www.eurordis.org

Rare Disease Day

28 February 2010

Information Pack

“Patients & Researchers: Partners for Life!”

www.rarediseaseday.org

Content

1. How to use this information pack

- **Read the whole pack.** It will give you background information on the European 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.**
- **Decide on the specific targets** 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.rarediseasday.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?

- **Because we constantly need to raise awareness on rare diseases** among decisions makers, health professionals and the general public. Information is key to improving living conditions for rare disease patients; raising awareness is therefore one of our primary goals
- **Because acting simultaneously in many places and in many countries can ensure the voice of rare disease patients is heard by more people**
- **Because rare diseases are a public health priority** today in the European Union
- **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 keep fighting** for rare disease patients…
- **Because we need to coordinate policy actions** at national level and at the international level

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:

The rare disease patient is the orphan of health systems, often without diagnosis, without treatment, without research, therefore without reason to hope.

Rare diseases are life-threatening or chronically debilitating diseases with a low prevalence and a high level of complexity. 6000 to 8000 rare diseases have been identified, affecting 30 million European citizens. Patients with very rare diseases and their families are particularly isolated and vulnerable. The life expectancy of rare disease patients is significantly reduced and many have disabilities that become a source of discrimination and reduce or destroy educational, professional or social opportunities.

The lack of specific health policies and the scarcity of expertise translate into delayed appropriate diagnosis and difficulty of access to care. The national healthcare services for diagnosis, treatment and care of rare disease patients differ significantly in terms of their availability and quality. European citizens have unequal access to healthcare services and to orphan drugs.

Research on rare diseases is scarce

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* (November 2007)
- ❖ Commission Communication on Rare Diseases (November 2008)
- ❖ Council Recommendation on a European Action in the field of Rare Diseases, (June 2009)

Over the last few years, a certain number of Member States have developed or started planning and developing their own **National Plans for Rare Diseases**

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 background information, see:

- "Princeps paper" developed by Eurordis and its members:
  - English:
    - o http://www.eurordis.org/IMG/pdf/Princeps_document-EN.pdf
  - French
    - o http://www.eurordis.org/IMG/pdf/Princeps_document-FR.pdf
  - German
    - o http://www.eurordis.org/IMG/pdf/Princeps_document-GM.pdf
  - Italian
    - o http://www.eurordis.org/IMG/pdf/Princeps_document-IT.pdf
  - Portuguese
    - o http://www.eurordis.org/article.php3?id_article=934
  - Spanish
    - o http://www.eurordis.org/IMG/pdf/Princeps_document-SN.pdf
  - Hungarian

    http://www.eurordis.org/IMG/pdf/Princeps_document-HU.pd

4. The Focus Theme for 2010

"Bridging Patients and Researchers"

Main messages for Rare Disease Day

Rare Disease Research is an important area of research

Rare Disease Research needs to be better funded

Patients and Researchers win by working together

Patients need Research…

Research represents hope for the millions of rare disease patients who are without cure today. In the last decade huge leaps have been made in genetics and medical technology, raising great hopes from scientific and therapeutic progress.

However, existing public research programmes for rare diseases are not sufficient; drug development to treat a small number of patients remains very limited and the fact that patients and researchers are scattered makes it difficult to aggregate the value of the knowledge already acquired.

Research needs Patients…

Rare disease patients are the best partners researchers can ask for – Without their participation in clinical trials, bio banks, databases and registries, research would be brought to a standstill. In addition to being the subjects of the research, patients are 'experts by experience' – they and their families know their disease better than anyone else. They can therefore help find therapeutic clues and advance basic research by furthering understanding into the epidemiology and natural history of the disease.

"Families had reported the existence of breathing difficulties in patients without obesity problems. We passed on this information to clinicians. At a subsequent meeting, a scientist decided to research this symptom on a mouse model and got confirmation." Parent of a Prader Willi Syndrome patient

Our goal: Make each of our individual stories a milestone in the general progress of sciences

Rare disease **patient organisations can be valuable partners in research projects** – by funding research teams, equipment and training

or by helping constitute cohorts and organising campaigns to collect biological samples. Patients often act as catalysers for increased collaboration amongst researchers, clinicians, industry and patients. **This is why it makes sense for patients and researchers to work closer together!**

Why Rare Disease Research?

There are significant moral, scientific, economic and policy imperatives for conducting research into rare diseases.

Rare disease patients have the same rights as any other patient to health and to realistic hopes for new treatments.

Research into rare diseases can lead to therapeutic developments for more common diseases. Rare Disease can serve as models for more common conditions, such as diabetes or obesity. Moreover, the complexity of rare diseases often requires multidisciplinary, innovative approaches. The new tools, methods and products developed from research on rare diseases can often be applied in other, more common diseases, thereby benefiting and even wider public.

In a time when the pharmaceutical industry is approaching the "patent cliff" for many of its products, some companies have resolved to push drugs through a long testing process even if the diseases the drugs treat are rare and the initial markets minuscule. **Once a drug proves its worth against one disease, it can be tested against others.** Some orphan drugs like Gleevec, which was initially approved for a rare blood cancer that strikes just a few thousand people each year, has proven effective against six other life-threatening diseases.

Research into rare diseases is good for the economy. The Orphan Drug regulation has boosted the development of SMEs in the biotech sector. The economic value of research on rare diseases has also been acknowledged by the pharmaceutical industry, which is increasingly investing in this field.

Research into rare disease could save millions to health care budgets if improved understanding of only some of the estimated 7000 rare diseases leads to more treatment options and less delays in diagnosis.

For further reading: Corley and Daly, June 2009, "Importance of Research on Rare Diseases and Orphan Drugs"

What can help boost research in the field of Rare Diseases?

- Identify ongoing research projects and existing research resources so as to share the results and make the best use of these efforts
- Continue to identify needs and priorities for basic, clinical, translational and social research making a link with centres of expertise
- Cover biomedical, public health and social research,
- Foster participation of new researchers in EU-funded projects on RD
- Promote public-private partnership (help the bench-to-bed transfer)
- Create new additional financial resources for research

The need for more and better Funding

Research on rare diseases requires shared supranational common infrastructures, long-lasting projects and a sustained approach. However, because of the rarity of the diseases, and thus their limited commercial interest, it is very unlikely that a private sponsor would take over the long term funding needed for rare disease research infrastructures. Therefore **research in the field of rare diseases needs long-lasting infrastructures, such as biobanks, databases and registries, to benefit from sustainable public funding.**

There must be enough money for long-term research projects on specific rare diseases or groups of diseases, for both fundamental and clinical research projects. This issue is closely linked with the need for sustainable European Reference Networks of Centres of Expertise and European Research Networks, with a view at enhancing translational research.

What is the European added value?

Conducting research at the European level is of utmost importance because it is the only way to increase the number of patients available for each study and to gather the scattered specialists with complementary expertise allowing for the necessary multidisciplinary approaches and the exchange of good practice.

"Patients are scattered all over Europe which makes setting up cohorts and clinical trials difficult, clinical and scientific data is largely not centralised, there is insufficient funding for research teams, a relative lack of interest from the pharmaceutical industry and a need for a multidisciplinary and horizontal cross-cutting approach. These factors make rare diseases the perfect model for Europe to use to position itself at the forefront of R&D."

Eurordis/RD Patients' contribution to shaping the needs for research on rare diseases, recent milestones:

- Position Paper in 2005 for the preparation of the 7th FP
- European Workshop on "Gaining Access to RD Research Resources" in 2007
- Collaboration on the preparation of the EC conference on "Rare Disease research: building on success" (Sept 2007)
- Research Priorities for Rare Diseases
  Eurordis Specific Contribution to the Public Consultation: "Rare Diseases: Europe's Challenges" (Feb 2008)

5. Why is it a good time to push for RD Research?

The Council Recommendation on a European Action in the field of Rare Diseases

In the past two years, rare diseases have attained an even higher visibility in the European policy landscape. Starting with the successful Public Consultation on Rare Diseases in November 2007, followed by the adoption of the Commission Communication on Rare Diseases, in November 2008 and more recently the adoption of a Council Recommendation on a European Action in the field of Rare Diseases, in 2009, each step has demonstrated the vital importance of EU action, as well as cooperation between Member States.

Even if not legally binding for Member States, Recommendations and Communications carry much political weight. The new Council Recommendation will shape the future strategy of Community action in the field of rare diseases for public health, research and therapy development. In other words, it is the best tool to further promote rare diseases as a public health and research priority. The Council Recommendation also plays a crucial role at the national level, by facilitating the definition of priorities and guidelines for the creation of National Plans for Rare Diseases.

The Council Recommendation represents an important milestone for rare disease patients all over Europe. **Its adoption means that patient representatives will be increasingly involved in the rare disease strategies of each Member State and be able to monitor the implementation of key issues that are vital to advance rare disease research, such as:**

- Ensure that rare diseases are adequately coded and classified
- Enhance research in the field of rare diseases
- Identify Centres of Expertise and foster their participation into European Reference Networks
- Support the pooling of expertise at European level
- Share assessments on the clinical added value of orphan drugs
- Foster patient empowerment by involving patients and their representatives at all stages of the decision-making process
- Ensure the sustainability of infrastructures developed for rare diseases.

Shaping the EU Research Agenda

The Framework Programmes for Research and Technological Development, also called Framework Programmes or abbreviated FP, are the European Union's main instrument for funding research in. In order to shape the EU research agenda today and in the future, the arguments described above, together with the results of this Rare Disease Day campaign will serve as ammunition to convince policy-makers that rare diseases have to be paid attention to and that they should remain high in the Framework Programmes for Research of the European Union.

Until 2013, funds for research will be distributed under the 7th FP. The specific objectives and actions vary between funding periods, it is therefore very important to start advocating for the inclusion of rare disease research in the 8th FP as of now.

Advocating for more funding in the Framework Programmes cannot be disassociated from political victories such as the Council Recommendation, which include, more and better rare disease research as an important objective. This issue is closely linked with another main objective of the Recommendation which is to identify Centres of Expertise and foster their participation in European Reference Networks, with a view at enhancing translational research.

Shaping the National Research Agenda

Giving rare diseases a high visibility in their research agendas is one of the most important aspects that National Alliances will have to address in their countries as part of the implementation of the Council Recommendation, their own National Plans and their participation in the EUROPLAN Project.

For more information, see:

Eurordis' article on the Commission Communication and proposed Council Recommendation

Eurordis' article on the EuroPlan Project to promote National Plans for Rare Diseases

Eurordis' article on European reference networks of centres of expertise

Eurordis' article on Rare diseases and the 7th Framework Programme

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: National Alliances, Patient Organisations, 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)
- Organising the RD Research Hall of Fame
- Organising a survey to measure patient's contribution to research and find out their priorities (see Survey box pg.18).
- Organising the Photo and Video Contest
- Managing Web 2.0 Social Media Services : Facebook, Twitter, Youtube and Flickr
- Evaluation of results and analysis at European level

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 2010 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.

Reaching out to researchers

National alliances and their member patient groups are encouraged to invite researchers and research decision-makers to their events.

These encounters could be followed by a Play Decide Session on topics such as: Neonatal screening, Genetic testing & Counselling, and Pre-implantation genetic diagnosis. www.playdecide.org

National Alliances (and their members) are also asked to participate in this year's "RD Research Hall of Fame" by nominating a researcher that is working on their disease. To see an example go to NORD's website http://www.rarediseases.org/rare_disease_day/Hall_of_Fame

We are also interested in featuring successful stories of patient – researcher collaboration on the "This year's focus" page of the website. This type of stories will give a human face to the messages we seek to promote and will attract media attention.

If you would like to nominate a researcher or have a good story of patient-research collaboration, please send it to anja.helm@eurordis.org

National Alliances participating in the Rare Disease Day 2010:

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
Denmark	Rare Disorders Denmark	45 33 14 00 10	mail@raredisorders.dk
France	Alliance Maladies Rares	33 1 56 53 53 40	marcellebousbaci@yahoo.fr
Germany	ACHSE	49 30 33 00 7080	mirjam.mann@achse-online.de
Greece	PESPA	30 210 76 60 989	tsahellas@ath.forthnet.gr
Hungary	HUFERDIS	36 1 326 74 92	pogany@williams.ngo.hu
Ireland	GRDO	353 709 30 50	avril.daly@fightingblindness.ie
Italy	UNIAMO	39 0412410886	bellagambi.estero@uniamo.org
Luxembourg	ALAN	352 266 112 1	bvogel@pt.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
Portugal	FEDRA	35 1 217786100	assessoria.fedra@hotmail.com
UK	Rare Diseases UK	44 20 7704 3141	Melissa@raredisease.org.uk
USA	NORD	1 203 744 01 00	mdunkle@rarediseases.org

7. Who is the Rare Disease Day for?

- Policy makers
  - European and National Health Authorities
  - Parliamentarians
- Researchers, clinicians and academics
- Pharmaceutical and biotech industry
- General public
- Media (as a tool to reach the general public)

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Rare Diseases Europe

8. What are the objectives of the day?

The main objective of Rare Disease Day 2010 is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. More specifically, this year we are seeking to achieve the following objectives:

- Promote research interest in the field of rare diseases
- Promote collaboration between patients and researchers
- To shape public policy and the research agenda
- To empower patients as actors in research
- To define research needs and priorities for rare diseases

(the survey results will be useful for this, see text box Section 9)

In addition, Rare Disease Day will always seek to:

- Raise awareness on rare diseases and reinforce their importance as a public health priority
- Strengthen the voice of patients
- Bring stakeholders closer together
- Coordinate policy actions in different countries
- Get equity in access to care and treatment
- Provide hope, information and help to patients affected by chronic, rare diseases, in particular those for whom a support network is not available or known
- Raise funds to pursue our action, at both European and national levels

9. What will happen at the European level?

EURORDIS will organise an event in Brussels the 1st of March 2010.

The one day-workshop will gather European and national research authorities, policy-makers from the European Commission, the European Medicines Agency (EMEA), representatives from the industry, researchers, patient organisations and the media, in order to push for a **future research agenda of the European Union that takes into account the patients' perspective.**

The event will be co-organised with E-Rare (ERA-Net for research programs on rare diseases), a network of ten partners – public bodies, ministries and research management organizations – from eight countries, responsible for the development and management of national/regional research programs on rare diseases. The aim of E-Rare is to foster research on rare diseases in Europe.

The event will receive the support of the European Commission's DG Research. We are hoping the Commissioner for Research will open up the meeting with a political speech on the importance of patient-centred research. Followed by a presentation from the DG Research on the research activities they are currently funding.

E-Rare will present their initiative and the results of a survey conducted amongst researchers and other stakeholders to define the research areas that should be given priority.

EURORDIS will present the results of a survey it will have conducted on Patients' Support to Research and Patients' Priorities in Research (see Survey box pg.18).

The meeting will also be the opportunity for Orphanet to present the RD Platform fact finding study on the determinants of research trends. RD Platform is an initiative aimed at helping researchers in the field of rare diseases set up multidisciplinary teams, which will be able to structure future research proposals in the 27 Member States.

The afternoon will be devoted to presentations from the DG Research, about their perspective on future funding in the field of rare diseases; and the EuroPlan Project's recommendations to support RD research through National Plans or Strategies. EURORDIS will close the workshop by making the case for promoting rare disease research. We will present the moral,

legal, scientific, economic and policy arguments to invest in research into rare diseases.

At the end of each session there will be a panel discussion to identify the key messages and draw recommendations.

This exercise will **help define a common position of rare disease patients regarding research and will take our advocacy a step further to make sure rare diseases are included in the present and future Framework Programmes.**

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

The Survey

EURORDIS will be conducting an on-line survey amongst patient organisations, from mid-Oct to mid-Nov 2009 in order to find out **which are the research areas that should be given priority** from the patient's perspective. We are also interested in finding **out in what ways patients have collaborated with researchers** and to what extent this collaboration was positive or negative. The results will also help national patient alliances carry your voice and advocate for more and better research for rare diseases at the national level. In order to obtain the maximum advocacy impact, **the main messages coming out of this survey will be extensively publicised on the occasion of Rare Disease Day 2010**.
The success of this survey depends on the level of participation of patient groups. To fill out the on-line questionnaire go to:
EN:
https://www.surveymonkey.com/s.aspx?sm=g_2bF_2bx4d3x4rxh1pg9CcvXQ_3d_3d
FR:
https://www.surveymonkey.com/s.aspx?sm=Hd1kUVUsLjuJItHYaIDi0Q_3d_3d
ES:
https://www.surveymonkey.com/s.aspx?sm=09J9hduonjBWjzn4ztqLfQ_3d_3d
IT:
https://www.surveymonkey.com/s.aspx?sm=7Yf83Xbj_2fo2hV6NJ4ofBxw_3d_3d
DE:
https://www.surveymonkey.com/s.aspx?sm=xPKRu7haspkU9mNO_2fb7muA_3d_3d
HU:
https://www.surveymonkey.com/s.aspx?sm=4iLl5RA8yL_2fG2Wc_2ftNJ0QQ_3d_3d

10. What will happen in the different countries?

Activities taking place around Rare Disease Day in each country are the decision of the 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

Organise a visit of an MEP/ health minister to 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 awareness raising displays

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

Make appointments to meet with your local and national authorities

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.

For this year's focus theme:

Organise a meeting with research policy makers to discuss the inclusion of rare diseases in the research agenda in your country

Invite researchers to meetings organised by patients to promote better understanding between both parties

Organise a Play Decide Game session on a research-related topic

Organise interviews with the media to talk about **your organisation's support to research** (funding, clinical trial selection, etc)

Display a video interview with your favourite researchers on your website.

Have a **bank of stories** about rare disease patients advancing research, 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).

11. Useful Tools

1. **Logos**

2. **Slogan : *Patients and Researchers: Partners for Life!***

3. **Poster** : a photoshop version of the poster will be made available to national alliances shortly, allowing translation into the national languages.

4. **Website**: **www.rarediseaseday.org (updated soon)**

5. **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)

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

6. **Press release**

EURORDIS
Rare Diseases Europe

Press release

Rare Disease Day

28 February 2010

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

PLACE, DATE

[***YOUR NATIONAL ALLIANCE***] announces Rare Disease Day 2010 in [***REGION/COUNTRY***] on 28 February 2010.

The main objective of Rare Disease Day 2010 is to raise awareness of rare diseases and of their impact on patients' lives, and reinforce their importance as a public health priority. This year, Rare Disease Day will also be the opportunity to advocate relevant decision-makers and to reach out to the scientific community to raise interest and increase funding for rare disease research.

Organised by National Rare Disease Alliance members of EURORDIS and partners, it is hoped that the day will help raise awareness of life threatening or chronically debilitating rare diseases and the needs of the patients suffering from them.

"As a direct result of the attention we expect Rare Disease Day will raise, we hope national healthcare systems improve the availability and quality of diagnosis, treatment and care for rare disease patients in all participating countries", said Yann Le Cam, CEO of EURORDIS.

Rare diseases are chronic, progressive, degenerative, and often life-threatening with high levels of pain. There is no cure today for the 6000 - 8,000 rare diseases, 75% 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-

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Rare Diseases Europe

12. 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 "Participating Countries" 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:

-Introductory page in English (photo/image+text message or video message from patron or a few lines explaining what is happening for Rare Disease Day 2010 in your country)

- the same Introductory page in your language (optional)

- Events Calendar

Only National Alliances will have the option of adding a box, which will contain:

- logo of your organisation

-Short description of the National Alliance with a link towards their websites.

➢ How to become a "Friend of RDDay"

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 people getting involved and 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 displaying a message in the 'Downloads' section of the website saying:

To raise awareness of rare diseases and the need for safe, effective treatments, people around the world will join together to observe the 3rd Annual Rare Disease Day on the last day of February (Feb. 28, 2010).

If you would like to get involved, please contact your National Alliance. The list can be found in: "Country by Country" section, "View participating National Alliances on the website.

If your country does not have a national alliance or a country organiser, or if you are a European organisation, you can still get involved by contacting EURORDIS at rarediseaseday@eurordis.org.

EURORDIS and national alliances for rare diseases are inviting all patient organisations, caregivers, researchers, public authorities and companies developing orphan products to join in this observance. The purpose is to focus attention on rare diseases, the challenges encountered by those affected, and the importance of research to develop diagnostics and treatments.

If you would like to join in the observance of this special Day, you can add your name to the list of 'Friends of Rare Disease Day'.

'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

Click here to become a 'Friend of Rare Disease Day'

(Form to fill out)
Name of the organisation ……
Country……
()EURORDIS member () Other Patient Organisation, () Industry () Patient () caregiver () other
Contact e-mail:……..
Website: ……. webmaster e-mail ……

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.

Download key Rare Disease Day resources:

1. Poster in PDF (non-modifiable):
2. LOGO (large):
3. LOGO (small):
4. Banner
5. Email footer
6. Info Pack (pdf):
7. Info Pack (doc):

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. Your completed form will confirm your commitment to observing the spirit of this special day.

Thank you again for joining us in this very important event.

'Get Involved' section of the website:

Rare Disease Day is open to everyone.

If you would like to get involved, please contact your National Alliance. The list can be found in: "Country by Country" section, "View participating National Alliances on the website.

If your country does not have a national alliance or a country organiser, or if you are a European organisation, you can still get involved by contacting EURORDIS at rarediseaseday@eurordis.org.

You can download the logo and other communication tools from the 'Downloads' section of this website. **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.

If you are a rare disease patient or patient representative, you can also get involved by:

- Entering the Photo Contest or the Video Contest. In order to share your story, click here.
- Adding your photo and commentary to the Photo Wall (you can do it in your own language)
- Joining the Rare Disease Day 2010 Facebook Group
- Sending us stories of successful collaboration between rare disease patients and researchers to rarediseaseday@eurordis.org

The more participants, the more impact for the Day, and the more we'll be able to do for patients.

Thank you again for joining us in this very important event!

Ideas for supporting the campaign:

- Coordinate letter writing or email campaign to local or national policy and decision makers
- Send a press release to the media
- Organise interviews with the media
- Organise fund-raising events
- Organise events around rare diseases and the topics at heart of patients
- Approach a special/VIP to be the patron of the day
- Give awards to people who have acted for the cause of rare disease patients
- Hold a competition centred on rare diseases
- Set up a help line to respond to enquiries
- Display posters, images or other awareness raising displays
- Distribute stickers and flyers
- Make appointments to meet with your local & national authorities
- Organise a visit of an MEP/ health minister to a research lab working on a rare disease

➢ 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). In the scope of the POLKA project, six topics concerning rare disease patients will be available for download by December 2009 including: Stem Cell research, Pre-implantation Diagnosis, Cross-border health care, Neonatal Screening, The upper limit to spend on a single patient: the case of OD, and Diagnosis-Information to the patient-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. In the evening after the CNA meeting we will organise several groups to PLAY DECIDE on Stem Cell research with cocktails. This session will allow you not only to enjoy the experience yourself, but learn how to organise such events with your members, or teach them how to organise events themselves.

EURORDIS and its partners have decided to use these subjects, and to create new ones of particular importance for rare diseases. These subjects will be adapted to most EU languages so that patients, families, parents, policy makers, health care professionals can participate.

The goal is to facilitate between 600 and 1000 discussions across 27 countries, in 23 languages, with a minimum of 80 participants per country!

In order to achieve this goal, we ask you to organise as many PLAY DECIDE Sessions in your country as possible, and what better occasion than Rare Disease Day to it! 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 researchers and the scientific community, in general, by inviting them to participate.

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

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

- **How to organise an event in a Science Centre or Museum**

The PLAY DECIDE games have been developed by the European network of Science Centres and Museums "Ecsite". Sessions on xenotransplantation, pre-implantation diagnosis, stem cells etc. have already taken place in many of these museum network members across Europe, amongst the general public.

EURORDIS has been working with the Ecsite network since the beginning of the POLKA project and will be happy to liaise with the Ecsite coordinator to help you organise your event in a museum member of this network.

To organise such an event, contact the Conference and Communications Coordinator, Aliki Giannakopoulou at agiannakopoulou@ecsite.eu

For a complete list of member Science museums go to:

http://www.ecsite.eu/?cat=8