

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 94 countries and regions
- ▶ Training of **400 patient representatives and researchers** from 40+ countries through the EURORDIS Summer School
- ▶ Crucial role in establishment and development of the **24 European Reference Networks** (ERNs) and creation of **24 European Patient Advocacy Groups** (ePAGs) involving around **1,000 patient organisations** and **200 ePAG patient representatives**



OUR MISSION

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

CONTACT

eurordis@eurordis.org
+33 (0)1 56 53 52 10
eurordis.org

ENEWS

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



The Voice of
RARE DISEASE PATIENTS
in Europe



WHO WE ARE

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 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



All together, an estimated

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

300 MILLION
worldwide

Affects between
6% AND 8%
of the population in the course of their lives



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



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



Co-funded by the Health Programme of the European Union

« Better lives and cures for people living with a rare disease »

EURORDIS.ORG



OUR MEMBERS



Over **700** member patient organisations from **60+** countries



ADVOCATING FOR PATIENTS

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.



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



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.

EURORDIS.ORG

OUR INITIATIVES



EURORDIS Open Academy



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



The global alliance of people living with a rare disease



NGO COMMITTEE FOR RARE DISEASES

Making rare diseases a global public health priority