

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 uror listage by the large Uror Discussion of the Uror

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

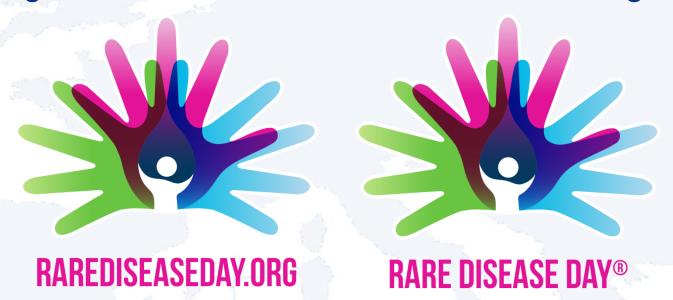


2016-2019 - Priorities?

- 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 grassroots 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



EURORDIS Rare Diseases Europe

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- Worlwide 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
- 5th 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?