The Spirit and History of Rare Disease Day

Anja Helm, Senior Manager of Relations with Patient Organisations, EURORDIS
The Spirit of Rare Disease Day

• EURORDIS / Council of National Alliances in 2008
• Patient-driven awareness campaign
• In 2010, anyone can participate: politicians, public authorities, policy-makers, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases
• The spirit of Rare Disease Day means that the logo and materials are not to be used for commercial purposes
Patient-driven - Countries and regions

84 in 2014
72 in 2013
63 in 2012
55 in 2011
46 in 2010
30 in 2009
18 in 2008…
Communications tools

Logo, Infopack, Poster in 2008

Added Facebook, Flickr, Twitter, YouTube in 2009

Friends of Rare Disease Day in 2010

New turquoise visual in 2011
Communications tools

Official video in 2012

Official video and poster in 2013

New website, Ambassador in 2014

Webinars in 2015
Rare Disease Day’s Success is YOU!

Questions?
Rare Disease Day in Ireland
Successes and Difficulties

Avril Daly
Vice President, EURORDIS
Chair, Genetics & Rare Disorders Organisation
Chief Executive, Fighting Blindness
Discussion Points

1. How did we get started?
2. Communication materials
3. Events that worked
4. Media attention
5. Fundraising
How did we get started?

• Building awareness

• Using international campaign materials
  - logo, slogan, poster

• Part of an international movement...
Successes and difficulties

• Events that worked
• Getting media interested
• Getting politicians involved
Fundraising

• Creating momentum and awareness
• Dangers?
Thank You

QUESTIONS?

Avril Daly, Ireland

Chair, Genetics & Rare Disorders Organisation
A tutorial on intellectual property, value and potential misuse.

EURORDIS Webinar - The Spirit of Rare Disease Day, 30 September 2014,
Presentation by Thomas Kanga-Tona, Client Executive, Healthcare, Burson-Marsteller
A. A consistent logo…

- Improves your initiative’s identity
- Improves the initiative’s coherence
- Improves the initiative’s visibility
- Makes the initiative memorable
- Has a wider reach
B. **Simple safeguards exist...**

- ...Always refer to the materials on the Rare Disease Day website
- ...Improve the accessibility of the Rare Disease Day website’s download section
- ...Improve the accessibility of the Rare Disease Day website’s disclaimer
- ...Ask EURORDIS if you have doubts
Preventing the misuse of the RDD logo by third parties

A. **Letting third parties misuse the RDD logo…**
   - …Harms the initiative’s identity
   - …Harms the initiative’s credibility
   - …Harms your organisation’s reputation
Preventing the misuse of the RDD logo by third parties (2)

B. You could address misuse by…

• ...Agreeing with external partners on the use of the logo
• ...Improving the accessibility of the disclaimer on good use of the RDD logo
• ...Referring to EURORDIS when a misuse occurs
Question time
Thank you!!

Contact details:
Thomas Kanga-Tona, Client Executive, Healthcare, Burson-Marsteller Brussels
thomas.kanga-tona@bm.com