



Membership Information

Rare Diseases International brings together umbrella rare disease patient organisations from around the world

Rare Diseases International aims to be the global voice of people living with rare disease

Rare Diseases International is an initiative launched & coordinated by

EURORDIS- Rare Diseases Europe

Rare Diseases International's objectives are:

- To promote Rare Diseases as an International Public Health priority through public awareness and policy
- To represent its members and people living with rare diseases internationally
- To enhance capacities of RDI members

Why become member of Rare Diseases International?

- Join a community of Rare Disease Alliances across the world
- Be represented at key international institutions
- Develop and advocate for common positions
- Share experience and information internationally
- Participate in the annual RDI meeting
- Be listed on the RDI website with a direct link to your website

What is required of your organisation?

- To adhere to the Mission Statement, sign the 'Mutual Understanding' and submit a well-informed membership application
- To provide a contact person and provide an Annual Activity & Financial Report, list of Board Members and list of Members on an annual basis
- To be listed on Rare Diseases International website
- To contribute, review & sign up to policy documents
- To take part in Rare Disease Day
- To add the RDI logo on your website
- To be active in communication exchange and other actions from the beginning

Who can apply?

Only umbrella organisations are eligible for full membership:

- **National Alliances** for Rare Diseases worldwide
National Alliances federate patient organisations from a wide range of diseases within their particular country.
- **International Federations** for Rare Diseases worldwide
A Federation is the union of patient groups from several countries representing the same disease or the same group of disease.
- **Pan-regional networks** for Rare Diseases worldwide

Pan-regional organisations for rare diseases can gather national Rare Disease Alliances and other patient organisations from a geographical region

In exception cases, **a patient group with an international scope for an extremely rare disease** which is not an umbrella organisation, will be considered for full membership.

Membership Criteria for Full Membership

- ❖ Rare disease organisation, according to country definition (i.e. EU 5 / 10 000, US ≥ 200, 000 people)
- ❖ Non-profit status
- ❖ Legal status of the umbrella organization or one of its members
- ❖ Patient-driven (ie Governing Boards made up of a majority of patients and/or relatives, majority of voting members are patients)
- ❖ Financial transparency and diversified funding showing independence and minimisation of risk of conflict of interest
- ❖ Proven activity as a collective/umbrella organisation (ie. adopting common positions, joint actions, integrative services)

Membership Criteria for Associate Membership

- ❖ ≥ 1 year of existence
- ❖ International federations for common diseases that include rare diseases
- ❖ Single rare disease patient groups in a country where there is no National Rare Disease Alliance
- ❖ Single rare disease patient groups in one country with proven links with other same-disease group in at least 3 countries
- ❖ Non patient-driven organisations or professional organisations or other type of entity active in the field of rare diseases and contributing to the objectives of RDI by their mission and work

Pharmaceutical or biotech companies cannot be Association members

Associate members cannot be elected to or vote at the Council of RDI

Any criteria for full or associate membership can be waived at the discretion of the Council of RDI.

For more detailed information on Membership eligibility, rules and benefits, please refer to [RDI By-Laws](#).

How do you apply?

To apply for RDI membership, umbrella patient organisations are required to:

- Fill out an RDI Membership Application Form and send it to the RDI Secretariat, with:
 - Short description (in English) of the organisation's main goals & activities
 - Statutes/By Laws
 - List of Board members, indicating for each person if she/he is a patient or family of patient
 - List of member organisation (The members of the organisations applying for RDI membership will not be members of RDI directly but their names can be used by RDI for communication purposes.)
 - Most recent annual report
- Sign a "Mutual Understanding" that contains RDI's Mission Statement

The Council of RDI will process and approve applications on a rolling basis.

Membership fees are annual and renewed every January. The fees are based on your organisation's annual budget for the previous year.

Member Organisation's Annual Budget	RDI membership fee
≥ 1 000 000	500
500 000 - 1 000 000	250
200 000 – 500 000	200
100 000 – 200 000	150
20 000 – 100 000	100
≤ 20 000	50

- ❖ 20% reduction for 3-year membership
- ❖ Membership dues are voluntary for the first year of membership but **will be mandatory from there after**
- ❖ Waivers may be granted on a case by case basis by the Council

Payments should be made to:

EURORDIS - RARE DISEASES INTERNATIONAL
Plateforme Maladies Rares
96 rue Didot 75014 Paris – France

Account n°: 30004 02837 00010906870 94
SWIFT CODE: BNPAFRPPXXX
IBAN: FR76 3000 4028 3700 0109 0687 094

BNP PARIBAS

Bank address :

BDDF ENTREPRISES Ile de France Institutions

37-39, rue d Anjou 75008 Paris

PayPal: If you wish to pay using Pay Pal please send your payment to payment@rarediseasesinternational.org from your Paypal account.

Please specify the name of your organisation very clearly and indicate 'RDI Membership' in the bank transfer

For questions concerning Membership, please contact paloma.tejada@eurordis.org