



The Voice of Rare Disease Patients in Europe

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BECOME A  
**MEMBER**

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

**EURORDIS.ORG**



## JOIN A THRIVING COMMUNITY OF OVER 800 PATIENT ORGANISATIONS ACROSS EUROPE!

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.

### OUR MEMBERS

Over

**800**

member patient  
organisations from

**70+**

countries



● Disease-specific  
patient organisations

● National rare disease alliances

● European federations

● International federations  
and alliances





THE VOICE OF  
RARE DISEASE  
PATIENTS IN  
EUROPE



## 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.



## 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.



## PATIENTS FIRST

## OUR INITIATIVES



RARE  
DISEASES  
INTERNATIONAL



NGO COMMITTEE FOR  
RARE DISEASES

# 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.



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## PARTICIPATE IN HEALTHCARE AND RESEARCH PROJECTS THAT BRING ABOUT CHANGE FOR RARE DISEASE PATIENTS



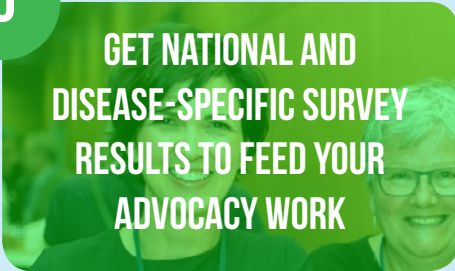
EURORDIS members guide **healthcare** and **research** policies, for example by participating in the research project RD-Connect. They ensure the patient voice is present and heard in projects on important topics including biobanks, registries, data storing and protection, health technology assessment, 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.

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## GET NATIONAL AND DISEASE-SPECIFIC SURVEY RESULTS TO FEED YOUR ADVOCACY WORK



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.

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## ACCESS AND SHARE EXPERTISE ON THE TOPICS THAT MATTER TO YOU



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.



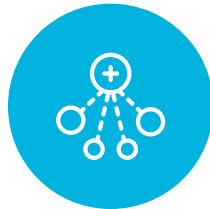
Stay up to date with rare disease news through our bi-monthly Member News, available in 7 languages.



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.



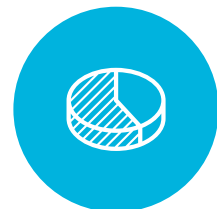
Have privileged access to fellowships for EURORDIS events and preferential registration rates for the European Conference on Rare Diseases & Orphan Products (ECRD).



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).



## WE BECAME A MEMBER OF EURORDIS AND SUDDENLY OUR HORIZONS EXPANDED.



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.

## HOW TO APPLY

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.



To apply to become a member, fill out the form at [www.eurordis.org/content/become-member](http://www.eurordis.org/content/become-member) and send it to [anja.helm@eurordis.org](mailto:anja.helm@eurordis.org)

Membership fees are based on your organisation's annual budget:

Income €	Fee €
<5.000	25
5.000 - 10.000	50
10.000 - 99.999	100
100.000 - 249.999	200
250.000 - 499.999	400
500.000 - 749.999	600
750.000 - 999.999	1000
1.000.000 - 2.999.999	1250
3.000.000 - 4.999.999	2000
5.000.000 - 19.999.999	5000
>20.000.000	10.000



### OUR MISSION

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

**EURORDIS.ORG**

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**GET IN TOUCH**

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



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