



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

1

#ShowYourRare on social media

2

Organise an event

3

Become a Friend

4

Tell your story

5

Take action locally

6

Share your photos

7

Download communication materials

1

#ShowYourRare on social media

Take part in an interactive social media campaign to raise awareness of rare diseases and show your support for the rare disease community!

Paint your face to #ShowYourRare

Paint your face with colourful face paints and share a selfie on social media using the hashtag **#ShowYourRare**. Share an image on your own or with your friends, family or colleagues!



Update your profile picture

Show your support for Rare Disease Day by adding [a Facebook frame](#) or Twibbon to your profile picture.

Follow us!

Stay up to date with the latest news from this year's Rare Disease Day campaign by following us on [Facebook](#) and [Twitter](#)

Join the Thunderclap campaign

Join the Rare Disease Day Thunderclap campaign with your Facebook and/or Twitter account. A message of solidarity with rare disease patients will be shared simultaneously from the social media accounts of those who join on Rare Disease Day itself, spreading a wave of support across social media.

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.



#RareDiseaseDay

#ShowYourRare

2

Organise an event

Every year, thousands of events are organized 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
- Organise a face painting event to #ShowYourRare



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.

3

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!



4

Tell your story

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!



5

Take action locally

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 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 [#ShowYourRare](#) post on social media.



6

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!



7

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.

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](#)
- [Social media banner images](#)
- [E mail signature](#)
- [Website countdown](#)
- [Flyer](#)
- [Rare Disease Day style guide](#)
- [Fonts](#)
- [Poster with white space](#)



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](#).

