

# Rare Disease Day

2012





# Rare Disease Day 2012

- February 29 – leap year!  
« rare day for rare diseases »
- 5th edition of RDD
- EURORDIS' 15th Anniversary
- Same date as EURORDIS' Gala
- ERTC Workshop the next day
- EU 3rd Public Health Program + 8 Research Framework Programme (2012-2020)
- Possible theme (to be decided today):



# International

- RDD 2011 = international event = 56 countries
- Objective: RDD official UN date
- RDD + (Orphanet ICD) part of EU CERD and EC action to promote RD as an international public health priority at WHO General Assembly 2013
- RDD mentioned as a systematic measure in every NPRD as a day for information and action on RDs!
- Princeps paper: RD as an Int'l Public Health Priority (endorsed by NA) +partnership with NORD, CORD, ZORD and ICORD



# Innovation theme

- Medical and scientific research but also in the organisation of health care and social innovation
- RD as a pioneering field in all of these areas
- Latch on to flagship initiative of the EU “Innovation Union”
- Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science (Oct 2010)



# International or Innovation?

- Ties in with the UN Calendar strategy
- Would work in any nation, no matter what the level of technological advancement
- 5<sup>th</sup> anniversary : Good opportunity to "celebrate" the achievements in policy, research, treatment & patient support and occasion for uniting the global village
- Acknowledges the "pioneering" role of RD in research, policy and social sphere
- Working towards WHO 2013 General Assembly
- Use EUCERD to expand outreach +MS + other stakeholders (ie. EUCERD ERNS and Observers to become Friends of RDD)



# Innovation

- Contacts with Commissioner for Innovation
- European event (DG SANCO, DG Research, DG Enterprise)
- Timely : Gala and ERTC
- Particularly attractive to pharma & biotech industry (need to manage their involvement)
- RD at the cutting edge
- RD leading the way into the future!



# New ideas for RDD 2012

- Video (to stress international dimension of RDD)
  - Video clips from different countries, recognisable landmarks, lipsinging, « Hi 5 », holding hands around the world
  - Video documentary: RD as a public health priority
- Innovation Fair (collection of stories / on-line poster session or award to PO demonstrated + innovative idea)
- School Pack (joint CNA project) outreach to teachers and children



# Steering Committee 2011

**Mirjam Mann, ACHSE, Germany**

**Claudia Delgado, FEDER, Spain**

**Simona Bellagambi, UNIAMO, Italy**

**Mary Dunkle, NORD, USA**

**Barbara, Flynn, GRDO, Ireland**

**Volunteered to work with Paloma and discuss practical issues, decide on promotion, website, poster...**



# RDD 2011 - communication

- **Country pages**
- + **European disease-specific campaigns (Spina Bifida or PHP blue lips campaign)**
- **«Friends of Rare Disease Day»**
- **Newsfeed (Meltwater)**
- **Social media : Facebook/Twitter/**
- **Photos on Flickr**
- **Videos on the RDD Youtube channel**
- **New poster to be developed**  
**potential images....**



**Daniel, Aspert Syndrome, Spain**



**Emilia, Tadas and Maria, MPS VI, Lithuania**



**Heta, Dysmelia, Finland**



# Other ideas...

- Doodle
- Count down to RDD
- Create virtual badges for Facebook users
- Pins & Bracelets
- RD Ribbons



# Slogan ideas:

- Rare Diseases at the forefront of health innovation
- Rare Diseases leading the way to a brighter future
- Rare Diseases: Innovation and Progress
  
- RDD: Holding hands around the world!
- RDD: Going Global
- Rare Diseases: A Global Village
  
- Alone we are rare : Together we are Strong (NORD)
- “a rare day for rare diseases”
- “a rare day to put rare diseases in the spotlight”