



## CEF October 2015 – Awareness Days

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# A successful example

- Rare Disease Day – 8 editions and still growing!
- 2008 – patients organisations from 18 countries
- 2015 – all continents, all EU-Countries, hundreds of events and patient groups
- Keys to success:
  - Empowering the network to democratic decisions
  - Providing « clean » communication materials
  - Open to anyone for non-commercial use

# What have we accomplished?

- Patient-driven campaign – public good
- Built a strong community
- These 85 countries represent
  - 73% of the world's population and
  - 91% of the world's income
- 2015 – with the video, reached a larger general population

# 2016-2019 – Priorities?

- Continue to build the community – reach out to new organisations and people living with a rare disease
- Keep those people who are interested in the cause and **get them involved and active**
- How? Build an international campaign with even better visuals and video elements – step up a notch
- Keep our strengths of patient-driven campaign – grass-roots with global collaboration of a strong network

# Rare Disease Day style sheet

- Logo with more options
- The logo is now more modern and even stronger



**RARE DISEASE DAY.ORG**



**RARE DISEASE DAY®**

# Visuals



# 2016 timeline – 100 days campaign

- 21 November - Website launch, style sheet
  - 25 November - Social media webinar
  - End of November - Video production in Rome, Visuals and poster ready to download. (Script to be translated)
  - December - teaser (English) and 30" video ready for TV
- Mid-January- Worldwide launch of full video
  - 23 February – EURORDIS Awards and Black Pearl Evening
  - 24-25 February – Multistakeholder event
  - 29 February – Rare Disease Day

# EURORDIS events for Rare Disease Day

- **EURORDIS Awards** presented by Princess Astrid of Belgium
- Streamlined live – 23 February 5:00 PM
- 5<sup>th</sup> annual event held in Brussels
- Over 200 attendees awarding and celebrating outstanding contributions to the rare disease cause





# EURORDIS Policy Event - Brussels

- Two-day symposium on the topic of HTA (Health Technology Assessment)
- *'Multi-Stakeholder Symposium on Improving Patient Access to Rare Disease Therapies'*
- To be held on **24-25 February 2016** at Hotel Le Plaza Brussels
- **Plenary and keynote speeches streamed live for the world**
- 30 fellowships for patients and patient representatives - up to 400€ per selected fellow

# Rare Disease Day 2017

- Overarching theme - Patient Involvement
- Theme 2016 - Patient Voice / Slogan – Join us in making the voice of rare diseases heard
- Themes?
- Ideas?