

MEMBERSHIP OF RDI

Join a vibrant Irish community of dedicated people facing similar issues and strengthen the voice of people living with rare diseases in Ireland.

What is required of your organisation?

- Nominate a contact person who will be the primary link with RDI.
- Pay the annual membership fee (see below).
- Keep us informed of changes in your organization (Board of Directors, contacts, funding, financial data, etc) and send your annual reports.

Who can apply?

Patient organisations:

- Rare disease organisations according to EU prevalence criteria (5/10,000) as defined in the: EU Regulation on Orphan Medicinal Products (1999), Commission Communication on Rare Diseases (2008), Council Recommendation on an Action on Rare Diseases (2009), and Directive on Patients' Rights in Cross-Border HealthCare (2011).
- From the Republic of Ireland.
- With governing boards made up of a majority of rare disease patients or of family members of rare disease patients.
- That are financially independent, particularly from the pharmaceutical industry (max. 50% of funding from several companies).
- Holding non-profit status.
- With proven activities such as patient support and/or advocacy activities and/or research.

Patient organisations that have been created recently (less than 1 year ago) are invited to apply for Full Membership, but will qualify for a provisional status as “**Associate Member**”. After one year, and upon examination of their first annual report or other documents provided to show activities and proof of compliance with the membership rules, their membership status can be revised by RDI's Board of Directors.

Individuals:

At the discretion of the Board of Directors, Associate Membership may also be offered to individuals, or their family members, where formation of a patient organisation in Ireland is not practical.

Affected individuals must be resident in the Republic of Ireland and be diagnosed with a rare disease (as defined for Patient Organisations) or be suspected to have a rare disease which remains undiagnosed.

One or all of these criteria can be waived in exceptional cases, due to the particularity of patient-driven organisations and of rare diseases, as well as for historical or contextual reasons. In all cases, the Board of Directors makes the final decision regarding membership and is not obliged to disclose the reasons of this internal decision, which are recorded in the minutes of the Board Meeting.

Rare disease organisations from outside of the Republic of Ireland or those exclusively dedicated to diseases with a higher prevalence than 5/10,000 can become **Associate Members**.

Annual review process for regular reassessment of Full Members

A self-reported update form and request for an annual report & composition of the Organisation's Board of Directors is sent to the following organisations every year:

1. Member organisations that present a candidate to the RDI Board elections.
2. Full Members that joined RDI 10 years before the year of the last update (all Full Members that joined before January 2018 were sent the reassessment form in 2018).

How do you apply?

To apply for membership, simply complete and return the Membership Application Form (found on RDI's website) with the following documents:

- Constitution of your organisation.
- The names of your Board of Directors, indicating for each person whether they are rare disease patients or family members of rare disease patients.
- Your most recent Annual Report (including the financial statement).
- A short description of your main activities and goals.

How do you know if you have been approved?

Once we have received all the relevant information, your application will be examined at the next Board of Directors meeting.

- If the application is approved by the Board of Directors, your organisation receives a welcome e-mail and the RDI member logo. The applicant organisation is officially a member of RDI once the first annual membership fees have been received.
- If the application is rejected by the Board of Directors, the organisation receives a notification letter from the Chair.

Full Membership fees

Fees are based on organisation's annual budget (previous year). Fees are due for payment Jan 1 each year, and will be pro-rated in year of joining.

Budget (€)	Fees (€)
Less than 100,000	50
Between 100,000 and 499,999	250
Between 500,000 and 999,999	600
1,000,000 or more	1,000
<i>Associate Membership fees</i>	
Associate Members	25

Files to download

Membership Application Form

REVISION HISTORY

Draft 1 initial draft 17/04/18
 Draft 2 revised membership fees, formatting/logo and version control – 22/05/18
 Draft 3 update to include potential role in governance of RDI by Full Members, option for individuals to become Associate Members, remove membership benefits & participation (to be included in website)
 Rev 1.0 initial release
 Rev 2.0 revised membership fees; renewal date fixed Jan 1 each year.