



**RARE DISEASE DAY®**

**2016**

# Information Pack

EURORDIS  
October 2015



This information pack together with the rest of the communication tool kit: logo, poster and banner, will help you raise awareness and organise your own communication around the Day.

Please use it as a guide and if you have any questions, do get in touch:  
[rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org)

Don't forget to share with us the details of your awareness campaign, as well as plans, media coverage and photos from your Rare Disease Day events. Send them to:  
[rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org)

## **EURORDIS**

### **Rare Diseases Europe**

Plateforme Maladies Rares

96 rue Didot

Paris 75014

Phone (33) 1 56 53 52 10

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

## Table of Contents

<b>What is Rare Disease Day?</b>	4
<b>Your Information Pack</b>	5
<b>Target Audience</b>	6
<b>Rare Disease Day 2016 Theme &amp; Slogan</b>	7
<b>Our International Campaign</b>	9
The Role of EURORDIS:	9
The Role of National Alliances	10
<b>Planning your Awareness Campaign</b>	12
<b>Materials you can Use</b>	15
Logo	15
Video	15
Banner	16
Poster	16
Information Pack	16
<b>Online Resources</b>	17
Website	17
Country Pages	17
Friends of Rare Disease Day	18
Tell your Story	19
Our Social Media	19
Joining Hands	20
<b>Reaching Out to the Media</b>	21
Tips & Tools	21
Media Materials Available	22

## What is Rare Disease Day?

Rare Disease Day takes place on the **last day of February each year**.

The main objective of Rare Disease Day is to **raise awareness** amongst the general public and decision-makers about **rare diseases and their impact on patients' lives**.

The campaign targets primarily the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases.

Since Rare Disease Day was first launched by EURORDIS and its Council of National Alliances in 2008, thousands of events have taken place throughout the world reaching hundreds of thousands of people and resulting in a great deal of media coverage.

The political momentum resulting from Rare Disease Day also serves **advocacy purposes**. It has notably contributed to the advancement of **national plans and policies for rare diseases** in a number of countries.

Even though the campaign started as a European event, it has progressively become a **world phenomenon**, with the USA joining in 2009, and participation in over 80 countries around the world in 2015. Hundreds of cities continue to take part in the event and we hope many more will join in 2016. Some countries have decided to raise rare disease awareness further, for example, Spain declared 2013 as the National Year for Rare Diseases.

Our objective is for the World Health Organization to recognise the last day of February as the official Rare Disease Day and to raise increasing awareness for Rare Diseases worldwide.

On [rarediseaseday.org](http://rarediseaseday.org) you can find information about the thousands of events happening around the world to build awareness for people living with a rare disease and their families. If you are planning an event, register your event details on our [Post your Event](#) page to get your event listed on the site.



*Photo: Rare Disease Day 2014 in Brazil*

## Your Information Pack



The European Organisation for Rare Diseases (EURORDIS) has developed this information pack to help you **plan and implement your own awareness-raising campaign** on or around the last day of February every year.

This information pack, together with the rest of the communication tool kit: logo, video, banner and poster, will help you **raise awareness** and **organise your own communication** around the Day.

Please use it as a guide and if you have any questions, do get in touch:  
[rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org)

Don't forget to share with us the details of your awareness campaign, as well as plans, media coverage and photos from your Rare Disease Day. Send them to:  
[rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org)

## Target Audience

Rare Disease Day was started by patient organisations and is patient-led. Therefore, the primary drivers and beneficiaries of the international campaign are **people living with a rare disease**. Other target audiences may vary from country to country.

Our main target audiences are the following:

- ✓ The general public and the media
- ✓ Politicians, policy-makers and public authorities
- ✓ Health professionals and caregivers
- ✓ Researchers, clinicians and academics
- ✓ Pharmaceutical and biotech industry

We encourage **everyone who has an interest in rare diseases** to join the campaign as long as they respect the spirit of Rare Disease Day.



*Photo: Rare Disease Day 2012 EURORDIS event in Brussels. Left to right: Ruxandra Draghia Akli, Director Health, DG Research; Terkel Andersen, President of EURORDIS; Nessa Childers, Member of the European Parliament, Sandra E. Roelofs First Lady of Georgia; Dr Ségolène Aymé, Chair of EUCERD*

## Rare Disease Day 2016 Theme & Slogan

*Theme: Patient Voice*

*Slogan: Join us in making the voice of rare diseases heard*

---

2016 marks nine consecutive, successful years of Rare Disease Day. Continuing the momentum, Rare Disease Day 2016 focuses on **making sure the voices of those living with a rare disease are heard**.

Nearly 7000 different rare diseases have been identified to date, directly affecting the daily life of more than 30 million people in Europe alone. On 29 February 2016, people living with or affected by a rare disease, patient organisations, politicians, carers, medical professionals, researchers and industry will come together in solidarity to raise awareness of rare diseases.

The Rare Disease Day 2016 theme '**Patient Voice**' recognises the crucial role that patients play in voicing their needs and in instigating change that improves their lives and the lives of their families and carers.

The Rare Disease Day 2016 slogan '**Join us in making the voice of rare diseases heard**' appeals to a wider audience, those that are not living with or directly affected by a rare disease, to join the rare disease community in making known the impact of rare diseases. People living with a rare disease and their families are often isolated. The wider community can help to bring them out of this isolation.

Patients and patient advocates use their voice to bring about change that:

- Ensures that politicians continuously and increasingly acknowledge rare diseases as a public health policy priority at both national and international levels.
- Increases and improves rare disease research and orphan drug development.
- Achieves equal access to quality treatment and care at local, national and European levels, as well as earlier and better diagnosis of rare diseases.
- Supports the development and implementation of **national plans and policies for rare diseases** in a number of countries.
- Helps to reduce isolation sometimes felt by people living with a rare disease and their families.

**Rare Disease Day amplifies the voice of rare disease patients so that it is heard all over the world.**

The patient voice:

- **Is stronger when patients receive training** so that patient advocates are equipped with the skills and information that they need to be able to represent the patient voice at the local, national and international level, within and on behalf of their patient organisations.



- **Is vital because rare disease patients are experts in their disease.** In situations when there is often a lack of medical expertise or disease knowledge because a disease is so rare, patients develop expertise on treatment and care options. With this expertise, the voice of a rare disease patient is often more inherent to the decision-making process regarding their treatment or care options.
- **Is increasingly present and respected in the medicines regulatory process, during which patients bring real-life perspective to the discussion.** This voice needs to be encouraged to become stronger all along the life cycle of the R&D process, from the early stages of development of a medicine, right through to when the medicine is in use in a wider population of patients. This will help to ensure that medicines are developed more efficiently and in turn will result in patients accessing more, better and cheaper treatments at an earlier stage.

EURORDIS, whose mission is to be the voice of an estimated 30 million people living with a rare disease in Europe, supports patients to make their voice stronger through various initiatives and activities, including:

- The [EURORDIS Access Campaign](#), which invites anybody living with a rare disease to voice the difficulties they experience accessing treatment or care through a questionnaire.
- The facilitation of the participation of patient advocates in numerous [scientific committees and working parties](#) at the European Medicines Agency and beyond.
- The [EURORDIS EXPRESS Summer School](#), aimed at empowering patient representatives through training in the areas of clinical research, regulatory affairs and health-technology assessment.
- The EURORDIS Patient Voices Programme, created to collect patient opinions on transversal topics and include them in the policy and decision-making process and other regular consultations with patients.
- [Rare Diseases International](#), the global voice for rare disease patients.
- [RareConnect](#), the online network of rare disease communities that provides a forum for people living with or affected by rare diseases to voice their experiences and meet others living with the same rare disease.





## Our International Campaign

Rare Disease Day was started by patient organisations and is patient-led. Therefore, the **primary drivers and beneficiaries** of the international campaign are **patients**. However, we encourage **everyone who has an interest in rare diseases** to join the campaign.

Rare Disease Day was **created** and is **coordinated annually** by **EURORDIS**. Many countries have **National Alliances** for their rare disease patient organisations and these alliances **coordinate activities at the national level**. The list of National Alliances can be found on page 10 of this booklet and on the [rarediseaseday.org](http://rarediseaseday.org) website.

We encourage patient groups to organise awareness raising events and to coordinate their actions informally with their National Alliance, whenever possible.

### The Role of EURORDIS:



EURORDIS has a **guiding role** in Rare Disease Day.

EURORDIS **coordinates** Rare Disease Day **internationally** by developing **common communication** and **awareness-raising tools** which are made available on the international [website](http://www.rarediseaseday.org). EURORDIS also **oversees** [Friends of Rare Disease Day](#), Rare Disease Day logo, poster and image, the Rare Disease Day website ([www.rarediseaseday.org](http://www.rarediseaseday.org)), Rare Disease Day social media: [Facebook](#), [Twitter](#), [YouTube](#), [Flickr](#) and [Google+](#) and the on-line news service.

EURORDIS hosts an annual **European-level event** (in Brussels) and manages **press relations** in order to raise awareness and move forward key policies and initiatives benefiting people living a rare disease.

EURORDIS **collects** and **disseminates patient stories, photos and videos** from the community and sends **regular updates** about the Campaign to the rare disease community.

We also **gather** and **evaluate data** on the results of Rare Disease Day in order to report back on the global campaign.

## The Role of National Alliances

### What is a National Alliance?

National Alliances are **umbrella patient organisations** that regroup a wide range of rare disease organisations within their particular country.

National alliances exist in many, but not all, European countries. The characteristics and activities of each alliance vary from country to country.

### What can National Alliances do?

National Alliances ensure the **coordination** of Rare Disease Day at the **national level** and organise a **national campaign** or single **event**.

National Alliances **update** the **information** and **events** on the country-by-country section of [www.rarediseaseday.org](http://www.rarediseaseday.org).

National Alliances can **adapt** the **common communication** and **develop** their **own tools** to raise awareness of their event(s) and to secure **funding** for local actions.

National Alliances **collect patient stories** for media and also to build and maintain **press** and **media contacts** at a national level. If possible, National Alliances should find a **patron** and obtain a video or written message of support.

National Alliances also **gather** and **evaluate data** results in order to report back on the national campaign.

### Who is your National Alliance?

<b>Australia</b>	Rare Voices Australia	<a href="https://www.rarevoices.org.au/">https://www.rarevoices.org.au/</a>
<b>Austria</b>	Pro Rare Austria	<a href="http://www.prorare-austria.org">www.prorare-austria.org</a>
<b>Belgium</b>	RaDiOrg- Rare Diseases Organisation	<a href="http://www.radiorg.be">www.radiorg.be</a>
<b>Bulgaria</b>	National Alliance of People with Rare Diseases (NAPRD)	<a href="http://www.rare-bg.com">www.rare-bg.com</a>
<b>Canada</b>	CORD- Canadian Organization for Rare Disorders	<a href="http://www.raredisorders.ca">www.raredisorders.ca</a>
<b>China</b>	CORD- Chinese Organization for Rare Disorders	<a href="http://www.hanjianbing.org/">http://www.hanjianbing.org/</a>
<b>Croatia</b>	Croatian Alliance for Rare Diseases	<a href="http://www.rijetke-bolesti.hr">www.rijetke-bolesti.hr</a>
<b>Cyprus</b>	Cyprus Alliance for RD	<a href="http://www.raredisorderscyprus.com">www.raredisorderscyprus.com</a>
<b>Czech Republic</b>	Czech National Association for Rare Diseases (CAVO)*	<a href="http://www.vzacna-onemocneni.cz">www.vzacna-onemocneni.cz</a>
<b>Denmark</b>	Rare Disorders Denmark (Sjaeldne Diagnoser)	<a href="http://www.sjaeldnediagnoser.dk">www.sjaeldnediagnoser.dk</a>
<b>Finland</b>	HARSO - Organisation for RD and Disabilities in Finland*	<a href="http://www.harso.fi/">http://www.harso.fi/</a>

<b>France</b>	Alliance Maladies Rares	<a href="http://www.alliance-maladies-rares.org">www.alliance-maladies-rares.org</a>
<b>Georgia</b>	Georgian Foundation for Genetic and Rare Diseases	<a href="mailto:grd.georgia@gmail.com">grd.georgia@gmail.com</a>
<b>Germany</b>	ACHSE Allianz Chronischer seltener Erkrankungen e.V.	<a href="http://www.achse-online.de">www.achse-online.de</a>
<b>Greece</b>	Greek Alliance for Rare Disease	<a href="http://www.pespa.gr">www.pespa.gr</a>
<b>Hungary</b>	Rare Diseases Hungary	<a href="http://www.rirosz.hu">www.rirosz.hu</a>
<b>Ireland</b>	GRDO- Genetic and Rare Disorders Organisation	<a href="http://www.grdo.ie">www.grdo.ie</a>
<b>Italy</b>	UNIAMO – Federazione Italiana Malattie Rare	<a href="http://www.uniamo.org">www.uniamo.org</a>
<b>Japan</b>	Japan Patient Association	<a href="http://nanbyo.jp/">http://nanbyo.jp/</a>
<b>Latvia</b>	Latvian Alliance for Rare Diseases	<a href="http://retasslimibas.lv">http://retasslimibas.lv</a>
<b>Luxembourg</b>	ALAN- Rare Disease Luxembourg	<a href="http://www.alan.lu">www.alan.lu</a>
<b>Macedonia</b>	National Alliance for RD of Rep of Macedonia	
<b>Netherlands</b>	Vereniging Samenwerkende Ouder en Patiëntenorganisaties ORPHAN - Polish National Forum on the Treatment of Orphan Diseases	<a href="http://www.vsop.nl">www.vsop.nl</a>
<b>Poland</b>		<a href="http://www.rzadkiechoroby.pl">www.rzadkiechoroby.pl</a>
<b>Portugal</b>	Aliança Portuguesa de Associações das Doenças Raras	<a href="http://www.aliancadoencasraras.org">www.aliancadoencasraras.org</a>
<b>Portugal</b>	Federação Portuguesa de Doenças Raras FEDRA	<a href="http://www.fedra.pt">www.fedra.pt</a>
<b>Romania</b>	Rare Diseases Romania	<a href="http://www.bolirareromania.ro">www.bolirareromania.ro</a>
<b>Russia</b>	National Association "GENETICA	<a href="http://www.nacgenetic.ru">www.nacgenetic.ru</a>
<b>Russia</b>	Russian Patients Union - RD Working group	<a href="http://www.rare-diseases.ru">www.rare-diseases.ru</a>
<b>Serbia</b>	National Organisation for Rare Disease	<a href="http://www.norbs.rs/">http://www.norbs.rs/</a>
<b>Slovakia</b>	Slovak Alliance of Rare Diseases*	<a href="http://www.sazch.sk">www.sazch.sk</a>
<b>Spain</b>	Federación Española de Enfermedades Raras	<a href="http://www.enfermedades-raras.org">www.enfermedades-raras.org</a>
<b>Sweden</b>	The Swedish Association of Rare Disorders (Riksförbundet Sällsynta diagnoser)	<a href="http://www.sallsyntadiagnoser.se">www.sallsyntadiagnoser.se</a>
<b>Switzerland</b>	Proraris	<a href="http://www.proraris.ch">www.proraris.ch</a>
<b>UK</b>	Genetic Alliance (Rare Diseases UK)	<a href="http://www.raredisease.org.uk">www.raredisease.org.uk</a>
<b>Ukraine</b>	Rare Diseases of Ukraine	<a href="http://rarediseases.org.ua/index.php/en/">http://rarediseases.org.ua/index.php/en/</a>
<b>USA</b>	NORD- National Organization for Rare Disorders	<a href="http://www.rarediseases.org">www.rarediseases.org</a>

## Planning Your Awareness Campaign

EURORDIS recognises that each country and/or region has unique needs and therefore requires different approaches to make the most of the campaign. We encourage you to **adapt** the campaign to reach **as wide an audience as possible** in your country.

The role of EURORDIS and the Council of National Alliances is to provide a framework for the Rare Disease Day campaign, offering guidance, advice and core materials. You are encouraged to use the theme “**Patient Voice**” that has been chosen for this year and to adapt the slogan “**Join us in making the voice of rare diseases heard**” to your language and culture. Theme and slogan translations for [French](#), [German](#), [Italian](#), [Portuguese](#), [Spanish](#) and [Russian](#) are already available for your use.

### Setting your own objectives

The overall objective of Rare Disease Day is to **raise awareness** amongst the general public about **rare diseases** and their **impact on patients’ lives**.

At the European Union level, the objective is to raise awareness amongst EU institutions in order to make rare diseases a priority in EU public health and research agendas and budgets.

However, you might want to set up your **own specific objectives** for this year’s campaign. For example:

- ✓ Make your disease better known
- ✓ Bring patients and researchers closer together
- ✓ Improve access to care and treatment
- ✓ Provide hope, information and help to patients, in particular those for whom a support network is not available or known
- ✓ Raise funds to pursue your action

### Ideas of awareness raising activities:

- ✓ **Coordinate a letter-writing or email campaign to local or national policy and decision makers and authorities** to urge them to act for people living with rare diseases. The topics covered in the letter need to be adapted to the particular situation of rare disease patients in your region or country
- ✓ Send a **press release** to the media in your region / country

- ✓ Organise **interviews with the media** to talk about the situation of rare disease patients in your region / country (magazines and newspapers, television, radio)
- ✓ Organise **events around rare diseases** and the topics important to patients in your country (conference, workshops and meeting, walks, demonstrations, sports events etc.)
- ✓ Organise a **political event to advocate** for rare diseases to your local authorities/ present a petition or a manifesto
- ✓ Approach a **special/famous person** and ask him/her to **be the patron of the Day** in your country, or use the existing patron of your organisation
- ✓ Give out **awards** to people who are recognised for having acted effectively or outstandingly for the cause of rare disease patients
- ✓ Hold a **competition centred on rare diseases**: photo competition, art contest, essays etc.
- ✓ Invite schools to involve children via essay-writing campaigns or other educational initiatives
- ✓ **Display posters, images or other awareness raising displays.** Images and videos can inspire many to take action. This toolkit includes posters, a logo and other tools that can be used for campaigning and at events
- ✓ **Distribute flyers** (stickers, pins, etc.) to people on the street, in schools, hospitals, or universities
- ✓ Make **appointments to meet with your local and national authorities**, in particular those involved in research and the diagnosis, treatment and care of rare disease patients
- ✓ **Organise a visit by a politician or local authority** to a rare disease research laboratory or centre of expertise. This could be done with patient representatives, and the media should be invited
- ✓ **Organise fund-raising events** or a special fund-raising campaign

For **more ideas** look at what has been done in previous years by national and local patient groups in the [Highlights](#) section of our website.

### Rare Disease Day is flexible but there are a few basic rules:

- Depending on individual and national environments, National Alliances and/or patient groups and other participants can choose to organise Rare Disease Day around one single day, one weekend, several days, or a week but **always around the last day of February!**
- Some National Alliances or patient organisations may take the opportunity to collect funds or convince sponsors to support their actions. Others may prefer not to make the Day a fundraising event.
- Rare Disease Day **should not serve to promote any specific commercial interest and no visibility should be given to specific products.**

### Measures to avoid manipulation of the campaign for private interests

Measures are being taken to prevent people using Rare Disease Day for commercial purposes or to promote an issue which is incompatible with this patient-driven awareness raising campaign.

The following disclaimer can be found in the [Downloads & Materials](#), [Get Involved](#) and [About this website](#) section of the website:

The Rare Disease Day logo is a registered trademark, not to be used for commercial purposes. The logo may only be used in support of activities organised commemorating and/or promoting the Rare Disease Day. The logo, if used, should stand alone. Do not alter the logo in any way such as by changing the design, colours or the proportions, or crop it or combine it within any other logo. In case it is not possible to use the correct colours due to technical limitations, use the logo in black and white. A non-compliant use of the logo constitutes an infringement of EURORDIS' trademark rights.



## Materials you can Use

EURORDIS makes available a variety of tools which are easy to download from the [Downloads & Materials](#) section of the **Rare Disease Day website**: [www.rarediseaseday.org](http://www.rarediseaseday.org).

### Logo

Logos play a fundamental part in creating a global, recognisable campaign and therefore their **consistent use** is vital in ensuring the message has maximum impact. There is a new logo for Rare Disease Day this year; please use this logo in **all communication pertaining to Rare Disease Day**. Do not change colours or proportions. The logo has been registered as a **trademark** in Europe, North America and Asia. EURORDIS, as the owner of a registered trademark, can commence legal proceedings for trademark infringement to prevent inappropriate use of the logo. For full details of what modifications can and cannot be made to the logo, see the Rare Disease Day style sheet on the website.



### Video

EURORDIS is preparing a **two-minute promotional video** for Rare Disease Day 2016. The video will seek to promote key information about rare diseases and convey the idea behind this year's slogan "*Join us in making the voice of rare diseases heard*" as well as focusing on the '**Special Moments**' in the lives of people living with a rare disease. The video will be filmed using **real patients**. It will be **patient-led** and **patient focused**.

The video will not seek to promote any one rare disease or organisation but refers to Rare Disease Day, the date, the theme and the website. All national alliances and patient groups involved in the production will be acknowledged.

There will be a teaser of the video released near the start of the campaign and the full version of the video will be posted on the Rare Disease Day [YouTube](#) channel and will appear on the Rare Disease Day [website](#) in the weeks leading up to 29 February 2016.

A **link** to the video will be sent via email to rare disease patient groups through participating **National Alliances** and **country organisers** during the campaign.

The video will also be featured in the EURORDIS weekly [eNews](#) and will be sent to [Friends of Rare Disease Day](#) and everyone who subscribes to the Rare Disease Day **mailing list**. It will also be promoted via the Rare Disease Day [Facebook](#) page and [Twitter](#) account.

Everyone will be encouraged to **send the video to a friend** and thus contribute to the **viral success** of the video campaign!

The video can also be used by **local** Rare Disease Day **organisers** to **introduce** their **events** and to **attract media attention**.

A **30-second version** of the video will also be available to National Alliances for **local** and/or **national TV spots**. Contact [rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org) for more information.

Last year, the video was translated into **27 languages**. If the video is not translated into your language, please email [rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org).

## Banner



A **static digital advert** for the 2016 campaign will be developed for use on your own online and printed resources. We encourage you to use it in **your website** and **email signature** during the month of February.

## Poster

The poster will highlight the **slogan**, the **date** and the **website** address. It will be coherent with the visuals presented in the official video.

The poster will be available for download on the [Downloads & Materials](#) section of the website as a PDF and also in a Photoshop format, in order to translate the slogan or add **your own text** and **logos**. A slightly different version of the poster is also available with a blank box for local organisers to **include specific event information**.



You can also use the logo and/or the visual identity of the campaign (as in the poster) to **create other communication materials** such as: postcards, stickers, t-shirts, mugs, etc.

## Information Pack

We encourage you to **use** this information pack or parts of it, to **translate** it, and to **send** it to your members and contacts in order to help them **organise** their **own Rare Disease Day activities**.

## Online Resources

### Website

The Rare Disease Day official international website is [www.rarediseaseday.org](http://www.rarediseaseday.org). In order to make it known by the largest possible audience year after year, the URL has been the same since 2008, and remains unchanged. As Rare Disease Day grows, each year we update the content in order to align the information with the theme and visual identity chosen. This year we have a brand new website which will be launched on 21<sup>st</sup> November, 100 days before Rare Disease Day.



Although National Alliances and other Rare Disease Day participants are free to create their own Rare Disease Day websites or sections devoted to Rare Disease Day on other websites, **it is important that everyone refers to [www.rarediseaseday.org](http://www.rarediseaseday.org) website as the official international Rare Disease Day website and includes the URL in their websites, posters and in all other communication material.**

The website provides **information** about the campaign in general, gives **ideas** of how to get involved and allows you to download common **tools** and **share your story** via photos and videos. It also includes displays all of the **events** being held around the world.

### Country Pages

Each National Alliance or any patient organisation will be able to manage their own event pages on the [rarediseaseday.org](http://rarediseaseday.org) website.

The first step is to write to [rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org), giving us the name of your organisation and your country or region. Then, you will be given a **login and password** so that you can post the **text**, **pictures**, **visuals** or **video** that you would like to appear on the **event page**.

Your **contact details** will also appear in the media contacts.

You will be able to include the following information:

#### ✓ NATIONAL ALLIANCES

Only National Alliances belonging to EURORDIS' Council of National Alliances will be able to include information in "National Alliances". In this section you can post a short description of your organisation, display your logo, add your contact details and link to your website.



### ✓ LOCAL LANGUAGE

The same Introduction text can be posted in your own language (optional)

### ✓ EVENTS

If your country or region does not appear on the list and you would like to announce your event, please send an email to: [rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org)

## Friends of Rare Disease Day

Although the Rare Disease Day campaign is driven by patient organisations and only they can advertise their events on the website, **Rare Disease Day is open to everyone who would like to participate.**

“**Friends of Rare Disease Day**” has been created to **give visibility** to those who want to do something to **create awareness** about rare diseases. Friends can be **researchers, health professionals, care givers, public authorities, industry, patient groups** and **any other person or entity** genuinely interested in improving the lives of people affected by rare diseases.

Being a “Friend” requires less commitment to the campaign and acknowledges the fact that not everyone can give the same level of time and effort. However, in order to be a Friend you have to at least:

- ✓ **Post the Rare Disease Day logo on your website**
- ✓ **Link your website to [www.rarediseaseday.org](http://www.rarediseaseday.org)**

Friends are also strongly encouraged to organise or participate in an awareness-raising activity and relay the EURORDIS and/or their National Alliance **press release** to their media contacts.

The website will display the list of people and organisations who have signed up as a “Friend of Rare Disease Day.” This list will be updated on a daily basis in the weeks preceding the Day, in order to show the growing list of supporters and people getting involved to **build momentum**.

## Tell your Story

The [rarediseaseday.org](http://rarediseaseday.org) website gives the possibility for anyone to **upload** a **video** or a **photo** and post a short **testimony** in their own language. The **Rare Disease Day Photo Wall** and the collection of **Rare Disease Videos** displayed on the website help to inform and raise awareness – sending a message of **solidarity** and giving a sense of **community**.

**Tell your Story** and encourage other people you know to do the same. If you belong to a patient group or have your own website include a **link** to your site.

## Our Social Media

The following **online tools** have been set up to enable **social interaction** between all those interested in rare diseases and Rare Disease Day.

[facebook.com/rarediseaseday](https://facebook.com/rarediseaseday)



*'Like' the RDD Facebook page, view our timeline and participate in the conversation on Rare Disease Day. 46,000 Likes to date.*

[twitter.com/rarediseaseday](https://twitter.com/rarediseaseday)



*Follow Rare Disease Day on Twitter (@rarediseaseday). Re-tweet us and use the hashtag #raredisease*

[youtube.com/rarediseaseday](https://youtube.com/rarediseaseday)



*Watch the videos, comment and link to the many videos and upload your video to the Rare Disease Day channel via [rarediseaseday.org](http://rarediseaseday.org)*

[flickr.com/rarediseaseday](https://flickr.com/rarediseaseday)



*Upload your photo on to the Rare Disease Day Photo Wall and add a comment in your own language*

[plus.google.com/103351106528925184946](https://plus.google.com/103351106528925184946)



*Follow Rare Disease Day on Google+. Watch the videos, comment and share.*

These are all excellent channels for **sharing information**, **making contacts**, **building the rare disease community** and **creating a buzz** around Rare Disease Day!



We encourage you to use the Rare Disease Day social media and to invite your members, friends or contacts to join. The more people who join, the more effective we will be at spreading the message of Rare Disease Day and raising awareness on rare diseases.

## Raise and Join Hands!

Join and raise your hands to show **Solidarity** with rare disease patients around the world!

### *How can you participate?*

**Take your picture, joining and raising your hands!** Ideally take your picture next to a landmark or in a location that is recognisable in your country. Record the event with a photo and send it by email to [rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org).

Remember to specify the location and the country where the photo was taken.

This initiative started in 2012 and has been very successful. It helps to show visually that we are **mobilised** for people living with a rare disease and share the **same objectives**.

Whether you are a **family**, **10 people in an office**, **100 people at a conference** or **1000 people at a public gathering**, we encourage people to upload photos raising and joining hands on [rarediseaseday.org](http://rarediseaseday.org). You can become part of the campaign and view your photo in our specific [Flickr Photostream](#).

It is **simple** and **requires no budget**. It can be integrated into activities you have already planned for the Day. It has caught on every year and become the **symbolic gesture** of the Day.



*Photo: Raising and Joining Hands in Croatia, 2014*



## Reaching Out to the Media

Rare Disease Day is primarily a **mass communication campaign** to **raise awareness** about **rare diseases** amongst the general public. The **media** is the best way of reaching the general public and serves to shape the opinions that will **convince policy makers**. Therefore, attention and energy should be given to the media when planning your Rare Disease Day awareness campaign.

### Tips & Tools

1. Before approaching the media, think about an **angle of interest** that will make journalists interested in covering your news. This angle is commonly known as a **'hook'**.  
Examples of hooks:

**Topical:** link your story to a more general topic in the news, such as health reform or pricing and reimbursement of medicines. Try to link it to the theme of this year's campaign and think about how the theme can be adapted to the situation in your region or country.

**Surveys and Statistics:** release or repackage existing surveys and reports that shed more light into the situation of rare disease patients for your disease or in your region or country. (For example: RDUK report on the situation of rare disease patients in the United Kingdom presented at Parliamentary receptions in Scottish, Welsh and Northern Ireland Assemblies)



**Events:** Invite journalists to your events and try to have a note of originality to make your event stand out. Also organise photo opportunities for journalists to illustrate their stories. (For example: in the USA a NORD member carried a Rare Disease Day flag while escalating Mt Everest)



**Competitions:** Give multiple opportunities to communicate about the launching, the objective and the winners. (For example in Spain, FEDER organised a marathon and the Hungarian alliance an art competition)

**Endorsements:** Support from a well-known local figure or celebrity, such as a First Lady, an actor or actress, musician or sports personality can attract media interest. Their involvement can go from a message of support on the website and a short video to being present at your event, making a speech or releasing a joint press release. (Example: Crown Princess Mary of Denmark invited two children with



rare diseases to her palace and a short documentary was made about it, which was then shown on national TV on Rare Disease Day)

**Patient stories:** Sometimes a real life perspective and an engaging personal account can be enough to secure coverage. Journalists often feature human interest stories and might run an article featuring a patient story or use it to link to wider policy issues that you would like to highlight. For example to talk about the launching of a national rare disease plan, they might start with the problems faced by one individual patient to obtain a diagnosis or get access to treatment.



2. Have a bank of stories about rare disease patients ready to respond to last-minute media requests. (Make sure the patients and families featured in the stories understand that their story might be widely used by media or might not be used at all).
3. Relay stories of interest to your National Alliance or country patient organiser (see our list on page 9 and 10 of this document and in the Country by Country section of the website).

## Media Materials Available

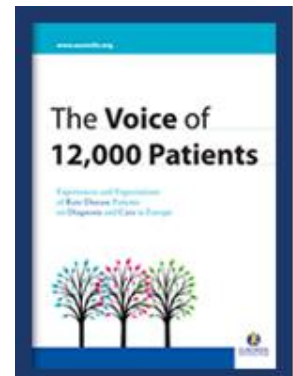
The Rare Disease Day website will make available the following materials that can be used to inform and engage the media:

- ✓ **Press release (general):** Announcing the date and the international campaign.
- ✓ **Press release (European):** Announcing the European advocacy event organised in Brussels by EURORDIS.
- ✓ **Rare Disease Day awareness video:** Can be shown at a press conference and the link can be included in your Media Pack. It can also be shown on national or local TV.
- ✓ **History of Rare Disease Day:** Past themes and slogans. Official statistics year to year with a summary of the events which took place around the world.

**EURORDIS Policy Fact Sheets:** Originally designed as tools for patient advocates when arguing in favour of national plans for rare diseases in their countries, these fact sheets are concise summaries of the main issues faced by rare disease patients today. They can serve to provide more in depth information to the media.



- ✓ **European Union Committee of Experts on Rare Diseases (EUCERD) 2014 Report on the State of the Art of Rare Diseases Activities in Europe:** the most comprehensive report of national and EU-level activities in the field of rare diseases and orphan medicinal products. The [2014 edition](#) includes an overview of Rare Disease Activities in Europe; key developments in Europe in 2013; European Commission activities; European Medicines Agency activities and other European activities; and activities of European Member States and other European countries. Comparing [policies in your country](#) with other countries can elicit media interest.
  
- ✓ **“The Voice of 12,000 Patients” book:** Compilation of results of two unprecedented surveys on the experiences and expectations of rare disease patients on diagnosis and care in Europe. The two surveys conducted by EURORDIS over a period of four years collected responses from 12,000 patients from 24 different countries representing 18 different diseases. Comparing the situation of rare disease patients in your country can elicit media interest.
  
- ✓ **“The Voice of Rare Disease Patients: Experiences and Expectations of over 3,000 Patients”:** A EURORDIS book published in 2013, [The Voice of Rare Disease Patients: Experiences and Expectations of over 3,000 Patients on Rare Disease Patient Registries in Europe](#) presents the results of an extensive consultation process including a survey of over 3,000 European patients conducted by EURORDIS as part of the EU-funded EPIRARE project to build consensus and synergies for the EU registration of rare disease patients.



Registries are instrumental tools for understanding the natural history of rare diseases, capturing unmet medical needs, gathering critical data for research, and tracking treatment benefits and risks.

The survey results show that patients understand and value a comprehensive European approach to rare disease registries, strongly favouring EU-level regulation for registries. A European registry platform should be publically funded and patients should be involved in all aspects of governance. Capacity-building is needed to ensure this patient involvement.

