

Session 2

Recognising rare diseases as a policy priority:

Empowering people living with a rare disease

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NGO COMMITTEE FOR
RARE DISEASES

Rare Disease Day: a global campaign



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RARE DISEASES

Show your rare
 Show you care


 RARE DISEASE DAY®

28 FEBRUARY
 2019
 #RareDiseaseDay
RAREDISEASEDAY.ORG



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Rare diseases seriously impact everyday life

7 in 10 patients & carers

reduced or stopped professional activity due to their or their family member's rare disease.



8 in 10 patients & carers

have difficulties completing daily tasks (household chores, preparing meals, shopping etc.)



2/3 of carers

spend more than 2 hours a day on disease-related tasks.



3 times more people

living with a rare disease and carers report being unhappy and depressed than the general population*



* Rare Barometer Voices sample compared to International Social Survey Programme, 2011



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Why?

- Raise awareness amongst the **general public, stakeholders and decision-makers**
- **Break isolation** of people living with a rare disease and their families
- Create a **sense of community** across the different rare diseases
- Generate an **international momentum** and a **common identity**

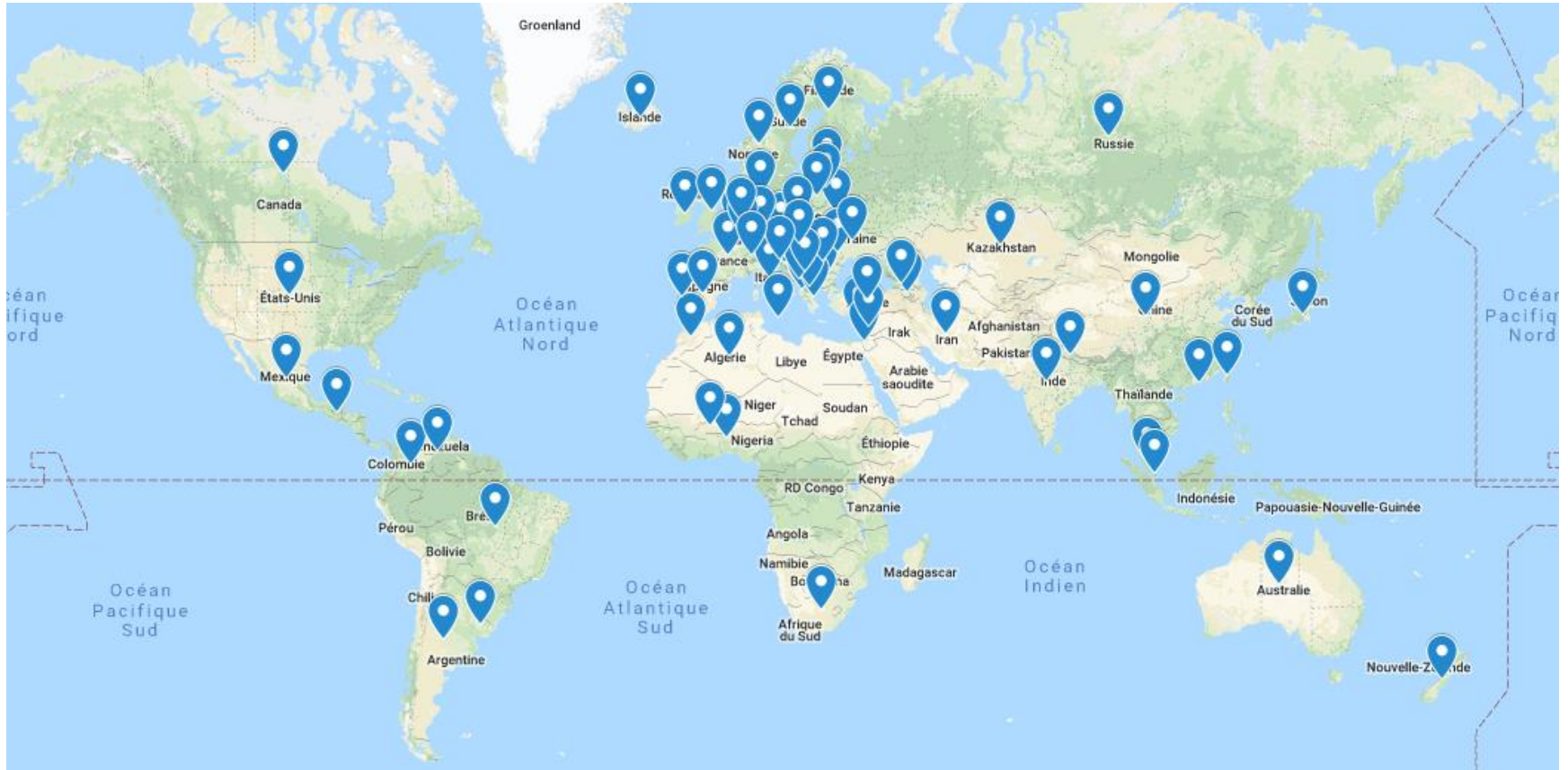


How?

- Rare Disease Day takes place on **the last day of February each year, 28 or 29, a rare day**
- The **first Rare Disease Day** was in 2008 and was celebrated in 18 countries (all European)
- **37 National Alliances**, umbrella organisations who group together several rare disease organisations in a given country or region, are the official partners of Rare Disease Day.



Worldwide coordination: Patient network



37 National Alliances of rare disease patient organisations



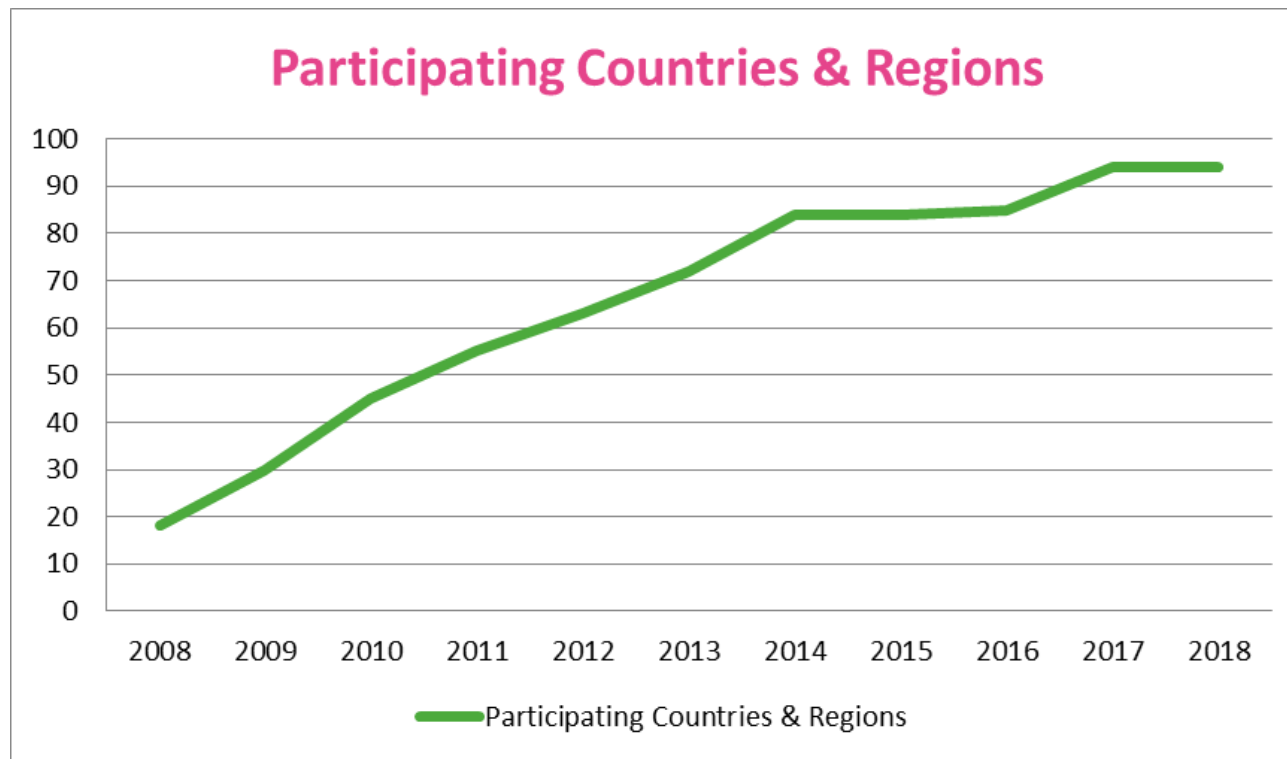
RARE
DISEASES
INTERNATIONAL



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Worldwide reach

- In **2018**, for the 11th edition, Rare Disease Day events took place in **over 90 countries and regions on every corner of the globe.**



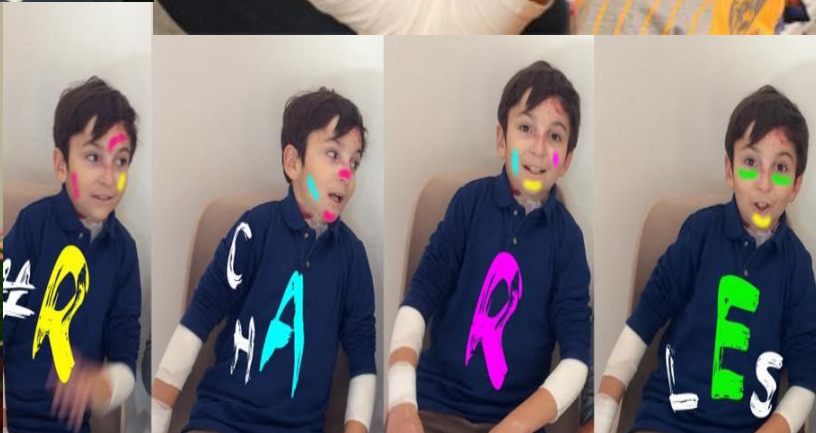
Worldwide reach



There are thousands of events for Rare Disease Day in over 90 countries, taking place in all continents



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Podemos melhorar o apoio à investigação.



يمكننا زيادة الدعم للأبحاث.



გავაძლიეროთ მხარდაჭერა აკადემიკური კვლევებისათვის

Official video translated into 35 different languages

研究への支援を高めよう



Ми можемо збільшити підтримку досліджень.



Possiamo aumentare il supporto alla ricerca



Nous pouvons davantage soutenir la recherche



můžeme podpořit výzkum



Podemos impulsar el apoyo a la investigación

Our plea

Rare Diseases Day
to become an
**official awareness day
by the United Nations**
on the last day of February





Thank you!

