



# Rare Disease Day

## How to participate?

MAY 2021

# AGENDA

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WHAT IS RARE DISEASE DAY

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## SECTION 1

# WHAT IS RARE DISEASE DAY?



# WHAT IS RARE DISEASE DAY?

- Created by EURORDIS and its Council of National Alliances in 2008
- An international awareness campaign for people living with a rare disease
- Takes place on the last day of February each year. This year, Sunday, 28 February 2021
- Brings together the worldwide community of patients, families, patient organisations, healthcare professionals, industry, institutions & policy-makers to raise awareness
- Global call to action: Share your colours
- Strength in the grassroots: lots of scope for adaption



## MEET YOUR COMMUNITY



**300 MILLION**  
PEOPLE WITH RARE DISEASES



**103**  
COUNTRIES WITH EVENTS



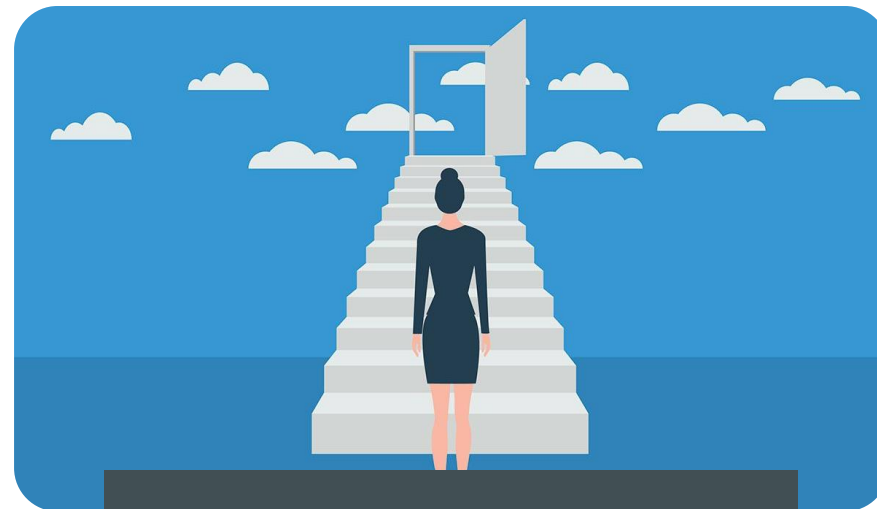
**THOUSANDS**  
OF EVENTS WORLDWIDE



**1,200**  
STORIES TO DISCOVER



# HOW TO PARTICIPATE-AN OVERVIEW



## GETTING CONNECTED

- Become a friend
- Follow us on Social Media
- Share your colours! (share your story, share a photo)



## ACCESSING RESOURCES

- Register for /access previous 'how-to' webinars
- Download campaign visuals
- Use the equity toolkit



## PREPARING FOR THE DAY

- Organise an event
- Monitor new campaign communications
- Work to light up a monument or building in your country or community

The background of the slide is an abstract composition. On the left, there is a solid dark blue vertical band. The rest of the slide is filled with a vibrant, painterly style illustration. It depicts a group of approximately 15-20 people, represented by colorful, rounded shapes in shades of orange, yellow, green, and blue. These figures are arranged in a loose, circular cluster, suggesting a group meeting or a collaborative work environment. The overall aesthetic is modern and energetic, with bold colors and visible brushstroke textures.

## SECTION 2

# GETTING CONNECTED





## HOW TO START ?



### **BECOME A RARE DISEASE DAY FRIEND**

Visit the RDD website fill your details to create your profile and keep it updated to help RDD community



### **SHARE YOUR COLOURS**

Show your interest and actions by uploading photos of you, your friends, family and colleagues participating in RDD

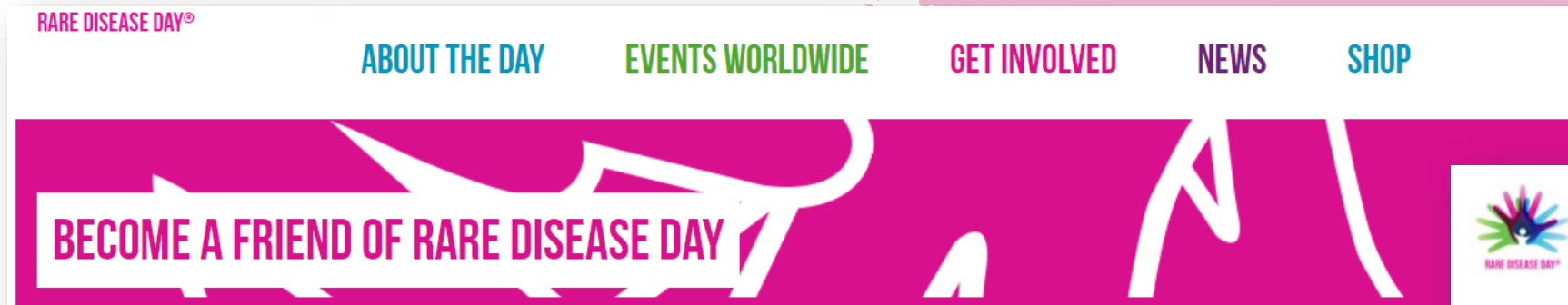


### **FOLLOW US ON SOCIAL MEDIA**

FB, Instagram & Twitter RDD accounts are available to join and share our content and messages. You can also use #RareDiseaseDay to raise RDD visibility



# FRIENDS — PHOTOS - SOCIAL



## BECOME A FRIEND OF RARE DISEASE DAY

RARE DISEASE DAY IS HELD THE LAST DAY OF FEBRUARY EACH YEAR AND IS THE OCCASION TO RAISE AWARENESS FOR RARE DISEASES.

BECOME A FRIEND OF RARE DISEASE DAY TO **SHOW YOUR ORGANISATION'S SUPPORT** FOR OUR 2021 CAMPAIGN!

THIS INFORMATION WILL BE VISIBLE ON YOUR EVENT/FRIEND PAGE

[SEE ALL RARE DISEASE DAY FRIENDS](#)

## FILL IN THE FORM AND BECOME A FRIEND !

TITLE OF YOUR ORGANISATION:\*

UPLOAD THE LOGO OF YOUR ORGANISATION

+ UPLOAD YOUR LOGO

ROLE OF YOUR ORGANISATION\*

EURORDIS Member

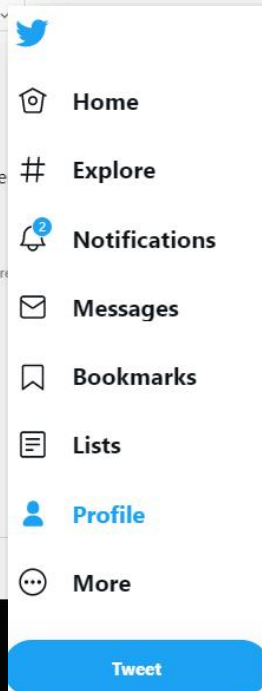
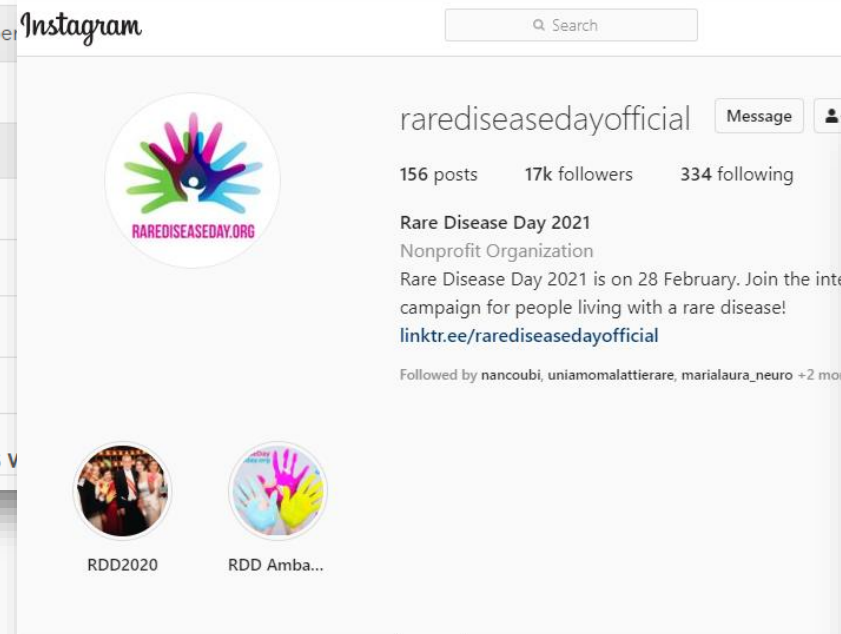
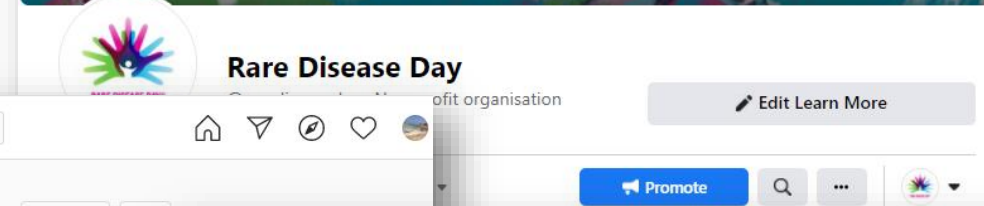
YOUR COUNTRY\*

Afghanistan

CONTACT NAME\*

YOUR EMAIL\*

ORGANISATION'S V







## SECTION 3

# ACCESS CAMPAIGN RESOURCES



# CAMPAIGN MATERIALS

The campaign has more than 100+ vibrant digital assets for Rare Disease Day and a video

- You can use the **translated materials** (Mandarin, English, Arabic, Spanish, Portuguese, French, Hindi & Russian).
- The **official video** campaign is translated in more than 40 languages.
- The campaign includes a wide range of different ready to use assets prepared and **customisable** graphics (logos, toolkits, etc.).



The screenshot displays the Rare Disease Day website with a navigation bar at the top including links for 'ABOUT THE DAY', 'EVENTS WORLDWIDE', 'GET INVOLVED', 'NEWS', 'SHOP', 'DONATE', and a 'SELECT LANGUAGE' dropdown. Below the navigation bar, four large colored boxes (pink, green, purple, and blue) represent different material categories: 'INFO PACK', 'LOGOS', 'FACT SHEET', and 'STYLE GUIDE'. A large 'CAMPAIGN MATERIALS' banner is overlaid on these boxes. Below the banner, a legal notice states: 'LEGAL BIT: REMEMBER, the materials may not be used for commercial purposes (full information about the use of the Rare Disease Day logo and the registered trademark)'. The main content area is divided into two sections: '... FOR THE SOCIAL MEDIA MASTERS' and '... FOR THE DESIGN GURUS'. The 'FOR THE SOCIAL MEDIA MASTERS' section includes icons for Facebook, Instagram, and Twitter, followed by three featured items: 'PICTURE FRAMES + BADGES' (showing a photo of a man with a child), 'SOCIAL IDENTITY PACK' (showing a man's portrait), and 'SHARING IMAGES + GRAPHICS' (showing a quote card). The 'FOR THE DESIGN GURUS' section includes icons for a computer monitor, Photoshop (Ps), and Adobe Illustrator (Ai), followed by three featured items: 'EDITABLE POSTERS + CARDS' (showing a 'RARE DISEASE DAY' poster), 'PORTRAITS + PAINTSTROKES' (showing a group of people's portraits), and 'ONLINE EVENTS PACK' (showing a 'DIAGNOSIS CAN BE THE LONGEST DETECTIVE MISSION' poster).



Я ПОДДЕРЖИВАЮ  
ДЕНЬ РЕДКИХ ЗАБОЛЕВАНИЙ  
28 ФЕВРАЛЯ 2021

#RAREDISEASEDAY RAREDISEASEDAY.ORG



НАСМНОГО МЫ-СИЛА МЫГОРДОСТЬ

RARE DISEASE DAY  
28 FEBRUARY 2021

SUPPORT RARE  
DISEASE DAY AS  
WE SUPPORT  
THOSE WITH  
NIEMANN-PICK  
TYPE C DISEASE

#NPCAUSTRALIA #RAREDISEASEDAY



我支持  
国际罕见病日  
2021年2月28日

#RAREDISEASEDAY RAREDISEASEDAY.ORG



罕见并不孤单 罕见即强大 因罕见而骄傲



## SOCIAL MEDIA MASTERS

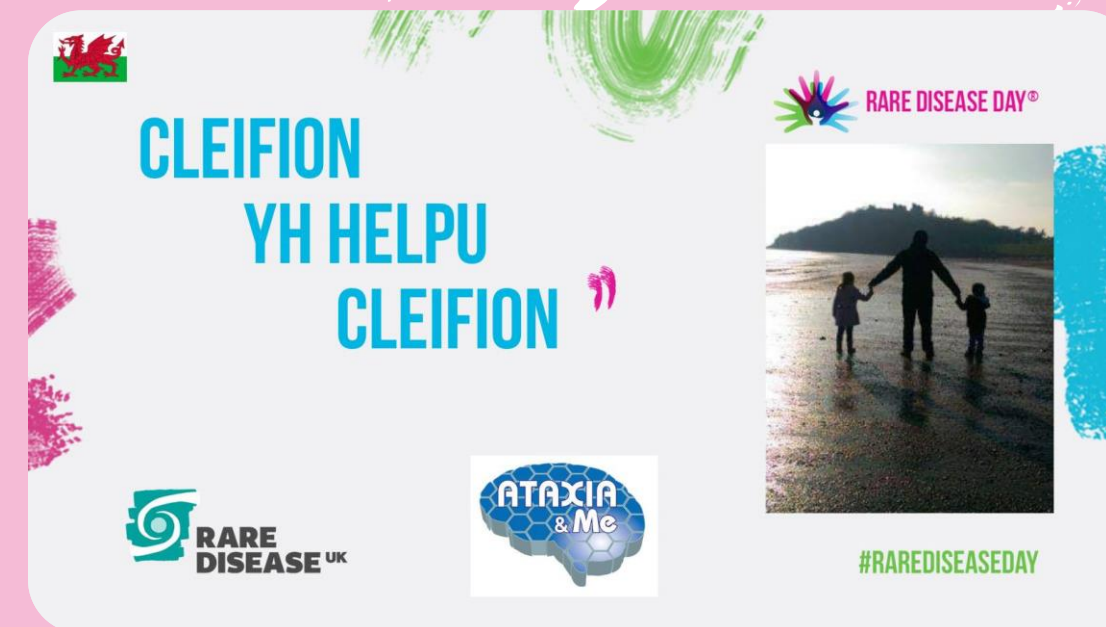
**Rare Disease Day community** works collectively.

Choose an existed asset or create your own version serving different needs.

Some materials available in 7 different languages

You can also use the social material which includes pictures, badges, images and graphics.





This includes materials designed for Facebook, Instagram, or Twitter ranging from frames and badges.







# TELL YOUR STORY

- Raise awareness about rare diseases and the impact on people's lives by sharing your story.
  - Submit a **written or video testimony** on the Rare Disease Day website and be connected with the existed ones.
-



# ACCESS OUR WEBINARS

Awareness raising advice from **experts and experienced patient advocates** from partner national alliances.

Multilingual – translated in 8 languages (including French, Spanish, Russian and Portuguese)

Keep an eye out for upcoming webinars.



Live webinar \* 19 November (09-11h CET)

## How to illuminate buildings for Rare Disease Day

[www.rarediseaseday.org](http://www.rarediseaseday.org)



Live webinar \* 21st October (14-16h CEST)

## How to prepare your digital communication for RDD 2021

[www.rarediseaseday.org](http://www.rarediseaseday.org)



Live webinar \* 9 December (16-18h CET)

## How to approach media for Rare Disease Day

[www.rarediseaseday.org](http://www.rarediseaseday.org)



11 FEBRUARY 15.00-17.00 (CET)

LIVE  
WEBINAR



PREPARING YOUR  
SOCIAL MEDIA  
COMMUNICATION  
TWO WEEKS AHEAD OF  
RARE DISEASE DAY

[RAREDISEASEDAY.ORG](http://RAREDISEASEDAY.ORG)





# EQUITY FOR PEOPLE LIVING WITH A RARE DISEASE

## WHAT DOES EQUITY MEAN FOR PEOPLE LIVING WITH A RARE DISEASE?

Equity in practice means meeting people's specific needs and eliminating barriers preventing their full participation in society. For people living with a rare disease equity means social opportunity, non-discrimination in education and work, and equitable access to health, social care, diagnosis and treatment.

On Rare Disease Day we call for action for people living with a rare disease to have equal opportunities to realise their full participation in family, work and social life.

The long-term goal of R is the next decade is incre living with a rare disease

## KEY STATISTIC



## #SOCIALOPP

## THE CHALLENGE

The 300 million people disease around the world face common challenges. As a vulnerable and ne they are disproportionately discrimination and social within their social enviro society at large.

There are over 6000 rare chronic, progressive, dege and frequently life threat rarity of each individual dis populations, expertise is scarce. In health and designed for common dis with a rare disease face ine diagnosis, care and treatm

People living with a rare discrimination at work, s For instance in a EURORD survey on 'Juggling care

## HOW CAN WE ACHIEVE EQUITY FOR PEOPLE LIVING WITH A RARE DISEASE?

### 1 ADVOCATING FOR SOCIAL INCLUSION FOR PEOPLE LIVING WITH A RARE DISEASE

In order to achieve equitable social inclusion for people living with a rare disease, they must first have access to holistic care covering the 360° spectrum of health, social and everyday needs as argued in a EURORDIS position paper on Achieving Holistic Person-Centred Care to Leave No One Behind.

The UN 2030 Agenda and its Sustainable Development Goals (SDGs) provide an important framework for addressing the full spectrum of needs of people living with a rare disease. The Goals target important issues including education, gender, work and inequality. Addressing the needs of people living with a rare disease is central to achieving the UN 2030 Agenda, the SDGs and its pledge to leave no one behind. Global institutions protecting human rights seek to address the health care challenges of people living with a rare disease. The Human Rights Council Resolution on access to medicines and vaccines recognises the importance of development, access and affordability of treatments for rare diseases.

The following legislation promotes social inclusion for people with a disability, including those whose disability is a result of living with a rare disease: The UN Convention on the Rights of People with Disabilities (CRPD) encourages governments to develop and implement policies and practices targeting the most marginalized groups of persons with disabilities such as those living with a rare disease.

### 2 INCLUDING RARE DISEASES IN UNIVERSAL HEALTH COVERAGE TO LEAVE NO ONE BEHIND!

Universal Health Coverage (UHC) included in national strategies for can access the qu ship. UHC includes costs covered.

quoted in the right to states adopted the P diseases. While co port of the rare dis oration of rare dis even if starting from

(can focus on 1) ex lication and diagn population, and 3)

POPULATION rare people covered.

## HOW CAN I ADVOCATE FOR EQUITY?

- 1 Write a LETTER TO A KEY POLICY-MAKER in your community to highlight the importance of addressing the needs of people with a rare disease and share this fact sheet with them.
- 2 Hold a RARE DISEASE DAY ONLINE EVENT that highlights a key local or national policy issue for the rare disease community and invite a decision maker to attend.
- 3 Use MEDIA ATTENTION on Rare Disease Day to launch a new initiative for the rare disease community.

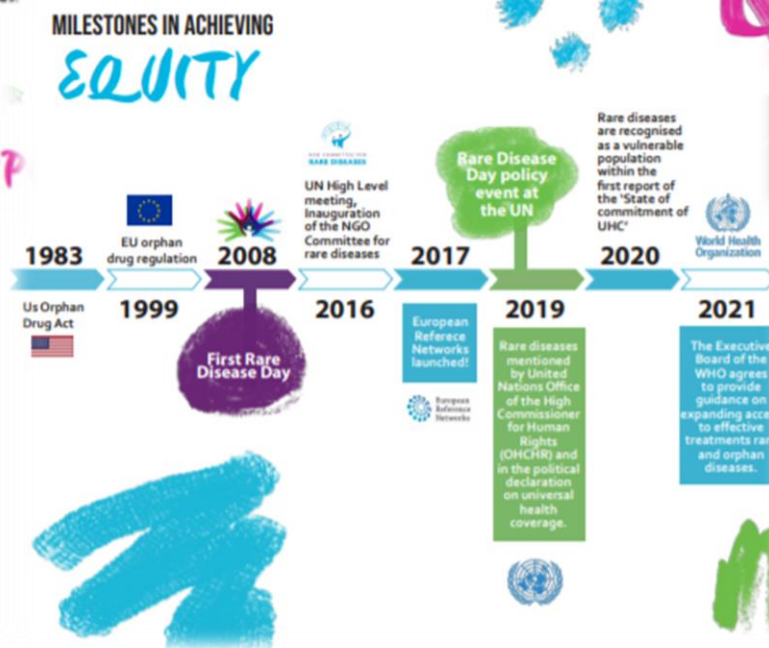
## KEY RESOURCES AND INFORMATION

- ABOUT RARE DISEASES
- Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. European Journal of Human Genetics, by EURORDIS Rare Diseases Europe, Orphanet & Orphanet Ireland.
  - EURORDIS press release: New scientific paper confirms 300 million people living with a rare disease worldwide
  - What is a rare disease webpage (on rarediseaseday.org)
  - Rare Disease Day 2020 Infographics
  - Dr Tedros lauret 18.02.20
  - Opening Remarks by H.E. Mr. Sven Jürgenson, Permanent Representative of Estonia at the Rare Disease Day Policy Event, New York, 23 February 2020

- THE IMPACT OF RARE DISEASES ON DAILY LIFE
- EURORDIS position paper: Achieving Holistic Person-Centred Care to Leave No One Behind
  - Rare Barometer survey report on Juggling care and daily life: The balancing act of the rare disease community
  - Rare Barometer survey infographic on Juggling care and daily life: The balancing act of the rare disease community
  - Disability and rare disease: towards person-centred care for Australians with rare diseases. The McKell Institute
  - Rare Barometer survey on rare disease patients' experience of COVID-19

- HUMAN RIGHTS OF PEOPLE LIVING WITH A RARE DISEASE
- Human Rights Council Resolution on access to medicines and vaccines
  - UN Convention on the Rights of People with Disabilities
  - Report of the Special Rapporteur on the rights of persons with disabilities to 72nd Session of the UNGA.

- RARE DISEASES IN THE SUSTAINABLE DEVELOPMENT GOALS AND UNIVERSAL HEALTH COVERAGE
- Rare Diseases International position paper: Universal health coverage
  - Universal Health Coverage campaign toolkit
  - State of UHC implementation report
  - UHC for Rare Diseases Campaign
  - Development of the roadmap on access to medicines and vaccines 2019-2023
  - News article, B2i: United Nations human rights body stresses the need to address rare diseases within Universal Health Coverage
  - EURORDIS press release: UN Member States include rare diseases in political declaration on universal health coverage
  - NGO Committee for rare diseases press release: Rare Disease Day 2020 Policy Event at the United Nations
  - NGO Committee for rare diseases event report: Rare Disease Day 2020 Policy Event at the United Nations
  - NGO Committee for rare diseases event report: The Right to Health: The Rare Disease Perspective. Rare Diseases International Policy Event 2021
  - NGO Committee for rare diseases event report: Global Gathering for Rare Diseases: Inauguration of the NGO Committee for Rare Diseases 2020



# MISSION: CALL FOR EQUITY

An updated equity toolkit provides references, data and tools to help your advocacy work





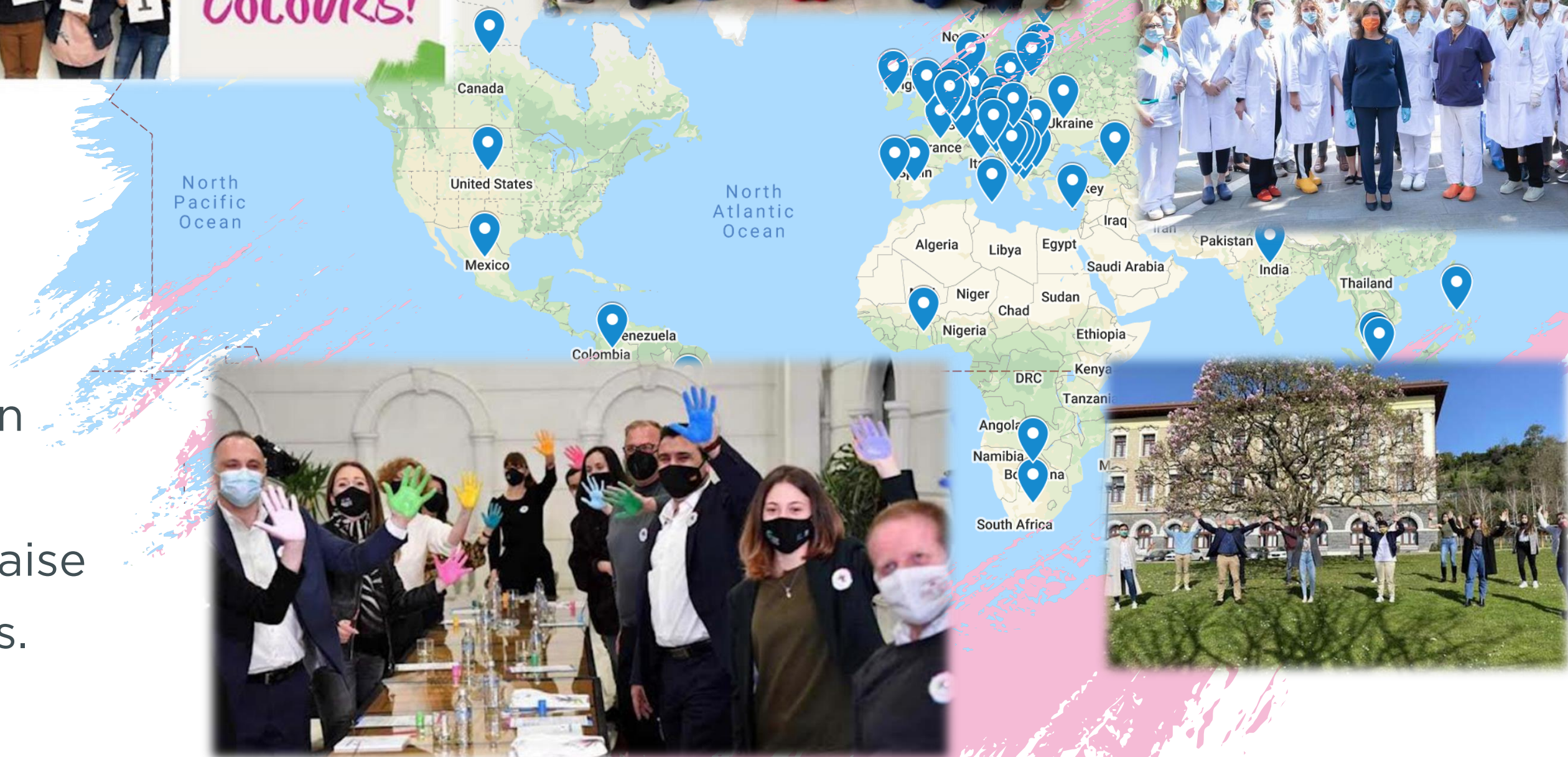
SECTION 4  
PREPARING FOR  
RARE DISEASE DAY





# WHY ORGANISE AN EVENT?

In the last campaign, more than 550 events were held in **100 countries** to raise awareness, raise funds, or educate policymakers.







Participation to the  
Global Chain of Lights  
(illuminate local  
buildings)



Ask for calls and  
meeting from the local  
authorities

Host webinars to raise  
awareness for Rare  
Disease Day with  
interesting speakers



## USE **RAREDISEASEDAY.ORG** TO PROMOTE YOUR EVENT

Adding an event to the event map helps to promote it  
and link it to the global community



# ILLUMINATING BUILDINGS

More than **500 buildings** were illuminated as an action of great support for Rare Disease Day

It's easier than you think!

Work on this project by starting approaching the local authorities of the building you tend to ask join the Global Chain of Lights.

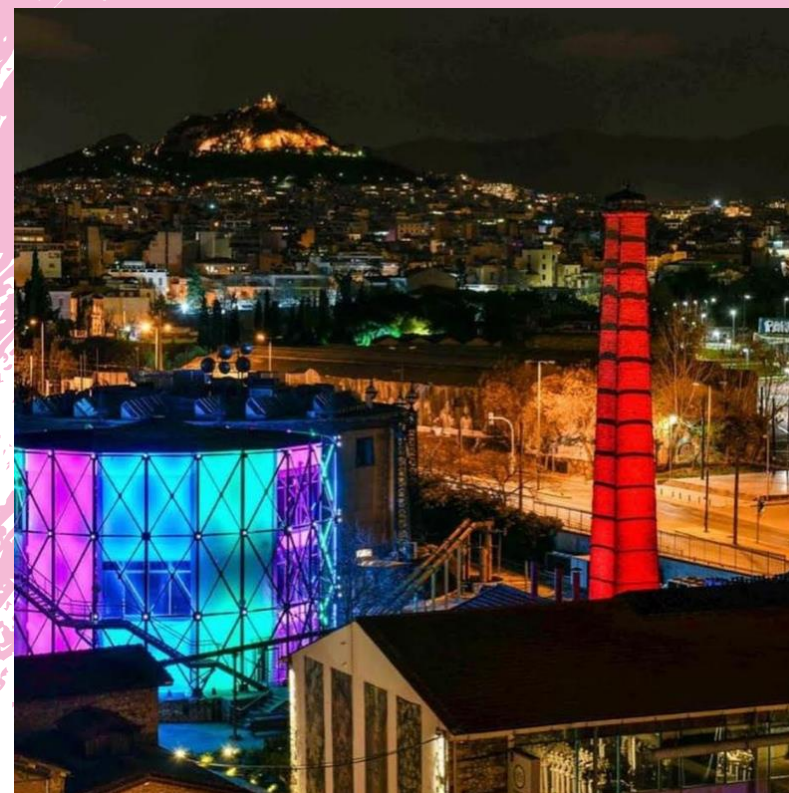
Watch our 'how to video' in English, French, Spanish or Portuguese



Nairobi



Andorra



Athens



Toronto



# WHAT'S COMING FOR 2022?

**New website!** With better features to support events and finding resources

**New 20 second video!** Delivered earlier and shorter so can be used by national alliances for public broadcast

Under discussion

**A toolkit** to talk about rare disease in schools

**Ideas** on how to share your colours at **home** and **work**







RARE DISEASE DAY®

**THANK YOU!**