# BUILDING AN EMPOWERED AND ENGAGED COMMUNITY OF PATIENT ADVOCATES

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EURORDIS.ORG

# European awareness of Rare Diseases Eurobarometer Survey

- This survey, published in 2011 aimed to analyse the European public's awareness and knowledge of knowledge of rare diseases and their support for policy initiatives actions taken at national and European level
- The results showed that the general understanding of rare diseases is relatively good but detailed knowledge and awareness remained low
- There is a widespread willingness to improve the treatment of rare diseases, however it is based on instinct and empathy rather than actual knowledge
- The survey concluded that future policy needs to be accompanied by education and awareness-building
- This will increase the general recognition and visibility of rare diseases and in turn will lead to stronger support
- http://ec.europa.eu/health//sites/health/files/rare_diseases/docs/ebs_361_en.pdf

# Rare Disease Day

RAREDISEASEDAY.ORG

- Main objective is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives

- Held on the last day of February each year

- Events organised by hundreds of patient organisations all over the world

- In 2017 94 countries and regions participated: new countries included Botswana, Nigeria, Sénégal and Sudan

- 2017 theme and slogan:
  **Research:** With research, the possibilities are limitless

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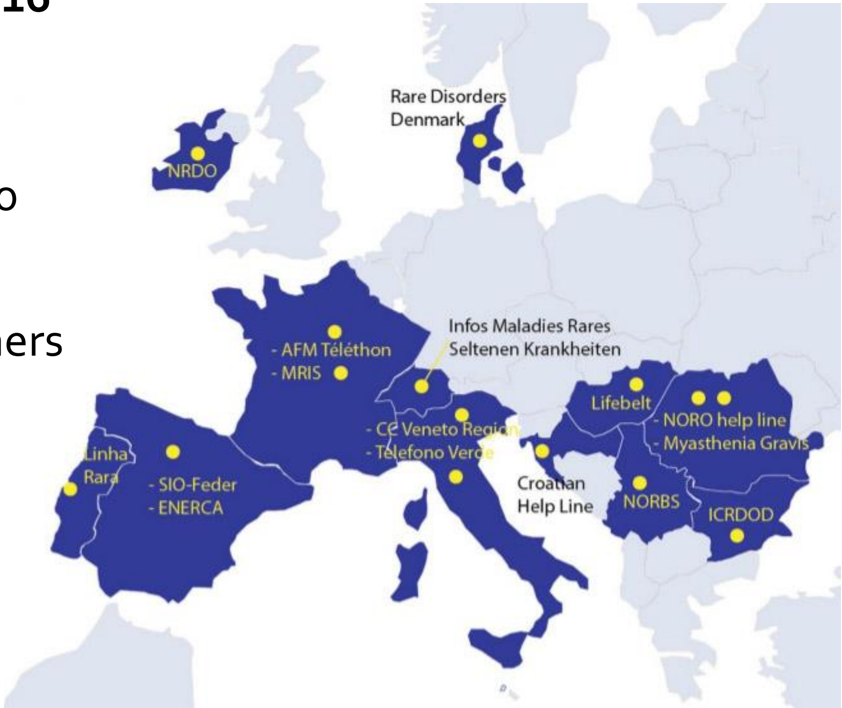
RARE DISEASES EUROPE

# Web information and helplines

**European Network of Rare Diseases Help Lines Caller Profile Analysis October 2016**

- 16 help lines in 12 countries
- October 2016: 1,633 enquiries (19,000 per annum)
- 58% by phone, 38% by email, 4% others
- 52 trained respondents, 777 hours of reply
- Average duration: 29 minutes
- 3,405 responses given
  - 16% on disease and care
  - 15% orientation to expert
  - 7% on treatment and regulatory affairs



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# EURORDIS Summer School

- A capacity-building programme for patients and researchers on information and access to orphan, paediatric, advanced therapies and health technology assessment
- Annual online and offline training programme in Barcelona
- Since it began in 2008 more than 300 participants have been trained from over 40 countries representing more than 75 different diseases
- These alumni have gone on to become involved in various advocacy activities at both a national and a European level
- Expert Patient and Researcher Eurordis Summer School (ExPRESS) 2015 and 2016 saw the inclusion academic researchers as participants for the first time.

# EURORDIS Membership Meeting

A capacity building annual event for rare disease advocates since 2002

Around Europe: Barcelona (2002), Namur (2003), Cork (2004), Venice (2005), Berlin (2006), Paris (2007), Copenhagen (2008), Athens (2009), Krakow (2010), Amsterdam (2011), Brussels (2012), Dubrovnik (2013), Berlin (2014), Madrid (2015), Edinburgh (2016), Budapest (2017)

- An opportunity for EURORDIS Members to:
  - Join Capacity Building Workshops in priority policy areas
  - Network
  - Be updated in main policy and emerging issues

# Patient Engagement

**Therapeutic Action Group (TAG) volunteers:**

- COMP
- PDCO
- CAT
- PCWP

**Policy Action Group (PAG)**

- The Network of European Federations of rare diseases
- The Network of National Alliances of rare disease patients' organisations of rare diseases
- EGAN - European Genetic Alliances' Network
- EURORDIS
- Observers

**European Commission Expert Group on Rare Diseases**

**Gabor Pogany: “…but if we are unable to enter through the door we enter through a window. We are the experts.”**

**Lesley Greene:“advocates need to be:-nurtured, guided, protected, vigilant, resilient, and diligent, but allowed to maintain individuality to preserve grass roots vision and energy within the corporate One Voice mission”**

**Dorica Dan: “If you want to be fast, go alone but, if you want to be efficient, find partners and build things step by step.”**

**François Houÿez:"To take part in the decision making when these decisions can affect our lives, we need to continuously demonstrate our credibility, trustworthiness, and to act in full transparency. This is already the case today, it will be even more the case with new partners in the future."**