



## Membership Information

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Rare Diseases International is the global alliance of people living with a rare disease of all nationalities across all rare diseases.

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's objectives are:

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

### Why become a member of Rare Diseases International?

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- Join a community of Rare Disease Alliances across the globe
- Be represented at key international institutions
- Develop and advocate for common positions
- Participate in the annual RDI meeting
- Be listed on the [RDI website](#) with a direct link to your website
- Become an official [Rare Disease Day](#) partner
- Share experience and information internationally

### What is required of your organisation?

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- To adhere to the Mission Statement, sign the 'Mutual Understanding' and submit a complete membership application
- To provide a contact person who will serve as RDI's main contact
- To be listed on Rare Diseases International's website
- To add the RDI logo on your website
- To contribute, review and sign up to policy documents
- To take part in Rare Disease Day
- To be active in communication exchange and other RDI initiatives

### Who can apply?

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RDI members are international, regional and national organisations for rare diseases. They may be:

- **National Alliances for Rare Diseases**

**National Alliances** federate patient organisations or patient advocates from a wide range of rare diseases within their particular country.

- **International Federations for Rare Diseases**

**International Federations** unite patient groups from several countries representing the same disease or the same group of diseases.

- **Regional Networks for Rare Diseases**

**Regional Networks** gather National Rare Alliances and other patient organisations from a geographical region

### Membership Criteria for Full Membership

- **Patient-driven** and patient-led (i.e. Governing Boards made up of a majority of patients and/or relatives, majority of voting members are patients)
- **Rare disease organisation** according to a recognised national or regional definition
- **Non-profit and non-governmental** organisation
- **Legal status** as an umbrella organisation or legal status through one of their members
- **Financial transparency** and diversified funding showing independence and minimisation of risk of conflict of interest
- Have **proven activity** as a collective/umbrella organisation

### Membership Criteria for Associate Membership

- **Non-profit and non-governmental** organisations demonstrating a commitment to rare disease
- Organisations that do not comply with all the criteria for full membership can become associate members.
- Patient organisations that have been recently created (less than 1 year) are invited to apply for “full membership”, but will qualify for a provisional status of “associate member”.

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

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

### How do you apply?

- Fill out the RDI Membership Application Form and send it to the RDI Secretariat at [hlawulani.mkhabela@rarediseasesint.org](mailto:hlawulani.mkhabela@rarediseasesint.org)
- Include the following documents with your application:
  - List of Board members with a short biography for each
  - List of member organisations (These members will not be members of RDI directly but their names can be used by RDI for communication purposes.)
  - Most recent annual report
- Sign a declaration of “Mutual Understanding”

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

### Membership Fees

Membership fees are annual and renewed every year. Fees are based on your organisation’s annual budget for the previous year.

Budget in €	Annual Membership Fees
Less than 20 000	50 €
Between 20 000 and 99 999	100 €
Between 100 000 and 199 999	150 €
Between 200 000 and 499 999	200 €
Between 500 000 and 999 999	250 €
More than 1 000 000	500 €

- 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

## How to make a payment?

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- online on this secure page:

<https://www.rarediseasesinternational.org/membership-fees/>

Payment may be made by credit card or on PayPal.

If your organisation is unable to make an online payment, please contact [Hlawulani Mkhabela](#) for bank transfer details.



For any questions concerning RDI Membership, please contact Hlawulani Mkhabela, RDI Outreach and Engagement Manager: [hlawulani.mkhabela@rarediseasesint.org](mailto:hlawulani.mkhabela@rarediseasesint.org)