

## Rare Diseases Ireland Round Table of Companies (RDI-RTC)

## **MEMBERSHIP BENEFITS**

The patient is at the centre of all of our efforts – nothing about us without us!

Why are we establishing the RDI-RTC?

To establish a long-term relationship between RDI and industry, putting the patient at the centre of this relationship:

- To stimulate companies to discover and address patients' needs.
- To support companies working with patient groups.
- To explore opportunities for collaboration between RDI and industry to meet the needs of the patient community.
- To promote open and frank interchange of information, in a neutral forum.
- To ensure transparency in RDI's relationship with industry.

To provide vital financial support to RDI (via industry membership fees of the RDI-RTC) for unrestricted funding for activities of common interest and benefit:

- Improving access to information for people living with rare diseases.
- Raising public awareness on rare diseases.
- Empowering rare disease patient groups and their advocacy capacity.
- Networking rare disease patient groups nationally and internationally.
- Providing secretariat to Oireachtas cross-party group on rare diseases.
- Conducting research into the lived experience of people living with rare diseases.
- Representing the voice and experience of people living with rare diseases in discussions and working groups such as HSE's National Rare Diseases Office, HSE's National Genetics & Genomics Office, Department of Health's National Rare Diseases Strategy Steering Committee.