

Rare Disease Day 2013



International momentum!

- Over 70 countries and regions around the world participated!
- **New countries:** Bahrain, Iceland, Israel, Lebanon, Macedonia, Palestine, Saudi Arabia and Singapore
- The slogan « Rare Disorders without Borders » was used globally as were the visuals of the website and poster.

National Alliances

29 official partners (Council of National Alliances)

- New alliances participating in Rare Disease Day this year – Finland, Slovakia, Czech Republic

Rare Disease Day Partners:



www.rarediseaseday.org

- Over 75,000 unique visits to rare diseaseday.org since January 1, 2013
- 18,000 visits in one day – February 28
- Our mobile phone audience is growing. It is now a solid and rapidly growing 20% of the entire visiting audience up from about 10% last year.

**RARE DISEASE DAY**
28 FEBRUARY 2013

Select Language ▼

[Home](#) [About the Day](#) [Get Involved](#) [Countries and Regions](#) [Media Center](#) [Downloads](#) [Tell Your Story](#) [News](#)

Participating countries and regions

+ Click on a continent



+

Thousands of patient groups and their partners all around the world are preparing a multitude of events to draw attention to rare diseases and the millions of people who are affected by them. Each year Rare Disease Day has enjoyed an ever growing number of participating countries. 63 countries participated in 2012.

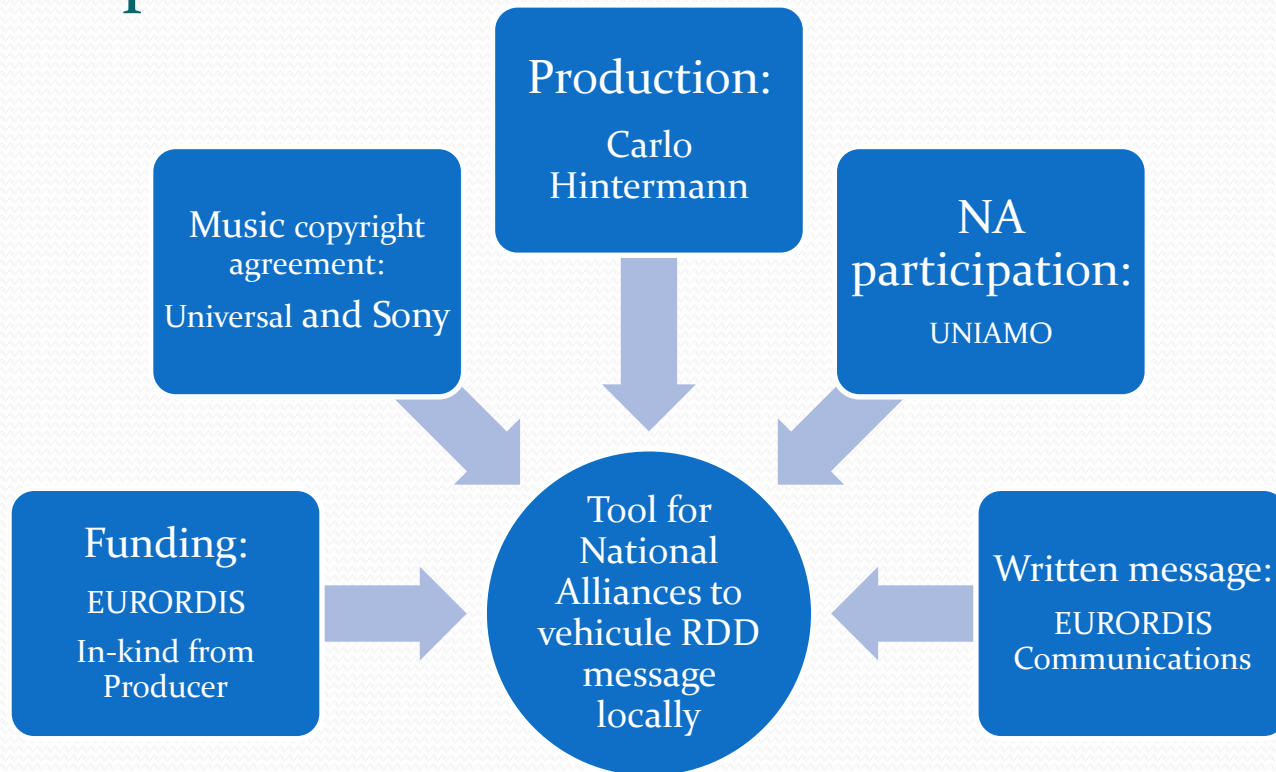
ALGERIA	ARGENTINA	ARMENIA	AUSTRALIA	AUSTRIA
SAHRAIN	BELGIUM	BRAZIL	BULGARIA	CAMEROON
CANADA	CHILE	CHINA	COLOMBIA	COSTA RICA
CROATIA	CYPRUS	CZECH REPUBLIC	DENMARK	EUROPE
FINLAND	FRANCE	GEORGIA	GERMANY	GREECE
GUATEMALA	HONG KONG	HUNGARY	ICELAND	INDIA
IRAN	IRELAND	ISRAEL	ITALY	JAPAN
KOREA	LATVIA	LEBANON	LITHUANIA	LUXEMBOURG
MACEDONIA	MALAYSIA	MALTA	MEXICO	NETHERLANDS
NEW ZEALAND	NORWAY	PAKISTAN	PALESTINE	PANAMA
PERU	PHILIPPINES	POLAND	PORTUGAL	ROMANIA
RUSSIAN FEDERATION	SAUDI ARABIA	SINGAPORE	SLOVAKIA	SLOVENIA
SOUTH AFRICA	SPAIN	SWEDEN	SWITZERLAND	TAIWAN
THAILAND	UKRAINE	UNITED ARAB EMIRATES	UNITED KINGDOM	URUGUAY
			USA	VENEZUELA

If you would like to organise and announce a special event for Rare Disease Day, please contact your National Alliance.

If you are planning awareness-raising events in a country that is not listed, please write to: rarediseaseday@eurordis.org

Official video: Effective tool for NA's

EURORDIS worked directly with producer Carlo Hintermann to write and create this year's video with stop motion technique, mixing animation and live participants.



Social media

Overall activity increased significantly this year

Facebook:

- 25,000 likes
- 22-28 February – 500,000 people viewed our content



Twitter:

- 28,000 tweets on February 28
- 17 tweets per minute about Rare Disease Day



« Tell your story » on Flickr and YouTube

- over 500 new stories added in February



Joining hands @ the world



- 150 joining hands photos sent in from around the world

Emails, Press releases, News

- Mass e-mails (RDD updates, Friends, database)
 - 8 emails with strategic timing November – February
 - to build excitement and momentum
 - NA's, PO's, policy makers, industry
- Press contacts
 - Press conference in Paris with Plateforme Maladies Rares
 - 3 press releases from EURORDIS (Press handled locally by country organisers)
- News on website – [click to site](#)
 - Storify - Regroups information coming in from countries and social media

Video message from Yann LeCam

- Professionally produced
- Pushed on social media
- For advocacy puposes



European EURORDIS event

Faster Access to Medicines for Rare Disease Patients “The Transparency Directive”

- 26 February, Brussels, Radisson Blu EU Hotel
- Co-Hosted by MEPs
 - Antonia Parvanova (Bulgaria), ENVI Committee
 - Cristian Silviu Buşoi (Romania), IMCO Committee



Rapporteurs of the EU Transparency Directive

- Panelists:
 - **Industry:** Richard Bergström, EFPIA Director General
 - **EC:** Salvatore D’Acunto, Head of Unit, DG Enterprise & Industry
Jaroslaw Waligora, Policy Officer, DG Health and Consumers
 - **Patient:** Terkel Andersen & François Houyez, EURORDIS



Policy meeting

100 participants on-site.

Streamlined on the EURORDIS website – 217 viewers watched LIVE from 31 countries

Video presentations now available on eurordis.org/tv

