



RARE DISEASE DAY 2016

RARE DISEASE DAY 2016

THE VOICE OF
RARE DISEASES HEARD



RARE DISEASE DAY 2016
29 FEBRUARY

JOIN US IN MAKING
THE VOICE OF
RARE DISEASES HEARD



RARE DISEASE DAY 2016 Recap



OUR THEME: PATIENT VOICE



**JOIN US IN MAKING THE
VOICE OF RARE DISEASES
HEARD**

[ABOUT THE DAY](#)

[EVENTS WORLDWIDE](#)

[GET INVOLVED](#)

[NEWS](#)



THANK YOU EVERYONE

A worldwide movement that was
bigger and better than ever.

[>> FIND OUT MORE](#)



[SIGN UP FOR
UPDATES](#)



[EVENTS WORLDWIDE](#)




[DOWNLOAD
MATERIALS](#)

[FOLLOW US](#)



2016 EVENTS

Country 

THE LAUNCH OF THE CHINESE RARE

Rare Disease Development

29 Feb 2016 Beijing, China

[+ READ MORE](#)

LEGISLATIVE ASSEMBLY OF ONT

Join CORD at the Legislative

29 Feb 2016 Toronto, Canada

[+ READ MORE](#)

RARE DISEASE CONFERENCE

In 2014 the National Rare

29 Feb 2016 Dublin, Ireland

[+ READ MORE](#)

[>> SEE ALL EVENTS](#)



OUT NOW

2016 RARE DISEASE DAY VIDEO!

Share this video



WEBSITE STATS

ABOUT THE DAY

EVENTS WORLDWIDE

GET INVOLVED

NEWS

- New look for the website which was more **dynamic and engaging!**
- Visitors to the website stayed **20% longer** and viewed **more pages** than in 2015.
- Average **pages visited per session** went **up by 81%!**
- On Rare Disease Day, visits were higher at **48,000** visits!



SIGN UP FOR
UPDATES



EVENTS WORLDWIDE



DOWNLOAD
MATERIALS

FOLLOW US



Share this video





الجمهورية الجزائرية الديمقراطية الشعبية
الجمعية الجزائرية لمتلازمة
وليامس و بوران

Association Syndrome de Williams & Beuren

جمعية متلازمة وليامس و بوران
تنظم بالتنسيق مع

مديرية الشباب والرياضة والترفيه لولاية الجزائر و بلدية الجزائر الوسطى
يوم تحسيس حول الأمراض النادرة في الجزائر يوم 29 فيفري 2016

POSTER SUCCESS!



ZIUA BOLILOR RARE 2016
29 FEBRUARIE
VOCEA
PACIENTILOR
UNIȚI, VOM FI AUZIȚI!



South Carolina



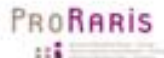
Mauritius

PARTNER ORGANISATIONS

OFFICIAL PARTNERS



Co-funded by
the Health Programme
of the European Union





"CAPS" RAINE-BOW (IN HONOR OF SKYELAH RAINE TRUEVY RUDD)

CONTACT: Angela Rudd

[Other Patient Groups](#)



UNITED STATES

[+ VIEW DETAILS](#)



ACHALASIA AWARENESS ORGANIZATION

CONTACT: Nancy Iazarus

[Other Patient Groups](#)



UNITED STATES

[+ VIEW DETAILS](#)



#GYNCSCM COMMUNITY

CONTACT: Christina Lizaso and Dee Sparacio

[Others](#)



UNITED STATES

[+ VIEW DETAILS](#)



RARE DISEASE DAY®



SPAIN

[+ VIEW DETAILS](#)



CONTACT: Vesna Vujicic

[Other Patient Groups](#)



SERBIA

[+ VIEW DETAILS](#)



A.I.M.O. ASSOCIAZIONE ITALIANA MEDICI OCULISTI

CONTACT: Segreteria A.I.M.O.

[Health Professionals](#)



ITALY

[+ VIEW DETAILS](#)



ITALY

[+ VIEW DETAILS](#)



Alfie's Trust
alfie milne lymphangiomatosis trust

ALFIE MILNE LYMPHANGIOMATOSIS

CONTACT: Tracy Milne

[Other Patient Groups](#)



UNITED KINGDOM

[+ VIEW DETAILS](#)



AANORA

CONTACT: Ekaterina

[Others](#)



AMERICAN PARTNERSHIP FOR EOSINOPHILIC DISORDERS

CONTACT: Mary Jo Strobel

[Other Patient Groups](#)

178 FRIENDS OF RARE DISEASE DAY



TELL YOUR STORY

We now have...

- **606 stories**
- **330 videos**
- **1,810 pictures**



Upload your photo



Upload your video



Write your story

'Tell Your Story' posts had a great reach on Facebook

Rare Disease Day
Published by Stevie Grieves [?] · 29 February at 17:45 · 🌐

Today is Rare Disease Day and Anna's 20th Birthday! Anna lives with Bilateral Moyamoya and after having to defer from her studies as a result of the disease, she is now an undergraduate at university! Why don't you [Tell Your Story](#) about living with Rare Disease?



Tell your story for Rare Disease day 2016!
See, watch and read stories about others living with a rare disease.
RAREDISEASEDAY.ORG

53,600 people reached

Boost Post


👍 Like 💬 Comment ➦ Share

Suncica Zivkovic, Dee Juhl, Michèle Béven and 816 others like this. Top comments ▾

120 shares

Rare Disease Day
Published by Stevie Grieves [?] · 18 February at 19:00 · 🌐

Heather is a survivor of a rare cancer caused by asbestos exposure called mesothelioma. After being properly diagnosed she was able to seek treatment immediately, and ten years later Heather and her husband Cameron are advocates for the disease, looking to spread global awareness for this rare cancer. Why don't you tell us about your rare disease on [Tell Your Story](#), and check out others while you're there.
<http://www.rarediseaseday.org/tell-your-story>



Read Heather's story about living with the rare cancer mesothelioma

When I was younger, I would wear my dad's work jacket around the house to do outside chores. My dad worked in construction and it was common that he...

RAREDISEASEDAY.ORG

17,709 people reached

Boost Post

👍 Like 💬 Comment ➦ Share

Kelly Rhea Langley, Amber Kelly Bayly, AortaDissektion sidan and 158 others like this. Top comments ▾

26 shares

Rare Disease Day
Published by Stevie Grieves [?] · 14 February at 19:00 · 🌐

Happy Valentine's Day! What will you and your loved ones be doing on this special day? Show your appreciation and share a special moment that you have had with your loved ones here.



Rare Disease Day 2016 - 29 Feb - Tell your story!
See, watch and read stories about others living with a rare disease.
RAREDISEASEDAY.ORG

12,532 people reached

Boost Post

👍 Like 💬 Comment ➦ Share

Kelly Rhea Langley, Allison Armstrong-robinson, Ciara Sammut and 161 others like this.

46 shares



RAISE AND JOIN HANDS

RARE DISEASE DAY 2016



DAY 2016

ASMAC
CATANIA

GIORNATA DELLE MALATTIE RARE

RAISE AND JOIN HANDS



Rare Disease Day

Published by Sarah Blake [?] · 29 January · 🌐

Raise and join hands to get involved in Rare Disease Day! It can be with two people or hundreds- everyone can get involved!



Rare Disease Day 2016 - 29 Feb - Joining hands around the world for rare diseases!

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...

[RAREDISEASEDAY.ORG](#)

34,596 people reached

Boost Post

Like Comment Share

Julie Elizabeth, Colleen McGrath, September Menzia and 451 others like this.

Top comments ▾

263 shares



Write a comment...



Kayla Sheppard I'm doing this <http://www.virtualrunevents.com/.../leap-year-virtual-2.../>



Leap Year Virtual 2.29 Mile Race in Honor of Rare Disease Day

[VIRTUALRUNEVENTS.COM](#)



Rare Disease Day

Published by Stevie Grieves [?] · 29 February at 21:00 · 🌐

You can still get involved for Rare Disease Day! Take a picture 'Raising and joining hands' and show your solidarity with people living with rare disease and their families.



Raise and Join hands for #RareDiseaseDay 2016

[RAREDISEASEDAY.ORG](#)

18,001 people reached

Boost Post

Like Comment Share

Hanna Sinervä, Rey NA Radcliffe, Kellz Naona and 406 others like this. Top comments ▾

147 shares



Write a comment...



Gaylon Estes McCoy I had the opportunity to get involved last year. My daughter's situation is long term, but improving immensely. I still want to have doctors press the importance and require patients to have their DNA Genetic Counsel. There is a DNA indicator for pe... See more

Unlike · Reply · Message · 1 · 1 March at 05:26 · Edited



Beth Kress My son has a rare Disorder called Spasmodic Torticollis aka Cervical Dystonia. See Dystonia Medical Research Foundation for more info.

Unlike · Reply · Message · 1 · 29 February at 23:15

View 12 more comments

RARE DISEASE DAY 2016
29 FEBRUARY



RAREDISEASEDAY.ORG

WATCH THE OFFICIAL
RARE DISEASE DAY 2016 VIDEO

Collectively over 300,000 views (youtube and facebook)


Over 4,500 shares on facebook!

Translated into over 34 languages!



Rare Disease Day
Published by Jean-Marc Steir (?) · 2 February · 🌐

Out now! The official 2016 #RareDiseaseDay video! Time to celebrate the special moments in the lives of people living with a rare disease! Watch and share the video with your friends, families and colleagues. <http://www.rarediseaseday.org/videos>



262,724 people reached Boost Post

88k Views

👍 Like 💬 Comment ➦ Share

Sarah Blake, Georgie Weston, Juli Luebbe and 1,186 others like this. Top comments ▾

3,662 shares

Rare Disease Day
Published by Georgie Weston (?) · 26 February at 16:50 · 🌐

3 days to go until #RareDiseaseDay! Break the isolation of millions of patients and families around the world living with a rare disease. Show your solidarity and join us in making the voice of rare diseases heard!



79,199 people reached Boosted

27k Views


👍 Like 💬 Comment ➦ Share

Lorelle Holland, Peggy Schneider-Foster, Caroline Ryan and 256 others like this. Top comments ▾

333 shares

Rare Disease Day
Published by Georgie Weston (?) · 12 February at 19:00 · 🌐

Now in 30 languages! The #RareDiseaseDay 2016 video is spreading around the world! This message of solidarity is reaching more and more people as together we raise awareness for people living with a rare disease and their families.



**RARE DISEASE DAY 2016
29 FEBRUARY**
WATCH THE OFFICIAL
RARE DISEASE DAY 2016 VIDEO

Rare Disease Day video now in 30 languages!
This message of solidarity is reaching more and more people as together we raise awareness for people living with a rare disease and their families.
RAREDISEASEDAY.ORG

56,410 people reached Boost Post

👍 Like 💬 Comment ➦ Share

Rare Disease Day, Kelly Rhea Langley, Chayma Ktaifi, Linda Matter Chenin and 493 others like this. Top comments ▾

334 shares

Jos välität ihmisestä, jolla on
harvinainen sairaus, et ole yksin

starate o někoho se

有少数疾患を持つ人と共に暮らすあなたは独りではありません

אתם דואגים למישהו עם מחלה נדירה? אתם לא לבד

Ако се грижите за некој со ретка болест, не си сам

la nonfidi vialat avy rika hataenak, nam van

TRANSLATED IN TO 34 LANGUAGES!

kamu peduli kepada seseorang yang
sakit langka, kamu tidak sendirian

Jei jūsu artimas izmogus serga reta liga, jūs nesatē vi

희귀병 환우를 돌보고 계시다면
당신은 혼자가 아닙니다

Se tenete a qualcuno con una malattia rara

თუ ზრუნავ იშვითი დაავადების
მქონე პირზე, შენ არ ხარ მარტო...

If you care for someone with a
rare disease, you are not alone

AMBASSADOR SEAN HEPBURN FERRER!





Rare Disease Day

Published by Sarah Blake (7) · 24 February at 19:01 ·

Find out more about [Sean](#) Hepburn Ferrer, the Rare Disease Day Ambassador for the third year running and son of the late Audrey Hepburn



Sean Hepburn Ferrer- Rare Disease Day Ambassador

Find the latest Rare Disease Day news

[RAREDISEASEDAY.ORG](#)

33,883 people reached

Boost Post

Like Comment Share

Vitafo VitaFriends, Jennifer Kaiser, Linn Kanck Ursin and 445 others like this.

Top comments ·

120 shares



Write a comment...



Margaret Watkins I am a survivor of a rare cancer called pseudomyxoma peritonei. This is my 5th year free of this rare disease

Like · Reply · Message · 5 · 25 February at 20:34

2 Replies



Melinda Yeary This man is a hero and he wrote a book about my friend who has a rare and disfiguring disease. The book is titled Mauricio of Uruguay. Written by [Sean](#) Hepburn Ferrer. (available online) \$ goes to studying rare disease.

Like · Reply · Message · 2 · 25 February at 21:44



Melinda Yeary This man is a hero and he wrote a book about my friend who has a rare and disfiguring disease. The book is titled Mauricio of Uruguay. Written by [Sean](#) Hepburn Ferrer. (available online) \$ goes to studying rare disease.

Like · Reply · Message · 2 · 25 February at 21:44

Once again a popular choice of Ambassador and gained significant reach on social media

INDEPENDENT 15 March 2016, Tuesday RSS Login/Register Search

MY HOME WORLD DEBATE SPORTS BUSINESS ARTS LIFE VIDEOS NEWSPAPER

NEWS INTERVIEWS MOST READ BUDGET 2016

Home > Local > News > National Alliance for Rare Diseases Support launched

National Alliance for Rare Diseases Support launched

Wednesday, 17 February 2016, 18:40 Last update: about 26 days ago



TIMESOF MALTA.COM

Forfait B&You 3Go Sans engagement

9€99 /mois pendant 6 mois

News Sport Business Comment Life Escape Classifieds Ca

National World Social & Personal Education Interview Environment Gozo Pictures Reli

f t G+ in p + 20

Email Print

Wednesday, February 17, 2016, 16:23

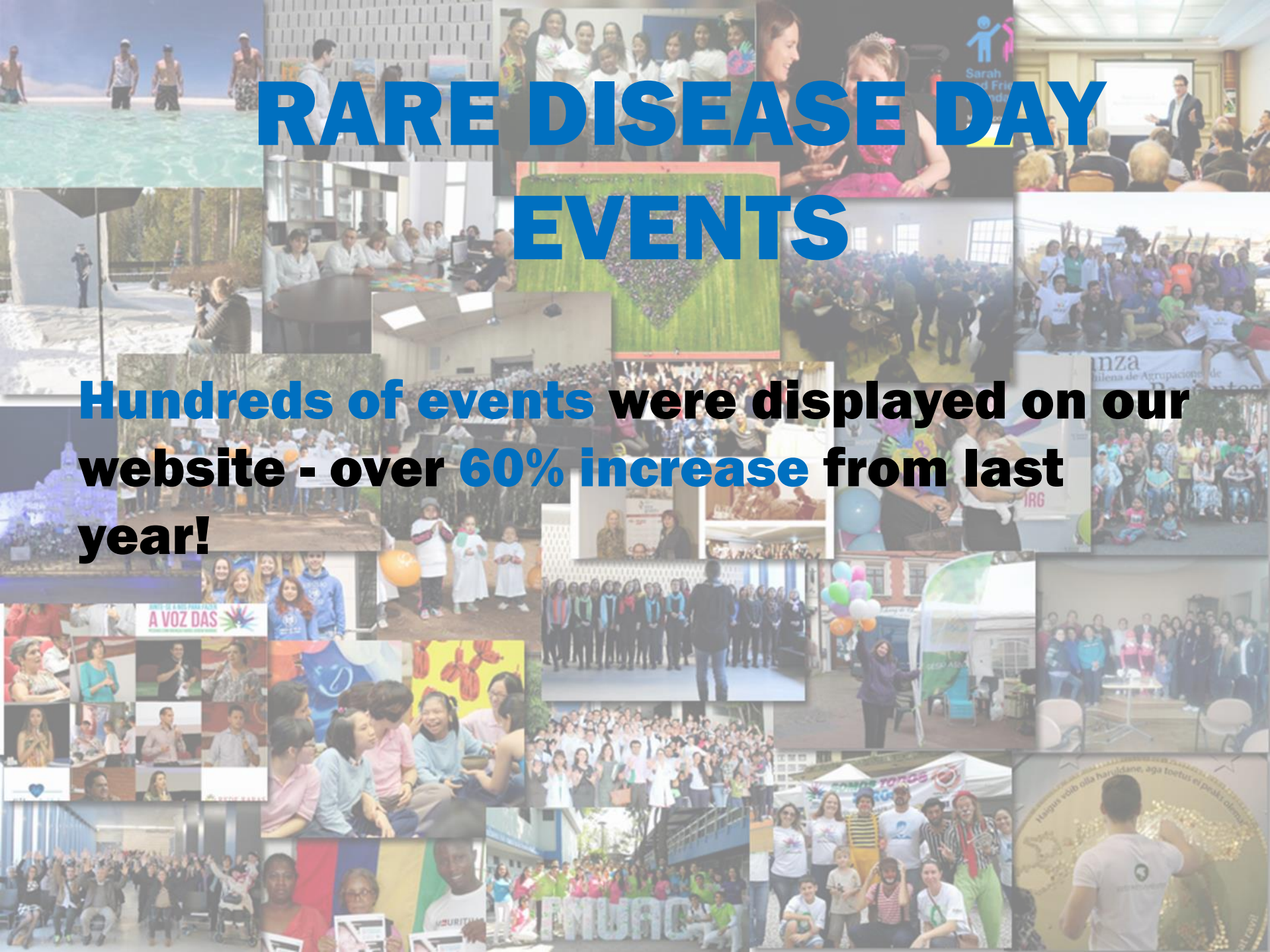
National Alliance to support victims of rare diseases



33,883 people reached

RARE DISEASE DAY EVENTS

Hundreds of events were displayed on our website - over 60% increase from last year!





Map

Styled Map



Google

RARE DISEASE DAY EVENTS ALL OVER THE WORLD!

10 NEW COUNTRIES!



ARUBA



INDONESIA



TANZANIA



UGANDA



ZIMBABWE



TUNISIA



ANDORRA



MAURITIUS



MOLDOVA



LIBYA

rare voices
A U S T R A L I A

A unified voice for all Australians living with a rare disease.



Standing Tall for Rare Diseases



Federación Peruana de Enfermedades Raras - FEPER
22 February at 16:14 · 🌐

NOTA DE PRENSA
Federación Peruana de Enfermedades Raras Ministerio de Salud

"Únete a nosotros para hacer que la voz de las Enfermedades Raras se oiga"

El 29 de febrero es un día raro y por eso es el Día Mundial de la Enfermedades raras.

La Federación Peruana de Enfermedades Raras (FEPER), el Ministerio de Salud, el Congreso de la República y otras instituciones comprometidas en el mejor manejo de nuestras enfermedades, organizamos la Celebración del Día Mundial de las Enfermedades Raras.

Una enfermedad rara, huérfana o poco frecuente es aquella que afecta a una proporción reducida de la población.

El tema de este año es "La voz del Paciente", para reconocer el papel crítico que desempeñamos los pacientes para expresar nuestras necesidades y promover una mejor calidad de nuestras vidas, la de nuestras familias y cuidadores.

Nuestro lema es "Únete a nosotros para hacer que la voz de las enfermedades raras se oiga". Queremos que te unas a nosotros, no importa si padeces o no de una enfermedad rara. Si estamos unidos podemos...

- Asegurar que los políticos reconozcan cada vez más las enfermedades raras como una prioridad de salud pública.
- Aumentar y mejorar la investigación de las enfermedades raras y sus medicamentos.
- Lograr la igualdad en el tratamiento y la atención de calidad a nivel nacional. También, lograr un más rápido y mejor diagnóstico de las enfermedades raras.
- Apoyar el desarrollo y ejecución de planes nacionales y políticas a favor de los pacientes con enfermedades raras.
- Ayudar a reducir el aislamiento y a veces sentimos nosotros y nuestras familias, quienes vivimos con una enfermedad poco frecuente.

Highlights from #raredisease day @
#Scottishparliament 2016 @rarediseaseuk
@eurordis @fragilexuk #RareDiseaseDay2016



RETWEETS 6 LIKES 4

1:35 PM Casa dos Marcos shared Raríssimas - Associação Nacional de Doenças Mentais e Raras's post.
29 February at 19:16 · 🌐



Raríssimas - Associação Nacional de Doenças Mentais e Raras added 12 new photos

29 February at 16:07 -

Why - Participation

Translated from Portuguese - See Original

VERMONT STATE HOUSE RDD EVENT

23 FEBRUARY 2016

MONTPELIER, UNITED STATES

HOSTED BY SMALL GROUP OF INDIVIDUALS


Governor Peter Shumlin signed the proclamation for Vermont to recognize Rare Disease Awareness day. Our first public event but our 4th year being recognized!



Draft policy seeks to make treatment accessible to all

TIMES NEWS NETWORK

The high treatment cost aside



MY UNIQUE VOICE

29 FEBRUARY 2016

ARUBA

HOSTED BY WE ARE UNIQUE ETHAN FOUNDATION

For the first time in Aruba we will celebrate RARE DISEASE DAY. We are very happy to be part of this day. Raise your hand and Let your Voice be heard.

entVoice

Advocacy – Patient Voice



SYMPOSIUM



EURORDIS
Rare Diseases Europe

MULTI-STAKEHOLDER

Symposium

ON IMPROVING
PATIENT ACCESS
TO RARE DISEASE
THERAPIES

24-25
FEBRUARY 2016
HOTEL LE PLAZA
BRUSSELS

Value Determination, Appropriate
Pricing & Reimbursement

IN PARTNERSHIP WITH



efpia

European Federation of Pharmaceutical
Manufacturers Associations

EuropaBio

A EURORDIS RARE DISEASE DAY® EVENT



SYMPOSIUM AIMS

To get multi-stakeholders around the table progressing in improving access to medicines, and furthering discussions about improving the regulatory process.



Andriukaitis calls for closer links to reimbursement on drug access

Improving authorization procedures and time to approval will not improve patient access to innovative medicines, EU Health Commissioner Vytenis Andriukaitis acknowledged today.

He told a Eurordis (the European Organization for Rare Diseases) meeting in Brussels that Commission-led discussions on safe and timely access to medicines — in the STAMP expert group that was set up in 2014 — have shown that it is also necessary to link the discussion to health technology assessment and to pricing and reimbursement decisions.



Karen Facey @KMFacey · Feb 25

#RareEU2016 fantastic workshop simulating payer decisions - everyone stepping into payers shoes to reduce drug budgets and negotiate prices



4



4



Amanda Bok @Amanda_Bok · Feb 25

"Just because we're negotiating a task of influence doesn't mean we are in competition"- great talk by Charles Barker #RareEU2016



1



1



Emma Rooney @blumencasey · Feb 25

"Getting to Yes" book applauded by patient advocate as changing life for his family. #RareDisease therapies #RareEU2016 #LetsWorkTogether



1



Yannis Natsis @YNatsis · Feb 25

Affordability is once again the key issue at #RareEU2016 when will #pharma change their "sky is the limit" business model? #PatientsFirst



RD-Action Policy @RareDiseasesEU · Feb 24

1 of my take-home messages #RareEU2016: real potential for #ERNs to support therapy development for RD @eurordis @V_Andriukaitis @EU_Health



4



2



Health Awareness ▶ Rare Diseases ▶ Patients must be at the centre of research into rare diseases

Patients must be at the centre of research into rare diseases

RARE DISEASES More than 30 million people across Europe suffer from a rare disease. Whilst scientific developments have led to improvements in diagnostics and treatments, patient care must remain a priority to ensure continued progress.



Yann le Cam
CEO of EURORDIS

17

THE BLOG

Rare Disease Patients Fighting Isolation Through Social Media

02/26/2016 11:00 am ET | Updated Feb 26, 2016



Like 546

Jim Luce
James Jay Dudley Luce Foundation

February 26, 2016 is the rarest day of the year. It is **Rare Disease Day**. Every year on Rare Disease Day taking place on February 26th, people living with rare diseases and their families and friends come together to raise awareness of rare diseases and the challenges they face to health professionals.

Anyone can get involved. Hundreds of thousands of people will come together on February 29th to hold [events all over the world](#).

The MIGHTY

Real People. Real Stories.
We face disability, disease and mental illness together.

1,800
CONTRIBUTORS

85 Million
READERS

300
NON-PROFIT PARTNERS

Submit a Story

Like

Partner With Us

CONDITIONS A-Z DISABILITY & DISORDER MENTAL ILLNESS CHRONIC ILLNESS RARE DISEASE

News Parenting Autism Down Syndrome Anxiety Cerebral Palsy

Teen Partners With Soccer Star to Design Shirt Just in Time for Rare Disease Day



By Kyle Mauch

Feb 24, 2016

Crohn's Disease

Share on Facebook



An opening in Evan's own words:

"My name is Evan, and I'm now a junior in high school.

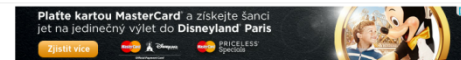
I grew up playing soccer and dreamed of going pro one day. An unexpected pre-season injury when I was 9

Editor: UK



FRONT PAGE NEWS POLITICS LIFESTYLE PARENTS TECH YOUNG VOICES COMEDY ENTERTAINMENT STYLE WHAT'S HOT

Tech • Reviews • Gaming • Space • Science • Innovation • How To • Buyer's Guides



THE BLOG

Featuring fresh takes and real-time analysis from HuffPost's signature lineup of contributors

Richard Scott

Clinical Lead for Rare Diseases at Genomics England

The 100,000 Genomes Project and Rare Disease Day

Posted 26/02/2016 11:46 GMT | Updated 26/02/2016 11:58 GMT



English 09/03/2016 Join us | Log in | Like 1.4M

NEWS EUROPEAN AFFAIRS BUSINESS SPECIAL REPORTS SPORT CULTURE

euronews Africa Americas Asia Europe Middle East Search euronews.com

News World news Rare diseases a cause for concern for Europe's health service

NEWS

Rare diseases a cause for concern for Europe's health service

Rita Pálfi

12:17:25 CET | updated at 2902 - 13:08



Mashable

SMS Text APIs to assemble your \$19 billion project 99% messages delivered < 1 sec. Free trial

World

AdChoices Rare Disease List of Diseases Disorder Symptoms

9 ways to support people living with rare diseases and disorders

7.4k SHARES 6396 946

Share Tweet



BRIDE VICKY LETARSHIR

La Región se vuelca hoy contra las enfermedades raras

Cuatro de cada cien murcianos están afectados por alguna de estas patologías

LA VERDAD

MURCIA. La delegación de la Fe-

más de 80.000 en la Región.

Desde Feder «se quiere alertar sobre las graves situaciones de injusticia e inequidades a las que de manera constante se ven sometidas las personas con estas patologías en las diferentes fases de su enfermedad». Los afectados y sus familias editan de la im-

Europe

CyprusMail



Home / Cyprus

Around 60,000 people in Cyprus suffer from a rare disease

FEBRUARY 08TH 2016

STAFF REPORTER

CYPRUS

18 COMMENTS

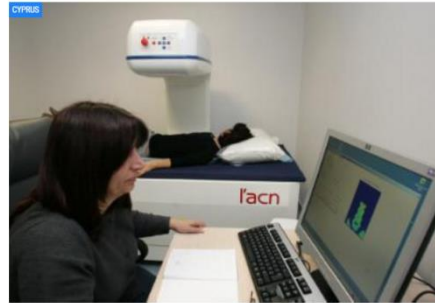


Photo: CNA

i inFranken.de

Region Überregional Sport Gemeinde Termine Anzeigen Abo & Service

Aktuelle Themen: Asyl und Flüchtlinge in Franken ICE-Ausbau broseBaskets

Überregional

Tag der seltenen Krankheiten am 29. Februar 2016: Betroffene kämpfen meist alleine

Der Tag der seltenen Krankheiten macht 2016 auf die aufmerksam, die bereits eine Odyssee hinter sich haben, um überhaupt herauszufinden, an was sie leiden.



BILDER

VOLLBILD

f teilen

tweet

mail

EL PAÍS

EL PAÍS SEMANAL

ANDY WARHOL CUBA EL PULSO CHERNÓBIL LECTURAS NO OBLIGATORIAS SOLEDAD BECERRIL ANDONI LUIS /

MANERAS DE VIVIR >

Estamos rodeados de héroes

Hay cerca de 7.000 enfermedades raras. Todas sumadas, afectan a cerca del 7% de la población, lo cual es una cifra abultadísima

'As doenças raras já não são assim tão raras'

LA STORIA

25 febbraio 2016

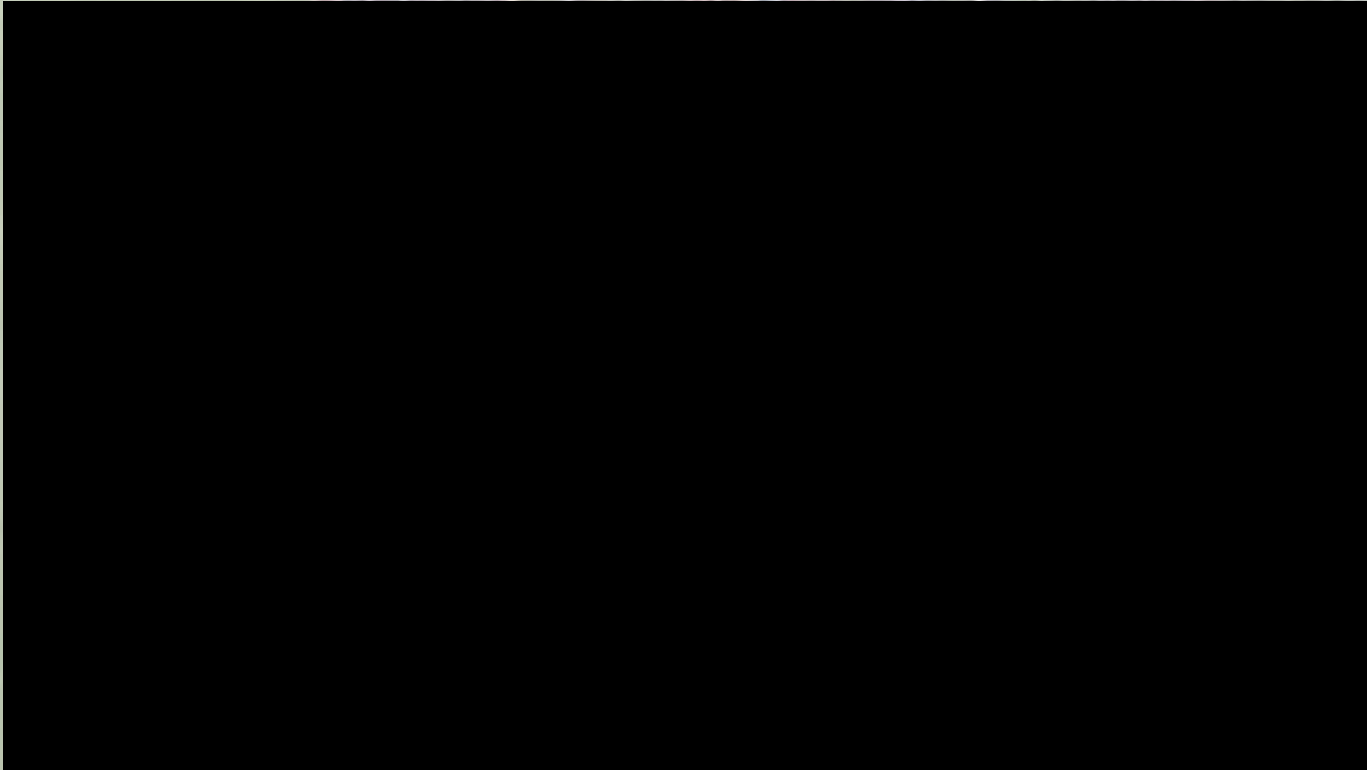
Alessandro che corre più veloce della sua malattia

pais&filhos

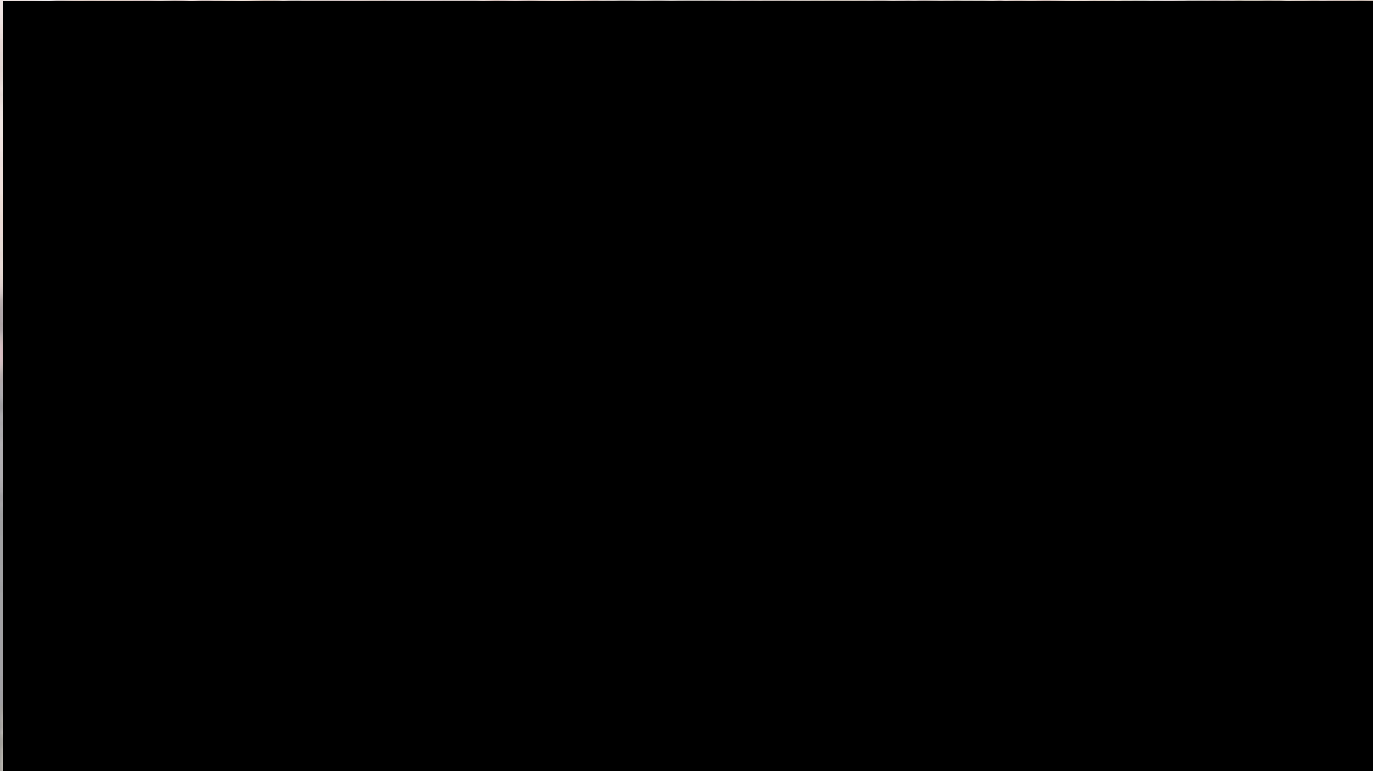
Combate ao preconceito é o principal objetivo do Dia das Doenças Raras

SOMENTE NO BRASIL CERCA DE 13 MILHÕES DE PESSOAS SOFREM COM ESSE PROBLEMA

ROMANIA



GERMANY



BBC

UK

The children living with the world's rarest diseases

By Beth Rose
BBC News

29 February 2016 | Disability



Imagine having a disease so rare it doesn't have a name - or even another sufferer. On the rarest of days - 29 February - three families mark Rare Disease Day.

HOME | LIFESTYLE | HEALTH & LIFE | YOUR HEALTH

Working life: Avril Daly, chair of the Genetic and Rare Disorders Organisation

24 | 24 | 24 | 24

Saturday, February 27, 2016

7am

The news headlines are my alarm clock.



GOV.UK

Blog

Public health matters

Organisations: Public Health England

Rare Disease Day- why a patient voice is central to rare disease registration at PHE

Charlotte McClymont, 29 February 2016 — Chief Knowledge Officer



RAREDISEASEDAY.ORG

Rare Disease UK Reception at the House of Commons 2.3.16



MARCH 6, 2016



BY NICOLA WHITEHILL

IN NEWS.

'A disease might be rare, but information and support shouldn't be,' says Addenbrooke's patient

By CambridgeNews | Posted: March 07, 2016

By Freya Leng



29/02/16 Rare disease Day at Addenbrooke's 29/02/16 Rare Disease Day is being marked at Addenbrooke's at the Addenbrooke's Treatment Centre . Picture: David Johnson

FRANCE

RTL INFO

Marina, 28 ans et juriste, est atteinte d'une maladie rare: "Ça fait 12 ans que j'espère que ça se finisse"

ÉCOUTEZ, ON EST BIEN ENSEMBLE

Journée internationale des maladies rares : sortir de l'ombre

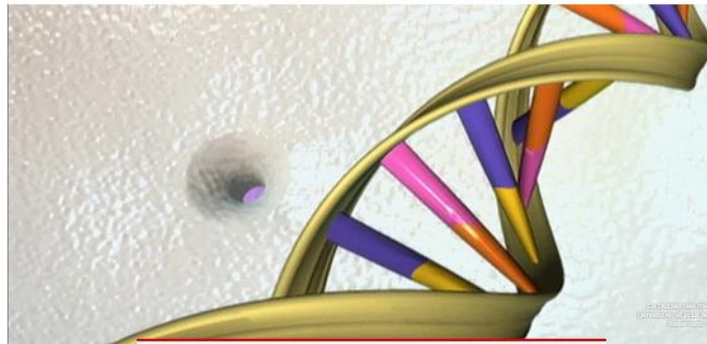
Par Lisa Moll, France Bleu Gard Lozère et France Bleu
Lundi 29 février 2016 à 6:00



Curtis, un jeune homme souffrant du syndrome Down © Muzeyip

Maladies rares: "Les blouses blanches partout, quand on est enfant, c'est traumatisant"

© 29/02/2016 à 13h11



RETOUR SUR LA JOURNÉE INTERNATIONALE 2016 EN CHAMPAGNE-ARDENNES - LORRAINE

Facebook Twitter Google+ IMPR



dénombrées.

Événement annuel organisé le 29 février, jour de la Journée internationale des maladies rares est l'occasion d'unir nos forces et de sensibiliser aux défis quotidiens relevés pour **Faire entendre la voix des malades** ! Pour la 9^e édition, la journée sera relayée par de nombreux bénévoles sensibles à la cause des maladies rares dans plus de 81 pays du monde. millions de Français, sont concernés par l'une des 6000 à 8000 maladies rares dénombrées en France. millions d'Européens, dont 3 sur 4 sont concernés par l'une des 6000 à 8000 maladies rares.

AFMTELETHON
INNOVER POUR GUÉRIR

29 février 2016

29 février : une journée rare pour des Maladies Rares



APPEL POUR UN 3^{ème} PLAN NATIONAL MALADIES RARES

#MALADIESRARES

#RAREDISEAIDAY #APPELPLAN3

A l'occasion de la 9^{ème} Journée Internationale des Maladies Rares qui se tient aujourd'hui, dans plus de 80 pays à travers le monde, les acteurs de la Plateforme Maladies Rares ont lancé un Appel pour un 3^{ème} Plan National Maladies Rares.

Découvrir le contenu de cet appel

Les MALADIES RARES et ORPHELINES

En France >3 millions de personnes touchées

soit 4,5% de la population française



Parlons-en ! Parlons-en ! Parlons-en !

29 février 2016
9^{ème} Journée Internationale des maladies rares



7000 maladies rares recensées à ce jour

80 d'origine génétique

moins de <200 traitements spécifiques



Définition :

Une maladie est dite rare quand elle atteint moins d'une personne sur 2000, ou 1000 selon les définitions nationales.

Des enjeux quotidiens forts pour les patients

Thématiques les plus associées aux maladies rares



1	Traitement	18%
2	Manque de budget	15%
3	Innovation et recherche	11%
4	Scolarisation	7%
5	Recherche scientifique	5%

Recevez tous les conseils et solutions santé Inscrivez-vous avec votre email OK

AFMTELETHON 2015 2016

RARE DISEASE DAY

28 Février 2015

#RareDiseaseDay

JOURNÉE INTERNATIONALE DES MALADIES RARES

RareDiseaseDay.org

Like This Page 19 February 2015 · Edited ·

Le samedi 28 février 2015 aura lieu la 8^e Journée Internationale des Maladies Rares, un événement initié en 2008 et coordonné par EURORDIS - European Rare Diseases Organisation, l'Organisation européenne des associations de maladies rares. Au programme cette année : "Vivre avec une maladie rare : ensemble, jour après jour"

► Tout savoir sur cette journée : <http://bit.ly/1ZQM55a>

► La page de l'événement : Rare Disease Day

► Les événements en France : Alliance Maladies Rares

Like Comment Share

401 216 shares

View 1 comment

Write a comment...

USA

FMD Chat

It's Rare Disease Week in Washington!

The world marks [Rare Disease Day](#) on Feb. 29, and fibromuscular dysplasia patients will be in Washington, D.C. to increase awareness of the disease and policies impacting the rare community. [Rare Disease Week on Capitol Hill](#) brings rare disease community members from across the country together to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators. You can join in as a supporter!

On Monday, advocates and members of the general public are invited to join the [National Center for Advancing Translational Sciences](#) and the [National Institutes of Health \(NIH\) Clinical Center](#), for presentations, posters and exhibits, an art show, and tours. The [event](#) is free, and a [live webcast](#) will be available for those who can not attend in person.

Tuesday brings [Rare Disease Legislative Advocate's conference](#). Advocates from across the United States join together to review critical legislation and practice effectively communicating with



You Can Make The Voice of Rare Diseases Heard

Today is Rare Disease Day – a day we come together to share the #WhatIsAngelman story with the world and all people overcoming the challenges of a rare diseases diagnosis. Today is about making the voices of rare diseases heard and there is no better way to tell the Angelman story than using YOUR story.



Share the 'Life with Angelman' video on your social media channels using the hashtags #WhatIsAngelman and #RareDiseaseDay. Together we will answer the question #WhatIsAngelman and help raise awareness for Angelman syndrome.

[See the video on Facebook](#).

If you are not on social media, [click here to view the video on YouTube](#). Forward this email to family, friends and co-workers to help share the stories of AS families everywhere.

Los Angeles Daily News

DISEASES AND CONDITIONS

News Sports Entertainment Lifestyle Obituaries Opinion Special Rep

Home Lifestyle Health Diseases and conditions

Rare Disease Day draws family from San Fernando Valley into global cause



Jennifer Greene with her daughter Madison, 3-years-old, at their West Hills home on Friday, February 26, 2016. Madison suffers from the rare genetic neurological disorder Neurodegeneration with Brain Iron Accumulation (NBIA) Beta-propeller Protein-Associated Neurodegeneration (BPAN). (Photo by Hans Gutknecht/Los Angeles Daily News)

By Susan Abram, Los Angeles Daily News

Rare disease advocates visit AL State House

Published: Friday, February 26th 2016, 12:33 am CET
Updated: Saturday, March 5th 2016, 12:33 am CET

By David Buchholz [CONNECT](#)



Fox Valley family's message on Rare Disease Day



By Kristyn Allen

Published: February 29, 2016, 6:06 am | Updated: March 1, 2016, 10:10 am



[Send](#)

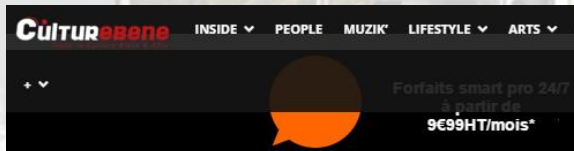


HEALTH & FITNESS

RARE DISEASE DAY RAISES



AFRICA



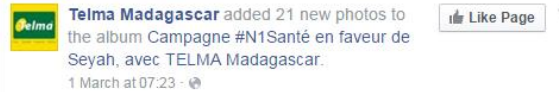
Home > Inside > Maladies rares: une obligation de solidarité nationale au Cameroun.

Inside

Maladies rares: une obligation de solidarité nationale au Cameroun.

24 février 2016

0



29 février 2016, Journée Mondiale des maladies rares - TELMA vient en aide à Seyah, 7ans, atteinte d'une vascularite non étiquetée

Sur Facebook, les internautes ont été mobilisés à poster leurs vœux de rétablissement de la petite Seyah avec le hashtag #N1Santé, à l'issue duquel TELMA lui verse Ar 500 par Hashtag. 5 102 personnes se sont mobilisées sur les réseaux sociaux pour démontrer leur soutien et leur solidarité à Seyah. TELMA lui a remis ce jour 2 551 000 Ariary, récolté à l'issue de la campagne! Merci à tous!

Photo by Ando Harivola - photo&video pour Telma Madagascar



How we cope with rare multiple sclerosis

By PETER NGILA Mar. 07, 2016, 6:00 am 0 Comments



support: Robai Musilivi with her husband Martin Muiruri

Rest of the world

THE TIMES OF INDIA CITY

JK Lon Hosp offers hope for patients with 'rare diseases'

Видео 16.03.2016 19:21

АМИ российское агентство медико-социальной информации

Отрасль Общество Регионы В мире Наука Индустрия Информатизация Интервью Анонсы Видео

ЕВРОСЕРВИС Стабильное сотрудничество в рамках выполнения госзаказов учреждений и коммерческих структур РФ специализированных

ОТРАСЛЬ Архив 16 марта 2016 ИНТЕРВЬЮ

Финансирование лечения орфанных заболеваний - непомерное бремя для регионов 29 февраля 18:24

Николай Герасимов: «Рекламизировать рецептурные препараты нежелательно»

Аркадий Столпняк: «Будет первый госцентр протонной терапии»

Ольга Еремкина: «Область совершенства здравоохранения»

Юлия Михайлова: «Глобальная цель - снижение смертности»



THE STAR ONLINE

Featuring the latest prop trends, statistics and

News Business Sport Metro Tech Lifestyle Opinion Videos Property

Letters Home > Opinion > Letters

Monday, 29 February 2016

Rare diseases in Malaysia

Европа PLUS TV ПРЕДСТАВЛЯЕТ **ФИЛИПП КИРКОРОВ** ШОУ Я

TUT.BY Финансы \$20675 Афиша Работа Погода +2° Автообъявления

ВОСТИ T.BY Поиск по проектам TUT.BY НОВОСТИ TUT.BY Найти

ОБЩЕСТВО

Люди с редкими болезнями. Жизнь как преодоление 21 комментарий

About 70 Million Indians Have Life-Threatening Rare Diseases: Clinical Research

Health | Press Trust of India | Updated: February 26, 2016 23:20 IST

indiamart PRESENTS **THE ECONOMIC TIMES** #GAMECHANGER **BUDGET 2016**

About 70 million Indians have life-threatening rare diseases: ISCR

By PTI | Feb 26, 2016, 09:36 PM IST

Post a Comment

Arabian Gulf University

RARE DISEASES CAMPAIGN 2016 CONCLUDED





FACEBOOK BUZZ!

facebook



We reached over 6 million people on facebook alone!

Over 75,000 likes!

Téléthon shared their video.
29 February at 13:49 · 🌐

Journée internationale des Maladies Rares. Pourquoi cette journée ? La réponse en vidéo...



Si vous vous préoccupez de quelqu'un avec une maladie rare, vous n'êtes pas seul

37,964 Views

Téléthon
19 February at 16:56 · 🌐

Le 29 février est la 9ème Journée internationale des maladies rares (Rare Disease Day). Des associations de plus de 80 pays et régions participent à cet évènement...

See more

Like Comment Share

Arthur Le Boulanger, Alain Gendre and 769 others · Top comments

ClioMakeup fun page
29 February at 18:14 · 🌐

Elisa è una ragazza di 18 anni con un'straordinaria passione per il makeup, che ho avuto modo di conoscere in occasione del suo compleanno. Elisa soffre del morbo di Williams: una malattia genetica che colpisce 1 nato ogni 20.000. Nonostante la diagnosi continua a inseguire i suoi sogni, che l'hanno portata fino a Parigi sulle note di un pianoforte per la Giornata delle Malattie Rare, di cui è testimonial nazionale e che si celebra oggi in tutto il mondo. Voglio fare un grossissimo in bocca al lupo ad Elisa e ai suoi cari per il futuro e invito tutte voi ragazze a fare girare questo bellissimo video! [video: Eurordis]

See translation



115k Views

Love Comment Share

You, Valeria Martin, Fiorella Esposito and 2.9k others · Top comments

The Mighty
29 February at 13:00 · 🌐

Today is Rare Disease Day. Share if you love someone who is rare. ❤️



Like Comment Share

Kymi Waters, Theresa Brier and 1.6k others · Top comments

Like Comment Share

Kymi Waters, Theresa Brier and 1.6k others · Top comments

MedTech
29 February at 14:30 · 🌐

of four. She and her mum found crucial support in RareConnect, a place where people affected by rare diseases can interact and support each other cc: EURORDIS - European Rare Diseases Organisation <http://medt.ec/1SbYIYZ>



Rare disease patients find comfort in numbers
Sometimes when you're ill or you're caring for a loved one who's ill, you just want to talk to someone who understands exactly what you're going through. If the illness is a rare disease, however, that 'someone' may live on the other side of...
THISISMEDTECH.COM

Like Comment Share

Eru Rodriguez, Mila Fernández Gabarro and 685 others · Top comments

197 shares

Aspau with Eliana Soledad Florez and 6 others.
29 February at 08:38 · 🌐

El día 29 de Febrero se conmemora el Día Mundial de las Enfermedades Raras. Se escogió por ser un día "inusual".
No es raro, tener una enfermedad rara.
VACUNATE CONTRA LA INDIFERENCIA.... See more

See translation



Like Comment Share

Chronological

Téléthon feeling determined.
29 February at 09:54 · 🌐

Aujourd'hui, c'est la journée internationale des Maladies Rares - Rare Disease Day.
Nous, acteurs de la Plateforme Maladies Rares, lançons un appel pour un 3ème Plan National #MaladiesRares. >> www.afm-telathon.fr/AppelPlan3

APPEL POUR UN 3ème PLAN NATIONAL MALADIES RARES

JOURNÉE INTERNATIONALE DES MALADIES RARES 2016

29 FÉVRIER

#APPELPLAN3 La co-construction, c'est maintenant!

Aujourd'hui, c'est la Journée Internationale des Maladies Rares !

APPEL POUR UN 3ème PLAN NATIONAL MALADIES RARES

6000 à 8000 maladies génétiques

#APPELPLAN3 La co-construction, c'est maintenant!

Parce que 6000 à 8000 maladies rares sont connues à ce jour...

Like Comment Share

You, Alain Gendre, Eliane Dufour and 234 others · Top comments

TWITTER SUCCESS

The #RareDiseaseDay Influencers











Top 10 by Mentions

	@rarediseaseday 3,378
	@rarediseaseuk 1,887
	@raredayus 1,558
	@rarediseases 1,389
	@amgen 681
	@eurordis 603
	@rareconnect 494
	@NIH 445
	@bham_childrens 395
	@globalgenes 373



Tweet











Top 10 by Tweets

	@rarediseaseuk 354
	@softlysmiling 343
	@marthawithepp 282
	@alanroygbiv 276
	@raredayus 243
	@lissiebeachgirl 203
	@dea_way 141
	@jccolyer 140
	@homebymartha 133
	@houstoncrps 129



Tweet

Top 10 by Impressions

	@mashable 20,313,323
	@blessedatworld 14,315,797
	@simonpegg 6,730,407
	@telethonitalia 6,298,110
	@mayoclinic 5,037,239
	@menshealthmag 3,175,354
	@rarediseaseuk 3,081,209
	@segsocialerai 2,910,475
	@indiatoday 2,374,799
	@novartis 2,179,284



Tweet

The Numbers

219,067,205 Impressions

52,189 Tweets

21,912 Participants

78 Avg Tweets/Hour

2 Avg Tweets/Participant



Tweet

PublicHealthEngland
@PHE_UK

Blog: why a patient voice is central to rare disease registration bit.ly/1UthWv6
#RareDiseaseDay

There are over 6000 recognised rare diseases and, whilst each specific condition affects less than 1 in 2000 of the UK population, collectively rare diseases are not rare. 1 in 17 people will be affected by a rare disease at some point in their life

#RareDiseaseDay

RETWEETS 87 LIKES 51

4:02 AM - 29 Feb 2016

EU_Health
@EU_Health

Our colleagues in #Luxembourg attended the #RareDiseaseDay event w. #ALAN & @UE_Luxembourg alan.lu/index.php/en/



Pegg News
@simonpegg

I'm supporting @SKC_Europe for #RareDiseaseDay! Find out why this is such an important day solvingkidscancer.org.uk/rare-disease-d...



Help Solving Kid Cancer fund vital research to children with cancer have the chance to grow up!

Text: 'PEGG46 £3 to 70070'

RETWEETS 203 LIKES 390

2:29 AM - 29 Feb 2016

Sarah Pilling
@serpilling

@rarediseaseuk @SWAN_UK having a child with a rare/undiagnosed condition is a challenge no one can comprehend. Your help makes it easier!

RETWEETS 6 LIKES 8

7:10 AM - 29 Feb 2016

BBC News (UK)
@BBCNews

The children living with rare diseases bbc.in/215jT5m



The children living with the world's rarest diseases - BBC News

On the rarest of dates three families mark Rare Disease Day and consider the struggle to come to terms with their child's isolating or life-limiting disease.

bbc.co.uk

RETWEETS 66 LIKES 47

9:23 PM - 28 Feb 2016

Rare Diseases Europe
@eurordis

#RareDiseaseDay Platform team members including EURORDIS staff raise & join hands for #RareDiseaseDay @rarediseaseday



RETWEETS 31 LIKES 31

5:17 AM - 29 Feb 2016

EurActiv Health
@EurActivHealth

What is being said about Rare Diseases in the EU euractiv.com/section/health...
#RareDiseaseDay

WHAT IS BEING SAID IN THE EU?

Yann Le Cam, Luxembourg: "If a medicine is approved but does not reach those who need it, it fails in its objective."

Philippe de Becker, ALCE Belgium: "The EU could still do more to make patients more aware that there are already groups helping people with rare diseases. When you compare the 28 Member States across the EU, you see huge differences."

Francine Groszstein, epp: "Speed is essential, they should not have to wait years before being correctly diagnosed. They deserve prompt and appropriate diagnosis, equal access to care and to have their voices heard through patient associations - irrespective of which country they reside in."

Christa Dethlefs, ALCE UK: "It is our duty, as European policymakers, to address the disparities between EU countries by fostering European Reference Networks. Unfortunately, the nature of the networks is still fragmented and piecemeal, hampering their effectiveness."

Vilijana Andriusaitis, European Health Commissioner: "Fortunately, being part of the European Union means that someone with a rare disease in one country can see a leading expert in another EU country as the Cross-Border Healthcare Directive gives EU citizens the right to seek treatment abroad if the treatment they need isn't available at home."

"Patients face years of uncertainty waiting for a disease to be diagnosed and

European Parliament
@europarl_en

RareDiseaseDay: watch the video bit.ly/1QnDn0f, look for more information bit.ly/1QnDngs and get involved @rarediseaseday

Rare Disease Day Official Video 2016

<http://www.rarediseaseday.org/> This is the official video for #RareDiseaseDay 2016! Patient Voice: Join us in making the voice of rare diseases heard! Read m... youtube.com

RETWEETS 35 LIKES 21

EU Medicines Agency
@EMA_News

Find out how EMA supports development and authorisation of #medicines for rare diseases: bit.ly/16Zy2IA #RareDiseaseDay

Pheno Para Project

RETWEETS 29 LIKES 12

4:37 AM - 29 Feb 2016



WE TRENDED ON TWITTER WITH **#RareDiseaseDay**



Follow

Absolutely delighted to see that
[#RareDiseaseDay](#) is trending already!
[#raredisease](#)

Trends · Change

#VFOscarParty

15.8K Tweets

#LeapDay

36.8K Tweets

#RareDiseaseDay

Trending for 2 hours now

#Budget2016

119K Tweets

#WGT16

Started trending in the last hour

Sam Smith

271K Tweets

Bertie Ahern

Just started trending

Trump

1.43M Tweets

FAN TRAILER TONIGHT

20.9K Tweets

Star Wars

237K Tweets

RETWEETS
45

LIKES
65



3:07 AM - 29 Feb 2016



Athletes Brand
@AthletesBrand

Follow

[#RareDiseaseDay](#) is trending in the USA!
Proceeds from every sale go to
[@rarediseaseday](#): [AthletesBrand.com/Alexi](#) <<

United States Trends · Change

#DayItForward

Promoted by Chevrolet

#LeapDay

#MakeDonaldDrumpfAgain

#MotivationMonday

#RareDiseaseDay

Medal of Honor

Justice Thomas

Vive

Raspberry Pi 3

Flight of the Conchords

Allahu Akbar

RETWEETS

3

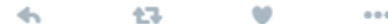
LIKES

4



8:29 AM - 29 Feb 2016

[Rare Diseases Europe](#), [Rare Disease Day](#) and [Alexi Lalas](#)



by Rare Disease Day

category: **Charity**

**“29 February: A rare day for
#RareDiseaseDay. Join us in making the voice
of rare diseases heard today!**

<http://thndr.me/XpiLj>”



Rare Disease Day

EMBED
</>

SUPPORTERS

1,179 of **500**

236% of goal supported

SOCIAL REACH

1,442,447

People

TIME LEFT

Complete

Ends Feb 29, 12:00 PM CET

**THUNDER
CLAP**

**1,179 supporters
with nearly a 1.5
million reach!**

COMPLETE

This campaign ended on February 29 at 12PM

ORGANIZER

Rare Disease Day

@rarediseaseday

#RareDiseaseDay takes place on the last day of February each year. The main objective of #RareDiseaseDay is to raise awareness amongst the general public and decision-

RARE DISEASE DAY 2016
29 FEBRUARY