Session 2
Recognising rare diseases as a policy priority:
Empowering people living with a rare disease

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Rare Disease Day: a global campaign
Show your rare show you care

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#RareDiseaseDay
RAREDISEASEDAY.ORG

NGO COMMITTEE FOR RARE DISEASES
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.

2/3 of carers
spend more than 2 hours a day on disease-related tasks.

8 in 10 patients & carers
have difficulties completing daily tasks (household chores, preparing meals, shopping etc.)

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
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
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.

![Graph showing increasing number of participating countries and regions from 2008 to 2018.](image-url)
There are thousands of events for Rare Disease Day in over 90 countries, taking place in all continents.
Official video translated into 35 different languages
Our plea

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