease community with pride! The likely truth is that you know somebody affected by a rare disease.

Rare Disease Day is an opportunity to raise awareness of what **rare really means**:

- There are over **300 million people around the world are living with a rare disease¹**, each supported by family, friends and a team of carers.
- There are **over 6,000 identified rare diseases**.
- Rare diseases currently affect **5%** of the worldwide population.
- Each rare disease may only affect a handful of people, scattered around the world, but collectively the number of people living with a rare disease is equivalent to the population of the **world's third largest country**.
- **72% of rare diseases are genetic** whilst others are the result of infections (bacterial or viral), allergies and environmental causes or are rare cancers.
- 70% of genetic rare diseases **start in childhood**.
- A disease defined as rare in Europe when it affects **fewer than 1 in 2,000 people**.

¹ Research recently published in the European Journal of Human Genetics, article authored by EURORDIS-Rare Diseases Europe, Orphanet & Orphanet Ireland - Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. The analysis is of rare genetic diseases and is therefore conservative as it does not include rare cancers, nor rare diseases caused by rare bacterial or viral infectious diseases or poisonings <https://www.nature.com/articles/s41431-019-0508-0>

The long-term goal of Rare Disease Day over the next decade is **increased equity** for people living with a rare disease and their families. Rare Disease Day is an opportunity to raise awareness that people living with a rare disease around the world face **inequitable access to diagnosis, treatment, care and social opportunity**. They have the right to equal opportunity to realise their potential.

Take part in Rare Disease Day 2020

Rare Disease Day 2020 is on track to be a huge success. Thousands of events are expected to take place in over 100 countries around the world! This year there are **a record 60 national alliance patient organisation official partners** from across the globe, as well as the many other patient organisations, hospitals, research centres, companies and policy makers that organise Rare Disease Day activities.

[Download the official campaign materials](#) (poster, logo, social media materials, infographic cards) and take action to be part of the global Rare Disease Day community:

- [Find an event](#) taking place in your country.
- [Download the official campaign materials](#) (poster, logo, social media visuals). This year's poster features [Gauthier](#), who is living with sickle cell anaemia, and his mum.
- [Organise and post your own events](#) on rarediseaseday.org.
- **Share a photo and your rare disease story on social media** to show solidarity with people living with a rare disease. You can share individual photos of yourself supporting the campaign, with your friends or colleagues, or photos from your events. Paint and raise your hands or print the logo and hold it up. [See here for inspiration](#). Remember to use **#RareDiseaseDay**.
- [Become a friend of Rare Disease Day](#) on behalf of your company or organisation.
- [Tell your rare disease story](#).
- [Upload your Rare Disease Day photos](#) to rarediseaseday.org.

Follow Rare Disease Day [Facebook](#), [Twitter](#) and [Instagram](#) (new this year!).

EURORDIS events for Rare Disease Day

To mark the occasion of Rare Disease Day, EURORDIS is holding several events in Brussels on 18 February: a policy event at the European Parliament (contact clara.hervas@eurordis.org for more info) and the EURORDIS Black Pearl Awards ([watch online](#) or [purchase tickets to attend](#)).

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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

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.

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