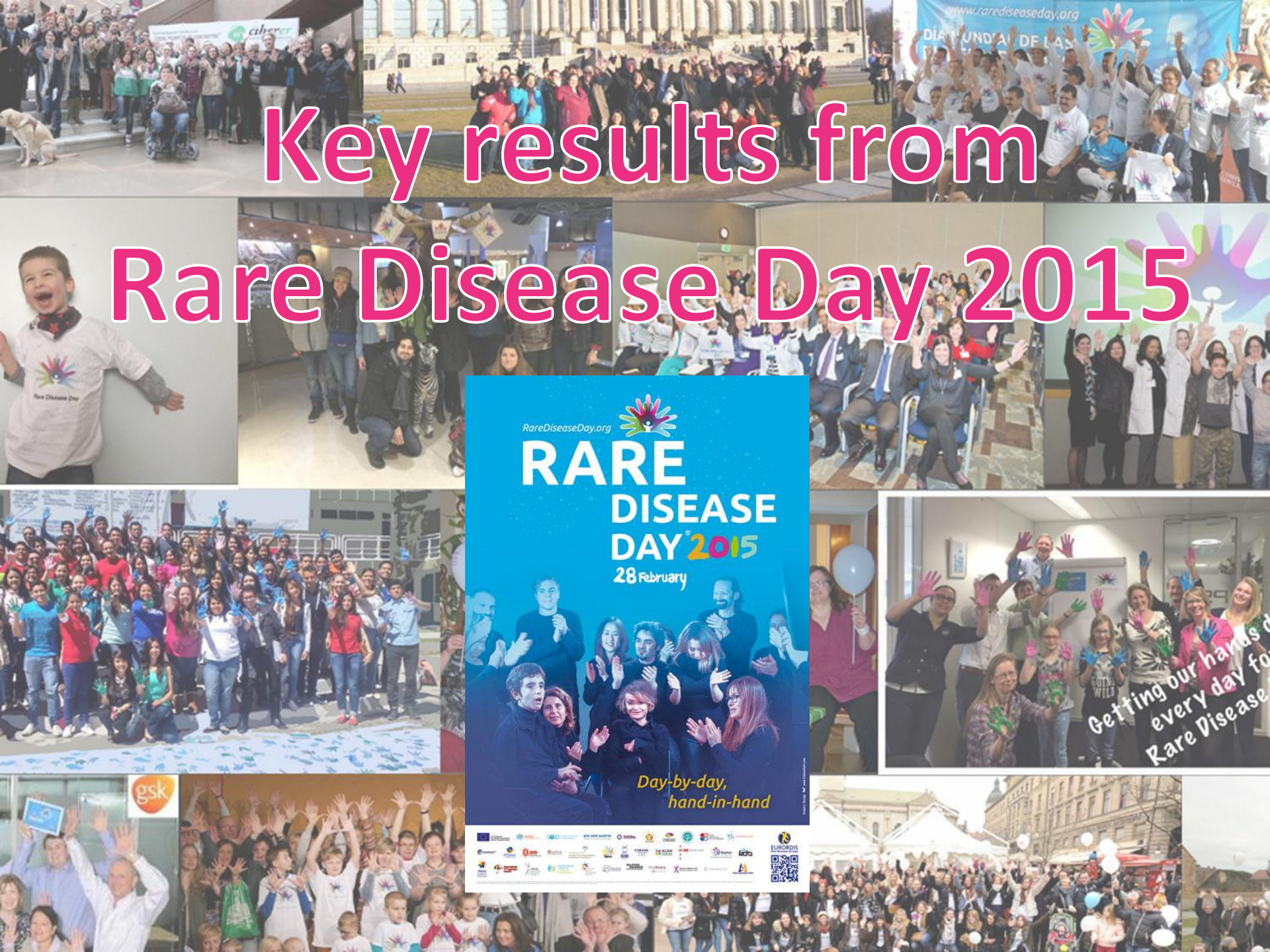




2015 Theme and slogan

Living with a Rare Disease
Day-by-day, hand-in-hand



Key results from

Rare Disease Day 2015

RareDiseaseDay.org

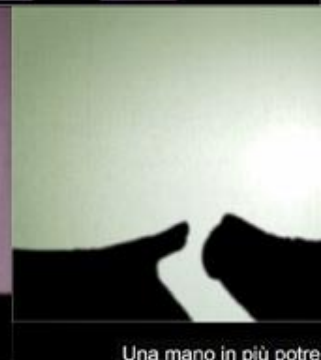
RARE DISEASE DAY 2015

28 February

Day-by-day, hand-in-hand

Logos of various organizations and sponsors are displayed at the bottom of the poster.

Getting our hands
every day for
Rare Disease



The Video



The background is a collage of various silhouettes and hands. Some hands are raised in the air, while others are shown in different poses, some holding objects. The silhouettes appear to be of people of different ages and ethnicities. The colors are muted, with a lot of greys, blues, and yellows.

Rare Disease Day Video

Shared around the world by
patient organisations via
social media and events

Translated into **27** languages
(compared to **21** in 2014 & **15** in 2013)

The most successful to date!

Via EURORDIS social media alone,
over **1.5 million** people
viewed the video!

Pomoc môže byť
rozhodujúca

Podejme ruku pacientům a jejich rodinám

Ist eine weitere Hand hilfreich.

clanov
je voljene

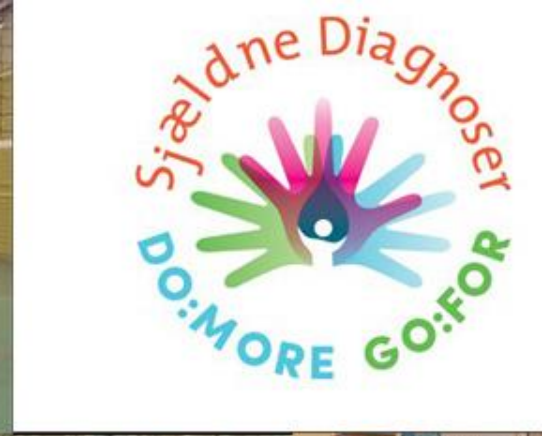
Via EURORDIS social media alone,
over **1.5 million** people
viewed the video!

Pour améliorer la vie des personnes
atteintes d'une maladie rare

بد إضافية يمكنها أن تكون مفيدة

A betegszervezetekkel,
szakemberekkel, nevelőkkel közösen

грижећи се за своите любими хора, заедно



Events



السادره 2015
28 فبراير



بیماریوں کا عالمی دن
بمقام: فوجی فاؤنڈیشن ہسپتال راولپنڈی

A truly international
and worldwide
campaign – events in
over 80 countries
and regions

Including all 28 EU
Countries!

Events around the
world, held by 317
associations in
Europe, North and
South America,
Africa, Asia and
Australia!

> Rare Disease Day in Estonia

Patient organisations in Estonia will participate in Rare Disease Day for the first time in 2015 under the slogan *Day-by-day, hand-in-hand*. It is hoped the event will grow each year to inform and raise awareness of rare diseases in the country.
You can make a difference! To get involved, write to us at rarediseaseday@eurordis.org.

> Events in Estonia

 Tallinn, Estonia, 27 Feb 2015 - 28 Feb 2015

Raising media awareness for rare diseases



 Tartu, Tallinn, Estonia, 16 Feb 2015 - 28 Feb 2015

Children's Foundation Rare Disease Day



New countries:

You can make a difference! To get involved, write to us at rarediseaseday@eurordis.org.

> Rare Disease Day in Madagascar

Patient organisations in Madagascar will participate in 2015 under the slogan *Day-by-day, hand-in-hand*. It is hoped the event will grow each year to inform and raise awareness of rare diseases in the country.
You can make a difference! To get involved, write to us at rarediseaseday@eurordis.org.



> Events in Madagascar

 Madagascar, 28 Feb 2015

Rare Disease Day Walk and Round Table

Bolivia, Estonia, Madagascar

> Events in Bolivia



> Rare Disease Day in Estonia

Patient organisations in Estonia will participate in Rare Disease Day for the first time in 2015 under the slogan *Day-by-day, hand-in-hand*. It is hoped the event will grow each year to inform and raise awareness of rare diseases in the country.

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> Events in Madagascar

 Madagascar, 28 Feb 2015

Rare Disease Day Walk and Round Table

> Rare Disease Day in Bolivia

Patient organisations in Bolivia will participate in Rare Disease Day for the first time in 2015 under the slogan *Day-by-day, hand-in-hand*. It is hoped the event will grow each year to inform and raise awareness of rare diseases in the country.

You can make a difference! To get involved, write to us at rarediseaseday@eurordis.org.



> Events in Bolivia

Awareness-raising

Fundraisers

Seminars

Runs

Film nights

Walks

Conferences

655 Events listed
on our website

Quizzes

Art activities

Family activities
and fun days

Advocacy

Symposiums

Photography
Exhibitions

Concerts

[HOME](#)

[ABOUT THE DAY](#)

[EVENTS WORLDWIDE](#)

[GET INVOLVED](#)

[NEWS](#)

The NEW Mobile Site

THEME OF THE YEAR:

LIVING WITH A RARE DISEASE

Day-by-day, hand-in-hand

Patients, families and organisations are pivotal to creating solutions for the daily challenges of living with a rare disease.

[> See what it means](#)

[ABOUT THE DAY](#)

28 February 2015 - What is Rare Disease Day?

[> Upcoming Events
around the world](#)

[CHOOSE A LOCATION ▼](#)



Day-by-day
Hand-in-hand

OFFICIAL VIDEO





HOME

ABOUT THE DAY

EVENTS WORLDWIDE

GET INVOLVED

NEWS

The number of Mobile phone users continues to increase with a peak of 60% of the total visitors on 28 February viewing from a smartphone!

ABOUT THE DAY

28 February 2015 - What is Rare Disease Day?

> Upcoming Events around the world

CHOOSE A LOCATION ▼

LIVING WITH RARE DISEASE
Day-by-day, hand-in-hand

Patients, families and organisations are joined to create solutions for people living with a rare disease.

>> See what it means



OFFICIAL VIDEO



> Become a Friend!

- Show your organisation's support!
- View all Friends

> Download and Share our Communication Materials!

- Logos and Banners
- Social Media Badges

> Raise and join hands for Rare Disease Day

> Tell your story



Whether you are with your family at home, 10 people in an office, 100 people at a conference or 1000 people at a public gathering. RAISE AND JOIN HANDS to show your solidarity with rare disease communities around the world! Help us show we are all mobilised and people living with rare diseases and driven by the same objectives.

This symbolic gesture can be done by a group of activities you have already planned on Rare Disease Day.

Record the event with a photo and upload here. (Remember to specify the location and the country where the photo was taken.)



Participants in Rare Disease Day from around the world have shared their personal stories about living with a rare disease.

Click on the links below to see the stories of people who would like to share their story. You can also upload your own story on the Rare Disease Day website. It will be a great opportunity for your community to share their experiences.

Online Interaction



Upload your photo



Upload your photo



Upload your video



Write your story

> Latest photos



✓ Latest photos

> Latest videos

> Latest stories



Interaction with
patients, families and

people interested in Rare
Disease Day increased in
all categories!

This year there are
295 Friends of Rare

We have received

over **300** Raise
and Join Hands
photos

Disease Day



> Become a Friend!

- Show your organisation's support!
- View all Friends

> Download and Share our Communication Materials!

- Social Media Badges

163 Stories

> Raise and join hands for Rare Disease Day

> Tell your story



Whether you are with your family at home, 10 people in an office, 100 people at a conference or 1000 people at a public gathering. RAISE AND JOIN HANDS to show your solidarity with rare disease patients around the world! Help us show we are all



Participants in Rare Disease Day from around the world have shared their personal stories about living with a rare disease.



Upload your photo



Upload your video



Write your story

> Latest photos

256 Photos

Tell Your Story

✓ Latest photos

> Latest videos

> Latest stories

94 Videos

Day-by-day
Hand-in-hand



Rare Disease Day
No priority Organisation

Social Media



TWEETS 754 FOLLOWING 3,579 FOLLOWERS 12.8K FAVORITES 9 LISTS 20

PEOPLE >

58,543 likes

Status



Rare Disease Day

@rarediseaseday

28 February 2015 is Rare Disease Day. Raising awareness for patients, families and carers living affected by rare diseases worldwide. #raredisease

Worldwide
rarediseaseday.org
Joined February 2009

39 Photos and videos



Tweets Tweets & replies Photos & videos

Pinned Tweet

Rare Disease Day @rarediseaseday · Feb 16

The 2015 video is OUT - bring people #livingwith a #raredisease out of the shadows: ow.ly/J8oHn



flickr You People Groups Explore



facebook

More than 58,000
likes on Facebook
compared with 40,000 in
2014



More than 7 million
users reached on
Facebook alone



Rare Disease Day

Non-profit Organisation

Timeline

About

Photos

TWEETS
754

FOLLOWING
3,579

FOLLOWERS
12.8K

FAVORITES
9

LISTS
20

Status

Rare Disease Day

@rare diseaseday

28 February 2015 is Rare Disease Day.

It's a day to raise awareness of rare diseases and the people who live with them.

Worldwide

rarediseaseday.org

Joined February 2009

Tweets

Tweets & replies

Photos & videos

Pinned Tweet

Rare Disease Day @rare diseaseday

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Worldwide

rarediseaseday.org

Joined February 2009

shadows: ow.ly/J8oHn

Rare Disease Day

rarediseaseday

Photostream

Albums

Favorites

Day-by-day

Hand-in-hand



twitter



Rare Disease Day

Non-profit Organization

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Nearly 13,000

Followers

Compared with 9,000 in
2014

TWEETS
754

FOLLOWING
3,579

FOLLOWERS
12.8K

FAVORITES
9

LISTS
20

replies

Photos & videos

58,543 likes

28 February 2015 is Rare Disease Day.
Raising awareness for patients, families
and carers living affected by rare
diseases worldwide. #rare diseases
Join February 2009

39 Photos and videos

Rare Disease Day @rare diseaseday - Feb 16

The 2015 video is OUT - bring people

#live with #rare diseases out of the

Rare
Disease
Day
2015

Day-by-day,
Hand-in-hand



flickr

You

People

Groups

Explore

Rare Disease Day

rare diseaseday

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Albums

Favorites

Day-by-day
Hand-in-hand

1706

Supporters

Vs 749 in 2014

Rare Disease Day
Non-profit Organisation

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THUNDER
CLAP

Rare Disease Day
@rarediseaseday

Photostream

Albums

Favorites

A social
reach of

1,220,403

people

Vs 882,441 in

2014

Rare Disease Day

@rarediseaseday

28 February 2015
Raising awareness
and carers living with
diseases worldwide.

Worldwide
rarediseaseday.org
Joined February 2009

39 Photos and videos

Tweets

Tweets & replies

Photos & videos

Day-by-day, Hand-in-hand
Living with a rare disease out of the
shadows: ow.ly/J8oHn

Day-by-day,
Hand-in-hand

>Media

Media Coverage

1. 2015 Press releases and official communication

- [Official information about the 2015 campaign](#)
- [EURORDIS Rare Disease Day event in Brussels](#)
- [News from 2015](#)

[2. Press articles, television and radio](#)

[3. Rare Disease Day History](#)

Each year Rare Disease Day has seen events take place all over the world. See year-by-year highlights and how Rare Disease Day has grown since its first celebration in 2008: [2014](#), [2013](#), [2012](#), [2011](#), [2010](#),

[2009](#), [2008](#)

[Read more](#)



OFFICIAL VIDEO



2015 AMBASSADOR

SEAN HEPBURN FERRER

[Media](#) 

↓ [Press Releases](#)

↓ [Facts and Figures](#)



ication

Rare Disease Day 2015 - the impact on daily life

RARE DISEASE DAY Rare Disease Day takes place on the last day of February each year and aims to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

Each year Rare Disease Day has seen events take place all over the world. See and how Rare Disease Day has grown since its first celebration in 2008: [2014](#), [2013](#), [2012](#), [2011](#), [2010](#), [2009](#), [2008](#)

[Read more](#)



The photo is of 4-year-old Thaïs and her 6-year-old brother Matthieu from France hand in hand against their rare disease. They both have Hurler syndrome, a variant of mucopolysaccharidosis type 1.

Do you have a rare disease & face problems accessing treatment?

RARE CONDITION TREATMENT The EURORDIS (European Organisation for Rare Diseases) Access Campaign invites anybody who is living with a rare disease who has experienced difficulties accessing treatment - including medicines, medical devices, surgeries or medical consultations - to respond to a brief online questionnaire available in 19 European languages.



>Media

Patient organisation: Unacceptable differences in member states for people with rare diseases

Share 11 in Share Tweet 25 Share 4

Published: 27/02/2015 - 08:42



Patients celebrating Rare Disease Day in Croatia. 29 February, 2012. [Rare Disease Day/Flickr]

There are huge differences when it comes to access to therapies for patients with rare diseases. The Commission could do more to make member states aware that this is unacceptable, says Terkel Andersen.

Terkel Andersen is the president of Eurordis, a non-governmental patient-driven alliance of rare disease patient organisations. He spoke to EurActiv's Henriette Jacobsen ahead of Rare Disease Day on 28 February.

What are some of the challenges for people with rare diseases in the EU?

Les maladies rares affectent 30 millions d'Européens

Share 44 in Share 17 Tweeter 17 Share 4

Published: 26/02/2015 - 12:09 | Updated: 27/02/2015 - 08:32



Le commissaire européen à la santé, Vytis Andriukaitis. [Henriette Jacobsen]

Les personnes atteintes d'une maladie rare sont les grands délaissés des systèmes de santé. Pourtant, ces maladies affectent plus de 60 millions de personnes en Europe et aux États-Unis.

Peu ou pas du tout diagnostiquées, les maladies rares, qui intéressent peu les industries pharmaceutiques, ne bénéficient généralement pas de traitement. Elles affectent pourtant 30 millions de citoyens européens.

Organisée chaque année depuis huit ans, la nouvelle édition 2015 de la journée internationale des maladies rares se tient le 28 février. Cette initiative d'Eurordis, l'organisation européenne pour les

maladies rares, qui réunissait à l'origine des associations de patients de 18 pays européens a pris une envergure mondiale. Désormais, des associations de patients de plus de 84 pays y participent dans le but de sensibiliser l'opinion publique et les décideurs politiques aux maladies rares et à leur impact sur la vie des patients.

and how Rare Disease Day has grown since its first celebration in 2008: 2

2009, 2008

Read more

tion



↓ Press Releases

RAPS

REGULATORY AFFAIRS
PROFESSIONALS SOCIETY
Driving Regulatory Excellence™

ABOUT THE DAY

EVENT

>Media

Rare Disease Patient Group Commends EMA, Wants EU-Wide Access to Treatment

Posted 02 March 2015

By Michael Mezher

A rare disease advocacy network has [applauded](#) the European Medicines Agency's (EMA) efforts to incentivize the development of treatments for [rare diseases](#), but says the variance in treatment access across the EU is "unacceptable."

In an interview with *EurActiv*, Terkel Andersen, president of the advocacy group EURODIS, said that EMA and the European Commission (EC) are "doing their utmost to try to make rare diseases 'attractive' for the pharmaceutical industry."

Andersen finds dialogue between patient groups, regulatory authorities and members of industry to be highly beneficial, and says that the EC has helped foster patient participation in the drug development process.



Rare disease day promo

DAILY
Mirror



00:00

01:17



Day-by-day
Hand-in-hand

OFFICIAL VIDEO



2015 AMBASSADOR

SEAN HEPBURN FERRER

Mirror

Parents write moving tributes to their inspirational daughters living with rare diseases

Raising Awareness of Rare Diseases in Europe

TAGS: CLINICAL TRIALS, DYSTONIA, EU HEALTH FOR GROWTH PROGRAMME, EURORDIS, GLENIS WILLMOTT, HEALTH, RARE DISEASES
POSTED IN BLOG, HOME STORIES, NEWS ON 28/02/2015



Saturday 28th February is **European Rare Disease Day 2015**, which aims to raise awareness of rare diseases and the impact they have on the lives of people who suffer from them.

A rare disease affects fewer than 5 in 10,000 people. In Europe alone it is estimated that 30 million people suffer from a rare disease but the true figure may be higher due to under-diagnosis.

For example, Dystonia is a little-known brain disorder that causes continuous muscle spasms and severe pain but because it is not revealed in brain imaging it can take years to diagnose. Raising awareness of rare diseases, such as Dystonia, can help to reduce the stigma and

isolation experienced by patients and make mis-diagnosis less likely, and I hosted an event in the European Parliament last year to help raise awareness of the condition among my MEP colleagues.



The Latest Developments
in Life Sciences & Medicine

[television and radio](#)

[y History](#)

Rare Disease Day 2015 raises awareness of challenges faced by rare cancer patients

Rare Cancers Europe Press Release: Rare Disease Day 2015

Written by Rare Cancers Europe (RCE) on 25 February 2015 in Press Release

Rare Disease Day 2015 seeks to raise awareness of the challenges faced by patients and their families.



Joining forces for action

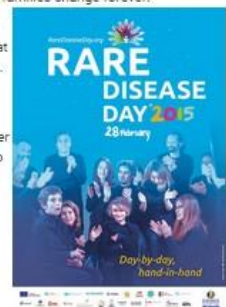
Within the "umbrella" of rare diseases, rare cancer patients confront particular problems. Most rare diseases have an identified genetic origin. In contrast, rare cancers are mainly acquired diseases.

A rare cancer affects only 6 out of 100,000 people in all of Europe annually, that is why it is considered rare. Although some very rare cancers may only affect one person in Europe every year, around 500,000 cases of rare cancers are diagnosed annually in Europe alone, making up 20% of all new cancer cases (1). So, taken together, rare cancers are not so uncommon at all.

But patients are not numbers. When a rare cancer is diagnosed, the lives of patients and their families change forever.

Chordoma (2) is one of the 198 types of rare cancers (3) that have been identified so far. The annual incidence of chordoma is approximately one new case per million people per year. That means that roughly 300 patients are diagnosed with chordoma each year in the United States. The incidence in Europe appears to be similar, but is unknown in other continents.

Hans Keulen, a Dutch ICT entrepreneur was diagnosed with Chordoma in 2009, after several misdiagnoses. He explains that 'when your neurologist, looking at your scan says: 'I have never seen this before', you know you have a problem! Luckily, soon after, I met a neurosurgeon who not only made the right diagnosis but also was wise enough to say that there were probably surgeons that could do this better ... across the Atlantic! After the initial shock many rare cancer patients are unfortunately left to manage their healthcare on their own. That is how it has remained for me: searching for a cure in different countries, with doctors who do their utmost in their specialty, but who need resources and support. In many cases the patient directs his own treatment as there is still a long way to go to co-ordinate efforts between oncologists, radiologists, surgeons, etc. for the treatment of rare cancers.'



highlights
11. 2010.

Media

↓ Press Releases

Radio Interviews

TELEVISIÓ 3

RÀDIO

3 alacarta

ABOUT THE DAY

EVENTS

> Media

Espai Terra. Divendres 27 de febrer

27/02/2015



13

INSEREIX

I divendres parlarem de les herbes remeieres. Al plató tindrem un conegut del programa, l'Albert Rami, gran coneixedor de tots aquests remeis, i que ens vindrà a parlar dels principals beneficis d'aquestes herbes per a la nostra salut.

1. 2015 Press releases and official communication

- [Official information about the day](#)
- [EURORDIS Rare Disease Day 2015](#)
- [News from 2015](#)

Dag van de Zeldzame ziekten

vrijdag 27 februari 2015

12 reacties

Afdrukken



Rare Disease Day

28 februari is het Zeldzame Ziektendag. Dan zetten patiëntenverenigingen over heel de wereld acties op om de mensen even te doen stilstaan bij de problematiek van de zeldzame ziekten.

Niet alleen is er vaak maar weinig begrip voor mensen die aan zeldzame ziektes lijden. Door hun uitzonderlijk karakter wordt er meestal ook maar weinig geld geïnvesteerd in aangepast medicatie en behandeling.

Bij ons in de studio: Sylvie De Maegd, mama van een kind dat lijdt aan [epidermolysis bullosa](#), een zeldzame huidaandoening waarbij de minste wrijving of aanraking blaren doet ontstaan op de huid

Day-by-day
Hand-in-hand

OFFICIAL VIDEO



2015 AMBASSADOR

SEAN HEPBURN FERRER

Media

↓ Press Releases



Altijd benieuwd



EURODIS Rare Disease Day Brussels Event



09:30 - 10:30 Event registration & welcome coffee
10:30 Event starts

Opening Remarks

Vytienis Andriukaitis, European Commissioner for Health & Food Safety

•
An MEP's Perspective

Philippe De Backer, Belgian Member of the European Parliament

•
Talk 1: Changing the Reimbursement Decision for 100 Cystic Fibrosis Patients in Ireland

How CF Ireland successfully reversed the decision on the reimbursement of a cystic fibrosis medicine

Ri De Ridder, Director General, RIZIV-INAMI & Philip Watt, CEO, Cystic Fibrosis Ireland

•
Talk 2: Changing the Clinical Trials Protocol

A patient representative's experience of collaborating with a sponsor on the design of a CT protocol

Carla Fladrowski, the mother of a tuberous sclerosis patient & Veronica Foote, Head of Patient Strategy, Oncology Region Europe, Novartis (clinical trial sponsor)

•
Talk 3: Participating in Scientific Advice at the EMA

A patient's contribution to a scientific advice procedure at the European Medicines Agency

Nathalie Bere, Patient Relations, European Medicines Agency & Helma Gussek, a retinitis pigmentosa patient

•
Talk 4: Changing Policy on Prenatal Screening

How the mother of a Batten disease patient influenced change in the prenatal screening law in Serbia

Bojana Miroslavljivic, the mother of a Batten disease patient & Hajrija Mujovic Zornic PhD, Legal Consultant, Institute for Social Sciences & Association for Medical and Health Law of Serbia

•
Rare Diseases in Romania

Viorica Dănciă, Member of the European Parliament & Leader of the Romanian Delegation to the Group of the Progressive Alliance of Socialists and Democrats

•
Close of Event

Terkel Andersen, EURORDIS President

•
Event moderator

Kathy Redmond, Editor of Cancer World

13:00 Event finishes

Lunch will be provided to all event attendees



Vytenis Andriukaitis,
European Commissioner
for Health and Food Safety

Terkel Andersen
EURORDIS President

Speakers included...

Bojana Miroslavjevic
The mother of a batten disease
patient

Philippe De Backer
Belgian MEP



**Over 150 people participated
in Brussels**



**Touching and inspiring
testimonies were given by
patients and family members**



People from
30 different countries
tuned in to the live event online



Over 800 tweets were
exchanged during the event on
#RareEU2015

Brussels Event Media Coverage

Health Commissioner calls for national plans to tackle rare diseases

Share 33 | LinkedIn Share 8 | Tweet 84 | Share 10

Published: 26/02/2015 - 07:31 | Updated: 26/02/2015 - 16:27



Health Commissioner Vytenis Andriukaitis [Henriette Jacobsen]

Patients with rare diseases are more vulnerable, as they live with more ambiguity about their affliction than others, according to Health Commissioner Vytenis Andriukaitis. But with the help of patient groups and national action plans in member states, their lives can be improved.

This coming Saturday (28 February) is Rare Disease Day. The date has been chosen to raise awareness on the impact that rare diseases have on patients and their relatives.

Speaking on Tuesday (24 February) at a conference organised by patient

organisation Eurordis, Andriukaitis noted that people living with rare diseases "struggle with uncertainty about their illness and suffer in isolation" when they try to get the right diagnostics and care.

APMHealthEurope.com
For the Daily Agenda in European Health Care

Patient input influencing study design, helping pharma develop better drugs - conference

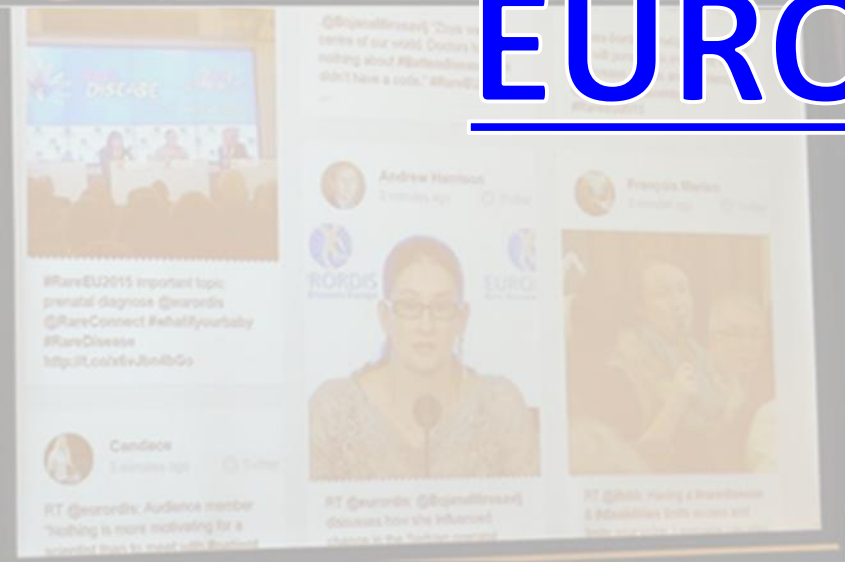
LONDON, Feb 24 (APM) - Patients are playing a key role in the design of European rare disease clinical trials, influencing endpoints and suggesting ways for pharma to improve their products, a conference heard on Tuesday.

Speaking at the European Organisation for Rare Diseases (EURORDIS) conference in Brussels, which was broadcast online, Nathalie Bere, patient relations representative from the European Medicines Agency (EMA) said about half of the input provided by patients involved in regulatory processes ends up in final advice to companies.



EU News & policy debates,
across languages

Watch the event on EUROORDIS TV



Yann Le Cam's visit to the Croatian national rare disease alliance to watch the premiere of their rare disease documentary, and to meet with regional representatives.





Thank you for
another successful
year!



السادره 2015
28 فبراير



بیماریوں کا عالمی دن
بمقام: فوجی فاؤنڈیشن ہسپتال راولپنڈی