

#RAREDISEASEDAY

RARE DISEASE DAY 2024

INFORMATION PACK

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RARE DISEASE DAY®

WHAT IS RARE DISEASE DAY?

Rare Disease Day is the official international awareness-raising campaign for rare diseases, observed annually on the last day of February. The primary goal of this campaign is to **increase awareness** among the general public and decision-makers about rare diseases and their influence on the lives of families living with these conditions.

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

HOW TO SUPPORT RARE DISEASE DAY

CELEBRATE THE UNIQUENESS OF BEING RARE

With over **300 million people** globally living with a rare disease, we join hands across borders and amidst the 6000+ rare diseases to advocate for **equitable access to diagnosis, treatment, care, and social opportunities**.

Our key message for Rare Disease Day 2024 is **SHARE YOUR COLOURS!**

HERE ARE SOME WAYS TO GET INVOLVED IN THIS YEAR'S CAMPAIGN:

1. Share a photo: express your support for those living with rare diseases in your community by sharing a photo with painted hands on social media. Use the hashtag **#RareDiseaseDay** and tag **@rare diseaseday**.
2. Download and showcase the Rare Disease Day logo. Get creative - use it on flyers, t-shirts, or even cakes. There's no limit to how you can feature it!
3. Use crucial rare disease statistics¹ to convey to the media that while each disease may be rare, collectively, they impact a vast number of people.

- 300 million people worldwide live with a rare disease.
 - There are over 6000 different rare diseases.
 - 72% of rare diseases are genetic.
 - 70% of these genetic rare diseases begin in childhood.
4. Encourage policymakers to provide people living with a rare disease equitable access to diagnosis, treatment, and care. For detailed strategies and information, refer to the position paper by Rare Diseases International on incorporating rare diseases into Universal Health Coverage.
 5. Utilise the new campaign materials available in the downloads section to help amplify our message.
 6. Enhance your social media profiles by adding the official Rare Disease Day Facebook frame!



1. EURORDIS-Rare Diseases Europe, Orphanet, and Orphanet Ireland. "Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database." European Journal of Human Genetics. The study focuses on rare genetic diseases, excluding rare cancers and diseases from rare infections or poisonings. <https://www.nature.com/articles/s41431-019-0508-0>

1. JOIN US ON SOCIAL MEDIA

GET INVOLVED ON SOCIAL MEDIA

Share your Rare Disease Day event videos and photos on social media using [#RareDiseaseDay](#) and tag [@rarediseaseday](#).

FOLLOW US!

Keep up with the latest from this year's Rare Disease Day campaign by following us on [Facebook](#), [Twitter](#), [LinkedIn](#) and [Instagram](#).

Add the official Facebook frame and profile frames to your photo!

USE THE OFFICIAL HASHTAG

[#RareDiseaseDay](#) is our unique campaign hashtag. Use it in your social media posts to help build momentum around the global campaign!

2. ORGANISE AN EVENT

Every year, thousands of events across over [100 countries](#) commemorate Rare Disease Day.

Owing to the current COVID-19 situation, most events will be online, allowing people worldwide to participate.

Plan an online event in or around February for Rare Disease Day to heighten awareness of rare diseases in your community.

Here are some successful ideas from global organisers:

- Host a webinar.
- Illuminate a building for Rare Disease Day: see our toolkit and webinar for top tips.
- Raise awareness on Facebook and Instagram Live, and invite your friends.
- Hold an art, photography, or essay-writing competition.
- Organise a socially distanced walk.
- Plan a sporting event.
- Present a manifesto to your local authorities.

POST YOUR EVENT

Once you have planned 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

Have you organised an event, but you don't know how to promote it? Use the official Rare Disease Day downloadable materials.

If you are a graphic design lover you can create your own materials using some of the elements of the campaign (Rare Disease Day colours, brush strokes, hero portraits and more...).



3. BECOME A FRIEND

Would you like to showcase your organisation or company's support for the campaign?

[Become a Rare Disease Day friend!](#) Simply fill in your details to create a profile page on the Rare Disease Day website. This will display your commitment to supporting people living with a rare disease.

Don't forget to include details about your Rare Disease Day activities!

4. TELL YOUR STORY

Raise awareness about rare diseases and their impact on people's lives by [sharing your personal experience](#) of living with a rare disease or caring for someone who does.

Submit your written or video testimony on the Rare Disease Day website and explore stories already shared by others!

5. TAKE ACTION LOCALLY

In addition to organising events, you can act locally in your country, region, or area to raise awareness of rare diseases!

On Rare Disease Day, we advocate for equity for people living with a rare disease worldwide.

CONTACT THE PRESS

Reach out to local or regional newspapers and radio stations to cover your Rare Disease Day event.

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

Watch our webinar '[How to Use Rare Disease Day to Advance Your Advocacy Objectives](#)' to learn the basics!

ALL LANGUAGES ARE WELCOME!



SHARE YOUR STORY WITH US!

PARTAGEZ VOTRE EXPÉRIENCE AVEC NOUS !

¡COMPARTA SU HISTORIA CON NOSOTROS!



29 RARE DISEASE DAY

FEB 2024



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SHARE YOUR COLOURS

Raise awareness for the 300 million people living with a rare disease and their families worldwide, together with EURORDIS-Rare Diseases Europe and 71 national alliances for rare diseases.



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दुर्लभ है
मज़बूत!
गर्व!
अनेक!

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GET POLITICAL

Write to key decision-makers about the pressing issues facing rare disease patients in your country, urging them to prioritise rare diseases!

Advocate to policymakers for equitable access to diagnosis, treatment, care, and social opportunities for those living with a rare disease. For guidance on advocating for rare diseases within Universal Health Coverage, refer to the RDD Equity toolkit.

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

Famous faces

Enlist celebrities in your country to support the rare disease cause. Encourage them to support Rare Disease Day by sharing a #RareDiseaseDay post on social media.

6. SHARE YOUR PHOTOS

If you, your friends, family, and colleagues took part in Rare Disease Day, don't forget to

share your photos from activities worldwide with us by uploading them to the Rare Disease Day website!

7.DOWNLOAD COMMUNICATION MATERIALS

The official Rare Disease Day [communication materials and logo](#) are freely available for your Rare Disease Day events promotion.

This year's theme is sharing your colours! We've created a selection of materials for you. Edit them, add your logo, and share them – join the most international Rare Disease Day yet.

Materials available in Mandarin, English, Arabic, Spanish, Portuguese, French, Hindi, and Russian.

Also available for download:

- The official Rare Disease Day logo
- Website countdown
- Rare Disease Day style guide
- Fonts
- Webinar toolkits.

HISTORY OF RARE DISEASE DAY

Created by EURORDIS and its Council of National Alliances, the first Rare Disease Day occurred in 2008 with events in 18 countries.

EURORDIS continues to lead the international campaign with a global patient community. Patient organisations from North America joined in 2009, followed by all continents by 2010. National Alliances ensure Rare Disease Day coordination at a national level, collaborating with local patient organisations and often organising national events targeting policymakers.

The number of participating countries has grown annually, with thousands of events now occurring on all continents in or around February. Since 2008, events have been held in over 100 countries.

Disclaimer: Rare Disease Day must not be used to promote any commercial interests, and no visibility should be given to any products.

For guidelines on using the Rare Disease Day logo, please consult the conditions of use and the style guide.

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29 FEB 2024

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