Rare Disease Day

2012

Theme:

Solidarity

Slogan:

RARE BUT STRONG TOGETHER!

New visual identity:

Participating Countries

18 in 2008

30 in 2009

46 in 2010

55 in 2011

64 in 2012

33 from Europe

Newcomers: Chile, Costa Rica, Czech Republic, Guatemala, Pakistan, Venezuela

National Alliances

25 official partners (Council of National Alliances)

Belgium, Denmark, France, Germany, Greece, Hungary, Ireland, Italy, Netherlands, Romania, Spain, Sweden, UK, Bulgaria, Croatia, Luxembourg, Portugal, Russia, Canada and USA

New alliances joining in from

Georgia, Russia and Portugal

www.rarediseaseday.org

- 89,000 unique visits to rarediseaseday.org in the last 2 months

(compared with 44,000 last year for the same period)

- 22,000 visits in one day – February 29

- Twice the amount from last year!

New look and feel

Key Rare Disease Day Events

Stay up to date with events around the world

- HU: The newly formed exclusive Hungaria...
- IT: "Controvento", spettacolo teatrale
- IT: Stand informativo in farmacia
- AR: Interactive meeting at the Argentin...
- IT: Stand informativo in Ospedale
- IT: Stand informativo in farmacia
- HU: Round table discussion about rare d...

Friends of Rare Disease Day

A way for you or your organisation to share what you will do this year

Individuals, Patients, Patient Organisations, health professionals, researchers, drug developers, public health authorities and everyone having an interest in rare diseases are invited to join this year's campaign

View all Friends of Rare Disease Day

Joining hands

Joining hands around the world for rare diseases!

Raise and hold hands at 12 noon GMT on February 29 and show your Solidarity with rare disease patients around the world.

Find out more

Join the community

Official #RareDisease Day video eclipses 100k views in all languages. Watch the interview w/young stars on @TV3Ireland http://t.co/08grFyFU

Mar-06-2012 Read full tweet..

Watch videos

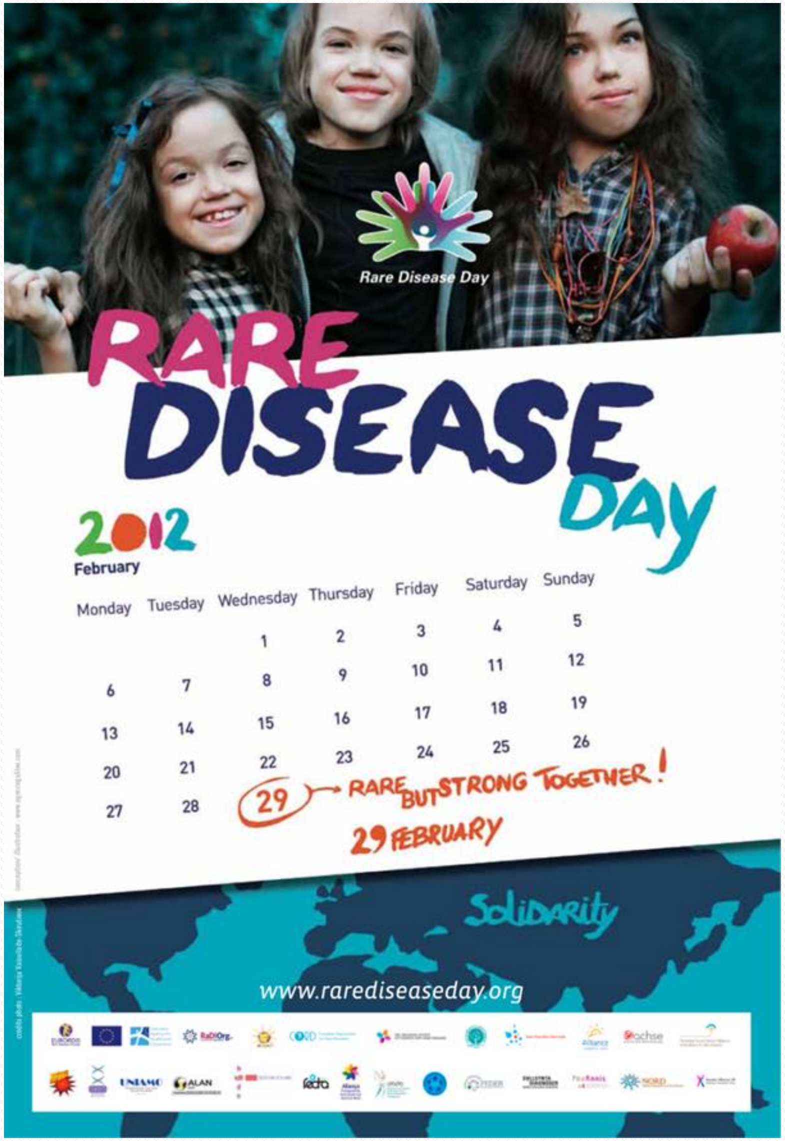
View photos

Sign up for updates

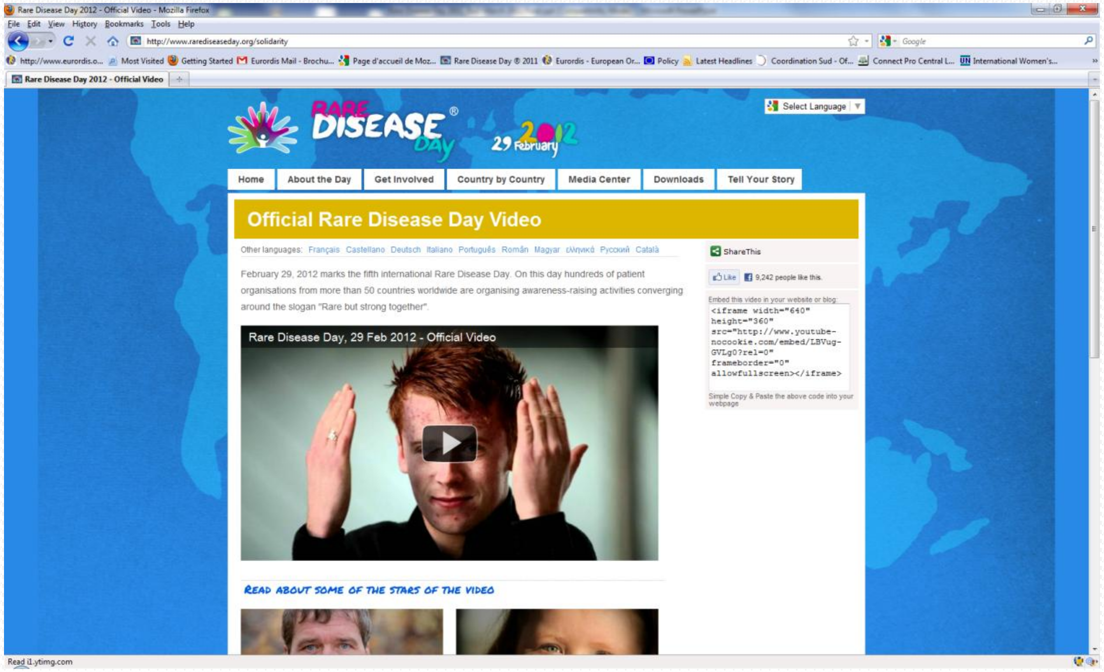
Communication material

- Logo
- Banner
- Badges (for Facebook profile)
- Poster
- Info pack (new! Full of tips to organised your own campaign and attract media attention)
- RDD ribbon
- HD screen for videos and presentations

…all downloadable from the RDD website



RDD official video



Official Rare Disease Day Video

Other languages: Français Castellano Deutsch Italiano Português Român Magyar ελληνικά Русский Català

February 29, 2012 marks the fifth international Rare Disease Day. On this day hundreds of patient organisations from more than 50 countries worldwide are organising awareness-raising activities converging around the slogan "Rare but strong together".

Embed this video in your website or blog:

```
<iframe width="640"
height="360"
src="http://www.youtube-
nocookie.com/embed/LBVug-
GVLg0?rel=0"
frameborder="0"
allowfullscreen></iframe>
```

Simple Copy & Paste the above code into your webpage

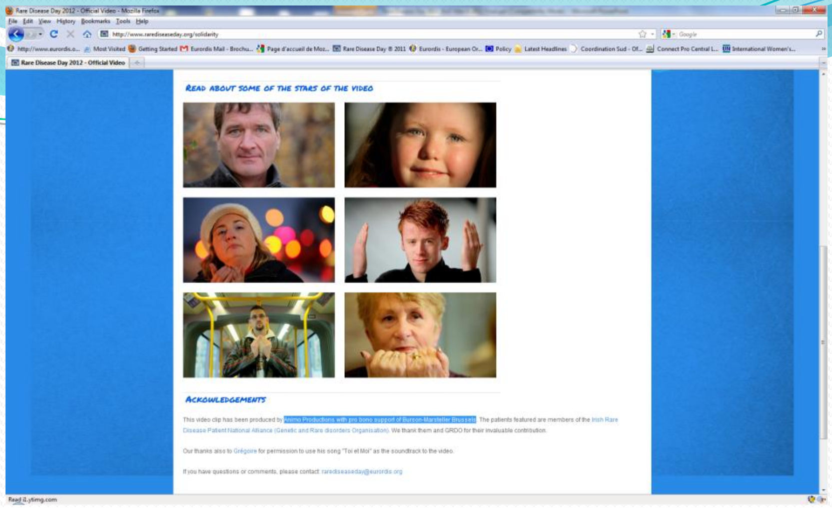
Special thanks to:

Avril Daly, Kathy Tynam and the Irish National Alliance (GRDO) for coordinating production, liaising with patients from their network, helping the day of the shoot and facilitating filming locations in Dublin

Animo Productions with pro bono support of Burson-Marsteller Brussels

Singer Grégoire and MyMajorCompany for permission to use his song "Toi et Moi" as the soundtrack to the video

Over 100,000 views!



READ ABOUT SOME OF THE STARS OF THE VIDEO

ACKOWLEDGEMENTS

This video clip has been produced by Animo Productions with pro bono support of Burson-Marsteller Brussels. The patients featured are members of the Irish Rare Disease Patient National Alliance (Genetic and Rare disorders Organisation). We thank them and GRDO for their invaluable contribution.

Our thanks also to Grégoire for permission to use his song "Toi et Moi" as the soundtrack to the video.

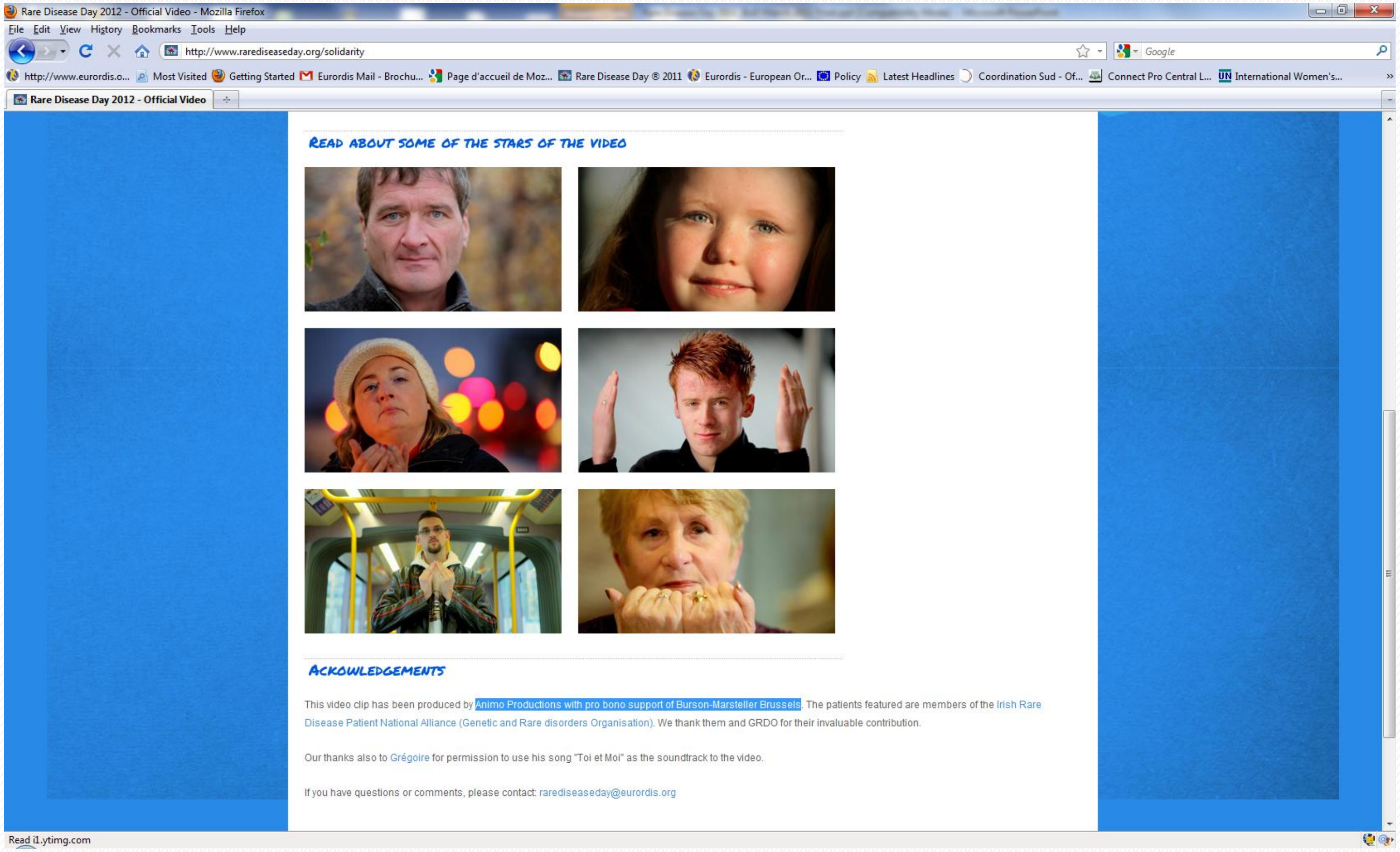
If you have questions or comments, please contact: rarediseaseday@eurordis.org

- Translated into 11 languages
- The video specific landing page http://www.rarediseaseday.org/solidarity

received 12,344 visitors in 3 weeks

- The video was “liked” on facebook 9,213 times
- Audience retention was well above YouTube averages
- Ranked first on YouTube in NGO category
- Included stories of the 6 patients featured in the video

The video page featured stories on patients who participated in the video (viewed by 6,075)



READ ABOUT SOME OF THE STARS OF THE VIDEO

ACKOWLEDGEMENTS

This video clip has been produced by Animo Productions with pro bono support of Burson-Marsteller Brussels. The patients featured are members of the Irish Rare Disease Patient National Alliance (Genetic and Rare disorders Organisation). We thank them and GRDO for their invaluable contribution.

Our thanks also to Grégoire for permission to use his song "Toi et Moi" as the soundtrack to the video.

If you have questions or comments, please contact: rarediseaseday@eurordis.org

Breakdown of the video viewership by language (as of March 8, 2012):

English	47420
Spanish	23708
Italian	15822
French	11221
Russian	3688
Portuguese	3587
German	1835
Catalan	1335
Greek	818
Romanian	537
Hungarian	167

TOTAL 110,138

Referral traffic to video page

- 28% from facebook.com
- - 6% from eurordis.org
- - 6% from orpha.net
- - 3% from rarediseaseday.us the NORD rdd website
- - 3% from NORD's website
- - 2% from NIH's Rare Disease portal rarediseases.info.nih.gov

Video promotion

- Shown on several national and regional TV stations in Italy, Portugal and Ireland
- Two of the patients featured were interviewed in an Irish TV morning show
- EU Health Newsletter (on EC Health portal)
- OrphaNews Europe
- AFM Live Telethon and AFM FB
- CBS News.com
- Le Point
- The Examiner

Friends of RDD

376 Friends signed up on our webpage

(industry, patient organisations, research networks, universities, public authorities)

Compared to 292 in 2011

Some interesting friends!

French Ministry of Health

Harvard Medical School

European Medicines Agency

Slovenian Ministry of Health

Social media

Facebook: 13,400 likes

Twitter: 3,127 followers
compared to 1,446 last year

Flickr: 423 photos added

You tube: 88 videos

Facebook & Twitter

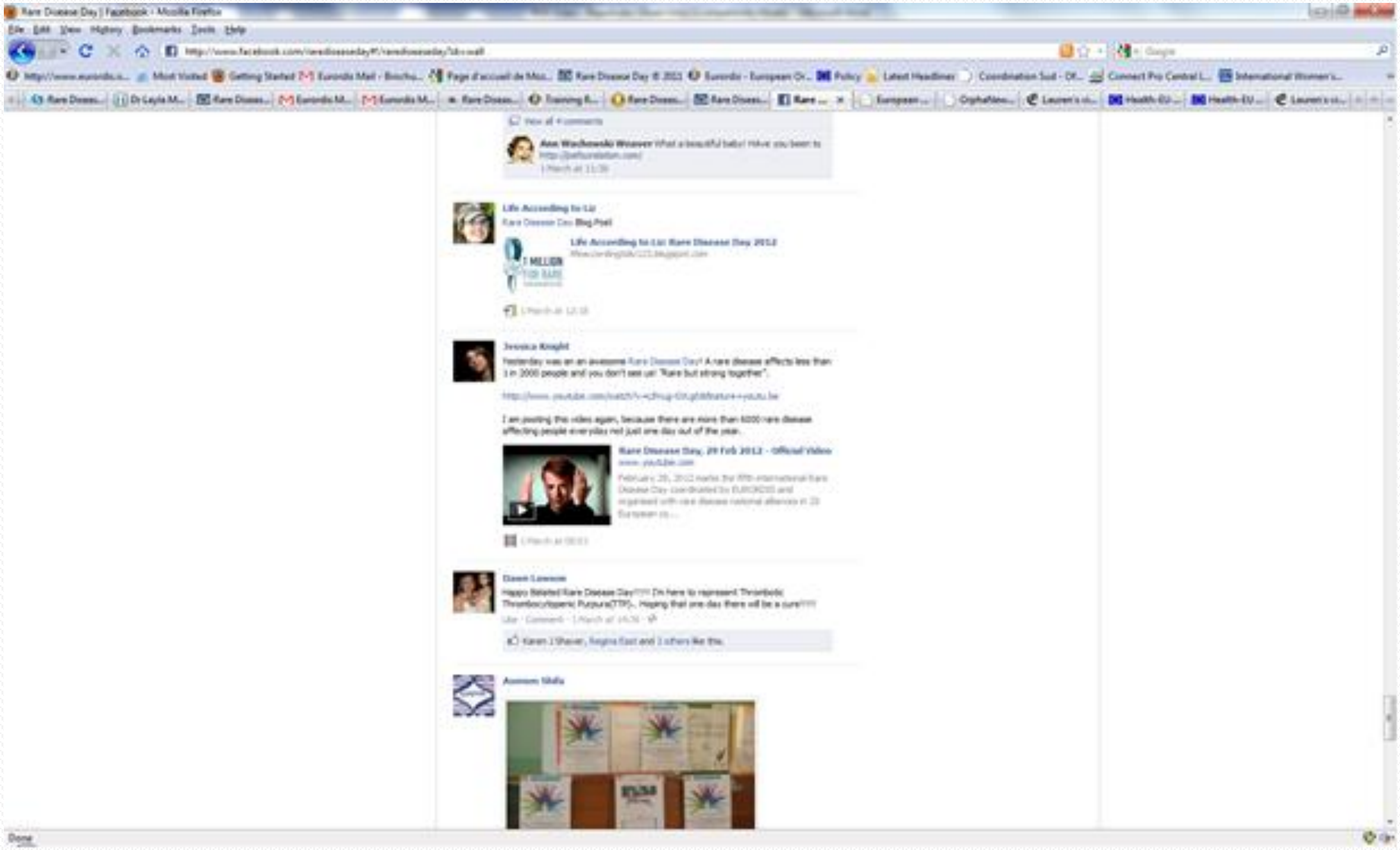
Our Facebook community grew significantly this year jumping to 13,400 likes

from 8,000 followers a short few weeks ago and just 4,000 last year

10 video specific tweets about the video on RDD Twitter account

These were re-tweeted 113 times reaching 63,386 users in total (Source: http://retweet.co.uk)

facebook.com/rarediseaseday



Rare Disease Day | Facebook - Mozilla Firefox

Life According to Liz

Life According to Liz: Rare Disease Day 2012

Jessica Knight

Yesterday was an an awesome Rare Disease Day! A rare disease affects less than 1 in 2000 people and you don't see us! "Rare but strong together".

I am posting this video again, because there are more than 6000 rare disease affecting people everydau not just one day out of the year.

Rare Disease Day, 29 Feb 2012 - Official Video

www.youtube.com

Dawn Lawson

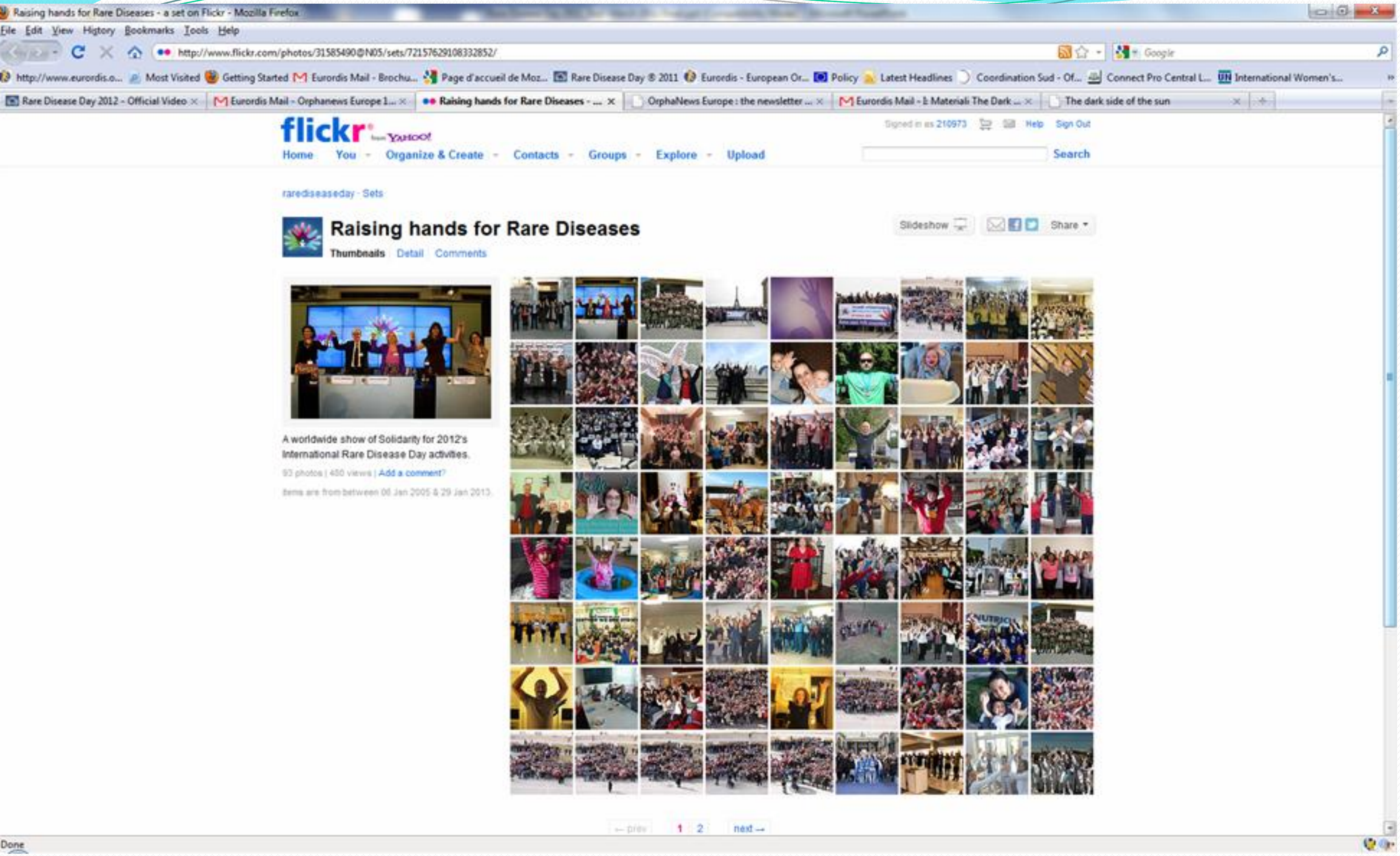
Happy Belated Rare Disease Day!!!!! I'm here to represent Thrombotic Thrombocytopenic Purpura(TTP)... Hoping that one day there will be a cure!!!!!

Tell your Story

- Special feature on website allowing visitors to upload their photo and video stories has been a great success - over 350 photo went online 10 days before Feb 29
- bringing the total to 853 photos overall on Flickr now gathering over 16,000 views on Feb 29 alone and almost 500,000 views, yes **half a million views** since we started this feature 4 years ago!
- 88 new videos uploaded on RDD YouTube since Dec 2011 bringing the total to 194 videos and more than 350 000 total views

Joining hands around the world

- Thousands of people responded to our call to Raise & Holds hands to show Solidarity with rare disease patients
- 91 photos from more than 20 countries uploaded to rarediseaseday.org
- Many more raised and joined hands



Raising hands for Rare Diseases

A worldwide show of Solidarity for 2012's International Rare Disease Day activities.

93 photos | 450 views | Add a comment?

Items are from between 06 Jan 2005 & 29 Jan 2013.

Video greetings from EURORDIS

- Yann Le Cam recorded a video greeting shown at
- At an advocacy event for NPRD organised by the Finnish RD Network at the House of Parliament in Finland on Feb 29
- At the first Rare Disease multi-stakeholder conference in Slovakia. Right after the Ministry of Health committed to a first step towards a NPRD
- At the Ukrainian Institute of Clinical Genetics with support of National Security and Defense Council and regional Administration as well as patients' organizations. (simulatanous interpreation in Ukrainian!)

Media coverage

- Online press clipping - over 3000 articles during the month of February
- 1388 on the week leading up to Feb 29
- Le Point
- Huffington Post
- The Lancet
- Nature
- Gulf News.com
- AztecaNoticias

Dissemination strategy

- RDD Website (first ranked on Google)
- Social media
- …. mass mailings to members & other RD stakeholders (including EURCERD members)
- Poster mass mailing to members, Alliances, Federations and Industry
- Video viral campaign
- 3 press releases
- Presentations at CNA, CEF and EUCERD

Important events

- Publishing of a consultation for a United Kingdom plan for rare diseases (learn more)
- Official launch of the French Foundation for Rare Diseases (learn more)
- Creation of the Northern Ireland Rare Disease Partnership (learn more)
- Launch of the Genetic Testing Registry by the National Institutes of Health in the USA (learn more)
- All day event at the National Institute of Health

Creating momentum for National Plans and National Alliances

- SLOVAKIA: New Alliances launched
- FINLAND: a Rare Disease Day event at the Finnish Parliament
- CYPRUS: Press conference with the Ministry of Health
- SWEDEN: Hand-outs about NPRD at Stokholm Central Station

European Symposium

“Rare Diseases a model of EU Solidarity”

- At Residence Palace in the International Press Centre in Brussels on Feb 29
- Event to highlight rare diseases as a model of EU solidarity in today’s crisis-stricken Europe
- Showcased 4 European Reference Networks to illustrate successful collaboration and pooling of expertise at EU level

European event

Some 120 participants

Key note speakers

- First Lady of Georgia Sandra Roelofs
- Ms. Ness Childers (MEP)
- Paola Testori Coggi (Head of DG Sanco)
- Ruxandra Draghia Akli (Head of Health atDG Research)
- Dr. Ségolène Aymé (EUCERD Chair)
- Terkel Andersen (EURORDIS President)
- 4 EU-funded Reference Networks (ERN) project leaders and patient representatives

European event

- DG Sanco leader Paola Testori Coggi supported the call to make rare diseases a priority in the next Public Health Programme
- Dr Draghia Akli said 'together we are stronger' referring to the International Rare Disease Research Consortium
- MEP Nessa Childers said we need to ensure enough resources made available in 3rd PHP, to put in place an infrastructure of European Reference Networks to cover all diseases
- She
- She called upon those countries without a national plan to develop one by 2013

European event

The event was streamlined live on the EURORDIS website and on FB throughout the day (........ people tuned in)

Presentations and videos available on eurordis.org