

Rare Disease Day

2011

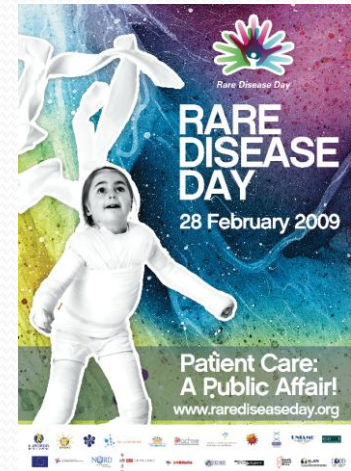


Past events

2008 : RD as a Public Health Priority

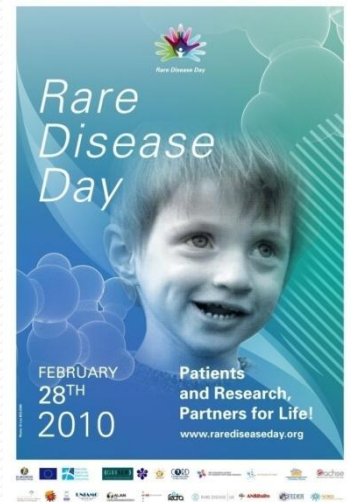
(overarching theme x 4 years)

“A rare day for special people”



2009 : Patient-centred care

“Patient Care: A Public Affair!”



2010: Bridging Patients and Research

“Patients & Researchers: Partners for Life!”

2011

Theme: Rare Disease & Health Inequalities

Slogan:
“Rare but Equal”



Participating Countries

18 in 2008

30 in 2009

46 in 2010

56 in 2011

28 from Europe

Newcomers:

Mexico

Uruguay

Iran

Thailand

Nepal

United Arab Emirates

Panama

Morocco

Armenia

Peru

Countries that participated in RDD 2008-11



0 1000 Km

National Alliances

- Official partners (22 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: Switzerland and Cyprus



RDD website

Number of visits: 49,387 from 150 countries*
(compared to 38,000 same period last year)

10,000 visitors on Monday Feb 28
- 3 times the amount from last year!

*Jan 1, 2011 – Mar 3, 2011



Rare Disease Day® 2011

February 28

[Home](#)[About the Day](#)[Get Involved](#)[Country by Country](#)[Media Center](#)[Downloads](#)[Tell Your Story](#)

This year's focus :
Rare Diseases & Health Inequalities

[This year's focus](#)[What is Rare Disease Day?](#)[What is a Rare Disease?](#)[Tell your story](#)

Key Rare Disease Day Events

Stay up to date with events around the world



RO: Playdecide



EU: European Symposium Rare but Equal Ad...



RO: Lessons about Rare Diseases



DE: Essen: mehr als 20 Selbsthilfeorganis...



HU: Press conference about rare diseases



IT: HEALTH INEQUALITIES - RARE BUT EQUAL

--Select a country overview-- ▾

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

Become a Friend of Rare Disease Day

Join the Community

Be part of Rare Disease Day 2011



You
Tube



Facebook



Flickr



Twitter

Rare Disease Day in the News

2011-03-16 Cofares.es

MADRID. Jornada en el Ateneo sobre Investigación y Tratamiento de las Enfermedades Raras

2011-03-16 14:55:00



Rare Disease Day® 2011

February 28

[Home](#)[About the Day](#)[Get Involved](#)[Country by Country](#)[Media Center](#)[Downloads](#)[Tell Your Story](#)

Participating countries/territories

[View Participating National Alliances](#)

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. The following countries have joined in 2011 : If you are planning awareness-raising events in a country that is not listed, please write to: rarediseaseday@eurordis.org

| | | | | |
|----------------------|----------------|--------------|--------------|----------|
| ARGENTINA | ARMENIA | AUSTRALIA | AUSTRIA | BELGIUM |
| BRAZIL | BULGARIA | BURKINA FASO | CAMEROON | CANADA |
| CHINA | COLOMBIA | CROATIA | CYPRUS | DENMARK |
| EUROPE | FINLAND | FRANCE | GEORGIA | GERMANY |
| GREECE | HONG KONG | HUNGARY | INDIA | IRELAND |
| ITALY | JAPAN | LATVIA | LUXEMBOURG | MALAYSIA |
| MEXICO | MOROCCO | NEPAL | NEW ZEALAND | NORWAY |
| PANAMA | PHILIPPINES | POLAND | PORTUGAL | ROMANIA |
| RUSSIAN FEDERATION | SERBIA | SLOVENIA | SOUTH AFRICA | SPAIN |
| SWEDEN | SWITZERLAND | TAIWAN | THAILAND | UKRAINE |
| UNITED ARAB EMIRATES | UNITED KINGDOM | URUGUAY | USA | |

Rare Disease Day Partners:

RDD website

www.rarediseaseday.org

...first ranked on Google!

- Info pack
- Banner
- Logo
- Poster

all downloadable from the RDD website

Logo and slogan

translated
into many languages

Logo appeared in all RDD
communication



**DZIEŃ
CHORÓB
RZADKICH**

Warszawa 28 lutego 2011

facebook

Name:
Ziua Bolilor Rare
2011

Status:
Bolile rare sunt
cronice, unele
progresive,...



**ZIUA
BOLILOR RARE** 28 Februarie
2011

Fans:
104



Rare Disease Day
2月29世界罕见病日



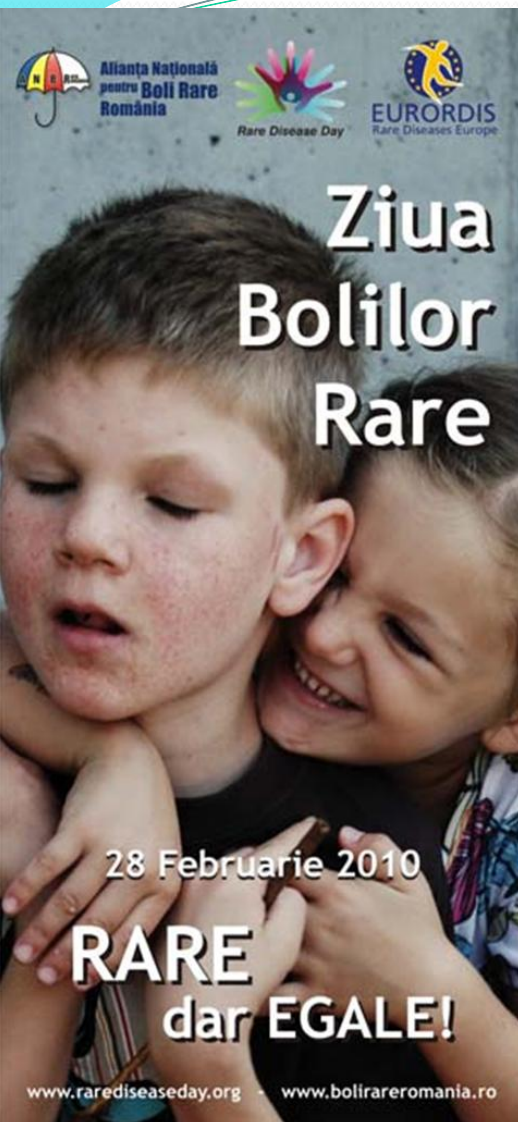
CHINA DOLLS
www.chinadolls.cn
010-63459745


Nossa ação afirmativa!





Dia das Doenças Raras






 Alianța Națională
pentru Boli Rare
România


 Rare Disease Day


 EURORDIS
Rare Diseases Europe

Ziua Bolilor Rare

28 Februarie 2010

RARE dar EGALE!

www.rarediseaseday.org
www.bolirareromania.ro

RARE dar EGALE!

Sunteți invitați să participați împreună cu noi la o
Campanie dedicată Oamenilor Speciali
O zi rară pentru oameni rari!

Alianța Națională pentru Boli Rare România
(ANBRaRo, www.bolirareromania.ro) anunță
marcarea Zilei Internaționale a Bolilor Rare în
România pentru 28 februarie 2011.

Programul Campaniei:

21 februarie, ora 12.00, Zalău
Marșul bolilor rare,
pe traseul: parcare din spatele
Primăriei Mun. Zalău până la Casa de
Cultură a Sindicatelor

21 februarie, ora 13.00, Zalău
Conferință de presă
Lansare de carte
„Rare inegale - povești ale pacienților”
Sala Avram Iancu a
Primăriei Municipiului Zalău

22 februarie, ora 13.00, Zalău
Playdecide (Dezbatere Publică) pentru cadre
didactice, Sala Festivă a
Școlii Corneliu Coposu

25 februarie, ora 12.00, Zalău
Playdecide pentru persoanele din sistemul sanitar,
locația: sediul Asociației Prader Willi din România,
Strada Avram Iancu Nr. 29, Zalău

1 martie, ora 12.00, Zalău
Playdecide pentru autoritățile și presa locală,
locația: sediul Asociației Prader Willi din România,
Strada Avram Iancu Nr. 29, Zalău

14-28 februarie pe raza județului Sălaj
Lecții în grădinițe, școli și licee

www.rirosz.hu
<http://sites.rirosz.hu/rbv>


 2011.hu


 Rare Disease Day



RITKÁK, DE EGYENJOGÚAK!

RITKA BETEGSÉGEK

2011.
Február 26. 09:30-17:30-ig
Magyar Mezőgazdasági Múzeum, Városliget
Kiállítás, családi nap és szakmai programok

VILÁGNAPJA

www.rarediseaseday.org



Rare Disease Day

RAROS MAS IGUAIS

DIA DAS DOENÇAS
RARAS
28 DE FEVEREIRO 2011

26 DE FEVEREIRO
IBMC | Porto
R. do Campo Alegre, 823

ENTRADA LIVRE

ORPHANET - APRESENTAÇÃO DO PORTAL DE ACESSO ÀS DOENÇAS RARAS E AOS MEDICAMENTOS ÓRFÃOS.



INFORMAÇÕES: S. Comunicação e Imagem - 22 405 53 91 / 93 403 32 79 - secretariado@comunicacao.com



Rare Disease Day

A l'occasion de la Journée des Maladies Rares 2011
L'association Marocaine Enfance et Maladies Orphelines
Organise

Une Formation au profit des professionnels de la santé
sur le thème

"Craniofaciosténoses du diagnostic à la prise en charge"

Le Dimanche 27 Février 2011 à 14h30
Salle des réunions du Conseil Communal de Marrakech
Avenue Mohamed VI Guéliz

Merci de confirmer votre présence en contactant l'AMEMO



www.amemo-asso.org

Tel : 0669 183548
Fax : 0524421821
Email : amemo.asso@gmail.com

« Rare but Equal »

This year's theme was taken up by many alliances and patient groups

EURORDIS collected 55 testimonies of health inequalities from different diseases and countries

Visible on “Tell your Story” section of RDD website
www.rarediseaseday.org/yourstory/inequality

Friends of RDD

Number: 292 (187 in 2010)

Partners other than national alliances:
patient organisations, caregivers organisation,
healthcare professionals or researchers
organisations, industry
and public authorities

*Example: Official endorsement of the European
Medicines Agency*

Friends of RDD

European Medicines Agency - News and press release archive - Rare Disease Day: 28 February 2011 - Mozilla Firefox


File Edit View History Bookmarks Tools Help

http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2011/02/news_detail_001217.jsp&url=menus/news_and_events/news_and_events.jsp&mid=WC0b01ac058004d5c1

http://www.eurordis.o... Most Visited Getting Started Eurordis Mail - Brochu... Page d'accueil de Moz... Rare Disease Day © 2011 Policy Latest Headlines Coordination Sud - Of... Eurordis - European Or... Connect Pro Central L... International Women's...

www.eurord... Rare Disease... Eurordis Mai... Europea... X europlan ko... Wissenheit.ch Legavolley - ... Rare Disease... Romania lib... Milano in m... Giornata dell... JPEG Image... Fél pár keszt... (3684 unrea... 104 - CENT...

An Agency of the European Union

 **EUROPEAN MEDICINES AGENCY**
SCIENCE MEDICINES HEALTH

Text size: A A A Site-wide search GO

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Home > News and Events > News and press release archive


Rare Disease Day: 28 February 2011

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News

25/02/2011

Rare Disease Day: 28 February 2011

 The European Medicines Agency supports [Rare Disease Day](#), which is taking place on Monday 28 February.

Rare Disease Day is held every year on the last day of February. Started in 2008, it seeks to raise awareness of rare diseases, and to improve access to treatment and medical representation for individuals with rare diseases and their families. It is co-ordinated by the [European Organisation for Rare Diseases](#) (EURORDIS).

In 2011, the day's theme is 'rare but equal'. It is focusing on the differences between and within countries for patients with rare diseases, and compared to other segments of society. It is advocating for equal access for these patients to healthcare, social services, basic social rights, medicines and treatments.

About 30 million people living in the European Union (EU) suffer from a rare disease. The EU offers incentives to companies developing 'orphan' medicines for conditions affecting fewer than 5 in 10,000 people. These include reduced fees for marketing-authorisation applications and protection from market competition once the medicine is authorised. These incentives aim to bring more medicines for rare diseases to the European market.

The Agency plays a central role in the development and authorisation of these medicines: the European Commission grants orphan designation to medicines on the recommendation of the Agency's [Committee for Orphan Medicinal Products](#) (COMP), and designated orphan medicines are assessed centrally on a European level by the Agency's [Committee for Medicinal Products for Human Use](#) (CHMP), rather than in each Member State separately. To date, the European Commission has granted [838 orphan designations](#), and authorised [65 orphan medicines](#).

The Agency works closely with its international partners on the designation and assessment of orphan medicines. In particular, it collaborates with the United

Related information

- ▶ [Rare Disease Day](#)
- ▶ [European Organisation for Rare Diseases](#)
- ▶ [Medicines for rare diseases](#)
- ▶ [Orphan designation](#)
- ▶ [Working with the United States of America](#)
- ▶ [Food and Drug Administration](#)
- ▶ [The European Union and the FDA working together to create common application for orphan designation for medicines \(26/11/2007\)](#)
- ▶ [FDA and EMA agree to accept a single orphan drug designation annual report \(26/02/2010\)](#)
- ▶ [Working with patients and consumers](#)

Social networks

Facebook: over 14 000 fans



Twitter: 1,446 followers



Flickr: 432 photos



You tube: 100 videos



Creating momentum for National Plans

- Announcement of French 2nd NPRD
 - Annoucement of UK NPRD
 - New announcements towards NPRD in Ireland, Croatia, Hungary, Luxemburg and Action Plan 2011-2012 of Spanish NPRD
- In Switzerland, a member of the Health Commission proposed a vote for a NPRD
- In Belgium, there was a symposium for the drafting of the NPRD



Reports, surveys

- Launching of “Rare diseases: a national survey on the situation of persons with rare diseases in Luxembourg”
- Rare Disease UK released recommendations for a strategy for rare diseases at a reception at the House of Commons on Rare Disease Day



Country highlights - France

Awareness raising weekend in
partnership with
iDTGV (SNCF) organised
By l'Alliance Maladies Rares
and Orphanet

26-27 Feb trains going to
Toulouse, Hendaye, Lyon,
Grenoble, La Rochelle et
Strasbourg

iDTGV présente

Alliance
maladies rares

orphanet
insERM

Les maladies rares concernent
plus de **3 millions**
de personnes.

Les maladies sont **rare**s, mais les malades **nombreux**.

Lundi 28 février 2011
Journée internationale
des maladies rares

Plus d'infos sur : www.rarediseaseday.org

Avec le soutien de :
Fondation Géraud
pour la santé
Valons les maladies rares

Rendez-vous maintenant en voiture bar **iDZINC** !

<http://blog.iDTGV.com>

iDTGV / **SNCF**

Country highlights - Hungary

Rare Disease Day 2011 Conference on Rare
Diseases & Health Inequalities "Rare but Equal"
and EUROPLAN Conference
Informal central event of
EU Hungarian Presidency
Family Day
RD Fair



Italy

Second March for Rare Diseases in Milan, Italy with
Head of Health for Lombardy region – 200 people



Volley league is a partner - 21 volley matches during
RDD week, all players wore the RDD T-shirts
4 matches transmitted on National TV Channels

Spain

Official act in the Spanish Senate in Madrid
supported by Her Royal Highness the Princess of
Asturias - 350 people attended



Intra ministerial Rare Disease plan of action for
2011-2012 announced as a result of the wave of the
RD Day events and their impact on the media.

Romania

- Educating about RD in schools
- 3 play decide sessions
- 6 conferences
- A march and street information activities in 3 towns - 1000 participants
- Massive media coverage
- “RD & health inequalities” was a good way to advocate at the MoH for the NPRD to be included in National Strategy for Public Health.



Rare Inegale

povesti ale pacientilor

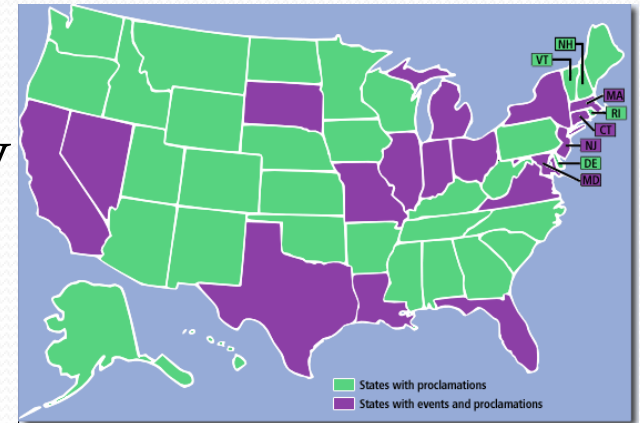


28 februarie 2011

More highlights - USA

A National Resolution!

The U.S. Senate adopted, by unanimous consent, a resolution designating February 28 as Rare Disease Day across the U.S.



Recognition in All 50 States!

Thanks to an amazing grassroots campaign, proclamations were obtained in 48 states and similar documents were obtained in the two other states.



MORE COLORS AVAILABLE

[NORD Kids Light T-Shirt](#)
\$15.99



MORE COLORS AVAILABLE

[Rare Disease Day Bib](#)
\$12.99



MORE COLORS AVAILABLE

[Rare Disease Day 2010 Infant Bodysuit](#)
\$15.99



[Rare Disease Day Teddy Bear](#)
\$14.99



MORE COLORS AVAILABLE

[NORD Beach Tote](#)
\$24.99



[Rare Disease Day Large Mug](#)
\$13.99



[NORD Ceramic Travel Mug](#)
\$19.99



[NORD Sigg Water Bottle 0.6L](#)
\$23.99



[Rare Disease Day Sigg Water Bottle 1.0L](#)

In **Switzerland** - First conference organised by ProRaris, the new Swiss Alliance, more than 400 participants met in Bern - 35 POs, health professionals, scientists and politicians.

In **Croatia** - President of the country Ivo Josipović gave his official support and a
His message was broadcasted
On National TV



And further afield

In **Ukraine** - video played in Kharkiv metro for one month



In **Brazil** – Romario, former international football player and now a politician, agreed to support in Parliament the project of an official National Rare Disease Day in 2012



In India – Family Day in Chennai organised by Lysosomal Disorders Society and attended by famous tamil actor



In the Middle East -The 1st International Rare Disease Day organised in Dubai:
Genetics Conference and family get-together



Even the Pope acknowledged Rare Disease Day

Italian RD Alliance, UNIAMO,
succeeded in reaching
the secretary of the Holy Father



On Sunday morning Feb 27 in St Peter Square
the Holy Father sent His personal message to
Rare Disease Patients and families and His wish
that research advancement can effectively help
RD patients

Federations

- PHA Europe – Blue lips campaign
- Spina Bifida International Federation – Prevention of NTDs



2011-02-28 "Blue Lippen"-Aktientag, Initiative Lundenhochdruck, Wien

(c) DreshSchaller.com #20110228Lundenhochdruck0065

**The right advice at the right time
can reduce Neural Tube Defects now**

On Rare Disease Day, 28 February 2011, take action on one of the few preventable rare diseases. Neural Tube Defects, such as Spina Bifida, can be prevented.

Spina Bifida is a birth defect caused when the neural tube does not close properly within the first 28 days after conception. 4,500* pregnancies are affected every year in Europe by a Neural Tube Defect (NTD). Up to 70% of NTDs could be prevented through adequate folate levels before and during early pregnancy.

Access and equity to prevention of rare diseases needs to be further improved.

The International Federation for Spina Bifida & Hydrocephalus and Bayer Schering Pharma AG are partners in a joint campaign to raise awareness of the need to improve prevention of NTDs in Europe. **JOIN US, ACT NOW!**


For more information read our report at
http://ec.europa.eu/health/rare_diseases/index/ntd_report_en.pdf
or contact us at reduceNTD@ifbhl.org

IFBHL
International Federation for Spina Bifida & Hydrocephalus
www.ifbhl.org

Bayer HealthCare
Bayer Schering Pharma
www.bayer-scheringpharma.de

The number of Neural Tube Defects by Pregnancy with Folate Acid Supplementation in Europe (ENIGCAP 2008)
This card is sponsored by Bayer Schering Pharma AG as a contribution to public policy debate.

Printed on recycled paper



European event

Organised by EURORDIS with the support of DG SANCO

‘European Symposium- Rare but Equal- Addressing Health Inequalities for Rare Disease Patients in Europe’

86 participants

4 European Commission rep

From 3 different DGs

+ 1 Member European Parliament



Venue

Residence Palace International Press Center, Brussels



...two steps away from EC and EP

European event

Stefan Shreck – New Head of Unit Public Info Unit
at DG SANCO

3 EU initiatives to address health
inequalities:

- EU Solidarity in Health Initiative
- EU Disability Strategy
- EU Directive on Cross Border Health Care



Ms. Antonia Parvanova, MEP and shadow
rapporteur on the new EU Directive on CBHC

European event

- Comparative demographic study of Cystic Fibrosis
- Comparative study of standards of care for childhood cancer

1 healthcare professional: CoE in Salzburg “EB Haus”

4 patient testimonies:

- PKU Life Romania
- Multiple Myeloma UK
- MPSII Bulgaria
- Hunter Syndrome Romania



Announcement of key results of the Eurobarometer survey on public opinion about rare diseases

Next challenge is including rare diseases with a higher budget in the Third EU Public Health Program (2014-2020) and the 8th Research Framework Program.



European event

The event was streamlined live on the EURORDIS website and on the RDD Facebook throughout the day (380 people from 39 countries tuned in)

Presentations and videos available on EURORDIS website



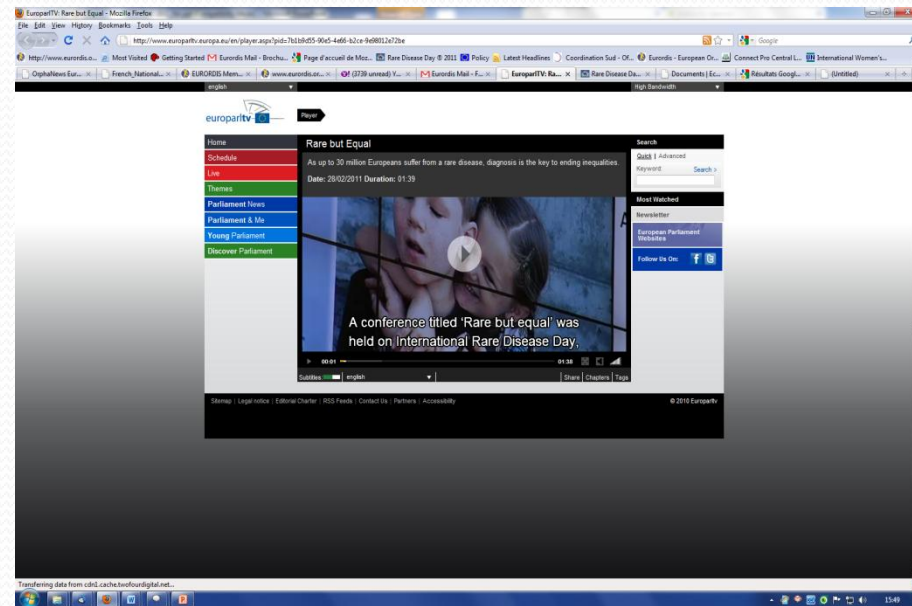
Media coverage

European Parliament TV

<http://tinyurl.com/6fmbhnm>

APM Health Europe

Romania Libera



Yahoo Health

Les Echos

The Independent

And more than 2000

on-line press clippings

