

# RARE DISEASE DAY 2011



*Rare Disease Day*

# Rare Disease Day 2011

**2008 : RD as a Public Health Priority**  
(overarching theme x 4 years)

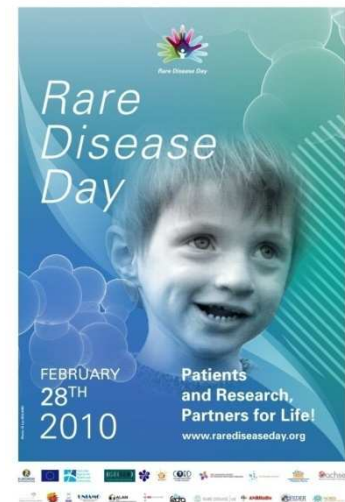
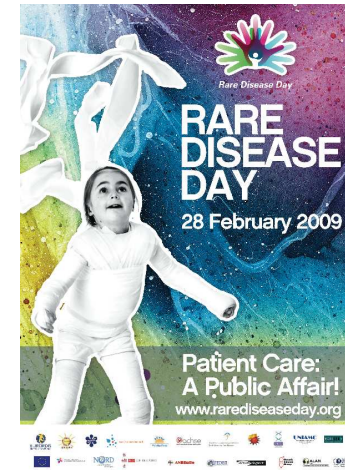
*“A rare day for special people”*

**2009 : Patient-centred care**

*“Patient Care: A Public Affair!”*

**2010: Bridging Patients and Research**

*“Patients & Researchers: Partners for Life!”*



# Rare Disease Day 2011

**Over arching theme:**

**RD as a Public Health Priority**

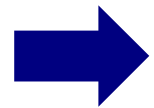
**Focus: Health Inequalities**

***RARE BUT EQUAL***

***RARE ≠ NEGLECTED***

- **Equal access to the same health care, treatments, social services and social rights as everyone else**
- **Social Justice / do more for those who have less / + vulnerable**

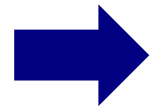
# Rare Disease Day 2011



## Link with National Plans

### “EuroPlan”

(same attention should be given to RD patients as to other groups in healthcare system and social services)



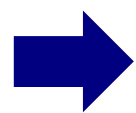
## Link with EU Health strategy to reduce inequalities

### “*Solidarity in Health Initiative*”

(Tackle gaps in health between and within MS. Same attention should be given to RD patients as to other groups in society)

# Rare Disease Day 2011

Advocacy objective at European level (organised by EURORDIS)



**Influence the third EU Public Health Programme 2014-2020**

How?

European event “**RD as a priority in 3rd EU Public Health Programme**” with the support of the DG SANCO

Possible venue: International Press Centre, Brussels

# Rare Disease Day 2011

**Date: 21 or 22 Feb or 28 Feb**

**Potential partners:**

**EU CERD**

**European Medicines Agency**

**European federations**

**EFPIA-EuropaBio**

**ESHG + learned societies**

**... and we may also include the WHO**

**Speaker / Patron: New Health Commissioner John Dalli**

# Rare Disease Day 2011

## RDD materials:

- **Princeps Paper**
- **Eurordiscare surveys & The Voice of 12.000 Patients**
- **EURORDIS contribution to EU Health Strategy, Feb 2007 and Patient Mobility, Jan 2007**
- **EURORDIS contributions to CCRD, Feb 2008**
- **RAPSODY work on RCS, TRP and integration to school**
- **FEDER Study (ENSerio), UNIAMO Study and other surveys .....+ your contributions!**
- **Testimonies / Patient stories**

# What can you do?

- Download logo, banner, poster
- Organise an awareness-raising event or activity
- Contact your National Alliance
- Advertise [www.rarediseaseday.org](http://www.rarediseaseday.org) and the RDD logo as widely as possible
- Encourage your members and partners to join in the campaign
- Sign up to the RDD Facebook Group
- Upload a photo or a video on Youtube/rarediseasday Channel
- Come to the European event in Brussels
- Send us stories, surveys, studies and other examples of health inequalities for rare disease patients