

RDI Board Statement

RDI Vision, Mission & Strategy 2022 to 2025

Rare Diseases Ireland (RDI) is the national alliance for rare disease patient organisations in Ireland, working across all rare diseases to improve the lives of the estimated 300,000 people living with rare diseases in Ireland.

We advocate for, empower and engage organisations and advocates, as well as people living with rare diseases, their carers and their families, to mobilise together with a strong voice to shape policies and solutions driven by the needs of all people living with rare diseases.

Our vision is a country where all people living with rare diseases live longer and better lives, reaching their full potential, and are included in a society that leaves no one behind. This means we want equity for people living with rare diseases in Ireland – equitable access to diagnosis, treatment, health and social care and opportunity.

Our mission is to improve the lives of all people living with rare diseases and their carers and families.

Our strategy is to

- **Empower** organisations and individuals across all rare diseases to advocate for themselves and their communities, by providing them with the knowledge and skills to demand better lives for people living with rare diseases.
- **Engage** organisations and individuals to ‘take a seat at the table’ and get involved by providing them with opportunities to advocate on their own behalf and on behalf of everyone living with rare diseases. This means giving individuals and groups the opportunity to advocate:
 - on their own behalf in areas such as healthcare where individual rare conditions have very specific needs or reimbursement of specific therapies.
 - for the entire rare community in areas such as access to genetic services, drug reimbursement policy, genetic discrimination, education, etc.
- **Advocate** for national and international policies and solutions driven by the needs of people living with rare diseases – we are the voice of people living with rare diseases in Ireland on the domestic and international stage.

We deliver our strategy by bringing together networks of stakeholders to exchange experiences, share best-practice and develop evidence to support our drive to improve the lives of people living with rare diseases, always keeping the voices of people living with rare diseases central to all our work.



Our Core Values are empathy, understanding, partnership, professionalism and integrity.

Our Strategic Objectives are:

- Grow awareness of people living with rare diseases in Ireland – bring the rare community together with a single strong voice that is heard across all levels of policy and by all decision makers.
- Build RDI as a strong and compliant organisation that is recognised as the united voice of people living with rare diseases in Ireland. Provide a home for all people living with rare diseases in Ireland, not just those represented by established patient organisations.
- Create networks of member organisations, advocates and people living with rare diseases and their carers and families to identify and capture the voices of people living with rare diseases. Hear the voices of the 300,000 people living with rare diseases in Ireland.
- Conduct research to demonstrate that the needs of people living with rare diseases in Ireland are unmet and to provide a tool against which progress can be measured into the future.
- Promote and facilitate the implementation of national and international policies and frameworks to improve the lives of people living with rare diseases and provide equitable access to diagnosis, treatment, health and social care and opportunity.

Our Operational Objectives are:

- Build diverse source of increased funding for RDI to enable RDI team to be filled out (beyond 0.6-0.8 FTE), thereby providing the organisation with the human resource capacity to achieve its strategic objectives.

Our Key Achievements 2019-2022 are:

- Rare Diseases highlighted as priority area in Programme for Government (2020)
- Secured Ireland's support for UN Resolution on people living with rare diseases (2021).
- Raised awareness through publication of proprietary rare disease research, Rare Disease Day campaigns and events, meetings with elected representatives, policy makers and HSE leadership, and engagement with media.
- Prioritised care and access for people with rare diseases during COVID pandemic
- Secured funding to allow employment of one part-time employee (CEO).

Approved at RDI Board meeting 09-22 for presentation at 10-22 AGM.