RARE DISEASE DAY

February 28th 2011

EURORDIS
Rare Diseases Europe

Information Pack

Rare Disease Day

Content

EURORDIS
Rare Diseases Europe

1. How to use this information pack

- **Read the whole pack.** It will give you background information on Rare Disease Day and will help you understand the choices that were made and how they will help us achieve our main goal of awareness raising.
- **Spend time thinking about the theme that was chosen for the day.** If necessary, according to the rare disease environment in your region or country, think about a sub-theme or subtitle that would translate the general theme to your own conditions. These conditions vary a lot from country to country, and so might the sub-theme.
- **Translate the slogan in your own language** and send back to EURORDIS**.**
- **Decide on the specific target audience** of the Rare Disease Day for your country or region.
- **Decide on the specific objectives** of the Rare Disease Day for your region or country; for example, you may not want to set up fund-raising objectives (section)
- **Read the suggestions for local events and activities** and think about which ones you could organise in your region or country.
- **Complete, personalise and translate the press release** to be sent to the media in your region or country.

Visit the www.rarediseaseday.org website

  - **Download logos and posters**
  - **Update your country page**
  - **Advertise the website address** as widely as possible!

- **You can use the whole pack or only part of it for your activities.** You may need to translate it in your own language to share it with your members.
- **For any questions, please contact Anja Helm.** (anja.helm@eurordis.org)

2. Why a Rare Disease Day?

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.

More specifically, in 2011, Rare Disease Day will seek to draw attention to the:

- **Gaps in health that exist for rare disease patients between and within countries**
- **Gaps in health that exist for rare disease patients compared to others in society**

The campaign will serve to advocate for:

- **Equal access for rare disease patients to health care and social services**
- **Equal access to basic social rights: health, education, employment, housing**
- **Equal access to orphan drugs and treatments**

Regardless of the theme, Rare Disease Day will always be needed

- **Because we constantly need to raise awareness on rare diseases and reinforce their importance as a public health priority,** among decisions makers, health professionals and the general public. Information is key to improving living conditions for rare disease patients.
- **Because acting simultaneously in many places and in many countries can ensure the voice of rare disease patients is heard by more people**
- **Because a day focussed on rare diseases can bring hope and information** to people living with rare diseases, their carers and their families
- **Because we want equity in access to care and treatment** for rare disease patients in Europe
- **Because we need an action that can bring all stakeholders of the rare disease community together** with the same goal
- **Because we need more funds** for research and care, and **more research** and efforts directed towards rare diseases
- **Because we need to coordinate policy actions** at national level and at the international level
- **Because we need to keep fighting** for rare disease patients…

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3. Rare Diseases: A Public Health Priority

Rare Diseases as a public health priority is a founding concept of the rare disease patient movement. It will be the over arching theme of every Rare Disease Day Campaign.

Rare Disease Day is the perfect occasion to inform or remind our target audience that rare diseases are a public health priority because beyond the diversity of the diseases patients and their families are confronted with the same wide range of difficulties arising directly from the rarity of these pathologies:

- **Lack of access to correct diagnosis**: the period between the emergence of the first symptoms and the appropriate diagnosis involves unacceptable and highly risky delays, as well as wrong diagnosis leading to inaccurate treatments: the pre-diagnosis maze;

Lack of information: about both the disease itself and about where to obtain help, including lack of referral to qualified professionals;

- **Lack of scientific knowledge**: this results in difficulties in developing therapeutic tools, in defining the therapeutic strategy and in shortage of therapeutic products, both medicinal products and appropriate medical devices;

- **Social consequences**: living with a rare disease has implications in all areas of life, whether school, choice of future work, leisure time with friends, or affective life. It may lead to stigmatisation, isolation, exclusion from social community, discrimination for insurance subscription (health insurance, travel insurance, mortgage), and often reduced professional opportunities (when at all relevant);

- **Lack of appropriate quality healthcare**: combining the different spheres of expertise needed for rare disease patients, such as physiotherapist, nutritionist, psychologist, etc… Patients can live for several years in precarious situations without competent medical attention, including rehabilitation interventions; they remain excluded from the health care system, even after the diagnosis is made;

- **High cost of the few existing drugs and care**: the additional expense of coping with the disease, in terms of both human and technical aids, combined with the lack of social benefits and reimbursement, cause an overall pauperisation of the family, and dramatically increases the inequity of access to care for rare disease patients.

- **Inequities in availability of treatment and care**: innovative treatments are often unevenly available in the EU because of delays in price determination and/or reimbursement decision, lack of experience of the treating physicians (not enough

physicians involved in rare diseases clinical trials), and the absence of treatment consensus recommendations.

For background information, read:

- "Rare diseases: Understanding this Public Health Priority", a paper developed by Eurordis and its members at http://www.eurordis.org/IMG/pdf/Princeps_document-EN.pdf

(Also available in French, Italian, Portuguese, Spanish and Hungarian)

RARE DISEASES AS A PUBLIC HEALTH PRIORITY AT EUROPEAN LEVEL

This concept needs to be looked at in the past and current context of development of rare disease legislation, both at European and national levels:

Since 1999, the European Union has taken measures to fight against rare diseases and their impact on patients' lives, and has made **rare diseases a priority of its public health programmes:**

- EU Regulation on Orphan Medicinal Products (1999)
- EU Regulation on Paediatric Drugs (2006)
- EU Regulation on Advanced Therapies (2007)
- Community Action Programme in the Field of Public Health (1999-2003)
- Community Action Programme in the Field of Public Health (2007-2013)
- EU 7th Framework Programme for Research (2007-2013)
- *Public Consultation on Rare Diseases: Europe's challenges* (November 2007)
- Commission Communication on Rare Diseases (November 2008)
- Council Recommendation on a European Action in the field of Rare Diseases, (June 2009)

RARE DISEASES AS A PUBLIC HEALTH PRIORITY AT NATIONAL LEVEL

The Council Recommendation on a European Action in the field of Rare Diseases, which was adopted in June 2009, ensures that common policy guidelines are shared everywhere in Europe and calls upon Member States to adopt National Plans for Rare Diseases, before the end of 2013.

EUROPLAN is an operational measure within this European strategy in the field of rare diseases, to provide tools to Member States to develop a plan on rare diseases, linking with a common strategy at the European level. This "double-level" approach will ensure that progress is globally coherent and follows common orientations throughout Europe.

Since September 2010, 15 National Alliances have organised national conferences with key stakeholders to start planning and developing National Plans for Rare Diseases in their own countries, following the recommendations included in the EU Council Recommendation.

Each country is at a different stage of development of their national plans or strategies so the communication regarding this issue must be adapted to the context of each country

For more information:

http://www.eurordis.org/content/europlan-guidance-national-plans-and-conferences

4. The Theme for 2011

RARE DISEASES & HEALTH INEQUALITES

"RARE BUT EQUAL"

"Everyone has the right of access to preventive health care and the right to benefit from medical treatment"

Art. 35, European Charter of Fundamental Rights

While the average level of health in most parts of the world have continued to improve over the last decades and huge progress has been made in scientific research and medical technology, health gaps amongst countries and within countries are widening, especially for the most vulnerable groups in society.

What about people living with rare diseases?

Every rare disease patient has his story of injustice to tell. For some of them it will be about obtaining life-saving treatments or being reimbursed, or about gaining access to specialised services or being considered eligible for disability compensation. Others have more difficulties finding a job, getting into school, obtaining a loan or accessing lifetime insurance.

For example, a haemophilia patient in Bulgaria had no access to life-saving treatment; in Austria treatment for an hereditary immunodeficiency was available but not reimbursed; the father of an SMA patient in Ukraine battled to obtain an electric chair for his child; an X fragile patient in France is still waiting to get state benefits for disability; Myasthenia Gravis patients in the UK have no access to mobility allowances; many rare disease patients in the US are denied lifetime insurance.

Many rare disease patients are treated unequally because their disease is not known or well understood by their health systems and society at large.

Fragile X

Florian suffers from Fragile-X syndrome and for two years, he has been waiting desperately for the renewal of his special "disability card" that allows him to get through daily life a little easier. "There is a definite lack of awareness about rare diseases in the public service's administration. They don't know about this syndrome, for them it's like any other disease, they don't have a clue about the difficulties that Florian is enduring since his card expired. Basically, at 25, he has become isolated," tells a patient representative from Mosaiques, a French X-Fragile association based in the suburbs of Paris. "We have so many patients that suffer from inequalities and are not recognised by the system. We must track down these malfunctions in our so-called welfare society."

The existing health gaps amongst and within countries and regions of the world are further aggravated for people with rare diseases.

Some examples:

Cystic Fibrosis

There are 40,000 patients with Cystic Fibrosis in Europe but depending on where they live, some die before their 10th birthday and other live well into their adulthood until their 30s or 40s on average. A study funded by the European Commission comparing the CF amongst several European countries, published in the Lancet of March 2010, shows a shocking disparity in number of patients and age at death between older and newer Member States, independent of population sizes and underlying gene frequencies for CF. This inequality can most likely be explained by the tragic fact that most children born with CF in some EU countries die in early childhood due to lack of access to appropriate diagnosis and healthcare.

Childhood Cancer

A survey conducted by the European Society for Paediatric Oncology (SIOPE) revealed the disparities in availability and quality in childhood cancer care that currently exist in Europe. With 21 responses from the EU Member States, only 5 countries: Austria, Belgium, France, Germany and Italy, have officially recognised regulations in place.

"Every year in Europe, approximately 20,000 children and adolescents aged up to 19 are diagnosed with cancer. Approximately 80% of these patients manage to recover if they use the proper and the best available method of treatment. With the progress of knowledge, it is possible to develop new methods of treatment –less toxic and also more effective. However, it is necessary to create the possibility to introduce these methods to the diagnostic and therapeutic standards and address the current disparity in treatment existing in Europe today,' says Professor Jerzy Kowalczyk, National Consultant in the Field of Pediatric Hematology and Oncology in Poland.

Epidermolysis Bullosa

The life of a person suffering from Epidermolysis Bullosa is not the same in Austria than in neighbouring Slovakia, for example. "In some countries, rare disease patients have to endure lack of medical specialists, great difficulties in reaching a diagnosis and absence of treatment," says Dr Gabriela Pohla-Gubo, co-founder of DEBRA Austria and since 2006, head of the EB Academy at the EB House Austria. The EB House Austria, founded in 2005, is an interdisciplinary clinical unit for diagnosis, medical care, academic affairs and research related to EB. Besides treating patients from Austria, EB patients from 18 other countries have been visiting the EB House up

to now. "Even though reimbursement can still be a problem, cross border healthcare is provided and includes communication with the referring physicians (for example, about post-treatment care) or training opportunities for foreign clinicians and laboratory personnel to allow patients to be diagnosed and treated at home thus avoiding them a long trip," tells Dr Gabriela Pohla-Gubo. According to her, next year's Rare Disease Day theme is very important because "patients should have direct access to cross border health care and reimbursement should be provided for their travel and treatment costs."

Surveys conducted at European and national level, reveal that there are disparities in access to diagnosis, health care and social services

EURORDIS CARE 2 & 3 SURVEYS

A European survey on diagnosis and access to health care and social services in 20 European countries revealed that 40% of rare disease patients were initially misdiagnosed, leading to severe consequences including inappropriate and costly medical interventions such as surgery and psychological treatment. In that same survey 59% of the respondents declared having to reduce or stop their professional activity because of their disease or to take care of a relative affected by a rare disease. On average, 16% of patients were forced to move house because of their disease. One out of 5 patients experienced rejection linked to their disease from healthcare professionals.

SPANISH STUDY

A study on the Public Health Situation and Needs of People with Rare Diseases in Spain, revealed that more than 40% of rare disease patients interviewed did not have access to treatment or received treatment they considered inadequate. The main barriers to access treatment are the excessive price of the products or the need to get the product in a different country. Almost half of the respondent has had to travel out of their province in the last two years to obtain diagnosis, receive appropriate care or get the needed medication.

UK STUDY

A new Rare Disease UK report highlights a number of worrying issues experienced by patients and families affected by rare conditions in the UK. The report,

“Experiences of Rare Diseases: An insight from patients and families”, deals with the views and experiences of 600 patients and families affected by over 100 different rare conditions on a wide range of topics ranging from research to diagnosis, and access to care, information, support and treatment.

Although some patients and families indicated positive experiences of timely diagnosis and good quality care and support from the National Health Service, this is not the case for the majority of patients and families with rare diseases

“The survey also highlights inequalities in the services received by patients with different rare diseases and even between those affected by the same rare disease in different parts of the country,” says Alistair Kent, Chair of Rare Diseases UK.

Read more:

“The Voice of 12,000 Patients” Experiences and Expectations of Rare Disease Patients on Diagnosis and Care in Europe, EURORDIS

“Public Health Situation and Needs of People with Rare Diseases in Spain" (Estudio sobre situación de Necesidades Sociosanitarias de las personas con Enfermedades Raras en España - Estudio ENSERio) FEDER

“Experiences of Rare Diseases: An insight from patients and families”, Rare Diseases UK

5. Why is it a good time to talk about health inequalities in Europe?

THE EU SOLIDARITY IN HEALTH INITIATIVE

In line with universal principles of social justice and the EU's overarching objective to create economic growth with social solidarity (Lisbon Treaty), the European Union has called for a concerted action to redress health inequalities - currently aggravated by the economic crisis. The *EU Solidarity in Health Initiative* highlights that:

- Gaps in health exist between and within countries in the EU
- Factors include income, education, living and working conditions and health behaviours
- Differences in life expectancy at birth between Member States reach up to 8 years for women and 14 years for men
- The financial crisis has deepened these inequalities and has rendered some groups in society even more vulnerable than before…

Therefore, the EU has launched this initiative since 2009 in order to unite efforts to level the playing field amongst and within Member States. **Although the Solidarity in Health Initiative does not mention rare diseases it recognises that special attention should be given to the needs of less advantaged people,** including the disabled and those suffering from discrimination, stigmatisation and barriers to accessing health and other services.

"For some groups, the issue of health inequality including reduced access to adequate health care, can be qualified as one which involves their fundamental rights"

Solidarity in Health: Reducing Health Inequalities in the EU, Commission Communication, Oct 2009

More information:

Communication from the Commission - Solidarity in health: reducing health inequalities in the EU

(available in all European languages)

EU Policy to reduce health inequalities

http://ec.europa.eu/health/social_determinants/policy/index_en.htm

EU Policy on Rare Diseases

http://ec.europa.eu/health/rare_diseases/policy/index_en.htm

INFLUENCING THE THIRD EU PUBLIC HEALTH PROGRAMME (2014-2020)

The 2nd EU Public Health Programme (2007-2013), managed by the Directorate General for Health and Consumer at the European Commission is coming to an end and **it is time to advocate for rare diseases to be high on the agenda of the 3rd Public Health Programme**, which will run from 2014 to 2020.

"People Living with Rare Diseases should be entitled the same access and quality of care as any other patients. But today reality is far from that. The rarity of patients, medical experts, knowledge and resources are aggravating the vulnerability of rare disease patients who are suffering from life threatening, debilitating, and chronic diseases. We are certainly not asking for more or better access and care than for other chronic diseases. To the contrary, we share the common cause of all chronic diseases. However, we believe that rare diseases is one of the most dramatic cases of health inequalities today internationally and in Europe in particular," argues EURORDIS' Chief Executive Officer, Yann Le Cam. "The campaign this year will seek to drive home the message that it is important to level the playing field within and amongst countries in the area of rare diseases. At the European level, the immediate objective is to put rare diseases high on the public health agenda of each country driving Rare Disease Day and to promote the explicit inclusion of rare diseases in the Third EU Public Health Programme, which will decide the policy and funding priorities in the period 2014 to 2020. »

More information:

EU Public Health Programme

http://ec.europa.eu/health/programme/policy/index_en.htm

INFLUENCING THE CROSS-BORDER HEALTH CARE DEBATE

In July 2008, the Commission proposed a new EU directive on the application of patients' rights in cross-border healthcare. It wants to provide legal certainty over patients' rights to seek diagnosis and care in another EU country and reinforce cooperation between those countries. The resulting legal framework will be especially relevant for rare disease patients.

For more information:

EURORDIS Newsletter article on Patient Mobility across EU health services, April 2007

EURORDIS Response to the Consultation regarding Community Action in Health Services, January 2007

EU Policy on Cross Border healthcare

http://ec.europa.eu/health/cross_border_care/policy/index_en.htm

WHAT ARE WE ADVOCATING FOR?

- **Equal access for rare disease patients to health care and social services**
- **Equal access to basic social rights: health, education, employment, housing**
- **Equal access to orphan drugs and treatments**

6. Organisation Principles

Rare Disease Day is an annual, awareness-raising event co-ordinated by EURORDIS at the international level and National Alliances at the national level. Who can take part? Anyone who wants to: patients, caregivers Patient Organisations, National Alliances, health professionals, researchers, drug developers, Ministries of Health - the more, the better!

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, visuals)
- Rare Disease Day website
- Development of common communication / awareness-raising tools
- European-level event (in Brussels) & press relations
- Collecting and disseminating patient stories of health inequalities
- Collecting and disseminating photos and videos from the community
- Managing Web 2.0 Social Media Networks: Facebook, Twitter, Youtube and Flickr.
- Evaluation of results and analysis at European level
- Managing on-line news service
- Send regular updates about the Campaign to the rare disease community

Role of National Alliances:

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

Rare Disease Day is flexible at national/local level:

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. Some National Alliances may prefer not to make the day a fundraising event. EURORDIS suggests a variety of tools for National Alliances, which they are free to adapt and translate if necessary. Target audiences may vary from country to country.

Common features:

- **VIP/ Patron/First Lady**

National Alliances are encouraged to secure the support of a patron: a first lady, royalty, VIPs or other well know persons in their country. The role of the patron is to provide a message of support, written or video, to the national alliance, to be displayed on the website and given to the media.

At a national level, patrons may host conferences, receptions, or give out awards, depending on what is agreed upon between the national alliance and the patron.

- **Tell your story** to raise awareness about health inequalities for rare

disease patients. Patients representing different countries and diseases are urged to share their experience regarding access to health care and social services. Likewise health professionals are encouraged to explain the difficulties of access their patients experience on a daily basis. Help us spread the word amongst your members and contacts. A form to fill out will be available on www.rarediseaseday.org or you can send an email to rarediseasedaystories2011@eurordis.org

- **Write a letter to your MEP** to raise awareness about rare diseases

(can be co-signed by the National Alliance) A standard letter to translate and adapt will be available to download on www.rarediseaseday.org

National Alliances participating in the Rare Disease Day 2011:

Country	Alliance	Telehone	Contact e-mail
Argentina	GEISER	54 261 424 00 76	virginialejandrallera@yahoo.com
Belgium	RaDiOrg	32 498 70 15 03	lut@boks.be
Bulgaria	NAPRD	359 888 323 748	tomov@gaucherbg.org
Canada	CORD	1 416 969-7464	durhane@sympatico.ca
Croatia	Rijetke Bolesti	38 1 481-28-46	rijetke.bolesti@gmail.com
Cyprus	CARD	357 22 319 129	thalassaemia@cytanet.com.cy
Denmark	Rare Disorders Denmark	45 33 14 00 10	mail@raredisorders.dk
France	Alliance Maladies Rares	33 1 56 53 53 40	ihoareau@maladiesrares.org
Germany	ACHSE	49 30 33 00 7080	mirjam.mann@achse-online.de
Greece	PESPA	30 210 76 60 989	gr-pespa@otenet.gr
Hungary	HUFERDIS	36 1 326 74 92	pogany@rirosz.hu
Ireland	GRDO	353 709 30 50	avril.daly@fightingblindness.ie
Italy	UNIAMO	39 0412410886	antodea@libero.it
Luxembourg	ALAN	352 266 112 1	info@alan.lu
Netherlands	VSOP	31 35 603 40 43	c.oosterwijk@vsop.nl
Romania	RONARD	40 260 616 585	doricad@yahoo.com
Russian Federation	Rare Diseases Russia	7 812 319 3 423	nacgenetic@mail.ru
Spain	FEDER	34 91 534 43 42	direccion@enfermedades-raras.org
Switzerland	ProRaris	41 21 887 6886	contact@proraris.ch
Portugal	FEDRA	35 1 217786100	assessoria.fedra@hotmail.com
Portugal	APADR	351 968 581 556	aliancadoencasraras@gmail.com
UK	Genetic Alliance/Rare Diseases UK	44 20 7704 3141	melissa@geneticalliance.org.uk
USA	NORD	1 203 744 01 00	mdunkle@rarediseases.org

7. Who is the Rare Disease Day for?

- Patients and patient representatives
- Policy makers
  - European and National Health Authorities
  - European and National Social and Welfare Authorities
  - Parliamentarians
- Health professionals and care givers
- Researchers, clinicians and academics
- Pharmaceutical and biotech industry
- General public
- Media (as a tool to reach the general public)

8. What will happen at the European level?

EURORDIS will organise an event in Brussels on February 28th, 2011. The **"Rare Diseases and Health Inequalities in Europe" Symposium** will bring together key stakeholders in the field of rare diseases in order raise the issue of rare diseases and health inequalities and discuss measures to mitigate them.

The conference will take place in the **International Press Centre in Brussels.** Attendants will include patients and patient representatives, European federations, health professionals, social researchers and academics working in the field of rare diseases, members of the EU Committee of Experts on Rare Diseases, industry representatives as well as high-level officials of the European Medicines Agency and the European Commission's Health and Social Affairs General Directorates.

The programme will be devoted to presenting the rare disease landscape in Europe and showing existing inequalities through patient testimonies, case studies, studies and surveys.

Potential studies for discussion:

At European level

- EURORDIS EurordisCare 2 and 3 surveys, which investigated patients' experiences and expectations regarding access to diagnosis and to medical and social services, in 24 European countries representing 18 different diseases.
- EURORDIS Inventory of Access and Prices of Orphan Drugs in 10 European countries, which revealed that for nearly 1 in 10 EU patients, a market authorised OD is officially unavailable.

At National level

- The ENserio Study on the Public health situation and needs of people with rare diseases in Spain, conducted by the Spanish Rare Disease Alliance (FEDER)
- The UK Study of experiences of rare diseases from patients and families in the United Kingdom, conducted by Rare Diseases UK
- The Italian Study on the social cost and social services needs of rare disease patients in Italy, conducted by the Italian Rare Disease Alliance (UNIAMO) and the Ministry of Welfare and Social Affairs

Disease-specific

- Comparative demographics of the European Cystic Fibrosis population: a cross-sectional database analysis, CF EUROPE
- European Standards of Care for Children with Cancer Project, SIOP Europe

Patients representing different countries and diseases will be invited to share their experience regarding access to health care and social services. Health professionals from selected centres of expertise will also explain the difficulties of access their patients experience on a daily basis.

At the end of the Symposium a panel debate will be organised around the question: how to mitigate health inequalities for rare disease patients within the Third EU Public Health Programme?

If you know of a survey or have a story that could help illustrate health inequalities for rare disease patients, please send an email to: rarediseasedaystories2011@eurordis.org

A press release, with more details, will be issued by EURORDIS, closer to the date. The agenda will be posted on the www.rarediseaseday.org website

9. What will happen in the different countries?

Activities taking place around Rare Disease Day in each country are the decision of the organisers in coordination with the patient Rare Disease National Alliance. EURORDIS suggests the following possible activities. These may vary depending on your resources, time, strategy and available funds.

You will need to enter those activities in the website section dedicated to your country, ahead of time.

Some ideas of possible activities include:

Coordinate letter writing or email campaign to local or national policy and decision makers. 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/country

Send a press release to the media

Make appointments to meet with your local and national authorities

Organise a visit of an MEP/ health minister to a rare disease centre of expertise or a research laboratory working on your disease. This could be done with patient representatives, and the media should be invited.

Organise interviews with the media to talk about the situation of rare disease patients (magazines and newspapers, television, radio)

Organise events around rare diseases and the topics at heart of patients (conference, workshops, walks, demonstrations, sports events, etc.)

Approach a special/famous person to be the patron of the day or use the existing patron of your organisation

Give 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.

Set up a help line to respond to enquiries or promote your existing help line

Display posters, images or other promotional displays

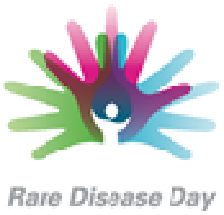
Distribute stickers and flyers to people on the street, in schools, hospitals, or universities

Organise fundraising events or a special fundraising campaign:

- Collect donations from people on the street
- Collect donations from your website
- Organise a fundraising dinner with a special guest
- Special mailings
- Sell specific items
- Approach corporate organisations for donations or long-term partnerships

10. Useful Tools

1. **Trademark Name**: Rare Disease Day®
2. **Logo**



3. **Slogan: *RARE BUT EQUAL***
4. **Poster**: a *Photoshop* version of the poster will be made available to national alliances shortly, allowing translation into the national languages.
5. **Website**: **www.rarediseaseday.org**
6. **Social media networks:**
    a. Rare Disease Day Facebook Group (will replace the Rare Disease Day 2010 Facebook Group with over 10,000 fans)
    b. Rare Disease Day YourTube Channel
    c. Rare Disease Day Flickr
    d. Rare Disease Day Tweeter
7. **Information Fact Sheets**:

What is a rare disease? (www.eurordis.org/IMG/pdf/Fact_Sheet_RD.pdf)
What is an orphan drug? (www.eurordis.org/IMG/pdf/Fact_Sheet_OD.pdf)
Rare disease patient groups in the EU (www.eurordis.org/IMG/pdf/Fact_Sheet_PO.pdf)

8. **Policy Fact Sheets**

Centres of Expertise
European Reference Networks
Needs and Priorities for Rare Disease Research

… and more to be found on www.eurordis.org

9. **Press Release**

EURORDIS
Rare Diseases Europe

LOGO OF ORGANISATION

Rare Disease Day

PRESS RELEASE

Rare Disease Day

28 February 2011

[*In CAPS = to be filled in by your alliance*]

PLACE, DATE

[***YOUR ORGANISATION***] announces Rare Disease Day in [***REGION/COUNTRY***] on 28 February 2011.

The main objective of Rare Disease Day is to raise awareness on rare diseases and reinforce their importance as a public health priority.

Organised by National Rare Disease Alliance members of EURORDIS and their partners, it is hoped that the day will help raise awareness of life-threatening and chronically-debilitating rare diseases and the challenges encountered by those affected.

This year, Rare Disease Day will also be the opportunity to draw attention to the aggravated gaps in health that exist for rare disease patients within and amongst regions and to advocate for equal access for rare disease patients to health care and social services.

"The existing health gaps amongst and within countries and regions in the world are further aggravated for people with rare diseases," says EURORDIS' CEO Yann Le Cam." It is our responsibilities to promote all patients have equal access to the best care available, regardless of their disease and where they live."

For more information, visit the official website, www.rarediseaseday.org

Rare diseases are chronic, progressive, degenerative, and often life-threatening with high levels of pain. There is no cure today for the 5,000 - 7,000 rare diseases identified to date, 50% of which affect children.

In [***YOUR REGION/COUNTRY***], there are [***X***] people living with rare diseases. [*Elaborate on situation of rare disease patients in your region/ country, what their needs are, and what is urgent to do*].

[*Contact person details*]

-ENDS-

EURORDIS
Rare Diseases Europe

11. Practical guide

How to update your Country Page on the website

Each National Alliance or country organiser(s) will be able to manage their own country page on the **"Country by Country"** section of the website. 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:

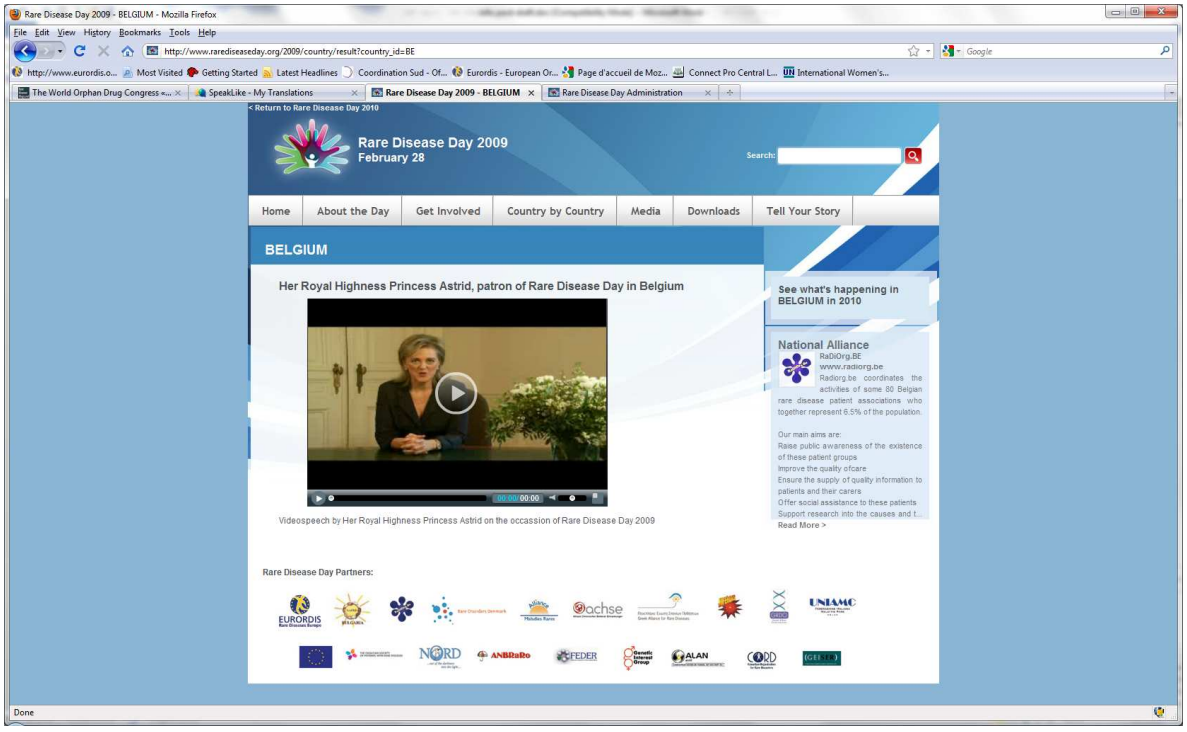
INTRODUCTION TEXT

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:

a) What is the rare disease situation in your country

b) Written message from a patron with photo or a video message



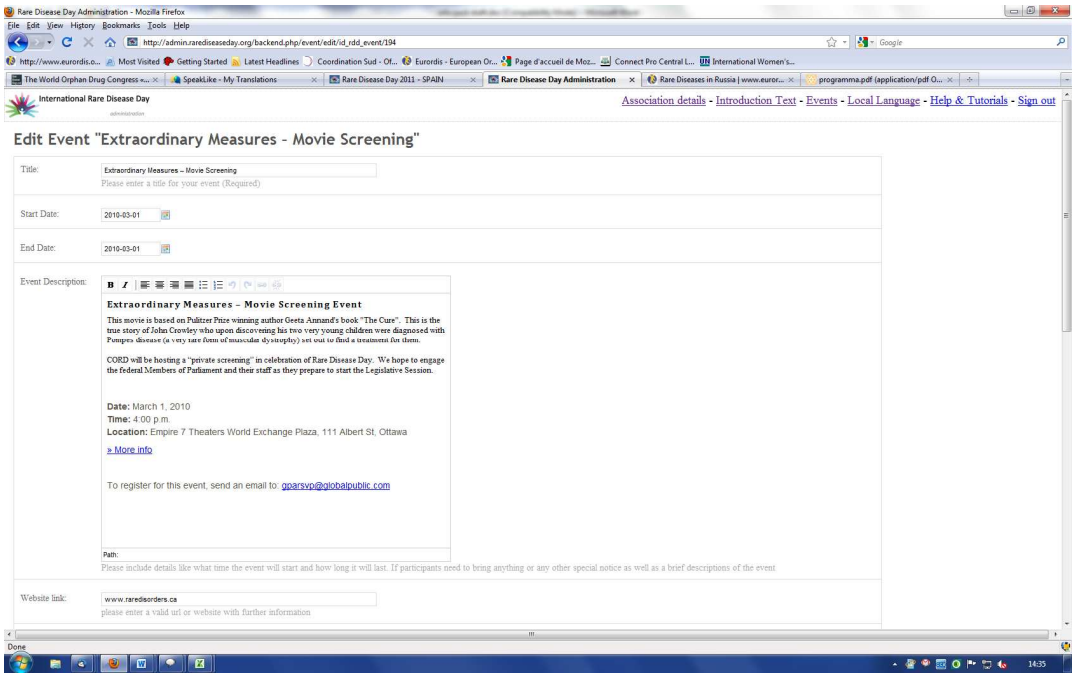
LOCAL LANGUAGE

The same Introduction text in your language (optional)

EURORDIS
Rare Diseases Europe

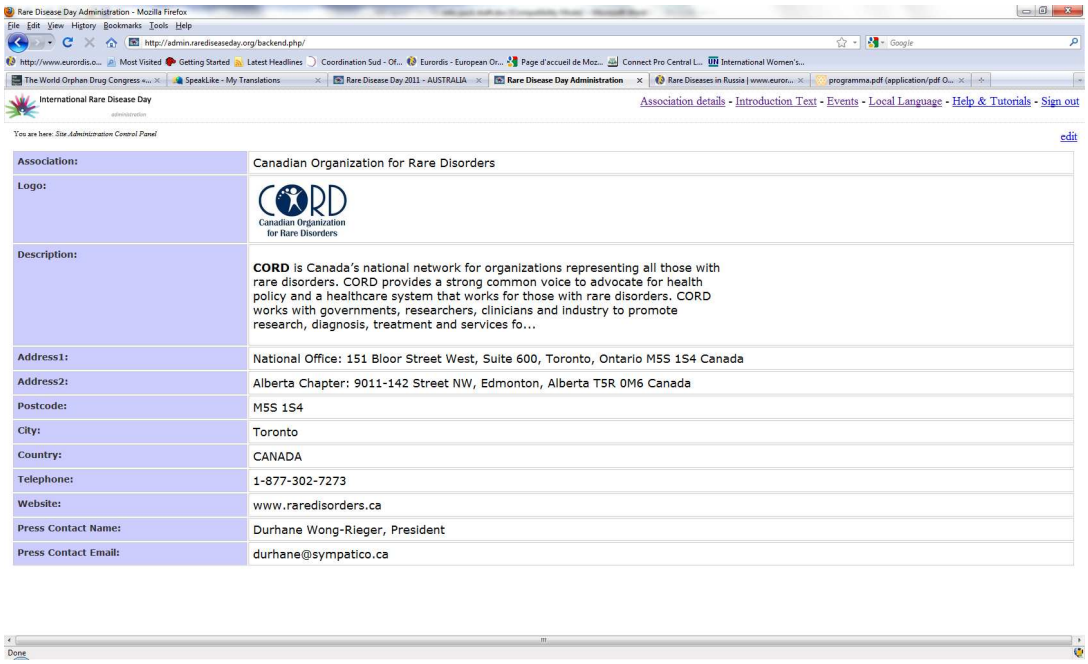
EVENTS

Add your event into a calendar



Only National Alliances will have access to:

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.**

EURORDIS
Rare Diseases Europe

How to become a *Friend of Rare Disease Day*

Rare Disease Day is open to anyone who would like to participate (individuals, patient groups, National alliances and European federations, health professionals, researchers, pharmaceutical and biotech companies, health authorities, etc)

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 sympathisers and people getting involved to build momentum.

In order to become "Friends of Rare Disease Day", interested parties will have to adhere to the spirit of Rare Disease Day and relay the information and raise awareness about the Day.
In practice, this will mean **filling out an on-line form**, like this:

Individuals, Patients, Patient Organisations, health professionals, researchers, drug developers, public health authorities and everyone having an interest in rare diseases are invited to join this year's campaign

When you send us your completed form, we will add your name and email address to a 'Friends of Rare Disease Day' list which will be displayed on the website.
Friends of Rare Disease Day' are being asked to:

* Post the Rare Disease Day logo on their websites and in their publications.
* Link their website to www.rarediseaseday.org
* Try to encourage media coverage of Rare Disease Day by suggesting stories to their media contacts for that day or the week leading up to it.
* Try to organise an awareness-raising activity on or around that date

Please enter the title of your organisation:
Contact person (not displayed):
Email: _____
Website:_____
Your website administrator's email (optional): _____
What will you do for Rare Disease Day (30 words max):_____
Country: _____
Role: _____

In addition, 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:

2. Download the Rare Disease Day logo and poster

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.

How to organise a Play Decide Game

Do you want to become involved in decisions on ethical issues that affect you and other rare disease patients and representatives? Is providing your views in surveys just not enough? Practice voicing your opinion and learn from those who may have opinions different from yours by participating in a new exercise called PLAY DECIDE (www.playdecide.org/polka). Six topics concerning rare diseases are already available:

- Stem Cell research
- Pre-implantation Diagnosis
- Cross-border health care
- Neonatal Screening
- The upper limit to spend on a single patient: the case of Orphan Drugs
- Diagnosis, Information to the patient and Genetic counselling

The PLAY DECIDE exercise comes in the format of a game and provides a structure that helps people feel safe discussing a topic that they may know little about.

The PLAY DECIDE initiative is designed to empower patients and their representatives to become advocates for their cause, to create awareness about the issues surrounding rare diseases but it can also serve to reach out to key stakeholders and the general public, by inviting them to participate.

PLAY DECIDE can be the ideal Rare Disease Day activity to organise as an event or as part of an event. The sessions can serve to 'warm-up' your audience to the topics that will be discussed. The act of 'playing and debating' will raise awareness amongst players and observers about the issues and challenges surrounding rare disease patients.

To know more about it and to download the games go to: www.playdecide.org/polka

If you have questions contact Anna Kole at: anna.kole@eurordis.org

EURORDIS
Plateforme Maladies Rares
96 rue Didot – Paris 75014 – France
Tel + 33 1 56 53 52 10
Fax + 33 1 56 53 52 15
Brussels office: Tel/fax + 32 2 733 81 10
eurordis@eurordis.org
www.eurordis.org

EURORDIS
Rare Diseases Europe