



Rare Disease Day

Report on the 2010 Campaign



Rare Disease Day

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Rare Disease Day

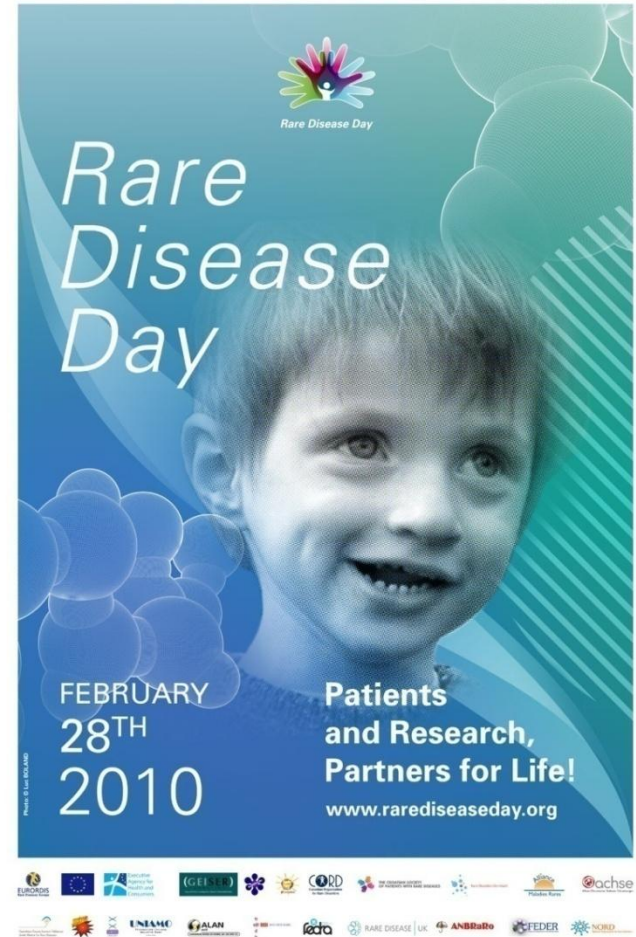
Rare Disease Day 2010

Date: 28 February 2010

Logo:



Poster:



Coverage: Truly international!
...46 countries participated
this year

Rare Disease Day 2010

EURORDIS : international organiser and coordinator

22 National Alliances

+ 24 POs acted as country organisers

**... which all together involved thousands of POs
in Europe and further afield**



Rare Disease Day 2010

All sorts of events:

- Meetings & Seminars
- Walks
- Music Concerts
- Cultural exhibits
- Information stands
- Balloon releases
- Fundraisers
- Press conferences
- Information days
- Lectures in schools
- Media blitz
- Marathons
- Auctions
- Art contests
- Awards
- Video displays
- Family happenings
- Fashion shows
- Play Decide Games
- Round tables
- Book Launches
- Tree planting

... and many more!

RDD 2010 more international

Total : 46 countries (officially)

27 European countries: Latvia, Lithuania and Slovenia

In North America, the US and Canada

In Latin America, events were organised in Argentina, Brazil and Colombia.

In Asia: China, Japan, the Philippines and India.

In Oceania: Australia and New Zealand

In Africa: Cameroon, Burkina Faso and South Africa



Rare Disease Day
28 February 2010

www.rarediseaseday.org



Theme + Focus 2010

Theme: (2008-2011)

Rare Diseases: a Public Health Priority

Focus 2010 : Bridging Patients & Researchers

**Slogan: Patients & Researchers:
 Partners for Life!**

Communication tools

The Website

www.rarediseasday.org

39.027 hits from 156 countries (Jan-March 2010)

Social media

RDD YouTube Channel : 38 new videos (32 video contest)

Flickr: 269 new photos (241 photo contest)

Facebook Group: 10238 fans

Twitter: 778 followers





Rare Disease Day 2010

February 28

[Home](#)[About the Day](#)[Get Involved](#)[Country by Country](#)[Media](#)[Downloads](#)[Tell Your Story](#)

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This year's focus:

Bridging Patients & Researchers

[This year's focus](#)[Why Rare Disease Day?](#)[What is a Rare Disease?](#)[Tell your story](#)

Key Rare Disease Day Events

Stay up to date with events around the world

-  **HR:** Rare Diseases in Croatia-On the thresh...
-  **RO:** Clinic evening for students from Medi...
-  **PT:** Rare diseases: The missing data
-  **RO:** Conferences, Discussions at Children'...
-  **UA:** Public action in the Kharkiv city metro
-  **HU:** Consultation with experts of the Mini...

Friends of Rare Disease Day

See what this selection of Friends are doing...

DEBRA Italia Onlus

associazione italiana amici della scim...

Kidney Cancer Support network

The International Palindromic Rheumati...

Sdružení Tarlovova cysta

Cushing Support and Research Foundation

LSD Support Society of India

Rare Disease Day on the Web

Follow Rare Disease Day 2010



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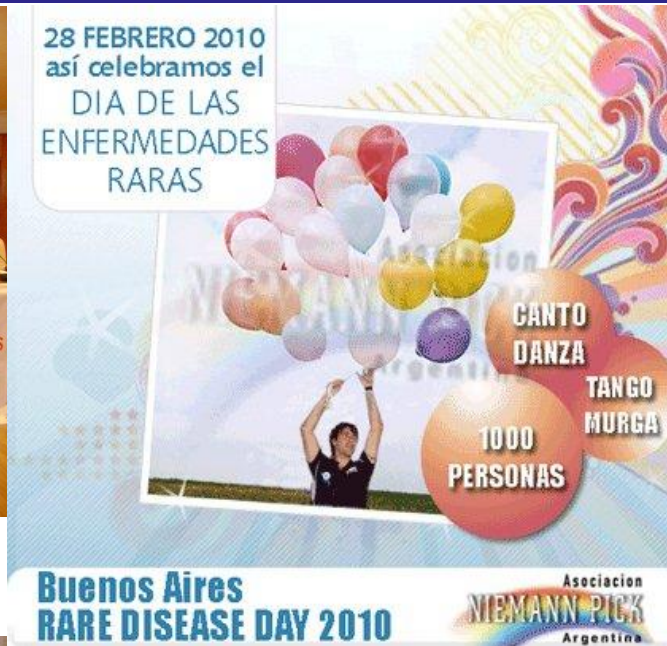
Rare Disease Day in the News

27-04-10 Дневник - Дневник
Фармацевтични гиганти финансират
пациентски организации в ЕС От
Дневник Всички статии на автора
Bulgaria

27-04-10 Acta Sanitaria
**REALIDADES Y EXPECTATIVAS FRENTE A
LAS ENFERMEDADES RARAS**
Spain

27-04-10 Angeli Press
Assistenza Domiliare e Malattie Rare

The power of Internet!



Saudi Arabia
Morocco
Mexico...

New features

Friends of Rare Disease Day - 189 people signed up!

Patient reps

LSD Support Society of India

We have just registered our society and we are organising the first Rare Disease Day function in India at New Delhi. Around 200+ parents are expected to attend the same. Parents are travelling to attend as far as from 2000+ km and we will be able to create an awareness India. We also have plan to use the media exposure.

Health Professionals

Werathah – Arabic genetics and health network

We are involved in providing a free genetics health education information for the Arabic speaking population . Genetic disorders are considered a rare disorders so spreading your word through our web site and forum is what we can do at this stage hopefully this can be extended in the next years to efforts in real life.

Industry

Genzyme will celebrate with a reception and Expression of Hope II art exhibition, a global awareness program in collaboration with patient associations worldwide, featuring works of art by people whose lives are touched by lysosomal storage disorders.

If you would like to add your country to this list, please write to: rarediseaseday@euordis.org

 ARGENTINA	 AUSTRALIA	 AUSTRIA	 BELGIUM	 BRAZIL	 BULGARIA
 BURKINA FASO	 CAMEROON	 CANADA	 CHINA	 COLOMBIA	 CROATIA
 DENMARK	 EUROPE	 FINLAND	 FRANCE	 GERMANY	 GREECE
 HONG KONG	 HUNGARY	 IRELAND	 ITALY	 JAPAN	 LATVIA
 LITHUANIA	 MALAYSIA	 NETHERLANDS	 NEW ZEALAND	 NORWAY	 PHILIPPINES
 POLAND	 PORTUGAL	 ROMANIA	 RUSSIAN FEDERATION	 SERBIA	 SLOVENIA
 SOUTH AFRICA	 SPAIN	 SWEDEN	 SWITZERLAND	 TAIWAN	 UKRAINE
 UNITED KINGDOM	 USA				

European event

EURORDIS organised a workshop bringing rare disease stakeholders together to discuss the future rare disease research agenda in Europe



**Manuel Hallen
DG Research**



Patient reps, researchers, policy-makers and RD experts



**Robert Madelin
DG SANCO**

European event

**RDD Workshop « Bridging Patients and Researchers to Build the Future Agenda for Rare Disease Research in Europe »
March 1st, 2010 at the Centre de Presse International in Brussels.**



Co-organised with [E-RARE](#) in partnership with the European Commission, [Orphanet](#) and [EuroPlan](#)
100 participants from 15 countries, including European and national research authorities, researchers, patient organisations and industry.

Advocating at national level

In Spain, FEDER held an official act for RDD in Congress. 10-point proposal to implement at network of centres of expertise. Awards given by Infanta Elena



El objetivo es evitar constantes desplazamientos a los enfermos en busca de un diagnóstico **Los afectados por enfermedades raras piden una red de centros de referencia**

Casi la mitad de las familias se ven obligadas a viajar al menos cinco veces fuera de su provincia para descubrir qué dolencia padecen y poder someterse a un tratamiento eficaz

Agencias
MADRID

La Federación Española de Enfermedades Raras (Feder) pidió ayer que se implante una red de centros de referencia para estas patologías que evitaría a los pacientes y sus familias los desplazamientos constantes en busca de un diagnóstico y un tratamiento eficaz. La presidenta de la entidad, Rosa Sánchez de Vega, explicó en un acto en el Congreso de los Diputados —en el que estuvieron acompañados por Gaspar Llamazares, presidente de la Comisión de Sanidad— que un paciente con una enfermedad rara tarda “una media de cinco años en obtener un diagnóstico” y añadió que “casi la mitad de las familias tienen que desplazarse más de cinco veces fuera de su provincia para tratar la enfermedad”.

Con la creación de estos centros “se ganaría en tiempo para el diagnóstico de la enfermedad”, afirmó Sánchez de Vega e indicó que “actualmente existen ya unidades hospitalarias que están trabajando con enfermedades raras, pero que sin una acreditación no podrán continuar haciéndolo a largo plazo”. Por ello explicó que en muchos casos, “no sería necesario crearlos, sino que bastaría con acreditarlos”.

Registro nacional
Los pacientes deberían ir un registro por comunidades para conocer el número de afectados y los recursos disponibles en cada zona

Desde la federación afirman sentirse “desamparados” ya que “no se han seguido las recomendaciones que desde hace años se vienen haciendo sobre centros de referencia, recomendación que en 2007



El vicepresidente de la federación, Monés Abascail, y la presidenta, Rosa Sánchez. / ere

Claves

Centros de referencia

Los afectados por patologías raras demandan una red de centros de referencia para evitar que los pacientes tengan que ir fuera de su comunidad

Diagnóstico

Los pacientes con estas dolencias tardan una media de cinco años en ser diagnosticados y la mitad debe desplazarse para ir al médico

Igualdad

Los afectados también piden un mayor uso de los recursos que existen en cada comunidad para evitar las desigualdades en las zonas que se den hoy en día

realizó el Senado, con el consenso de todos los partidos políticos, ni las directrices de la Comisión Europea que desde 2005 lleva insistiendo en el reconocimiento y acreditación de estos centros”.

Asimismo, antes de crear estos centros, Sánchez de Vega explicó que necesitan “saber dónde están los pacientes e igualmente dónde están los especialistas que tratan estas enfermedades”, es decir, que “se cree un registro y un mapa de recursos por comunidades autónomas que se rijan por una coordinación nacional”. De este modo, “se eliminarían las situaciones de desigual-

dad existentes hoy en día entre las diferentes comunidades”, afirmó. Estos centros de referencia “trabajarían en estrecha colaboración con centros de competencia a nivel local, que acompañarían el día a día del paciente”, explicó Sánchez de Vega. Igualmente, afirmó que se debe crear también “la figura del médico coordinador desde el nivel de las unidades generales de información y atención general a los afectados por enfermedades raras en cada comunidad”.

Este médico actuaría como “el coordinador de todos los especialistas implicados en la atención a es-

tos enfermos, que pueden incluir especialistas en varios niveles asistenciales, tanto locales y nacionales como internacionales”, explicaron. Para la creación del registro y mapa de recursos, desde la federación de enfermedades raras ven imprescindible que los pacientes y sus familias tengan participación en las decisiones pues “en muchas ocasiones, son ellos quienes más conocen sobre las enfermedades y quienes las pueden tratar”. En este sentido, añadió que “si el Estado quiere que estos centros sean rentables ha de contar con la colaboración de las familias”.

Advocating at national level

Rare Diseases UK organised Parliamentary Receptions in the Scottish, Welsh and Northern Ireland Assemblies to create awareness amongst MPs about RD and research



Many members contacted their local MPs to inform them about RDD

Many met with their elected representative at the parliamentary receptions to bring the issues to their attention.

Advocating at national level

Rare Disorders Denmark organised Play Decide with Parliamentarians

RadiOrg Belgium presented state of advancement towards their NPRD

Romanian National Alliance organised a meeting with the MoH to include the NPRD in the National Health Strategy



Advocating at national level

Bulgarian National Alliance organised a Conference to present preliminary results of NPRD

**A drive for signatures and formal petition
To the State Duma of the Russian Federation
To approve program on RD**

**In Australia organisation of a seminar to
encourage comments on the draft NPRD**

In the US 39 States signed RDD proclamations



Creating momentum for National Alliances

In Switzerland creation of Pro Raris multilingual National Alliance

In Georgia creation of National Alliance with Patronage of First Lady



Official endorsements

The European Commission – Public Health

The European Medicines Agency (EMA)

Social Security Administration as a Rare Disease Day partner in the US

All announced Rare Disease Day in their communication!

Main messages:

- **Rare Disease Research is an important area in research**
- **Rare Disease Research needs to be better funded**
- **Patients and Researchers win by working together**

Patients & Research

Research Hall of Fame : 46 nominations!

« Patients Advancing Research » Stories on EURORDIS e-Newsletter and RDD website

Play Decide Games on Stem cell research

A Survey on Patients & Research



Patients & Research

EURORDIS Survey “*European Rare Disease Patient Groups in Research: current role and priorities for the future*”

**How to patients support research?
What are their priorities in RD research?**

**772 questionnaires in 6 languages
309 valid responses from POs (40% response rate)
110 rare diseases
1.3 million patients
29 European countries**

**Results publicised on RDD website and communication
...and at European event**

Patients & Research

In France, AFM and Plateforme Maladies Rares organised a Press Conference about RD research



In Germany the Eva Luise Köhler foundation and ACHSE awarded a prize for a research project

In Spain, FEDER organised a scientific meeting entitled to « Research is to Advance »

Patients & Research

In Portugal, FEDRA launched the initial leg of a registry for RD

In Ireland, GRDO organised a “Rare Disease Research Journey”

In Greece, PEPSEA communicated with National Research Centres, University Departments and Hospitals



Patients & Research

In Hungary Conference on RD Health care and Research; opening speech by Health Secretary of State



In Malaysia press conference to create a special fund for RD research and registry

Patients & Research

In Lithuania, seminar for clinicians and researchers working with rare cancers. Part of ongoing academic research project

In US "Raise Your Hand for Rare Disease Research" donation campaign organised by NORD

In Canada, CORD organised a Café Scientifique offering an exchange between researchers and the public

Awareness Raising

Amongst the general public



Second RDD March in Austria



Solidarity demonstration on the Heroes Square of Budapest



Awareness-raising event in Science Museum in Finland



Balloon release in main square in Bulgaria



Public gathering in Rome



Children marching in Romania

Awareness Raising

Personalities supporting the campaign:

The First Ladies of Germany, Portugal, Bulgaria, Hungary;

The Infanta Elena of Spain,



**World-class Australian cricketer Steve Waugh
Football player from the Barcelona team**

Philippine President Gloria Arroyo who signed a declaration for the fourth week of February of every year to be a “National Rare Disease Week”.

Even the Pope drew attention to rare diseases in his weekly message on Sunday February 28th!

RDD on top of the world!



Geiser puts rare diseases on top of the world

On the summit of the Aconcagua

RDD on top of the world!



On our way to the Everest!