

Overarching Task Force Profile

The Task Forces are created to tackle specific topics within rare diseases research proposed by the Constituent and/or Scientific Committees and selected as prioritized actions by the Consortium Assembly and the Operating Committee. Each Task Force reviews current barriers to efficient and effective rare disease research, and proposes solutions through policy recommendations and/or technical applications including platforms, tools, standards and guidelines.

Qualities of all Task Force members:

- Thinkers and doers
- Collaborates well to accomplish the objectives of Task Force
- Experts
- Collectively diverse
- Able to commit fairly substantial amount of time to the Task Force for one year

The usual time commitment includes quarterly 1-hour teleconferences, one face-to-face workshop (1-2 days), and regular email correspondence. Each Task Force will include 1-2 members from the corresponding parent Committee to ensure clear communication and alignment.

Call for experts:

“Chrysalis” Task Force focusing on the "identification of key criteria that make rare diseases more attractive to industrial drug development"

The **Funders Constituent Committee (FCC)** has set up a jointly Task Force with the **Companies Constituent Committee (CCC)** and the **Patient Advocates Constituent Committee (PACC)**. The overarching goal of the **Chrysalis Project** is to identify key criteria (in terms of investments of time and resources) that would make rare diseases research more attractive to industry for research and development, so as to deliver solutions to meet **IRDiRC Goal 2**. This will be accomplished through several strategies, including identification of diseases that already respond to most criteria (as examples of “success stories”) and identification of criteria that are specific to particular geographic regions (including funding models, social priorities, etc.). The project will therefore maximize the potential of already existing research, reducing barriers and improving the uptake by industry for therapeutic research investments (e.g., via natural history studies, patient registries, epidemiology studies).

IRDiRC is currently assembling a team of experts to populate this Task Force and is specifically looking for members with the above qualities and expertise/experience in one or more of the following areas:

- Funding rare disease research as a public or private entity
- Involvement in strategic planning for rare disease research
- Personal or family experience with rare diseases and either (a) involvement in funding rare diseases research OR (b) advocacy on behalf of rare disease research OR (c) involvement in corporate investment strategy development/execution (not necessarily in rare disease research)
- Research in rare diseases AND either (a) experience with either corporate interests OR (b) institutional finance/investment strategic planning
- Translation of research results into clinical settings, including Technology Transfer activities
- Evaluation of investment in therapy development from the perspective of small and large companies

How to apply?

IRDiRC members

If you are interested in taking part in this IRDiRC activity or would like to propose candidate(s), please send the expression of interest with the following information to the Scientific Secretariat (scientificsupport@irdirc.org) before **30 April 2020**:

1. Name of the candidate
2. Affiliation and location of the candidate
3. Contact information of the candidate
4. The expertise that the candidate is expected to contribute to the Task Force

Non-IRDiRC members

If you are not an IRDiRC member but are interested in taking part in this Task Force, please send a short biography and letter of motivation (1 page) to the Scientific Secretariat (scientificsupport@irdirc.org) before **30 April 2020**.

Only selected candidates will be contacted. Other applications will be kept for potential future use.