

Rare Disease Day

2012



Rare Disease Day 2012

- February 29 – leap year!
- 5th edition of RDD

- EURORDIS' 15th Anniversary
- Same date as EURORDIS' Gala
- European advocacy: EU 3rd Public Health Program + 8 Research Framework Programme (2012-2020)

Theme: Solidarity

Working together on common goals

Solidarity:

- Between patients
- Between patients and carers
- Between experts
- Between rare diseases
- Between rare and common diseases
- Between countries
- Between society and vulnerable groups

Wide and flexible

Each participants or stakeholder could use it to bring forward issues that require solidarity

For example:

- reimbursement / health reform (US)
- access to orphan drugs
- healthcare pathways
- multidisciplinary care
- international research infrastructures
- cross border healthcare
- pooling of expertise /ERNs

Stressing international

- RDD 2011 = 56 countries = int'l movement
- 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
- Princeps paper: RD as an Int'l Public Health Priority (endorsed by NA) +partnership with NORD, CORD, ZORD and ICORD

Steering Committee 2012

Mirjam Mann, ACHSE, Germany

Claudia Delgado, FEDER, Spain

Simona Bellagambi, UNIAMO, Italy

Mary Dunkle, NORD, USA

Isabelle Houareau, AMR, France

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

Poster ideas:

2012
February

Rare Disease Day

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24		
27	28	29				

RARE DISEASE DAY
29 FEBRUARY

Solidarity

Rare Disease Day

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RARE BUT STRONG!
29 FEBRUARY

Slogan ideas:

- Rare but not Alone
- Rare but stronger, together
- Fighting rare diseases together

RDD 2011 - communication

- Website: Country pages
- + European page
- «Friends of Rare Disease Day»
- Newsfeed (Meltwater)
- Social media : Facebook/Twitter/
- Photos on Flickr
- Videos on the RDD Youtube channel

New ideas for RDD 2012

- Awareness-raising **video**
- Video can be used to introduce a local awareness-raising event
- **Viral campaign** to promote the video
- **Counter** for new countries, new Friend, new FB fans, new photo entry, new video entry...
- « Wear a Pearl: Show your solidarity with RDs »

Facebook application

to invite your friends to support the campaign



How can Federations participate?

- Europe page on website
- Disease-specific campaigns (ie. PH Blue lips and Fight against NTD campaign) can latch on to RDD
- Clarify RDD policy to endorse those campaigns (use of logo, play on multiplying effect but avoid cacophony of messages)
- Clarify EURORDIS/CEF policy to endorse other world days
- Reciprocity (in each other's communication)