Eurordis - Rare Diseases Europe

EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated **to improving the quality of life of all people living with rare diseases in Europe**. It was founded in 1997; it is supported by its members and by the French Muscular Dystrophy Association (AFM), the European Commission, corporate foundations and the health industry.

EURORDIS represents **more than 290 rare disease organisations in 33 different countries** (of which 26 are European member states), covering more than **1,000 rare diseases**. It is therefore the voice of **30 million patients** affected by rare diseases throughout Europe.

EURORDIS is a not-for-profit organisation with a stringent financial transparency policy and good governance practices.

A rare disease is a disease affecting less than 1 in 2,000 citizens (in Europe).

Eurordis' Mission

- To build a strong **pan-European community** of patient organisations and people living with rare diseases;
- To be their **voice at the European level**; and – directly or indirectly – **to fight** against the impact of rare diseases on their lives.

Work priority areas

- Build the community: networking & empowering rare disease patient organisations
- Patients' voice: advocating & raising awareness
- Public health & health care policy
- Therapeutic development & research
- Funding & organisation

Eurordis is present

In European Institutions:

- Committee for Orphan Medicinal Products (COMP) at the European Medicines Agency (EMEA)
- COMP Working Group with Interested Parties (EMEA)
- Patients and Consumers Working Party (EMEA)
- Rare Disease Task Force (DG Health and Consumer Protection – European Commission)
- EU Health Policy Forum (DG Health and Consumer Protection)

In European Platforms:

- European Patients' Forum (EPF)
- European Forum for Good Clinical Practice (EFGCP)
- European Platform for Patients' Organisations, Science, and Industry (EPPOSI)
- International Alliance of Patients' Organizations (IAPO)
- EFPIA Think Tank
- Pan-European Blood Safety Alliance (PBSA)




ACHIEVEMENTS

Networking and Information sharing

- More than 290 members in 33 countries;
- Website in 6 languages;
- Monthly e-newsletter in 6 languages;
- More than 400 patient organisations and 120 volunteers have taken part in Eurordis' activities in 2006;
- Organisation of the European Conference on Rare Diseases (Denmark 2001, France 2003, Luxemburg 2005, Portugal 2007);
- Creation of the Council of National alliance of rare disease patient groups;
- Organisation of annual membership meetings (Ireland 2004, Italy 2005, Germany 2006, France 2007)

Advocacy and Policy Development

- Contribution to the adoption of the EU Regulation on Orphan Medicinal Products in 1999;
- Contribution to the adoption of the EU Regulation on Paediatric Drugs in 2006;
- Contribution to the adoption of the EU Regulation on Advanced Therapy Medicinal Products in 2007;
- Contribution to the promotion and maintenance of rare diseases as a EU public health policy priority;
- Contribution to the promotion and maintenance of rare diseases as a priority in the EU Research Framework Programmes.

Access to Information, Diagnosis, Treatment and Care

- Guidelines to support creation and management of rare disease patient groups and information services;
- Scientific surveys on access to care (6 rare diseases, 50 organisations, 17 countries), and delay in diagnosis (8 rare diseases, 70 organisations, 17 countries, 6000 respondents);
- Pilot training sessions on clinical trial protocols (12 sessions, 170 people, 137 associations), internet information searching (6 sessions, 100 people, 58 associations), patient databases and registries (4 sessions);
- 4 surveys on patient access to orphan drugs in the EU;
- Mapping of rare disease patient organisations' profiles and activities in Europe;
- Development of the Eurordis Charter for Clinical Trials in Rare Diseases;
- Development of the Eurordis Charter for Patients' Discussion Lists.

Therapeutic Development and Research

- Contribution to the designation of more than 470 orphan drugs, by participating in the Committee on Orphan Medicinal Products (COMP);
- Contribution to transparent and quality information on medicines for patients, by participating in the European Medicines Agency PCWP;
- Creation of a European network of rare disease Biological Resource Centres (EuroBioBank) for DNA, cells and tissue;
- Contribution to obtaining EU funding for rare disease research projects;
- 31 pharmaceutical companies members of the Round Table of Companies;
- Proceedings of workshops: "Patient access to compassionate use", "Alternative methodologies in clinical trials"; "Relations between sponsors and patient organisations in rare disease clinical trials" etc.

The Rare Disease Platform

EURORDIS is a partner in the Rare Disease Platform, in Paris, with:

- Alliance Maladies Rares
- GIS Institut des Maladies Rares
- Maladies Rares Info Service
- Orphanet

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