

## MEMBERSHIP OF RDI

Join a vibrant 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.
- Get involved in RDI activities if and when you can – share your stories, raise awareness, attend meetings, input into position statements, support campaigns, etc.

### 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).
- Representing people living with rare diseases in Ireland.
- With governing boards made up of a majority of rare disease patients or of family members of rare disease patients.
- Be striving for or have achieved financial independence, 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.

There are two types of members: “Full Members” and “Associate Members”. Full Members must also be registered with the Charities Regulatory Authority in Ireland. All other eligible organisations will be classed as Associate Members.

All members have the right to receive notices of meetings of the Company (AGM, EGM) and to be represented at all such meetings. Only Full Members shall have the right to vote for Board members and to approve the annual accounts.

#### 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 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, as appropriate:

### **Patient organisations:**

- 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).

### **All (Individuals & patient organisations):**

- A short description of your main activities and goals or a statement of what you hope to achieve from RDI membership.

## 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, you/your organisation will be informed and invited to pay the relevant membership fee. The applicant 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, you/the organisation receives a notification.

### Full & Associate Membership fees

Fees are based on organisation's annual budget (previous year)

Budget (€)	Fees (€)
Individual ( <i>please feel free to use the donation button on our website if you would like to contribute to RDI</i> )	NA
Less than 100,000	50
Between 100,000 and 499,999	100
Between 500,000 and 999,999	250
1,000,000 or more	500

## 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 | Associate members includes any relevant group not registered with CRA & individual membership   |