



RARE DISEASE DAY 2017

28 February 2017



RAREDISEASEDAY.ORG

RARE DISEASE DAY 2017

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RARE DISEASE DAY 2017

BACKGROUND

- **10th edition of Rare Disease Day** – in 2008, events for the day were held in 18 countries
- Since 2008, events have been held in **over 100 countries**
- **Objective:** to raise awareness of rare diseases amongst the general public, decision-makers, public authorities, researchers and health professionals
- **Theme:** RESEARCH
- **Slogan:** 'With research, possibilities are limitless'
- **Hashtag:** #RareDiseaseDay



Σας περιμένουμε στην
εκδήλωση στο Ίδρυμα
Ευγενίδου - Πλανητάριο
Λ. Συγγρού 387,
17564, Π. Φάληρο
Ώρα: 17:00

Πληροφορίες
Τ. 210 7660989
www.pespa.gr

Εισόδος
ελεύθερη

ΜΕ ΤΗΝ ΕΡΕΥΝΑ
ΟΙ ΔΥΝΑΤΟΤΗΤΕΣ
ΕΙΝΑΙ ΑΠΕΡΙΟΡΙΣΤΕΣ

ΗΜΕΡΑ ΣΠΑΝΙΩΝ ΠΑΘΗΣΕΩΝ 2017
28 ΦΕΒΡΟΥΑΡΙΟΥ



JOURNÉE INTERNATIONALE DES MALADIES RARES 2017
28 FÉVRIER

LA RECHERCHE :
PLUS QUE L'ESPOIR
CHANGER DES VIES

JOURNÉE INTERNATIONALE DES MALADIES RARES 2017
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PLUS QUE L'ESPOIR
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ZIUA BOLILOR RARE 2017
28 FEBRUARIE

RARE DISEASE DAY 2017
28 FEBRUARY



RARE DISEASE DAY 2017
28 FEBRUARY

WITH RESEARCH
POSSIBILITIES
ARE LIMITLESS



ΗΜΕΡΑ ΣΠΑΝΙΩΝ ΠΑΘΗΣΕΩΝ 2017
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RARE DISEASE DAY 2017
28 FEBRUARY



VISUALS

- Poster: based on the theme of research, the poster embraces the possibilities that research can bring, a bright and hopeful future
- Rare Disease Day logo: becoming more and more widely recognised, continuing to convey togetherness and hope
- Social media banner: based on the poster, designed to be shared online to create a strong visual online presence
- Social media profile picture: also based on the poster, very widely used by people on Facebook and Twitter



VISUALS – POSTER & LOGO

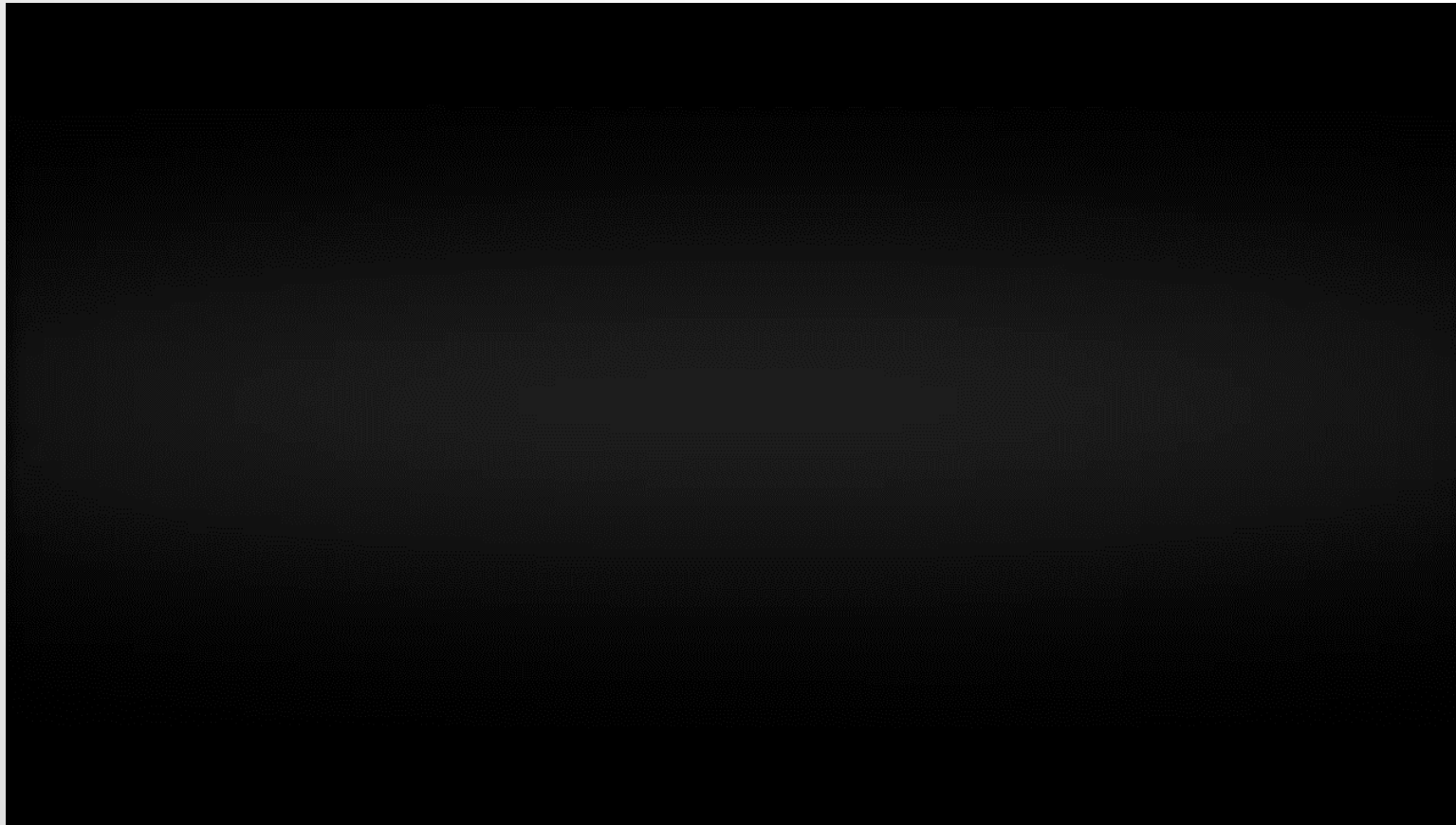


VISUALS – SOCIAL MEDIA



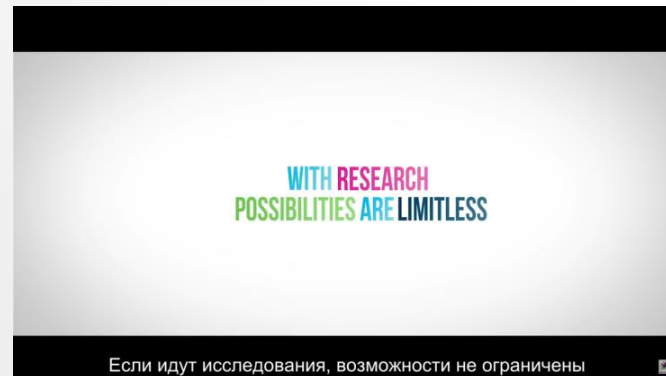
VIDEO

- [Video also available on YouTube](#)



VIDEO

- The video features rare disease patients Océane, Geoffray and Mathieu
- The video highlights how isolating it is when you search on the internet but receive the response '**your search had no results**'
- The official Rare Disease Day 2017 video has been translated into 33 languages
- Viewed **hundreds of thousands of times**, including **205,000 times** on the Rare Disease Day Facebook page alone. The video tweet was retweeted hundreds of times, reaching tens of thousands of people



HOW WOULD YOU FEEL?

چه احساسی به شما دست میدهد؟

TODAY THINGS CAN CHANGE

世界を変えることができます



Para Geoffray



DR MARIE-LAURENCE GOURLAY
Genethon

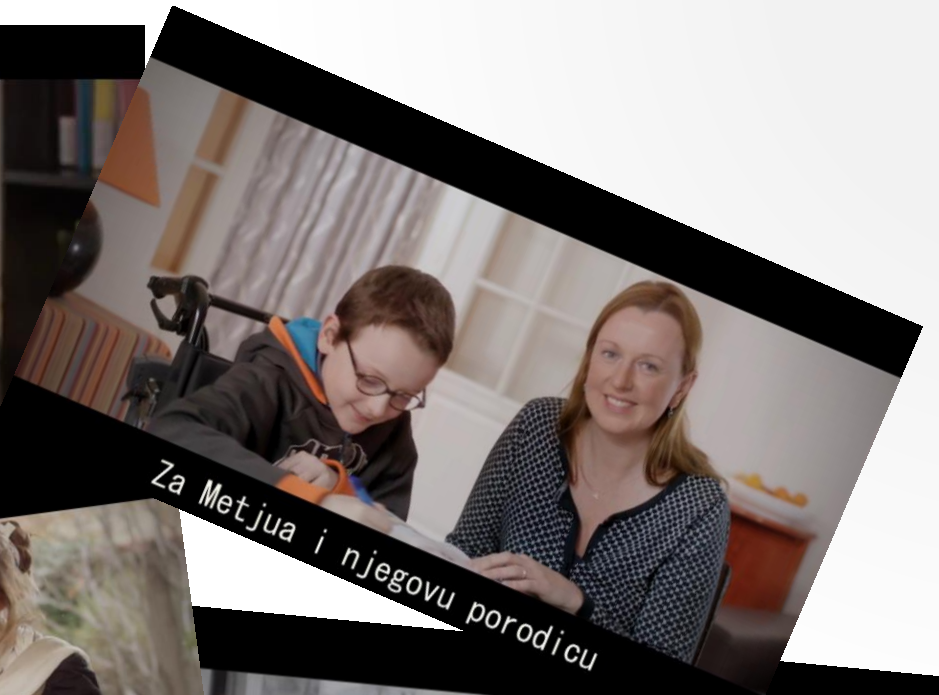
Retā ligā ievēkti sudētinga, norēdami
patientams padēti turite išbandyti daug ką.



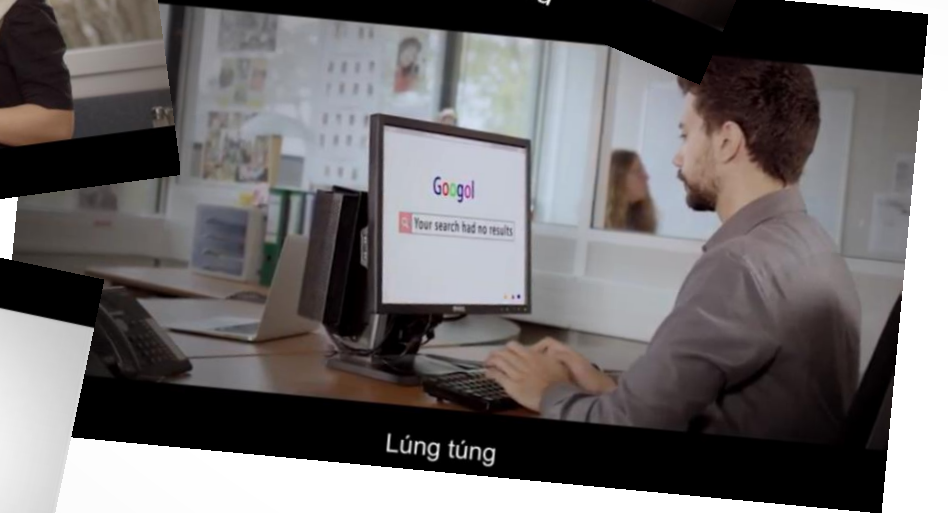
ჩვენ შეგვიძლია მოვიძიოთ მეტი პასუხი

WITH RESEARCH
POSSIBILITIES ARE LIMITLESS

Если идут исследования, возможности не ограничены



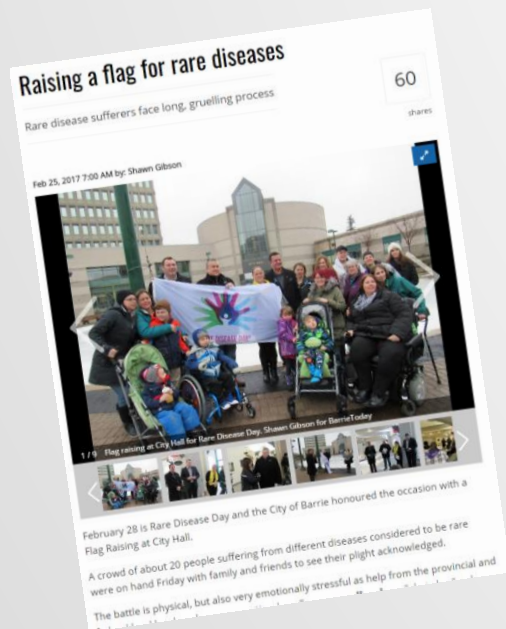
Za Metjua i njegovu porodicu



Lúng túng

MEDIA COVERAGE

- Rare Disease Day this year achieved incredible media coverage all around the world, even being mentioned in the **President of the United States' first speech to Congress!**
- Media coverage came in the form of newspaper articles, magazine articles, online articles, radio interviews, television mentions and tweetchats from all around the world



FACEBOOK

- Our posts during the week of Rare Disease Day reached **over 1 million people** more than the 'average' week
- The video and the announcement of the theme posts received **unanimously positive feedback**
- More than a **10% increase** in the number of likes on our page since the start of January, now at **88,000**



FACEBOOK – TOP POSTS

 **Rare Disease Day**
Published by Jacob Bullock [?] · February 27 at 4:54pm · 🌐

Geoffray, Océane, Mathieu and his family are part of the change for rare diseases - you can also raise awareness for over 300 million people worldwide living with a rare diseases? Share the #RareDiseaseDay video!




194,280 people reached [Boost Post](#)

202K Views

👍 Like 💬 Comment ➦ Share


👍❤️👉 محمد صادق محمد, Snezana Furian and 405 others [Top Comments](#)

1,552 shares

 **Rare Disease Day**
Published by Jacob Bullock [?] · January 25 · 🌐

THE RARE DISEASE DAY 2017 VIDEO IS OUT NOW!

With research, possibilities are limitless. By sharing this video on social media and with your friends and family, help to emphasise the importance of research and the possibilities that it can bring. Let's spread the word about #RareDiseaseDay!



421,009 people reached [Boost Post](#)

202K Views

👍 Like 💬 Comment ➦ Share

👍❤️👉 830 [Top Comments](#)

2,900 shares

 **Rare Disease Day**
Published by Jacob Bullock [?] · February 28 at 3:20pm · 🌐

With research, possibilities are limitless. Share and be a part of the change this #RareDiseaseDay! <http://bit.ly/2I739kZ>



533,975 people reached [Boost Post](#)

👍 Like 💬 Comment ➦ Share

👍❤️👉 2.6K [Top Comments](#)

5,107 shares



TWITTER

- In the build up to the day, posts on the [@rarediseaseday](#) account received **half a million impressions**, more than **60,000 more than the previous year**
- [#DiaMundialEnfermedadesRaras](#) trended worldwide
- [#RareDiseaseDay](#) trended in over 10 countries, including:
 - United Kingdom
 - United States of America
 - Canada
 - Spain
 - Italy
- Significant mentions include those from:
 - [@PressSec](#) (Sean Spicer, Press Secretary of the United States)
 - [@LuisSuarez9](#) (Luis Suarez, a prominent modern day footballer)
 - [@finolahughes](#) (Finola Hughes, British actress best known for role in US soap opera, General Hospital)
 - [@michellemalkin](#) (Michelle Malkin, US blogger)



TWITTER – TOP POSTS

 **Rare Disease Day**
@rarediseaseday

Good morning to North, Central and South America! Have a fantastic day and remember to share with us what you're doing!
[#RareDiseaseDay](#)



RETWEETS 125 LIKES 126

3:35 PM - 28 Feb 2017

4 125 126

 **Rare Disease Day**
@rarediseaseday

With research, possibilities are limitless. Share and be a part of the change this
[#RareDiseaseDay!](#)



Rare Disease Day © 2017
The main objective of Rare Disease Day 2017 is to raise awareness with policy makers and the public of rare diseases and of their impact on the lives of patients, and to reinforce their...
rarediseaseday.org

RETWEETS 413 LIKES 272

2:02 PM - 28 Feb 2017

5 413 272

 **Rare Disease Day**
@rarediseaseday

THE OFFICIAL RARE DISEASE DAY 2017 VIDEO IS OUT NOW!
Share the video to become part of the international [#RareDiseaseDay](#) campaign!



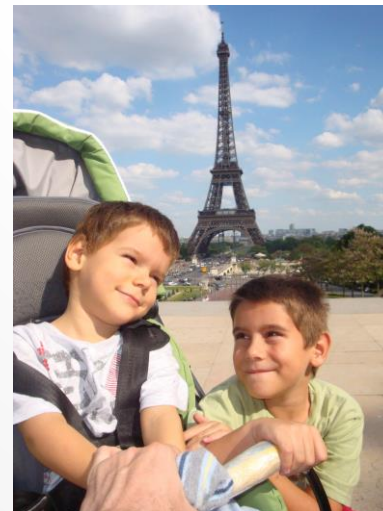
RETWEETS 379 LIKES 293

4:00 PM - 25 Jan 2017



THUNDERCLAP

- The most successful #RareDiseaseDay Thunderclap yet, with a social reach of nearly **2 million people**
- The campaign was featured on the Thunderclap homepage on Rare Disease Day
- The message that was shared the most times on Facebook
- Rare Disease Day also featured in MediaPlanet UK's Thunderclap campaign



THUNDERCLAP

Today is #RareDiseaseDay!

by Rare Disease Day

category: **Charity**

**“With research, possibilities are limitless.
Share and be a part of the change this
#RareDiseaseDay! <http://thndr.me/ZwRQ7c>”**



Rare Disease Day

EMBED
</>

SUPPORTERS

1,744 of **500**

348% of goal supported

SOCIAL REACH

1,807,669

People

TIME LEFT

Complete

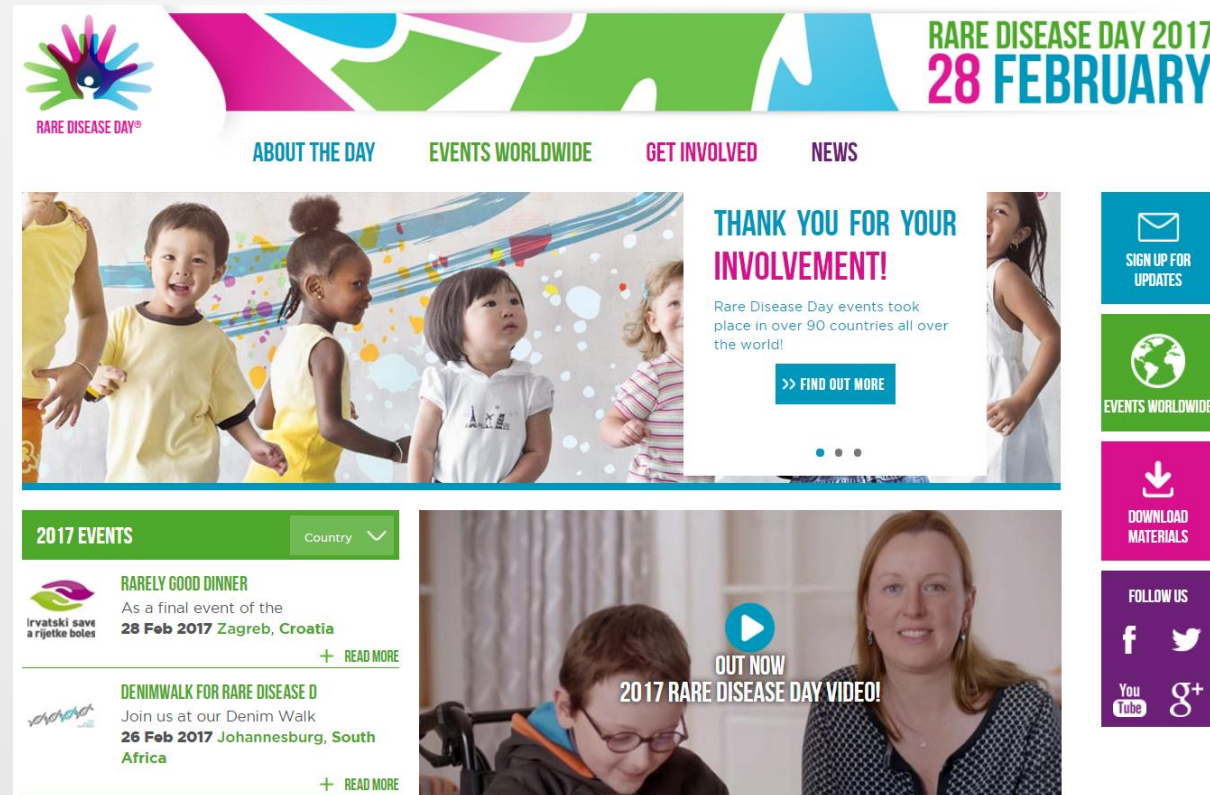
Ends Feb 28, 2:00 PM CET



RAREDISEASEDAY.ORG

WEBSITE

- The day: the website received **tens of thousands** of sessions on the day itself
- **Build-up:** In the 2017 build-up to Rare Disease Day, the website received **over a hundred thousand sessions**, a 30% increase on the same period last year



AMBASSADOR

- Sean Hepburn Ferrer was again selected as the Rare Disease Day ambassador, and this decision again was warmly received on social media
- Sean Hepburn Ferrer attended a Rare Disease Day event in Brussels organised by EURORDIS-Rare Diseases Europe



EVENTS

- Events took place in all continents, in **94 countries and regions** (more countries than ever before), including Botswana, Nigeria, Senegal, Sudan and Saint Pierre and Miquelon
- Events included everything from fun-runs to conferences and picnics in the park to film festivals
- In **Botswana**, the Botswana Organisation for Rare Diseases was officially launched
- In New Zealand, members of the Muscular Dystrophy Association of New Zealand ran from port to port all around the bay of Auckland
- A film festival is due to be held in Boston, MA in the USA, which will address the challenges of life with a rare disease





FRIENDS

- Thank you to all of our friends for raising awareness for Rare Disease Day!
- [See all of the friends here!](#)



STORIES

- Hundreds of stories from all around the world were posted on the Rare Disease Day website
- When posted on social media, the stories were very popular
- A touching story written by Jayne from the UK about her son, Sam, who lived with Donnai Barrow syndrome was one of the most viewed
- Another story, written by Tanya from the UK, about her life with a rare eye disease, punctate inner choroidopathy, touched many
- Stories have been very successful in connecting many people in similar situations, including one young man with Geoffray from this year's video



THANK YOU!

- Thank you for participating in Rare Disease Day 2017!

