RARE DISEASE DAY

INFORMATION PACK
**WHAT IS RARE DISEASE DAY?**

Rare Disease Day is the official international awareness-raising campaign for rare diseases. Rare Disease Day takes place on the last day of February each year. The main objective of the campaign is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

Rare Disease Day was launched by EURORDIS-Rare Diseases Europe and its Council of National Alliances in 2008.

**TAKE PART IN RARE DISEASE DAY**

1. Reframe rare for rare disease day
2. Join us on social media
3. Organise an event
4. Become a friend
5. Tell your story
6. Take action locally
7. Share your photos
8. Download communication materials
On Rare Disease Day we must re-double our efforts to re-think, re-envision, reimagine and reframe what it means to be ‘rare’. Rare isn’t scarce, rare isn’t infrequent, and rare isn’t remote. In fact – rare is not as rare as you think.

The statistics speak for themselves: more than 300 million patients, families and carers make up the rare disease community worldwide with Over 6,000 different diseases. Collectively, they make up the third largest country in the world.

The likely truth is that you know one of the 1 in 20 people affected by a rare disease. Rare is many. Rare is strong. Rare is proud.

We need society to understand that millions of people living with a rare disease around the world face inequitable access to diagnosis, treatment and care.

It’s time to take action to build a society where people living with a rare disease have equal opportunities to realise their potential.

For Rare Disease Day, we need everyone to join the movement to reframe rare!
Get involved on social media

Share videos and photos from your Rare Disease Day events on social media platforms using #RareDiseaseDay. Share an image on your own or with your friends, family or colleagues!

Follow us!

Stay up to date with the latest news from this year’s Rare Disease Day campaign by following us on Facebook, Twitter and Instagram.

Share the official video and poster

Promote Rare Disease Day across your social media channels by sharing the official Rare Disease Day poster and video with your friends and followers using #RareDiseaseDay.
Every year, thousands of events are organised around the world to mark the occasion of Rare Disease Day.

Organise an event during or around the month of February for Rare Disease Day to raise awareness of rare diseases in your community.

Ideas to get you started:

- Host a meeting, workshop or conference
- Hold an art, photography or essay-writing competition
- Organise a walk or march
- Plan a sporting or fundraising event
- Invite policy makers to a political event or present a manifesto to your local authorities

**Post your event**

Once you have organised your event, share it on the on Rare Disease Day website so it can be added to the map showing events taking place worldwide for Rare Disease Day.

Don’t forget to upload photos and videos of your event afterwards!

**Communicate about your event**

Use the official Rare Disease Day download materials when promoting your event.
Sign up to Become a Friend of Rare Disease Day to show your organisation or company’s support for the campaign. To Become a Friend, you need to fill in your details to create your profile page featured on the Rare Disease Day website. Don’t forget to include details about your Rare Disease Day activities!

Join the movement to raise awareness about rare diseases and their impact on patients’ lives by sharing your story of living with a rare disease or caring for someone that does.

You can submit a written or video testimony on the Rare Disease Day website and read the stories already uploaded!
As well as holding events you can take action in your country, region or local area to raise awareness of rare diseases!

Every year Rare Disease Day is centered around a theme reflecting the advocacy priorities of the rare disease community.

**Contact the press**

Reach out to local or regional newspapers and radio stations to get coverage of your event for Rare Disease Day.

Send out a press release to media in your area, highlighting the issues most important to rare disease patients in your country.

**Get political**

Write a letter to key decision makers about the important issues facing rare disease patients in your country, and urge them to make rare diseases a priority!

Invite politicians to visit your organisation, attend an event you are hosting or to visit a rare disease research laboratory. Encourage your MEP to join the network [Parliamentary Advocates for Rare Diseases](https://www.parliamentaryadvocates.org/).

**Famous faces**

Approach celebrities in your country to join the rare disease cause and show support for Rare Disease Day by sharing a [#RareDiseaseDay](https://www.rarediseaseday.org/) post on social media.
However you and your friends, family and colleagues participated in Rare Disease Day, don’t forget to share your photos from your activities around the world with us by uploading them to the Rare Disease Day website!

Share your photos
There are a variety of resources to support you in your Rare Disease Day activities available to download from the Rare Disease Day website.

The official Rare Disease Day communication materials and logo are free to use when promoting your Rare Disease Day events.

We encourage you to display the Rare Disease Day poster and share the official video.

Also available to download:

- The official Rare Disease Day logo
- Website countdown
- Flyer
- Rare Disease Day style guide
- Fonts
Created by EURORDIS and its Council of National Alliances, the very first Rare Disease Day took place in 2008 with events in 18 participating countries.

EURORDIS continues to coordinate the international campaign together with a worldwide patient community. Patient organisations from North America joined in 2009 and then all continents by 2010. National Alliances ensure the coordination of Rare Disease Day at a national level, working with patient organisations locally and often organising a national event aimed at policy makers.

The number of participating countries has increased year on year, with thousands of events taking place on all continents for on or around the month of February. In total, events have taken place in over 100 countries since 2008.

Disclaimer: Rare Disease Day must not serve to promote any specific commercial interest and no visibility should be given to any products.

For information on using the Rare Disease Day logo please read the conditions of use and the style guide.