

SOME OF OUR ACHIEVEMENTS

- Contribution to the adoption of **EU regulations** on **Orphan Medicinal Products** (1999), **Paediatric Drugs** (2006) and **Advanced Therapy Medicinal Products** (2007)
- Contribution to the **EU Commission Communication on Rare Diseases** (2008), the **EU Council Recommendation on an action in the field of rare diseases** (2009) and the **EU Directive on Patients' Rights in Cross-Border Healthcare** (2011)
- Promotion of rare diseases as an **EU public health priority**
- Promotion of **national rare disease plans** in EU Member States and other countries
- Promotion of rare diseases as a **priority in the EU Research Framework Programme**
- Contribution to bringing a significant number of rare disease products to market (**over 1,800 orphan designations** and over 130 orphan medicinal products)
- Organisation of the **European Conference on Rare Diseases & Orphan Products** (ECRD), held every two years since 2001
- Creation and coordination of the international campaign **Rare Disease Day**, held since 2008 in over 100 countries and regions
- Training of **700+ patient representatives and researchers** from 50+ countries through the EURORDIS Open Academy
- Crucial role in establishment and development of the **24 European Reference Networks** (ERNs) and creation of **24 European Patient Advocacy Groups** (ePAGs) involving around **300 ePAG patient advocates**



OUR MISSION

“ EURORDIS works across borders and diseases to improve the lives of all people living with a rare disease ”

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EURORDIS is supported by its members, the AFM-Téléthon, the European Commission, foundations and the health industry. EURORDIS was founded in 1997.



The Voice of
PEOPLE WITH RARE DISEASES
in Europe



“ Empower, partner, and advocate for people living with a rare disease ”

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EURORDIS – Rare Diseases Europe is a unique, non-profit alliance of over 1000 rare disease patient organisations from 74 countries that work together to improve the lives of over 30 million people living with a rare disease in Europe.

By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

WHO WE ARE

RARE DISEASES

OVER 6000
distinct rare diseases

Each one affects fewer than
1 IN 2000 PEOPLE



All together, an estimated

30 MILLION PEOPLE are living with a rare disease in Europe and

300 MILLION worldwide

Affects between **3.5 % AND 5.9%** of the population in the course of their lives

NO CURE for the vast majority of diseases and few treatments available



OUR MEMBERS

Over 1000 member patient organisations from 75 countries



ADVOCATE

We advocate for policies and innovative solutions driven by the needs of people living with rare diseases.

- Our advocacy is fuelled by real-life experiences of the rare disease community through the EURORDIS Rare Barometer programme.



PARTNER

We establish and facilitate networks with strategic partners and key stakeholders, including, but not limited to, policy makers who support active and meaningful engagement with people living with rare diseases.



EMPOWER

We empower organisations and advocates representing people living with rare diseases across all rare diseases and all European countries, by equipping them with the knowledge and skills they need to fight for better lives.



PEOPLE FIRST

EURORDIS.ORG

OUR INITIATIVES



Patient capacity-building training programme



EURORDIS' survey initiative



EURORDIS Round Table of Companies (ERTC)



The European Conference on Rare Diseases & Orphan Products



EURORDIS' annual awards ceremony



The global campaign to raise awareness of rare diseases



Rare Disease Week