



**RARE DISEASE DAY®**

# **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

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# 1

## HOW TO SHOW YOUR SUPPORT FOR RARE DISEASE DAY

### Raising awareness of what it means to be rare

There are over **300 million** people worldwide living with a rare disease. Together across borders, and across the 6000+ rare diseases we work towards **more equitable access to diagnosis, treatment, care and social opportunity.**

**Our key message for Rare Disease Day 2020 is that:**

**Rare is many worldwide.**

**Rare is strong every day.**

**Rare is proud everywhere.**

**Find some inspiration below for ideas to take part in this year's campaign.**

1. Share a photo to show solidarity with people living with a rare disease in your community! Share a photo with painted hands on social media using **#RareDiseaseDay** and tag **@rarediseaseday**.
2. [Download the Rare Disease Day logo and make it visible at events.](#) Here the logo on flyers, t-shirts and even cake-the possibilities are endless!
3. **Use key rare disease statistics<sup>1</sup>** to share the message that rare is many to the media.
  - 300 million people living with a rare disease worldwide
  - Over 6000 different rare diseases
  - 72% of rare diseases are genetic
  - 70% of those genetic rare diseases start in childhood



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<sup>1</sup> 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>

4. **Advocate to policy-makers** that people living with a rare disease need equitable access to diagnosis, treatment and care. For more information on advocating for rare diseases as part of Universal Health Coverage see a [position paper from Rare Diseases International](#).
5. **Share the new campaign materials** soon to be available in the [downloads section](#).
6. **Add the official [twibbon](#) and [Facebook frame](#)** to your social media profiles!



### Get involved on social media

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



Use **key rare diseases<sup>2</sup>** statistics to share the message that rare is many to the media.

- 300 million people living with a rare disease worldwide
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### 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](#).

Add the official [Facebook frame](#) and [Twibbon](#) to your profile photos!

### Use the official hashtag

**#RareDiseaseDay** is the unique campaign hashtag for Rare Disease Day, be sure to use it your social media posts in help build momentum around the global campaign!

# #RareDiseaseDay

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<sup>2</sup> 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/541431-019-0508-0>

# 3

## ORGANISE AN EVENT

Every year, thousands of events are organised around in over 100 countries 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.

Here are some successful ideas from organisers around the world:

- 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.

# 4

## Become a friend

[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!



# 5

## Tell your story

Raise awareness about rare diseases and their impact on peoples' 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!

On Rare Disease Day we call for equity for people living with a rare disease around the world.

### 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!

Advocate to policy makers that people living with a rare disease need equitable access to diagnosis, treatment, care and social opportunity. For more information on advocating for rare diseases as part of Universal Health Coverage see a [position paper from Rare Diseases International](#).

Invite politicians to visit your organisation, attend an event your hosting or to visit a rare disease research laboratory. Encourage your MEP to join the network [Parliamentary Advocates for Rare Diseases](#).

### Famous faces

Approach celebrities in your country to join the rare disease cause and show support for Rare Disease Day by sharing a [#RareDiseaseDay](#) post on social media.



# 7

# Share your photos

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!



# 8

## Download communication materials

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.

Also available to download:

- [The official Rare Disease Day logo](#)
- [Website countdown](#)
- [Flyer](#)
- [Rare Disease Day style guide](#)
- [Fonts](#)

# HISTORY OF RARE DISEASE DAY

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](#).

