

# 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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Graphic Design www.fabiennall.com



The Voice of  
**RARE DISEASE PATIENTS**  
 in Europe



“ Better lives and cures for people living with a rare disease ”

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# WHO WE ARE

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 800 rare disease pa-tient 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



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 800 member patient organisations from 70+ 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.



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

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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



Making rare diseases a global public health priority