



# Rare Disease Day

## Report on the 2009 Campaign



*Rare Disease Day*

**Yann Le Cam**  
Chief Executive Officer  
EURORDIS



*Rare Disease Day*



Rare Disease Day  
28 February 2009

[www.rarediseaseday.org](http://www.rarediseaseday.org)

- Theme: (2008-2011)

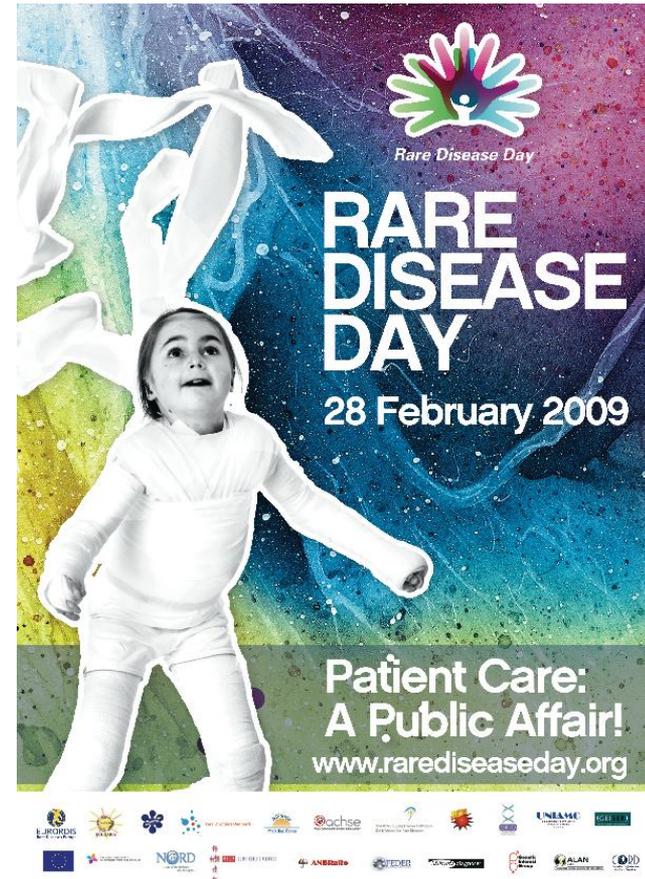
**“Rare Diseases:  
a Public Health Priority”**

- Focus 2009 :

**Patients Centered Care**

- Slogan:

**“Patient Care, a Public Affair!”**





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## RDD Facts & Figures

- EURORDIS initiator and international coordinator
  - Number of organisers at national level :**19** National Alliances
- ... which altogether involved over **600** patient groups in Europe.

Number of participating countries in RDD 2009: **30**



Rare Disease Day 2009 - Find out what is happening in your country - Mozilla Firefox

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http://www.rarediseaseday.org/countryfinder

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Participating countries/territories [View Participating National Alliances](#)

If you would like to add your country to this list, please write to [rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org)

ARGENTINA	AUSTRALIA	AUSTRIA	BELGIUM	BULGARIA	CANADA
CHINA	COLOMBIA	CROATIA	CYPRUS	DENMARK	EUROPE
FRANCE	GERMANY	GREECE	HUNGARY	IRELAND	ITALY
LUXEMBOURG	NETHERLANDS	POLAND	PORTUGAL	ROMANIA	RUSSIAN FEDERATION
SERBIA	SPAIN	SWITZERLAND	TAIWAN	UKRAINE	UNITED KINGDOM
USA					

Rare Disease Day Partners:



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## Target audience:

- Policy makers
  - Health authorities
  - National Parliamentarians
  - European Parliamentarians (and candidates)
- General Public & Media
- Health Professionals, Academics and Researchers

## RDD Facts & Figures

**21 000 visits** on the [www.rarediseaseday.com](http://www.rarediseaseday.com) website  
(Doubled from last year,

Doesn't aggregate the visits to  
Websites of all groups involved)  
Tell your story on the website:

- Videos – **40**
  - Photos – **100**
  - YouTube Channel especially created for RDDay
  - Facebook Group especially created for RDDay:
- 2,128** people signed up





# RDD Facts & Figures

Media coverage

More than **1500** media articles, including

- over 1200 on-line press clippings
- Much over 300 paper press clippings





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## RDD goes international!

Building on the success of last year's campaign, Rare Disease Day 2009 has spread well beyond Europe with partners from the **US, Canada, Argentina, Colombia, Australia, Taiwan and China** joining in the action.





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## First Rare Disease Day in the United States

2009 year is the first time for Rare Disease Day to be observed in the U.S.A. The National Organization for Rare Disorders (**NORD**) mobilised partners from patient organisations, government agencies, medical societies, and companies developing orphan products. Over **220 patient organisations, agencies and companies signed on**, including two government offices that are instrumental in rare diseases and orphan products in the US: the **NIH** Office of Rare Diseases and the **FDA** Office of Orphan Products Development.





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## Advocating at the European level: RDD in Brussels



**Patronage** of the EU Commissioner for Health, **Androulla Vassiliou**

Rare Disease Day Book Launch  
**“The Voice of 12000 Patients”**  
at the European Commission





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## Dinner Debate at the European Parliament

The event hosted by **MEP Prof. Antonios Trakatellis**, who is the Rapporteur of the Parliament's Opinion on the **Council Recommendation on Rare Diseases**.



The event was attended by several parliamentarians, policy-makers from the European Commission, patient advocates and representatives of the biopharmaceutical industry.





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## Lobbying at the national level

- **Official Act** organised at the **Spanish Senate** to announce the results of RD survey in Spain.

Speakers included the

**Minister of Health** and the

**State Secretary for Social Affairs**

**and Disability**, and the President

of the Spanish Alliance.

**Princess Letizia** gave out **Rare**

**Diseases Awards**. The event

received great media attention.





## Lobbying at the national level

- NORD asked its partners to write **letters to their US state governors**, requesting that February 28, 2009, be proclaimed Rare Disease Day in their state.
- Email campaign organised by RD **UK** encouraging their contacts to send an email petition asking their MPs to sign a **Parliamentary petition to get Rare Disease Day recognized by the UK Parliament.**
- **Signature collection** to support a proposal to discuss rare diseases in the two annual sessions of **China's top legislative body** and top political advisory body.





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## RDD creating momentum to : push for National Plans and Strategies

- Presentation of the National Plan for Rare Diseases in Portugal and Bulgaria



- In **Spain** the National Alliance actively asked its members , patient organisations, health authorities, celebrities, private companies to sign a petition « Pacto de Todos por las Enfermedades Raras ». This **petition asks for a National Plan, a RD national body** to implement it .



Pacto de Todos por las ER.pdf (application/pdf Object) - Mozilla Firefox

http://www.feder.org.es/panel/spaw/uploads/files/Pacto de Todos por las ER.pdf

Save e Copy Search Select 103% Sign

### Por un PACTO DE TODOS por las ENFERMEDADES RARAS

Las Enfermedades Raras (ER) plantean un reto de salud pública que requiere una acción urgente, porque sólo su reconocimiento y su visibilidad nos ayudarán a salvar vidas. No existe otro campo en el sector sanitario en el que la solidaridad nacional y europea tenga mayor valor añadido que en las ER.

Queremos que las ER dejen de ser la causa del 35% de las muertes de niños menores de 1 año.

Queremos, sobre todo, mejorar la esperanza y calidad de vida de todos los niños, jóvenes y adultos que sufren el dramático impacto de una ER en sus vidas.

#### PACTO POR LAS ER PARA:

- Buscar el **compromiso político definitivo** para impulsar una estrategia global 'multisectorial' que permita que los enfermos alcancen una verdadera integración sanitaria, social, educativa y laboral.
- Asegurar la **equidad, justicia y solidaridad** con los niños, jóvenes y adultos afectados por ER.
- **Garantizar el acceso en condiciones de equidad** al diagnóstico, el tratamiento y la rehabilitación de los pacientes, sin importar la rareza de su enfermedad o su lugar de residencia.

#### PACTO PARA DAR APOYO A:

- Los **3 millones de afectados** por ER en España.
- **Todas las familias que luchan en la invisibilidad, el aislamiento y el dolor** y que observan con demasiada frecuencia como se olvida su derecho a la salud y a otros derechos fundamentales por la rareza de su enfermedad.
- **Todas las personas que, sin diagnóstico o con sospecha de él, viven sumidas en la desesperanza, en el miedo y en la angustia** que supone una ER.
- **Todos aquellos que viven el dolor de haber perdido a un ser querido.**
- **Las nuevas generaciones**, para que encuentren un mundo más preparado para integrarlas de una manera justa.

### PETICIONES DEL PACTO:

1. **Impulsar la creación de la Organización Estatal de Enfermedades Raras** como el órgano que coordine la estrategia y todas las actuaciones relativas a las ER<sup>(1)</sup>.
2. **Poner en marcha el Plan de Acción para las ER** identificando claramente: sus plazos de ejecución, sus responsables y su presupuesto financiero.
3. **Hacer cumplir por parte del Estado Español y las CCAA** su compromiso común por garantizar la equidad en el acceso universal a una atención sanitaria de alta calidad, de manera justa y solidaria para todos los enfermos de ER, sin importar su lugar de residencia.
4. Impulsar de forma prioritaria los **centros especializados de referencia para ER**
5. **Conseguir el consenso y compromiso de los principales actores:** Administración Nacional, Autonómicas, Sociedades Científicas, Colegios Profesionales, Industria, Organizaciones de Pacientes, Medios y Sociedad Civil; para que el éxito del Pacto se traduzca en medidas concretas para los afectados.
6. **Apoyar la participación de los los pacientes** en la elaboración de políticas y toma de decisiones.

(1) La Organización Estatal para las Enfermedades Raras (OER) fue propuesta en el Informe de la Ponencia del Senado. Boletín Oficial de las Cortes Generales. 23 febrero de 2007.

**FEDER**  
Federación Española de Enfermedades Raras  
902 181 725

[www.enfermedades-raras.org](http://www.enfermedades-raras.org)



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## RDD creating momentum to :

### push for National Plans and Strategies

- Event organised by the Belgian Alliance on Feb 27 at the **Belgian Parliament** where they obtained a commitment by the Ministry of Health to contribute to a **RD Fund** which will work amongst other areas on a **National Plan for RD in Belgium**.
- At a Conference entitled '**Focus on Rare Disease in Ireland – What is our National Plan?**' the Irish Alliance obtained a **commitment from the Min of Health to work on a National Plan**. An Irish senator and candidate to the European Parliament assisted.





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**RDD creating momentum to :**

**push for Centres of Expertise**

- **Danish MEP visit Centre for Rare Disorders at Aarhus University Hospital**, Skejby in Denmark. The purpose with the visit was to introduce Britta Thomsen (S) to the daily work with patients with rare diseases as well as to discuss why rare diseases are a very important focus area in the EU.
- **Centres of expertise** were including as a **priority in the Spanish petition** « Pacto de Todos por las Enfermedades Raras »





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## RDD creating momentum to :

### build emerging national alliances

- In **Switzerland**, following RDDDay, the organisations involved met in March to discuss the possibility of forming an Alliance Maladies Rares.
- In **Australia** first RDD event . A seminar was held in Sydney to discuss the situation of rare diseases in Australia . This event was the launching pad for the creation of a group with a united voice for a national approach for rare diseases.





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## RDD raising awareness amongst the general public ...using VIP and celebrities to attract attention to the RD cause (some of them as patrons or good will ambassadors)



- First Ladies of Bulgaria, Hungary, Italy, Portugal, Germany
- Royal Princesses of Belgium, Denmark and Spain
- President of Austria, Greece and Croatia
- Governor General of Canada
- Football player in Spain
- Top model in Australia





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## RDD raising awareness amongst the general public

... informing ...



...educating...



...involving....



...debating...





## National RDD public awareness campaigns within the International RDD Campaign

...in France

Using the website [www.malades-pas-si-rares.org](http://www.malades-pas-si-rares.org) to spread the message

*Les maladies sont rares mais les malades sont nombreux.*

**E-mailing campaign**

*“Maladies rares: le saviez-vous?”*



...in Spain

Using the website [www.masde3millones.com](http://www.masde3millones.com) to spread the message

*“Somos más de 3 millones y aún así estamos solos.”*

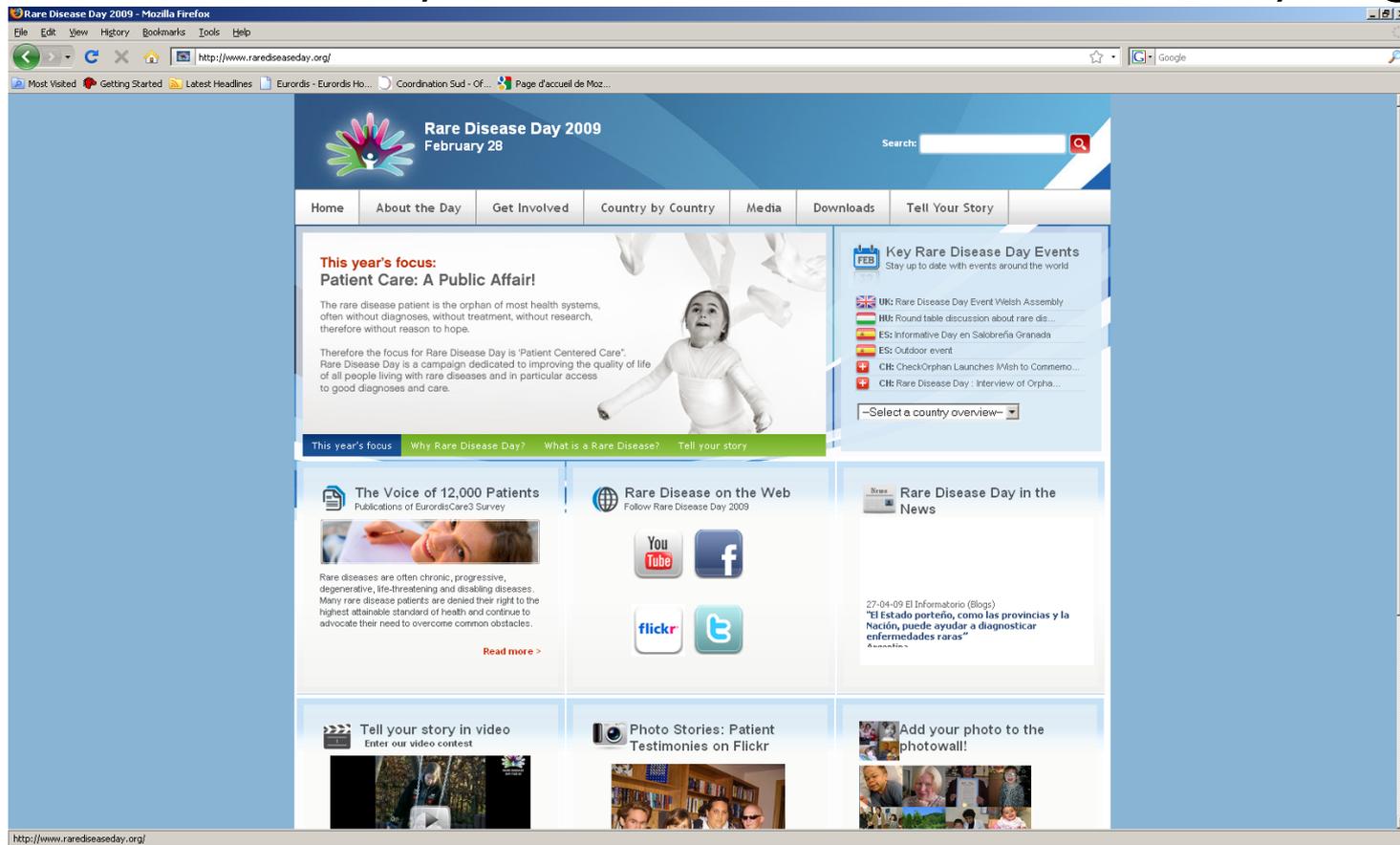
**On-line signing of petition**

*“Únete al Pacto de Todos por las ER”*





# The official RDDay website [www.rarediseaseday.org](http://www.rarediseaseday.org)



...all you needed to know about RDDay and more...



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EURORDIS would also like to thank all **insitutional partners** who helped promote the day, including:

- AFM- Téléthon
- European Commission's
  - DG for Health & Consumer Protection
  - « Europe for Patients » the public health portal for the EU
- Orphanet
- NIH and FDA (through NORD)
- Industry