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 500+ patient representatives and researchers from 45+ 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 200 ePAG patient advocates

Our Mission

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

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Enews

Sign up to receive our news at eurordis.org/enews

Who We Are

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 800 rare disease patient organisations from more than 70 countries that work together to improve the lives of the 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.

Rare Diseases

Over 6000 distinct rare diseases

Each one affects fewer than 1 in 2000 people

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

Over 30 million people are living with a rare disease in Europe and 300 million worldwide

EURORDIS is supported by its members, the AFM-Téléthon, the European Commission, foundations and the health industry. EURORDIS was founded in 1997.
We advocate to ensure that healthcare and social policies and services, research, and the development of medicines take into account the real needs of people living with a rare disease and their families. Our advocacy is fuelled by real-life experiences of the rare disease community.

Advocating for patients

Engaging patients

We make possible the engagement of patients in decision-making processes so that the patient voice is active, amplified and meaningful in research and medicines development, as well as in both healthcare and social policies and services.

Empowering patients

By uniting the rare disease community and building the capacities of patients, we empower them to become advocates equipped with the knowledge and skills needed to fight for better lives.

Patients First

OVER 800
MEMBERS

Our initiatives

- EURORDIS Open Academy
- EURORDIS survey initiative
- Rare Barometer Voices
- RareConnect

Our members

Over 800 member patient organisations from 70+ countries

EURORDIS survey initiative

The online network for rare disease patients & families

The European Conference on Rare Diseases & Orphan Products

The global campaign to raise awareness of rare diseases

RareDiseaseDay.org

The global alliance of people living with a rare disease

Making rare diseases a global public health priority

Rare Diseases International

NCP Committee for Rare Diseases

EURORDIS.org