



Rare Disease Day

2014

Information Pack

EURORDIS

October 2013

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Rare Disease Day

Rare Disease Day is an awareness campaign that 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 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.

The campaign targets primarily the general public but it is also designed to raise awareness amongst patients and patient representatives, politicians, public authorities, policy-makers, 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, more than 1000 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 has also served for 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 event, with the USA joining in 2009 and patient organisations in over 70 countries or regions participating in 2013. We hope many more will join in 2014.

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 to promote a European Rare Disease Year and for the World Health Organization to recognise the last day of February as the official Rare Disease Day.

On 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 awareness event, write to us at rarediseaseday@eurordis.org to get your event listed on the site.

This information pack

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

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

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.

The main targets are the following:

- The general public and the media
- Politicians, policy-makers, 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

The Theme & Slogan

Theme: Care

Slogan: Join Together for Better Care

Caring for people living with a rare disease has many facets. Some patients have access to medicines while others have no treatment available. Some patients are fairly independent while others require intensive physical assistance and equipment. Care can consist of medicines, products and devices, expert medical consultation, physical therapy, social services, respite for family members, and much more. For most children and adults living with a rare disease, primary care is provided by family members.

Rare Disease Day 2014 focuses on care and encourages everyone in the rare disease community to ***Join Together for Better Care.***

Patients and their families who feel isolated by the rarity of their disease should know that there are more than 6000 different rare diseases affecting over 60 million people across Europe and North America alone and millions and millions more throughout the world. Most of these diseases are genetic, serious, chronic and debilitating. Each disease is different, but they affect people in similar ways. Joining together can help patients and their families find common solutions for care and remind them they are not alone.

Healthcare professionals, researchers, pharmaceutical companies, and policy makers also frequently feel isolated in their struggle to find and provide care for rare diseases. Experience shows that bringing together scattered knowledge and resources for people living with rare diseases is the most efficient and effective way to mobilise the care patients and families need and deserve.

In Europe, there are several areas in which access to rare disease care is advancing:

- Shaping policies to improve access to medicinal products for rare diseases
- Identifying and improving access to specialised social services for rare diseases
- Centres of Expertise and European Network References
- National rare disease plans for countries in the European Union ... and beyond

The theme for 2014 highlights that the many different facets of rare disease care represents a universal need for patients and their families around the world. Advocating at the local and national level to improve the lives of people living with a rare disease and their families is necessary.

Considering rare diseases from an international perspective is also essential in order to send a strong message of hope to the millions of rare disease patients and families throughout the world who can break their isolation through a vast, united international network of solidarity.

This year Rare Disease Day encourages us to continue finding ways to work together to provide the different kinds of care that people living with a rare disease need.

Let's Join Together for Better Care!

Organisation of the 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 the rarediseaseday.org website.**

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



Role of EURORDIS:

- Decision on dates, themes and content
- International coordination of Rare Disease Day
- Management of “Friends of Rare Disease Day”
- Management of graphic identity (logo, poster, image)
- Rare Disease Day website (www.rarediseaseday.org)
- Development of common communication / awareness-raising tools
- European-level event (in Brussels) & press relations
- Collecting and disseminating patient stories, photos and videos from the community
- Managing RDD Social media: Facebook, Twitter, YouTube and Flickr.
- Managing on-line news service
- Send regular updates about the Campaign to the rare disease community

- Data gathering (results) & evaluation
- Report back on the global campaign

Role of National Alliances:

- Coordination at national level
- Organise national campaign or single event
- If possible; finding a patron and obtaining video or written message of support
- Updating of information and events on the country by country section of www.rarediseaseday.org
- Adaptation of common tools and development of own tools
- Funding for local actions
- Press / media contacts at national level
- Collecting patient stories for media
- Data gathering (results) & evaluation



Photo: Rare Disease Day 2011 March in Italy

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 “Care” that has been chosen for this year and to adapt the slogan “***Join together for better care***” to your language and culture. Find the theme and slogan translations for French, German, Italian, Portuguese, Spanish and Russian [here](#). Develop the messaging and activities that work best in your country/region.

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 “Get Involved” section of the 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 products.**

Measures to avoid manipulation of the campaign for private interests

The following 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.

- Disclaimer in the 'Downloads' section of the website saying:

"The Rare Disease Day logo is a non-commercial symbol of global partnership in the search for ways of improving the lives of those affected by rare diseases. We ask that the logo be displayed only in the spirit in which it was intended."

- Disclaimer in the 'Get Involved' section of the website, saying:

"We ask that this logo only be displayed in the spirit in which it was intended—as a non-commercial symbol of global partnership in the search for ways to improve the lives of those affected by rare diseases."

Materials

EURORDIS and the Council of National Alliances makes available a variety of tools which are easy to download from the '**Downloads**' section of the **Rare Disease Day website: www.rarediseaseday.org**. Local organisers are free to adapt them and translate them into their own language.

Logo

Logos play a fundamental part in creating a brand and therefore their consistent use is vital in ensuring the message has maximum impact. The Rare Disease Day logo has stayed the same since the Day was launched in February 2008. 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.



Banner

A static digital advert for the 2014 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 (see below).

The poster will be available for download on the 'Downloads' section of the website as a pdf and also 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. 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. The look and feel of the website will be new in 2014. As Rare Disease Day grows, each year we update the content in order to align the information with the theme and visual identity chosen. The site map will be very similar every year and the sections will remain the same, although the content may change and new sections or features may be added.

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 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, 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 website. The first step is to write to 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 enter the ‘back office’ of the website in order to copy paste 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@euordis.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 anyone 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

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 sympathisers and people getting involved to build momentum.

Tell your Story



One of the strongest tools patients have to raise awareness about rare diseases is their personal story. People are very interested in hearing from patients themselves or from their caregivers, about what it is like to live with a rare chronic and often debilitating disease and what problems, hopes and dreams they may have.

The 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.

Social media

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

facebook.com/rarediseaseday



'Like' the RDD Facebook page, view our timeline and participate in the conversation on Rare Disease Day. 15,000 Likes to date.

twitter.com/rarediseaseday



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

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

flickr.com/photos/rarediseaseday



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

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.

Video viral campaign

EURORDIS is preparing a two-minute promotional video for Rare Disease Day 2014.

The video will seek to promote key information about rare diseases and convey the idea behind this year's slogan "Join Together for Better Care". In line with this year's theme, the video will communicate the message that there is solidarity amongst all people active in the field of rare diseases and stress the importance of joining forces in order to improve the lives of people living with rare diseases and their families. 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.

The video will be posted on the Rare Disease Day You Tube channel and will appear on the home page of the Rare Disease Day website in the weeks leading up to 28 February 2014.

A link to the video will be sent via email to rare disease patient groups via participating National Alliances and country organisers during the month of February. The video will also be featured in the EURORDIS weekly eNews and 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 Group and Twitter channel. **Everyone will be encouraged to send it to a friend and thus contribute to the viral success of this video campaign!**

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

There will be a 30 second version of the video to be aired on local and/or national TV stations.

Joining Hands

This initiative started in 2012 and has been quite successful. It helps to show visually that we are mobilised for people living with rare diseases and all driven by the same objectives.

It is simple and requires no budget. It can be integrated into activities you have already planned for the Day. We hope it will catch on every year and become the symbolic gesture of the Day.

There are two ways of participating:

- **Take your picture, joining and raising your hands:** Join and raise your hands to show Solidarity with rare disease patients around the world! 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.

Remember to specify the location and the country where the photo was taken **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 rarediseaday.org. The photos will be displayed as a photo wall in a specific Flickr Photostream and maybe used as part of a larger exhibit.

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, a great deal of attention and energy should be given to the media when planning your Rare Disease Day awareness campaign.

Tips & Tools

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. (Example: RD UK 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 who carried an RDD flag while escalating Mr 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 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.



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).

Relay stories of interest to your National Alliance or country patient organiser (see list at the end 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. Can 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.

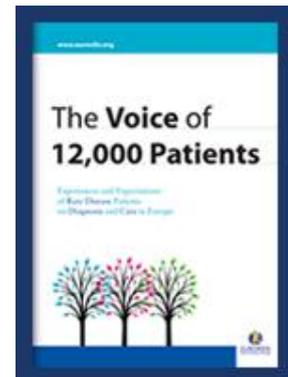
European Commission's short documentary video: Serves to illustrate the policy topics on which the EU is working for the benefit of rare disease patients. It features three patient stories illustrating cross-cutting issues: quest for diagnosis, living with the disease and access to treatment.

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's Committee of Experts on Rare Diseases (EUCERD) 2013 Report on the State of the Art of Rare Diseases Activities in Europe: the most comprehensive report of all the national- and EU-level activities in the field of rare diseases and orphan drugs. The 2013 edition includes all rare disease actions in each Member State, as well as other non EU European countries – including the progress of meeting the Council Recommendation for developing a national rare disease strategy. 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



Ideas from previous campaigns:

France

Awareness weekend in partnership with the French national rail, organised by the Alliance Maladies Rares and Orphanet to set up information desks and distribute rare disease quizzes in trains going to six major cities.



Spain

Official act in the Spanish Senate in Madrid supported by Her Royal Highness the Princess of Asturias - 350 people attended.



Brazil

Romario, former international football player and now a politician, agreed to support in Parliament the project of an official National Rare Disease Day.



Italy

The Italian volleyball league wore the RDD t-shirt during 21 volley matches during RDD week.



Four matches were transmitted on National TV Channels



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EURORDIS

Plateforme Maladies Rares

96 rue Didot

Paris 75014

www.eurordis.org

Phone (33) 1 56 53 52 61

Fax (33) 1 56 53 52 15

www.eurordis.org



Role of EURORDIS:

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