



Out now - Rare Disease Day 2018 video!

Show Your Rare, Show You Care

#ShowYourRare

29 January 2018, Paris - The [official Rare Disease Day 2018 video](#) launches today and is already available in [30+ languages](#), kicking off the international patient-led movement that puts rare diseases in the spotlight.

The video features patients and family members, researchers and doctors who **show their rare**.

Join them and show your support for the rare disease community - [#ShowYourRare](#) during the month of February on social media.



Read stories of some of the stars of the video - [Enzo](#), who is living with congenital myasthenic syndrome, [Yara](#), a rare disease researcher, [Annie](#), who is living with leber hereditary optic neuropathy, [Alexandre](#), who is living with fibrodysplasia ossificans progressive, and [Mirina](#), who is living with Ehlers-Danlos syndrome.

Patients as proactive actors in research

Rare Disease Day 2018 (28 February) focuses on this year's theme - [research](#). This year's video pays tribute to the role patients play in research.

The patient community needs researchers. They discover diseases and develop treatments and cures. But researchers also need patients and rely upon their participation to ensure research is meaningful. **Patients are not only subjects but also proactive actors in research.**

There has been great progress in rare disease research, in part thanks to the advocacy work of the rare disease patient community. However, the fact remains that there are over 6000 rare diseases, an estimated 30 million people living with a rare disease in Europe and 300 million worldwide, but no cures and few treatments available for the majority of these diseases. To help change this, patient involvement in research needs to be taken to the next level.

Rare Disease Day 2018 offers participants the opportunity to be part of a global call on policy makers, researchers, companies and healthcare professionals to increasingly and more effectively involve patients in rare disease research.

About Rare Disease Day

Over the last 10 years, Rare Disease Day has become iconic as the global campaign for raising awareness of rare diseases. Rare Disease Day is a **patient-led** campaign launched by [EURORDIS- Rare Diseases Europe](#) and its Council of National Alliances in 2008. Held on the last day of February each year, it seeks to raise awareness of the impact that rare diseases have on the lives of patients and those who care for them. Rare Disease Day brings together millions of patients, families, carers, medical professionals, policy makers and members of the public in solidarity.

Since Rare Disease Day began, thousands of events have been held throughout the world, reaching hundreds of thousands of people.

In 2018, organisations in over 90 countries and regions around the world are participating in Rare Disease Day by holding [local events](#). **For the first time ever, Togo, Ghana and Trinidad and Tobago will participate in Rare Disease Day.** The political momentum resulting from Rare Disease Day has also served advocacy purposes, contributing to the advancement of EU policies on rare diseases and to the creation of national plans for rare diseases in a number of EU Member States.

[Sean Hepburn Ferrer](#), the eldest son of the late actress and humanitarian, Audrey Hepburn, is Rare Disease Day 2018 Ambassador.

Get involved in Rare Disease Day 2018

Everyone can get involved in Rare Disease Day, those affected and unaffected by rare diseases alike!

- Download the official [Rare Disease Day 2018 poster](#) and logo, social media banner, email signature to use at your events and online.
- Add this [Facebook filter](#) or this [Twitter filter](#) to your profile picture.
- [#ShowYourRare](#) - paint your face and share your selfie during the month of February.
- [Sign up to the Rare Disease Day Thunderclap campaign](#) to automatically share a message on your Twitter or Facebook account on 28 February.
- [Post your event](#) on [rarediseaseday.org](#).
- [Tell your story](#) on [rarediseaseday.org](#).

###

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 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.

Press contact

Eva Bearryman, Communications Manager, EURORDIS-Rare Diseases Europe
eva.bearryman@eurordis.org +33 1 56 53 52 61