

#RAREDISEASEDAY

RARE DISEASE DAY 2023

INFORMATION PACK



RARE DISEASE DAY®

WHAT IS RARE DISEASE DAY?

Rare Disease Day is the official international awareness-raising campaign for rare diseases which 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.

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 2023 is

SHARE YOUR COLOURS!

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 online. Here the logo on flyers, t-shirts and even cake-the possibilities are endless!

3. Use key rare disease statistics¹ to share the message that rare is many to the media:

1 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>



TITLE: ESTIMATING CUMULATIVE POINT PREVALENCE OF RARE DISEASES: ANALYSIS OF THE ORPHANET DATABASE; EUROPEAN JOURNAL OF HUMAN GENETICS (2019)

300
MILLION PEOPLE
WORLDWIDE
LIVING WITH A RARE DISEASE

#RAREDISEASEDAY
28 FEBRUARY 2023



- 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.

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 already available in the downloads section.

6. Add the official Facebook frame to your social media profiles!

1. JOIN US ON SOCIAL MEDIA

Get involved on social media

Share videos and photos from your Rare Disease Day events on social media using **#RareDiseaseDay** and tag **@rarediseaseday**.

Follow us!

Stay up to date with the latest news from this

Organise an online 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 webinar
- Illuminate a building for Rare Disease Day: check out our toolkit and watch our webinar to learn top tips
- Raise awareness for people living with a rare disease on Facebook and Instagram Live and invite your friends to join
- Hold an art, photography or essay-writing



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!

2. ORGANISE AN EVENT

Every year, thousands of events are organised in over [100 countries](#) to mark the occasion of Rare Disease Day.

Due to the current COVID-19 situation, most of the events will be held online, which will give the opportunity to people to join events all around the world.

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

Do you want to share your organisation or company's support for the campaign?

Become a [Rare Disease Day friend](#)! You only need to fill in your details to create your profile page featured on the Rare Disease Day website. Then everyone will be able to see your compromise towards 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 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!

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!

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.

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!

¡COMPARTAN SU HISTORIA CON NOSOTROS!

PARTAGEZ VOTRE HISTOIRE AVEC NOUS!

WWW.RAREDISEASEDAY.ORG/TELL-YOUR-STORY



SHARE YOUR COLOURS

RARE DISEASE DAY | 28 FEBRUARY 2023



Rare Disease Day is organised globally by EURORDIS Rare Diseases Europe, Rare Diseases International and 68 national alliances of patient organisations for rare diseases


Rare Disease Association, Albania | Federación Argentina De Enfermedades Poco Frecuentes | Rare Voices Australia | Pro Rare Austria, Allianz für seltene Erkrankungen | RaDiOrg - Rare Disease Organisation Belgium
Alliance for rare diseases of Republic of Srpska, Bosnia and Herzegovina | Botswana Organization For Rare Diseases | Associação Brasileira De Enfermedades Raras | Instituto Vidas Raras | National Alliance of People with Rare Diseases
Canadian Organization for Rare Diseases | Chinese Organization for Rare Disorders (CHARD) | Federación Colombiana De Enfermedades Raras | Rare Diseases Croatia | Cyprus Alliance for Rare Disorders
Rare diseases Czech Republic (Ceska asociace pro vzacna onemocneni) | Rare Diseases Denmark (Sjældne Diagnoser) | HARSO-Rare Disease Alliance Finland | Georgian Foundation for Genetic and Rare Diseases
ACHSE Allianz Chronischer Erkrankungen e.V. | Rare Diseases Ghana Initiative | Rare Diseases Greece | Hong Kong Alliance For Rare Diseases | Rare Diseases Hungary - RIOSZ
Einstök Börn - Support Group for Children with Rare Disorders | Indian Organization For Rare Diseases | Organization For Rare Diseases India | Rare Disease Foundation of Iran | Rare Diseases Ireland
Coalition of Rare Diseases in Israel | UNIAMO - Rare Diseases Italy | Association Aux Pas du Coeur | Japan Patient Association | ASRID | Association of Support to Patients with Orphan Diseases in the Republic of Kazakhstan
Rare Diseases Kenya | Rare Diseases Kosovo (Shoqata e Semundje te Rralia Kosovo) | Latvian Alliance for Rare Diseases | Rare Diseases Lithuania | ALAN - Maladies Rares Luxembourg | Malaysian Rare Disorders Society
National Alliance for Rare Diseases Support, Malta | Federación Mexicana De Enfermedades Raras | National Organisation for Rare Diseases | VSOP - Vereniging Samenwerkende Ouder En Patiëntenorganisaties
New Zealand Organisation For Rare Disorders | Norwegian Federation of Organisations of Disabled People | Philippine Society For Orphan Disorders | Polish National Forum on the Treatment of Orphan Diseases - ORPHAN | RD-Portugal
Romanian National Alliance for Rare Diseases | Russian association of rare diseases | Russian Patient Union | National Organization for Rare Diseases, Serbia | APARDO | Slovak Alliance of Rare Diseases | Rare Disease Society of South Africa
ALIBER | FEDER - Federación Española de Enfermedades Raras | Rare Diseases Sweden (Riksförbundet Sällsynta Diagnoser) | ProRaris | National Alliance for Rare Diseases of R. Macedonia
Genetic Alliance UK | Rare Diseases UK | Non-governmental Organization "Rare Diseases of Ukraine" | NORD | Child & Youth Care, Zimbabwe

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RARE DISEASES INTERNATIONAL



दुर्लभ कई हैं ।
दुर्लभ मजबूत है ।
दुर्लभ होना गर्व की
बात है ।



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 the RDD Equity toolkit.

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](#).

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.

6.SHARE YOUR PHOTOS

If 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

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

This year we want you to share your colours! That's why we have created a selection of materials. Edit them, add your logo, share them... don't miss the chance of participating in the most international Rare Disease Day.

Some of the materials have been translated into the following languages: Mandarin, English, Arabic, Spanish, Portuguese, French, Hindi and Russian.

Also available to 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 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.

I SUPPORT

RARE DISEASE DAY

28 FEBRUARY 2023

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