



Rare Disease Day

Report on the 2009 Campaign



Rare Disease Day

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Chief Executive Officer
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Rare Disease Day



- Theme: (2008-2011)

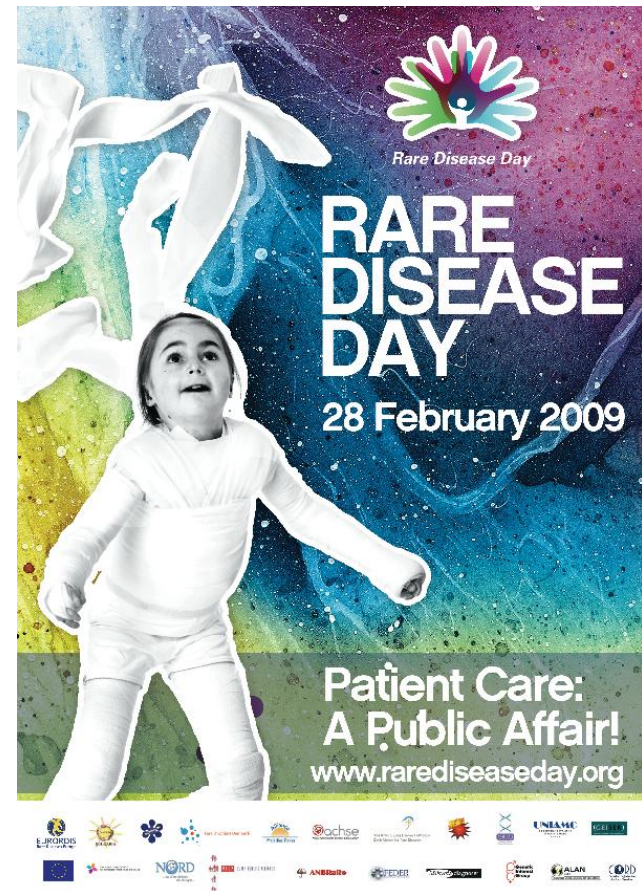
**“Rare Diseases:
a Public Health Priority”**

- Focus 2009 :

Patients Centered Care

- Slogan:

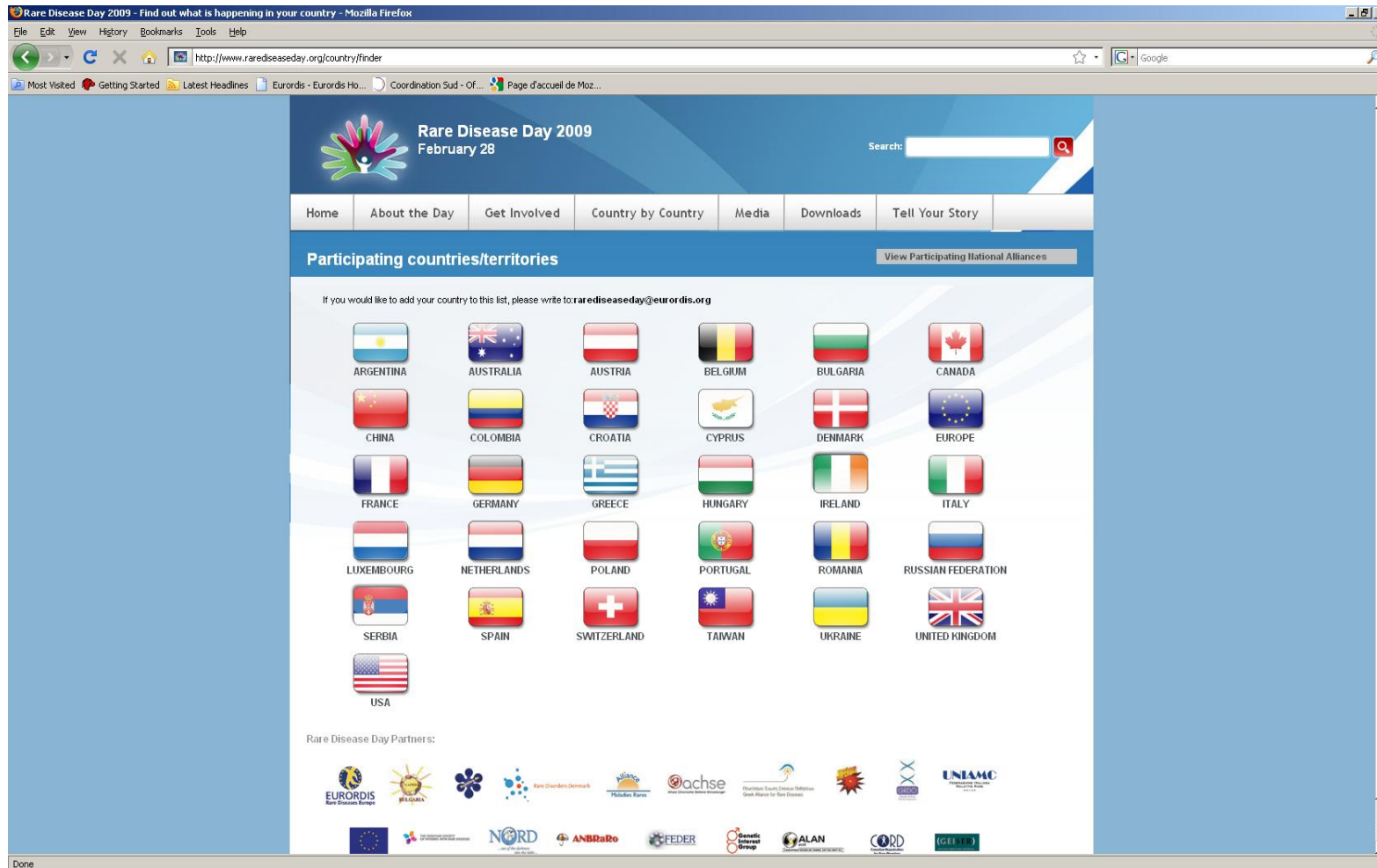
“Patient Care, a Public Affair!”



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**



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 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





KOSMOS TOU EPENDITI (PRESSE GRECQUE)

28/02/09

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Page 111

RDD Facts & Figures

Media coverage

More than **1500 media articles**, including

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

DIARIO DE NOTÍCIAS (PRESSE DU PORTUGAL)

25/02/09

Surface approx. (cm²) : 344

Les Echos

16 rue de la République
75001 PARIS FRANCE Tel: 01 43 88 60 00

EL MUNDO

15/02/09

Surface approx. (cm²) : 470

Editorial

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INNOVATION

Les maladies rares en mal de reconnaissance

Les systèmes de santé européens sont mal adaptés à la prise en charge des maladies rares et mal conçues que sont les maladies rares. La situation est d'autant plus inquiétante que les maladies rares sont souvent des maladies graves et peuvent entraîner la mort.

Listening to patients with rare diseases

On March 1, EURORDIS, the European umbrella organisation for patients with rare diseases, published the final of 12,000 Patients. The book summarises the results of two surveys (EuroDisCares and J), which explore the experiences of patients with 10 rare diseases in 12 European countries. Chronic diseases are dependent on existing patient organisations and included, for example, Fabry disease, Pompe disease, and Pompe 900 syndrome.

Shining a spotlight on glaucoma

March 1st was World Glaucoma Day, aimed at increasing awareness of glaucoma as a leading cause of preventable blindness worldwide. It affects nearly 70 million people and is predicted to increase by another 20 million by 2020. Most patients with glaucoma remain undiagnosed because symptoms are not present until late progression.

www.eurordis.org 14/02/2009 14:23:23

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.





Rare Disease Day
28 February 2009

www.rarediseaseday.org





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.

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



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.





Rare Disease Day
28 February 2009

www.rarediseaseday.org

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.



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

File Edit View History Bookmarks Tools Help

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

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Save a Copy 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 integrarles 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 ER¹.
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 pacientes en la elaboración de políticas y toma de decisiones.

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

www.enfermedades-raras.org

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.



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 »



RDD creating momentum to : build emerging national alliances

- In **Switzerland**, following RDDay, 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.

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



RDD raising awareness amongst the general public

... informing ...



...educating...



...involving....



...debating...





National RDD public awareness campaigns within the International RDD Campaign

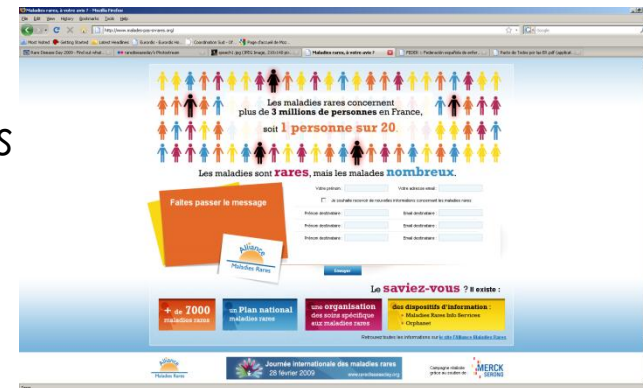
...in France

Using the website www.malades-pas-si-rares.org to spread the message

Les maladies sont rares mais les malades sont nombreux.

E-mailing campaign

“Maladies rares: le saviez-vous?”



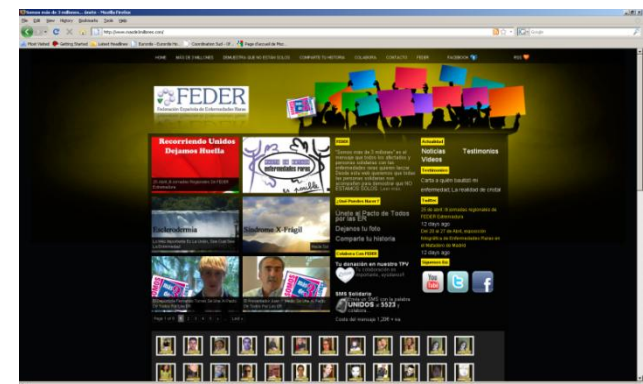
...in Spain

Using the website www.masde3millones.com 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



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



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