BECOME A MEMBER

The Voice of Rare Disease Patients in Europe

"Better lives and cures for people living with a rare disease"

EURORDIS.ORG
EURORDIS 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, we strengthen the patient voice and shapes research, policies and patient services.
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.

**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.

**Advocating for Patients**

Our initiatives focus on ensuring that patients’ voices are heard and their needs are met.
7 REASONS
TO BECOME A MEMBER OF EURORDIS

1. **BE PART OF A STRONG AND GROWING RARE DISEASE COMMUNITY**

Join a worldwide network of over 800 EURORDIS members. Connect with other rare disease patients, and also policy makers, healthcare providers, researchers and industry through EURORDIS initiatives including Rare Disease Day, the online portal Rare-Connect, trainings and events including the EURORDIS Summer School, as well as workshops held for the EURORDIS Round Table of Companies. Be part of an international movement, connected to global initiatives like the NGO Committee for Rare Diseases and Rare Diseases International.

2. **NETWORK WITH PEERS FROM AROUND THE WORLD**

Network with other people living with a rare disease, families and carers from across Europe and the world through the annual EURORDIS Membership Meeting, member capacity-building workshops and webinars. Benefit from preferential registration rates for the European Conference on Rare Diseases & Orphan Products, attended by over 800 participants.

3. **TRAIN TO BECOME AN EMPOWERED PATIENT ADVOCATE AND BUILD YOUR ORGANISATION’S CAPACITIES**

Participate in EURORDIS Open Academy trainings including the EURORDIS Winter School on Scientific Innovation and Translational Research. Build your knowledge in the areas of research and medicines development so that you and your organisation become empowered to make your voice heard. Gain the expertise needed to gain the respect of policy makers, industry representatives and researchers.

4. **INFORM AND SHAPE EUROPEAN ACTIONS AND POLICIES ON RARE DISEASES**

Participate in EURORDIS taskforces and working groups such as the Drug Information, Transparency and Access (DITA) Task Force, Health Technology Assessment Task Force and Social Policy Advisory Group (SPAG) to voice your opinion and shape EU policies that affect rare disease patients and families across Europe.

Participate in consultative webinars to contribute to EURORDIS position papers.

EURORDIS members also receive the monthly report of the EURORDIS Therapeutic Action Group (TAG), which provides the link between volunteers who participate in the scientific committees at the European Medicines Agency (for example, the Committee for Orphan Medicinal Products and the Patients’ and Consumers’ Working Party) to ensure the patient voice is taken into account in the development of orphan medicines.
EURORDIS members guide healthcare and research policies, for example by participating in the research project RD-Connect. They ensure the patient voice is present and heard in projects on important topics including biobanks, registries, data storing and protection, health technology assessment, diagnosis and clinical trials.

Members also participate in the European Patient Advocacy Groups (ePAGs), which facilitate active engagement of patients in the European Reference Networks (ERNs). Launched in 2017, the ERNs are networks of centres of expertise and researchers across Europe that allow rare disease healthcare expertise to travel, so the patient doesn’t have to. EURORDIS members who participate in ePAGs ensure that the needs of patients are taken into account in the development and governance of ERNs.

EURORDIS members also benefit from the EURORDIS EUROCAB Programme, through which EURORDIS provides support to patient organisations to set up and run a Community Advisory Board (CAB). A CAB is a group of patients who offer their expertise to sponsors of clinical research and helps to ensure clinical research is designed and carried out taking into account the patient’s view.

The EURORDIS Rare Barometer Survey Programme runs surveys and then provides results to EURORDIS members. Over 8,000 Rare Barometer Voices (patients, carers and family members) respond to surveys on the topics that matter most to the rare disease community. The results are then sorted by country and disease and provided to participants to use in their advocacy work.

Elevate the cause of your disease in the rare disease community at large. Through webinars, capacity-building programmes, events and online communication, EURORDIS members have direct access to EURORDIS team members’ expertise on rare disease medicines, health and social care, and research.
EXCLUSIVE BENEFITS
FOR EURORDIS MEMBERS

Participate in the annual EURORDIS Membership Meeting and free member capacity-building workshops.

Stay up to date with rare disease news through our bi-monthly Member News, available in 7 languages.

Participate in EURORDIS Open Academy trainings including the EURORDIS Winter School, Summer School and Digital School.

Become a member of a EURORDIS taskforce or working group and give your opinion to shape EU rare disease policy, including the Drug Information, Transparency and Access (DITA) Task Force, the Social Policy Advisory Group (SPAG) and the Therapeutic Action Group (TAG).

Benefit from the support of the EURORDIS EUROCAB Programme to create and run a Community Advisory Board (CAB) for your disease.

Have privileged access to fellowships for EURORDIS events and preferential registration rates for the European Conference on Rare Diseases & Orphan Products (ECRD).

Promote your organisation’s activities and events through the EURORDIS eNews, website in 7 languages and social media and be listed on EURORDIS website with a link to your website.

Guide EURORDIS’ organisational strategy by voting at the EURORDIS Annual General Assembly (full members only).

Run for election to the EURORDIS Board of Directors (full members only).
Our intuitions became certainties, our doubts found answers, our will to learn found mentors, and our desire to share and suggest found careful listeners. EURORDIS is our community and home, a place to move forward faster by being together. The networking and training opportunities we have gained through EURORDIS events and workshops have been very valuable.

Claudia Crocione, Project & Communication Manager of Italian patient group HHT Onlus and Managing Director of HHT Europe, the European Federation for Hereditary Hemorrhagic Telangiectasia, both EURORDIS member organisations.

Patient organisations can apply to become either a full or associate member of EURORDIS depending on the criteria they meet, as detailed in the application form.

Full membership fees are based on your organisation’s annual budget:

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The annual membership fee for associate members is 50€ and is independent of the organisation’s budget.

HOW TO APPLY

To apply to become a member, fill out the form at www.eurordis.org/content/become-member and send it to anja.helm@eurordis.org.

"We became a member of EURORDIS and suddenly our horizons expanded."
EURORDIS works across borders and diseases to improve the lives of people living with a rare disease.

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

Get in touch

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