



BECOMING a MEMBER



OF EUORDIS

THE EUROPEAN ORGANISATION
FOR RARE DISEASES

eurordis.org



EURORDIS
Rare Diseases Europe

EURORDIS is the voice of rare disease patients in Europe. We federate over **600 PATIENT ORGANISATIONS** representing over **4000 RARE DISEASES** in **60 COUNTRIES**.

We are the voice of **30 MILLION PEOPLE** living with rare diseases in Europe.

Our strength is in numbers and in coordinating our actions. Together we represent a broad range of diseases and countries. This gives legitimacy to the network and increases our impact.

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EURORDIS is an outstanding and excellent example of a dynamic, collaborative organisation that helps people in all the European Union States to work together for the Rare Disease community.

Richard West (Behçets Syndrome Society, United Kingdom)

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EURORDIS
Rare Diseases Europe





WHAT DOES EURORDIS DO FOR THE RARE DISEASE COMMUNITY?



Advocating for you and with you

EURORDIS represents patients within European government institutions and advocates for policies which address the needs of patients and their families. We consult our membership and other stakeholders extensively in developing each advocacy action.

Building your community

EURORDIS brings the rare disease community together. We enable patients to share information and learn from each other. We facilitate platforms like the Council of National Alliances and the Network of European Federations, and services like RareConnect Online Patient Communities where the rare disease community can grow and thrive.

Shaping policies that take your needs into account

EURORDIS conducts surveys and manages projects that aim at giving patients a voice in the health care policy that affects them. Based on these, we propose policy measures and social services adapted to the situation and special needs of people living with rare diseases. We promote the sharing of good practices amongst our members.

Informing & Raising Awareness

Positive change for people living with rare diseases cannot happen if decision-makers, health professionals, researchers and the general public are not aware of rare diseases and what they mean.

EURORDIS uses its pivotal position in the rare disease community to inform, educate and raise awareness about rare diseases.

Working in partnership to advance Research

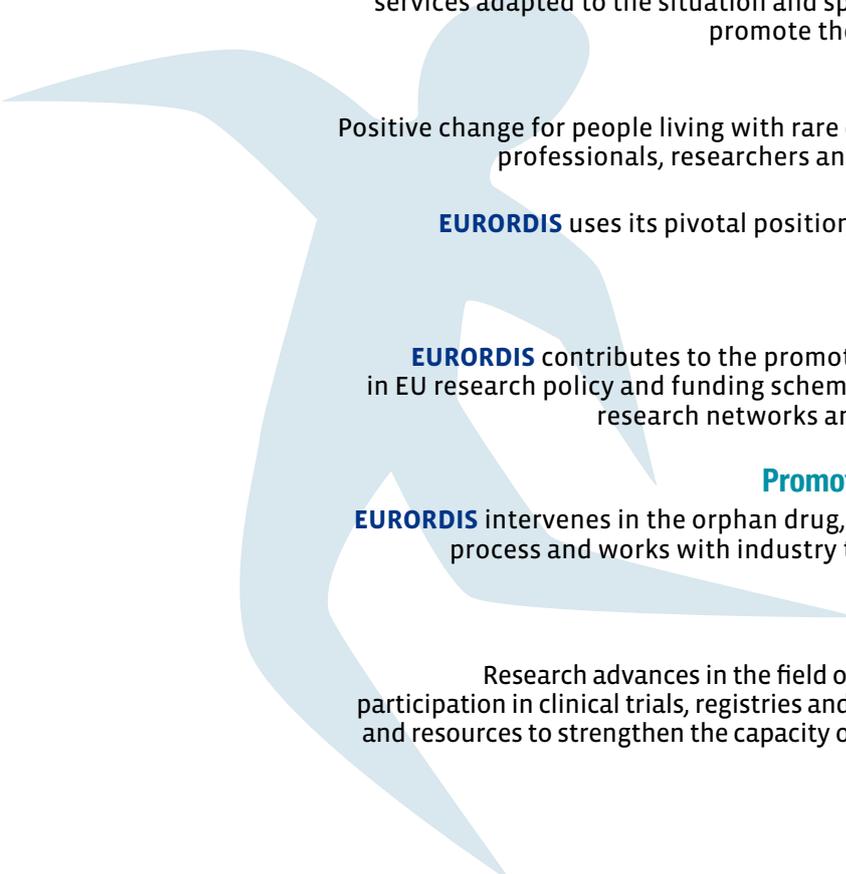
EURORDIS contributes to the promotion and maintenance of rare diseases as a priority in EU research policy and funding schemes. We defend the interest of patients in European research networks and empower patients in clinical research activities.

Promoting Drug Development & Access to Treatments

EURORDIS intervenes in the orphan drug, advanced therapies and paediatric-use regulatory process and works with industry to speed up the development and ensure the same availability of treatments in all EU countries.

Training patient advocates

Research advances in the field of rare diseases could not be possible without patient participation in clinical trials, registries and biobanks. **EURORDIS** provides training programmes and resources to strengthen the capacity of patients' representatives to advocate effectively in all aspects of therapy development.



WHY BECOME A MEMBER OF EURORDIS?

JOIN A VIBRANT PAN-EUROPEAN COMMUNITY OF DEDICATED PEOPLE FACING SIMILAR ISSUES AND STRENGTHEN THE VOICE OF PEOPLE LIVING WITH RARE DISEASES IN EUROPE AND BEYOND.



Membership Benefits

- ▶ Join a community of more than 600 patient organisations across the world
- ▶ Be represented at key European Institutions, such as the European Commission, the European Medicines Agency (EMA) and at all stakeholder forums
- ▶ Participate in the **EURORDIS** Membership Meeting, conference and capacity building workshops
- ▶ Be listed on the **EURORDIS** website with a direct link to your website
- ▶ Preferential registration rates to the European Conference on Rare Diseases & Orphan Products (ECRD)
- ▶ Post your news and announcements on the **EURORDIS** website
- ▶ Participate in training sessions, such as the **EURORDIS** Summer School for Patient Advocates in Drug Development, Clinical Trials & Regulatory Affairs
- ▶ Privileged access to fellowships to attend conferences such as the European Conference on Rare Diseases & Orphan Products (ECRD)
- ▶ Set up an online patient community for your disease through rareconnect.org
- ▶ Be a privileged Rare Disease Day participant (last day of February each year, rarediseaseday.org)
- ▶ Vote at the General Assembly (Full members only)
- ▶ Be elected to the Board of Directors of **EURORDIS** (Full members only)



EURORDIS is the most important organisation representing people with rare conditions in Europe. It has excellent contacts within the European Union, where it is a respected advocate and has patient representatives on the key committees relevant to rare disease therapy development at the European Medicines Agency... It is also extremely helpful as a source of information and networking. Those of us who are already members know just how valuable EURORDIS is, both in helping to set the international agenda and as an important source of information and support nationally.

John Dart (Debra International)



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From the start of our patient organisation, EURORDIS has provided us with a very professional structure of support. EURORDIS colleagues were of invaluable help in our advocacy battle for new medicines for the multiple myeloma patients.
Greetje Goosens (EMP, European Myeloma Platform)

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WHAT IS REQUIRED OF YOUR ORGANISATION?

- ▶ Nominate a contact person (English speaking if possible) who will be the primary link with **EURORDIS**
- ▶ Pay the annual membership fee (see page 7 for details)
- ▶ Keep us informed of changes in your organisation (Board of Directors, contacts, funding, financial data, etc) and send your annual reports

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Thank you for the opportunity to be involved, make friends, be treated like normal and especially for the fact that you help us go beyond the pain of our conditions and bring out the best in us, transforming a tragedy into a cause...

Camelia Lazar (Williams Association, Romania)

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HOW CAN YOU PARTICIPATE?

- ▶ Attend the **EURORDIS** Membership Meeting and European Conference on Rare Diseases & Orphan Products (ECRD)
- ▶ Take part in some of our projects
- ▶ Participate in regular surveys
- ▶ Contribute to **EURORDIS'** strategic orientations through its position papers, Committees and Policy Task Forces
- ▶ Put forward candidates (patients or medical experts on your disease) for European Medicines Agency committees or meetings
- ▶ Be a candidate for the **EURORDIS** Board of Directors (Full members only)
- ▶ Vote at the General Assembly (Full members only)

WHO CAN APPLY?

Patient organisations:

- ▶ That are rare disease organisations according to EU prevalence criteria (5/10 000) as defined in the: EU Regulation on Orphan Medicinal Products (1999), Commission Communication on Rare Diseases (2008), Council Recommendation on an Action on Rare Diseases (2009), and Directive on Patients' Rights in Cross-Border HealthCare (2011)
- ▶ From a European country (48 countries as defined by EURORDIS based on definitions by the EU, the Council of Europe and the WHO-Europe)
- ▶ With governing boards made up of a majority of rare disease patients or of family members of patients
- ▶ That are financially independent, particularly from the pharmaceutical industry (max. 50% of funding from several companies)
- ▶ Holding non-profit status
- ▶ With proven activities such as patient support and/or advocacy activities and/or research

Patient organisations that have been created recently (less than 1 year ago) are invited to apply for full membership, but will qualify for a provisional status as **“associate member”**. After one year, and upon examination of their first annual report or other documents provided to show activities and proof of compliance with the membership rules, their membership status can be revised by the Board of Directors.

One or all of these criteria can be waived in exceptional cases, due to the particularity of patient-driven organisations and of rare diseases, as well as for historical or contextual reasons. In all cases, the Board of Directors makes the final decision regarding membership and is not obliged to disclose the reasons of this internal decision, which are recorded in the minutes of the Board meeting.

Rare disease organisations from countries outside of Europe or those exclusively dedicated to diseases with a higher prevalence than 5/10 000 can become **associate members**.

Annual review process for regular re-assessment of FULL Members

A self-reported update form and request for an annual report & composition of the Organisation's Board of Directors is sent to the following organisations every year:

1. Member organisations that present a candidate to the EURORDIS Board elections
2. National Alliances & European Federations
3. Full members that joined EURORDIS 10 years before the year of the last update
(all full members that joined before December 2013 were sent the reassessment form in 2014)

HOW DO YOU APPLY?

To apply for membership, simply complete and return the membership application form with the following documents:

- ▶ Statutes of your organisation
- ▶ The names of your Board of Directors, indicating for each person whether they are patients or family members of patients
- ▶ Your most recent Annual Report (including the financial statement)
- ▶ A short description of your main activities and goals (in English if possible)
- ▶ Publications and/or educational materials (if available)



WHO IS YOUR CONTACT?

- ▶ Anja Helm, Senior Manager, Relations with Patient Organisations
EURORDIS
96 rue Didot 75014 Paris FRANCE
Tél: +33 (0)1 56 53 52 17 Fax: +33 (0)1 56 53 52 15
Email: anja.helm@eurordis.org

HOW DO YOU KNOW IF YOU HAVE BEEN APPROVED?

Once we have received all the relevant information, your application will be examined by our staff and submitted at the next Board of Directors or Board of Officers meeting.

- ▶ If the application is approved by the Board of Directors, your organisation receives a welcome e-mail and the EURORDIS member logo. The applicant organisation is officially a member of **EURORDIS** once the first annual membership fees have been received.
- ▶ If the application is rejected by the Board of Directors, the organisation receives a notification letter from the President.

MEMBERSHIP FEES

Full membership fees are based on your organisation's annual budget (previous year):

Annual budget	Full membership fee
Less than 10,000 euros	25 euros
Between 10,000 and 99,000 euros	75 euros
Between 100,000 and 499,000 euros	200 euros
Between 500,000 and 999,000 euros	600 euros
Over 1,000,000 euros	1,250 euros

Associate membership fees are independent of your organisation's budget.

Associate membership fee	25 euros
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Membership fees are annual and renewed every January.
The amounts of the fees are decided by the General Assembly.

JOIN US NOW!



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This publication has been funded with support from the European Union's Health Programme and by the Association Française contre les Myopathies - Téléthon (AFM). This material only reflects the views of the author, and funders cannot be held responsible for any use which may be made of the information contained herein.