



Rare Disease Day

Information Pack

EURORDIS

November 2011



RARE DISEASE DAY

2012

February

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
		1	2	3	4	5
		8	9	10	11	12
6	7	15	16	17	18	19
13	14	22	23	24	25	26
20	21					
27	28					

29 → RARE BUT STRONG TOGETHER!
29 FEBRUARY

credit: gettyimages.com

credit: gettyimages.com

Solidarity

www.rarediseaseday.org

Table of Contents

Rare Disease Day 2012	5
February 29: a rare day for rare diseases	6
Target Audience	7
The Theme	8
Organisation of the international campaign	11
Planning your Awareness campaign	13
Materials	16
Logo.....	16
Banner	16
Poster	16
Information Pack.....	17
Online Resources	17
Website.....	17
Country pages.....	18
Friends of Rare Disease Day	20
Tell your Story.....	21
Social media	22
Video viral campaign.....	23
Reaching out to the Media.....	24
Tips & Tools.....	24
Media Materials Available.....	25
Ideas from previous campaigns:.....	27
Participating National Alliances	28

Rare Disease Day 2012

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 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 but it is also designed for patients and patient representatives, as well as 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 the 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 US joining in 2009 and patient organisations in 56 other countries participating in 2011. We hope many more will join in 2012. Our objective is for the WHO to recognise the last day of February as the official Rare Disease Day.

February 29: a rare day for rare diseases

Rare Disease Day will be particularly special this year. 2012 is a leap year so the day will fall on February 29 “a rare day for rare diseases”. It is also the 5th edition of the day. Coincidentally EURORDIS will also celebrate its 15th anniversary in 2012.

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 patients. 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

However, we encourage everyone who has an interest in rare diseases to join the campaign as long as they respect the spirit.

The Theme



“Due to rarity of patients and scarcity of expertise together we can do more”

Solidarity has been selected as the communication theme of the 2012 campaign to focus on the importance and the need for collaboration and mutual support in the field of rare diseases.

The slogan of the 2012 campaign is:

“Rare but Strong Together”

People active in the field of rare diseases are not alone and should not act alone in order to meet their objectives. Even though they are few and far between, collectively they are many and if they act together they will be stronger.

United we are stronger

Acting together makes particular sense in the field of rare disease because patients are rare, expertise is scarce and people living with rare diseases face similar challenges.

Rare disease patients all over the world face the same type of challenges:

- Access to correct diagnosis
- Lack of information
- Overall lack of scientific knowledge
- Social consequences
- Lack of appropriate quality healthcare
- High cost of the few existing drugs and care
- Inequities in availability of treatment and care
- Isolation

Together we can do more

The following are areas in which it makes sense to aggregate efforts:

Access to correct diagnosis (Genetic testing, newborn screening)

Increase availability of information (Coding and classification, telemedicine)

Improve scientific knowledge (Registries and databases, international research platforms, multi-centred clinical research, development of drugs and diagnostic tests, training of professionals)

Mitigate social consequences (Specialised social services that would improve the quality of life of people living with a rare disease and their families, such as Help Lines, Respite Care Services and Therapeutic Recreation Programmes)

Increase provision of appropriate quality healthcare (International reference networks of centres of expertise, multidisciplinary care)

Improve access to the few existing drugs and care (Pricing and reimbursement, healthcare reform)

Breaking from isolation (Patients and families support and empowerment, networking and community building)

***“rare diseases is an area
where collaboration is
essential”***

Solidarity and international cooperation - Building a better world for rare disease patients

Given the rarity of both patients and experts, most actions related to rare diseases have to be performed in cooperation between different countries, regions and levels. Progress for the benefit of rare diseases patients can only be achieved through close international cooperation.

Rare diseases: a movement based on solidarity

Solidarity is particularly present amongst people active in the field of rare diseases

- Solidarity amongst patients
- Solidarity amongst diseases
- Solidarity amongst health care professionals, carers and patients
- Solidarity amongst researchers, industry and policy makers
- Solidarity amongst countries

We aim at extending this sense of solidarity to society at large.

This Rare Disease Day let's show them our solidarity!

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.

The campaign is co-ordinated by EURORDIS at the international level and National Alliances at the national level. In countries where there is no national alliance or there is more than one alliances representing rare disease patients, there will be no official coordination at the national level.

This does not mean that those countries cannot participate in Rare Disease Day. On the contrary we encourage those groups to organise awareness raising events separately and to coordinate their actions informally, 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

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 that has been chosen for this year “Solidarity” and to adapt the slogan “**Rare but Strong Together**” to your language and culture. However you are encouraged to develop messaging and activities that work 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 EU level, the objective is to raise awareness on rare disease 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 at heart of 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.
- 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 that play a central role 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 environment, National Alliances 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 on the Day.

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 only that the logo be displayed in the spirit in which it was intended."

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

"We ask only that this logo 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 in 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 is 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 2012 campaign has been 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 integrates the slogan "Rare but Strong Together", and highlights the uniqueness of the date and the international dimension of the campaign. The photo chosen incarnates Solidarity between one brother and two sisters suffering from the same rare genetic disease: MPS VI.

The poster is also available for download in Photoshop in order to translate the slogan, 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

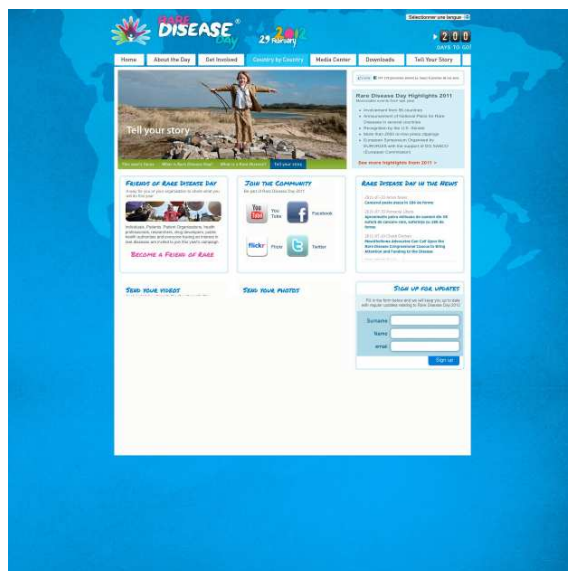
Website

The Rare Disease Day official international website is www.rarediseaseday.org. The URL has been the same since 2008 and will not change in order to make it known by the largest possible audience year after year.

The look and feel of the website may change slightly every year in order to align 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 RDD 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 a calendar of events by country.



Country pages


Each National Alliance or country organiser(s) will be able to manage their own country page. 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 you would like to appear on that section for your country.

You will be able to include the following information:

ASSOCIATION DETAILS

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

The screenshot shows a web browser window displaying the 'Association Details' form for the Canadian Organisation for Rare Disorders (CORD). The form is titled 'Association Details' and includes a navigation bar with links: 'Association Details', 'Introduction Text', 'Events', 'Local Language', 'Help & Contact', and 'Sign up'. The form fields are as follows:

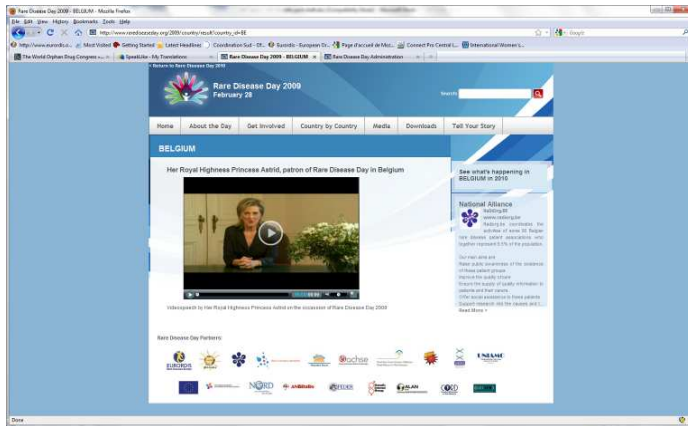
Association	Canadian Organisation for Rare Disorders
Logo	
Description	CORD is Canada's national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services to...
Address	National Office: 155 Bloor Street West Suite 400, Toronto, Ontario M5S 1S4 Canada
Address	Alberta Chapter: 9213-142 Street NW, Edmonton, Alberta T6H 0H6 Canada
Postcode	M5S 1S4
City	Toronto
Country	CANADA
Telephone	1-877-362-7276
Website	www.rarecanada.ca
Press Contact Name	Durkane Wong-Rieger, President
Press Contact Email	durkane@sympatico.ca

INTRODUCTION TEXT

The text you enter here is what the public will first see when they visit your country page.

The text in English should contain a few lines about one of the following:

- What is the rare disease situation in your country?
- Written message from a patron with photo or a video message

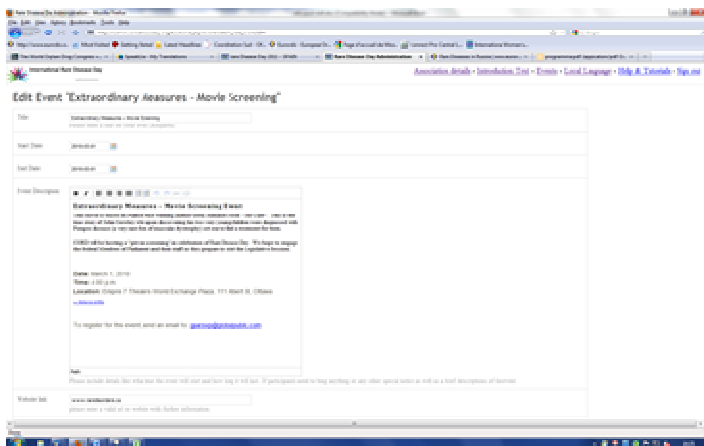


LOCAL LANGUAGE

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

EVENTS

Add your event into a calendar



Only National Alliances belonging to the EURORDIS' Council of National Alliances will have access to the Country by Country section of the website. In countries where there is no official Alliance, a patient group will be designated as country organizer.

We encourage anyone interested in organizing an awareness activity to contact the National Alliance or Country organizer in order to post their event in the event calendar and coordinate their actions with others in the same country. If your country does not appear on the list and you would like to announce your event, please send an email to:

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 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, individual patients, 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 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 a growing list of sympathizers 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, what it is like to live with a rare chronic and often debilitating disease. What are their problems, hopes and dreams.

The 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** that are shown on the website helps to inform and raise awareness – sends a message of solidarity and gives 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 Group, launched in 2009, with more than 18 000 fans to date- 'Like' or become a 'Friend' in the RDD Facebook page and contribute to the conversation on rare diseases.



- Twitter page, launched in 2009 – Follow Rare Disease Day on Twitter (@rarediseaseday) and receive the latest information and resources. Re-tweet our posts, or tag your own tweets #rarediseases and your comments will automatically appear on the Rare Disease Day Twitter page.



- You Tube channel: Comment on the RDD You Tube videos and link to your own. Include a link to your website in the description of the video.



- Flickr: Upload your photo and add a comment in your own language. The photos will be automatically fed on to the Rare Disease Day Photo Wall on the website.



These are all excellent channels to share information, make contacts, build the rare disease community and create 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 join the more effective we will be at spreading the messages of Rare Disease Day and raising awareness on rare diseases.

Video viral campaign

EURORDIS is preparing a 3-minute promotional video for Rare Disease Day 2012. The video will seek to promote key information about rare diseases and aim at creating awareness about rare diseases in general.

In line with this year's theme, the video will get across the message that there is solidarity amongst all people active in the field of rare diseases and stress the international dimension of the campaign. It will be patient led and patient focused.

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

The video will be posted in the RDD You Tube channel and will appear on the home page of the RDD website in the weeks before Feb 29.

A link to the video will be sent out via email to rare disease patient groups via participating National Alliances and country organisers during the month of February. It will also 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 success of this video viral campaign!

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

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 of your arguments. 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 UK 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: NORD's patient 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 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 disease patients to her palace and a short documentary was made about it, which was 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 are very interested by the human angle 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 reach diagnosis.



Have a bank of stories about rare disease patients 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): about the date and the international campaign.

Press release (European): about the European advocacy event organised in Brussels on Feb 29.

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.

European Commission's short documentary video: Serves to illustrate the policy topics on which the EU is working on 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.

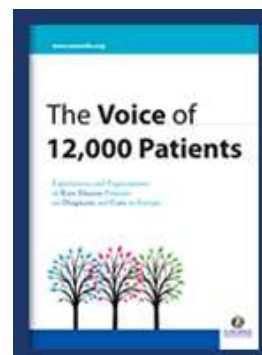
Joint Declaration « Rare Diseases: An International Health Priority»: This document has been elaborated by an informal network of rare disease rare disease patient alliances in Europe (EURORDIS), the US (NORD), Canada (CORD), New Zealand (ZORD) and other. It includes ten main recommendations to be addressed at international level as a matter of priority for the benefit of rare disease patients.

EURORDIS Policy Fact Sheets: Originally designed as a tool box 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 give more in depth information to the media.



European Union's Committee of Experts on Rare Diseases (EUCERD) 2011 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 2011 edition includes all rare disease actions in each Member State, as well as five other non EU European countries– including the progress of meeting the Council Recommendation for developing a national 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 Railroad, 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 in 2012.



Italy

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



Four matches were transmitted on National TV Channels

Participating National Alliances & Country Organiser

Belgium - RaDiOrg - Rare Disease Organisation Belgium			
office@radiorg.be	+32	4987015 03	www.radiorg.be
Bulgaria - National Alliance Of People With Rare Diseases			
tomov@raredis.org	+359	878 323 748	http://rare-bg.com/
Canada - Canadian Organization For Rare Disorders			
durhane@sympatico.ca	+1	969-7464	/www.raredisorders.ca
Croatia - Croatian Society For Rare Diseases			
vlasta@debra-croatia.com	+385	5 481 28 46	www.rijetke-bolesti.hr
Cyprus - Cyprus Alliance for Rare Disorders (CARD)			
card@thalassaemia.org.cy	+357	22 319 129	www.thalassaemia.org.cy/card.html
Denmark - Rare Disorders Denmark (Sjaeldne Diagnoser)			
dbf@bloderforeningen.dk	+45	33 14 00 10	www.raredisorders.dk
France - Alliance Maladies Rares			
ihoareau@maladiesrares.org	+33	1 56 53 53 40	www.alliance-maladies-rares.org
Georgia - Georgian Foundation for Genetic and Rare Diseases			
kvividze@gmail.com	+995	532 91 60 91	www.gerad.ge
Germany - ACHSE			
Mirjam.Mann@achse-online.de	+49	30 33 00 7080	www.achse-online.de
Greece - Greek Alliance For Rare Disease			
gr-pespa@otenet.gr	+30	210 76 60 989	www.pespa.gr
Hungary - Rare Diseases Hungary			
pogany@rirosz.hu	+36	1 788 38 81	www.rirosz.hu
Ireland - Genetic And Rare Disorders Organisation (GRDO)			
info@grdo.ie	+353	26 92 748	www.grdo.ie

Italy – UNIAMO

bellagambi.estero@uniamo.org +39 0412410886 www.uniamo.org

Luxembourg – ALAN

info@alan.lu +352 266 112 1 www.alan.lu

Netherlands – VSOP

c.oosterwijk@vsop.nl +31 35 603 40 40 www.vsop.nl

Portugal - Aliança Portuguesa de Associações das Doenças Raras

aliancadoencasraras@gmail.com +351 968 581 556 <http://aliancadoencasraras.org/>

Portugal – Federação Portuguesa de Doenças Raras

paula.costa@rarissimas.pt +351 217786100 www.fedra.pt

Romania - Romanian National Alliance For Rare Diseases

doricad@yahoo.com +40 360 103 200 www.bolirareromania.ro

Russian Fed. - National Association of RD Patients "GENETICS"

nacgenetic@mail.ru +7 812 319 3 423 www.rarediseases.ru

Russian Fed. - Russian Patients Union - RD Working Group

miv20@mail.ru +7 495 6122053 www.rare-diseases.ru

Spain - Federación Española De Enfermedades Raras

direccion@enfermedades-raras.org +34 91 533 40 08 www.enfermedades-raras.org

Sweden - Riksförbundet Sällsynta Diagnoser

dammert@sallsyntadiagnoser.se +46 8 764 49 99 www.sallsyntadiagnoser.se

Switzerland – ProRaris

contact@proraris.ch +41 21 887 6886 www.proraris.ch

United Kingdom - Genetic Alliance UK / Rare Diseases UK

melissa@geneticalliance.org.uk +44 207 704 3141 www.geneticalliance.org.uk

United States - National Organization For Rare Disorders

mdunkle@rarediseases.org +1 203 744 01 00 www.rarediseases.org



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.

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