



The International Rare Diseases Research Consortium (IRDiRC)



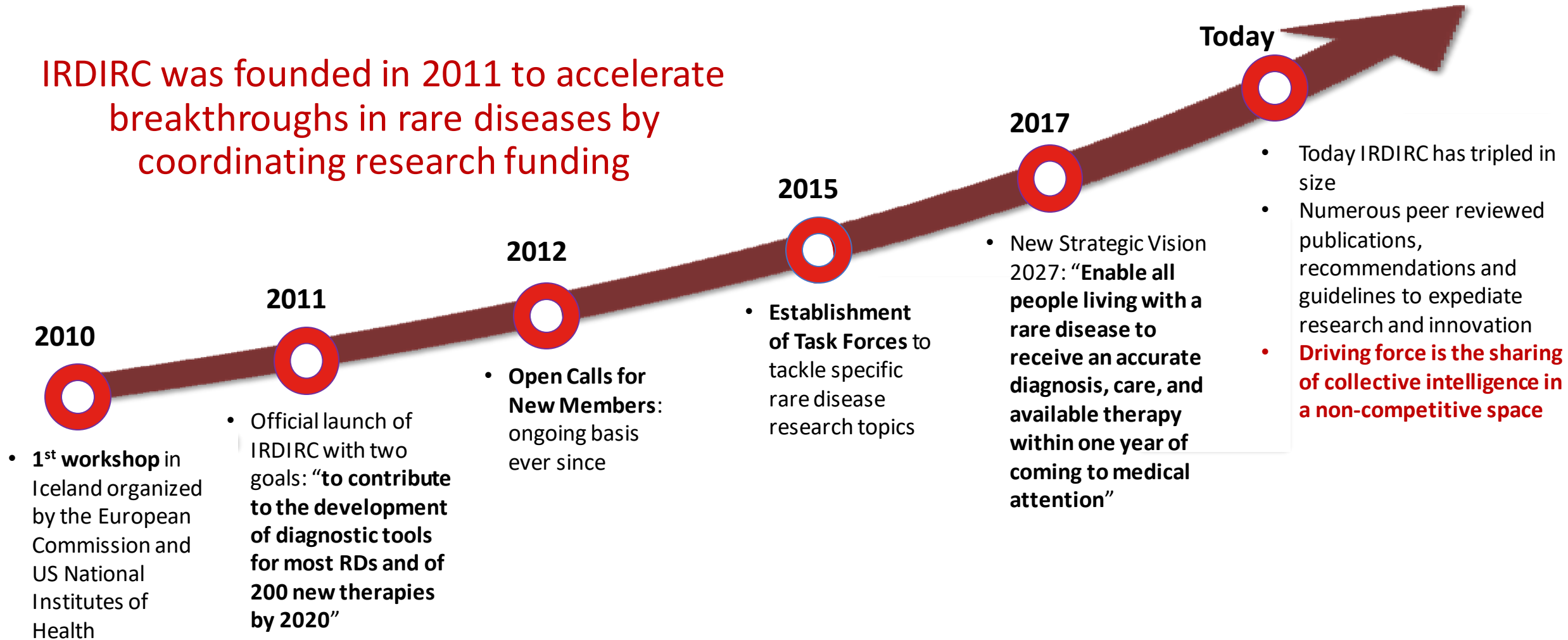
The Scientific Secretariat of IRDiRC is supported by the European Union through the European Joint Programme on Rare Diseases under the European Union's Horizon 2020 Research and Innovation Programme Grant Agreement N°825575.

International Rare Diseases Research Consortium

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- Vision and Goals
- Members
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History

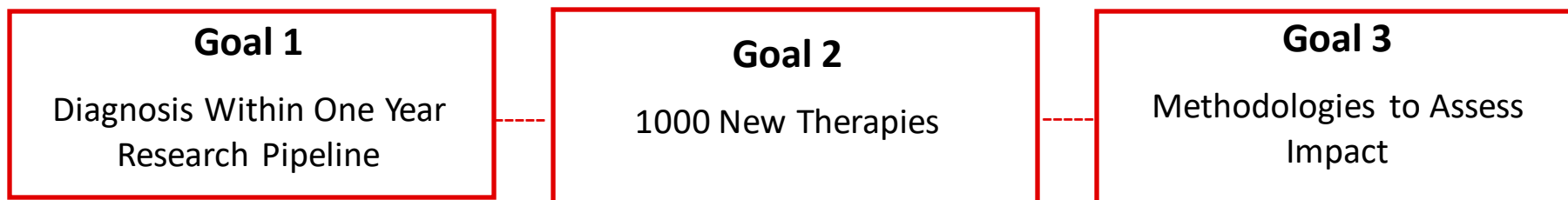
IRDIRC was founded in 2011 to accelerate breakthroughs in rare diseases by coordinating research funding



IRDiRC Strategic Vision

“Enable all people living with a rare disease to receive an accurate diagnosis, care, and available therapy within one year of coming to medical attention.”

IRDiRC Goals by 2027

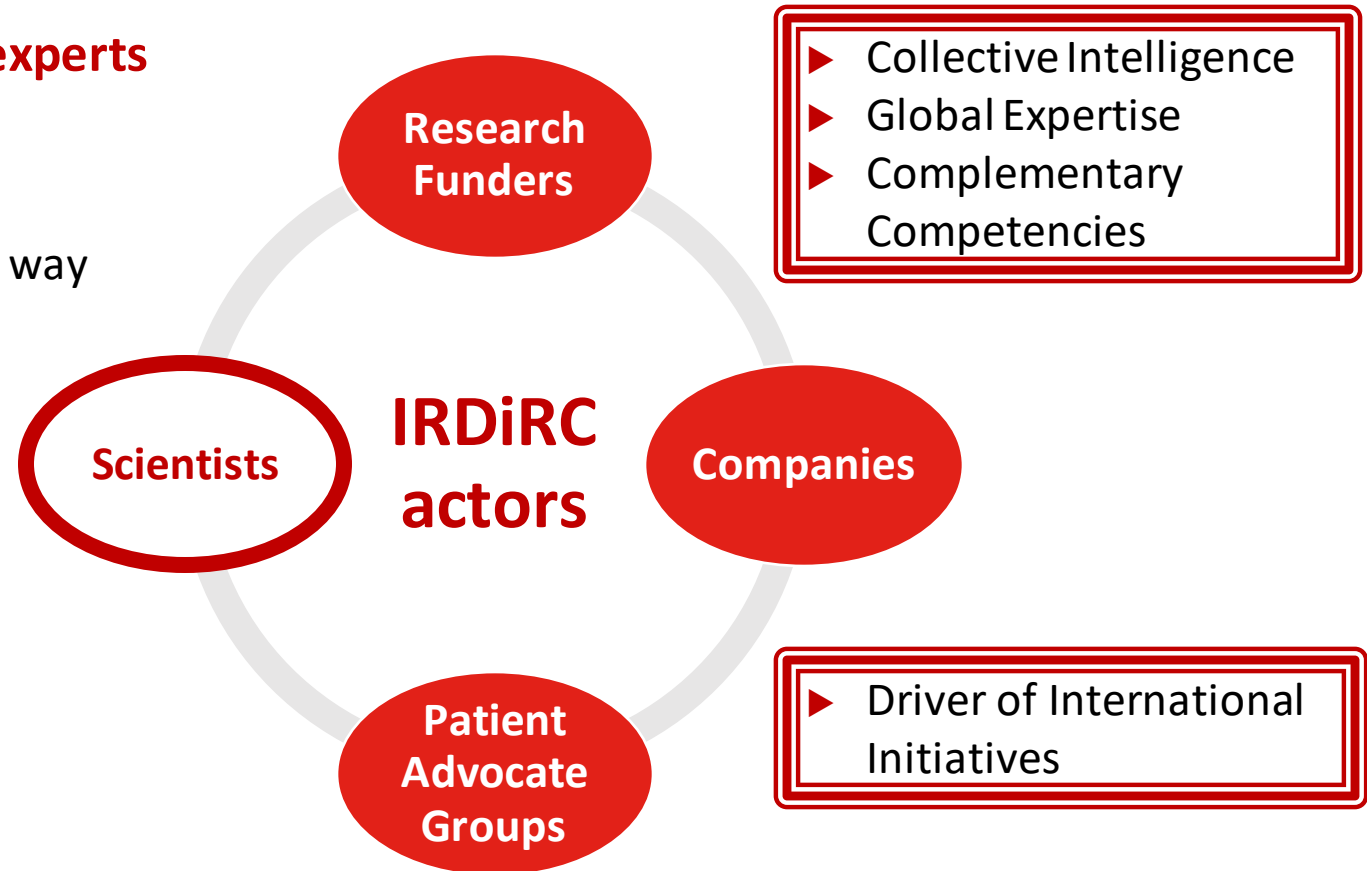


IRDiRC Thematic Research Actions

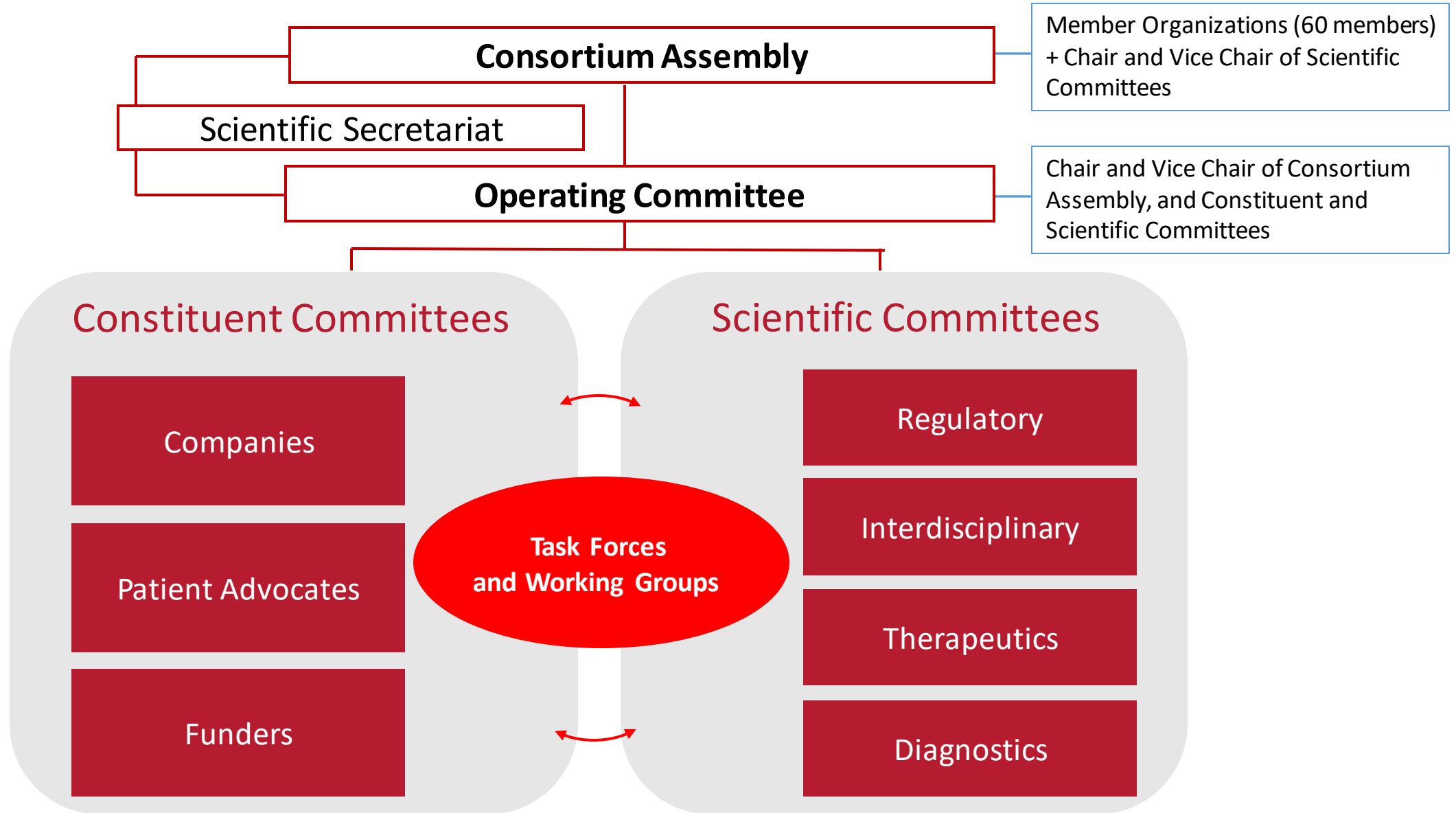


Members collaborate, stimulate, coordinate, and leverage output of rare diseases research efforts around the world

- **60 member organizations and over 100 experts**
- Unite **research funders** and **companies** investing in RD research
 - Each organization funds research its own way
 - Funded projects adhere to a common framework
- Umbrella **patient advocacy groups**
- **4 Scientific Committees**
 - Diagnostics
 - Therapies
 - Interdisciplinary
 - Regulatory



Governance and Operating Model



Task Forces & Working Groups

Task Forces (TFs) and Working Groups (WGs) are the instruments adopted by IRDiRC to address **actionable topics** identified by the Consortium and reflecting the **evolving priorities for RDs**.

Task Force

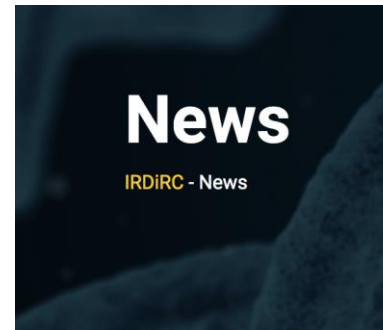
Time limited: 12-18 months.
Objectives and scope: Clearly pre-defined.
Commitment: Monthly conference calls and in-person meeting.
Composition: Leverage on the expertise of internal and external experts.
Output: Recommendation paper, technical application.

Working Group

Time limited: 6-9 months.
Objectives and scope: Exploratory work.
Commitment: Monthly conference calls.
Composition: Leverage on the expertise of internal and external experts.
Output: Recommendation paper, IRDiRC report.

Publications, News and Events

IRDIRC has developed **RD community engagement instruments** to present its activities, provide a forum for discussions and influence global RD research.



Recommendations, tools or guidelines by TFs and WGs, and IRDiRC reviews and commentaries are published as peer-reviewed articles or IRDiRC reports.

Dissemination via the IRDiRC website, newsletters, social media and member/partner channels effectively widens awareness and influence beyond the RD community.

Biannual conference engaging researchers, clinicians, patient advocates, industry leaders and policy makers from all continents.

State-of-Play Reports



State-of-Play Reports aim to inform stakeholders at large of developments in the field of rare diseases research in order to support decisions of policy makers and research funders. At the same time, the report is focused on informing the rare diseases community at large of the achievements and of observed trends, which shape the future of research and development for rare diseases.

It is based on a systematic survey of published articles, in scientific journals and press releases.

Recognized Resources



IRDiRC Recognized Resources label is a **quality indicator**, based on a specific set of criteria, created to highlight key resources which, if used more broadly, would **accelerate the pace of translating discoveries into clinical applications**.

Any resource compliant with the criteria may apply for the label. Selected platforms, tools, standards, and guidelines must be of **fundamental importance** to the international rare diseases research and development community.

Get involved

Become a Member Funders and Companies

The organization should **invest in rare disease R&D for minimum USD 10 million over a 5-year period.**

It includes expenses associated with the organization's internal and/or third-party RD innovation and improvements.

The organization should complete the **Letter of Intent** and send it to the Scientific Secretariat of IRDiRC.

Become a Member Patient Umbrella Groups

The group should represent patients with **different rare diseases (umbrella group)** and cover a **large region or country.**

The organization should complete the **Letter of Intent** and send it to the Scientific Secretariat of IRDiRC.

Scientific Contribution

External experts can apply to become member of **one of the IRDiRC Scientific Committees and/or to join a Task Force.**

Candidates should send their **CV, a biosketch and a letter of motivation** to the Scientific Secretariat of IRDiRC.

Candidates will be contacted based on the specific needs of IRDiRC Scientific Committees and Task Forces.



Thank You



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