

Rare Diseases International (RDI)

Membership

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

Rare Diseases International aims at being the global voice of people living with rare disease.

*Rare Diseases International is an initiative launched & coordinated by EURORDIS and the RDI Preformation Group**

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 on a dedicated online platform
- Participate in the annual RDI meeting
- Be listed on the RDI website with a direct link to your website
- Be a privileged Rare Disease Day participant (www.rarediseaseday.org)

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 & provide the list of their members
- 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 their website
- To be active in communication exchange and other actions from the beginning

Who can apply?

Only umbrella organisations are eligible:

- **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 given region, such as Asia-Pacific or Scandinavia.

Membership Criteria for full membership

- ❖ Rare disease organisation, according to EU prevalence criteria (5 / 10 000)
- ❖ The Governing Boards should be usually made up of a majority of rare disease patients or family of patients.
- ❖ Financial transparency and diversified funding showing independence and minimisation of risk of conflict of interest
- ❖ Non-profit status
- ❖ Proven activities such as patient support and/or advocacy activities and/or research

One, or all, of these criteria could be waived in exceptional cases, due to the particularity of patient-driven organisations, rare diseases or contextual reasons. The Council of RDI makes the final decision regarding membership, and is not obliged to disclose the reasons of this internal decision.

Associate membership: Patient organisations or any other entity contributing to the objectives of RDI by their mission and work. Associate members cannot be elected to or vote at the Council of RDI

Membership Reassessment: Every year, a self-reported update form and request for annual report & composition of the organisation's Board of Directors is requested from all members

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

Until a Council of RDI is elected, the RDI Pre formation Group will process and approve applications. The pre formation group is made of EURORDIS and National Alliances of the US (NORD), Canada (CORD), Japan (JPA), China (CORD), India (I-ORD), the pan regional network for IberoAmerica (ALIBER) and a disease-specific international federation (DEBRA International)

Voluntary Contributions

Contributions are annual and renewed every January. The fees are based on your organisation's annual budget. For 2015, the suggested voluntary contributions are as follows:

| Organisation's Annual budget in € | Annual RDI contribution in € |
|-----------------------------------|------------------------------|
| < 5000 | Fee waiver |
| 5000 – 10 000 | 50 |
| 10 000-100 000 | 100 |
| 100 000-1 000 000 | 250 |
| >1 000 000 | 500 |

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

For applications or questions concerning membership, please contact paloma.tejada@eurordis.org