**Instructions:** To complete your application, please fill out and sign the attached Letter of Intent and provide a separate Letter of Motivation (LOM) stating your organisation’s reasons for desiring to join IRDiRC and the explicit contributions your organisation will bring to IRDiRC. We ask that you answer the following specific questions in the LOM:

1. Why does your organization want to join IRDiRC?
2. How does your organization contribute to research on rare diseases?
3. What will your organization specifically contribute to IRDiRC to help advance IRDiRC’s vision, goals, and activities?

IRDiRC recommends that you nominate a representative who has direct experience with a rare disease and worked in the interest of patients for at least a year.

Dr Lucia Monaco

Chair of IRDiRC Consortium Assembly and Operating Committee

Attention to: IRDiRC Scientific Secretariat

IRDiRC – Inserm

Hôpital Pitié Salpêtrière

Pavillon des folles

4 rue des petites loges

75013 Paris

France

[scientificsupport@irdirc.org](mailto:scientificsupport@irdirc.org)

**LETTER OF INTENT**

**[NAME OF PATIENT ADVOCACY ORGANISATION]**

**TO JOIN THE**

**INTERNATIONAL RARE DISEASES RESEARCH CONSORTIUM (IRDiRC)**

The International Rare Diseases Research Consortium (IRDiRC) is coordinating international collaborative efforts to speed up the development of diagnostic tests and therapies for rare diseases. IRDiRC has set for itself the following vision to accomplish by 2027: 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.

This Letter of Intent is to inform the IRDiRC Consortium Assembly that [name of patient advocacy organisation] from [region/country/countries] would like to join the IRDiRC collaborative effort.

To join this initiative, aimed at fostering international research cooperation and coordination on rare diseases, our organisation and the scientists/representatives involved in the projects and activities will follow the policies and guidelines that have been ratified by the IRDiRC Consortium Assembly, and which are available on the IRDiRC website (<http://www.irdirc.org/>).

These policies and guidelines are relevant for:

* Coordination of efforts to minimise unnecessary redundancy,
* Harmonisation and standardisation of data and research results,
* Facilitation of access to data,
* Development and sharing of best practices,
* Coordination of public communications and dissemination of information to patients regarding individual efforts or the international effort as a whole, and
* Coordination of issues such as archiving and distribution to ensure the data and resources generated are readily accessible to the scientific research community.

[Name of patient advocacy organisation] will support the IRDiRC policies and guidelines, subject to [name of patient advocacy organisation]’s obligation to act in accordance with its policies and procedures regarding the protection of its intellectual property, patient and data privacy, publication of research results and making information publicly available in a manner consistent with its prior practices, while abiding by any agreements in place with collaboration partners limiting its ability to share information outside of such collaborations, and conducting all such activities in accordance with all applicable laws and regulations, including those related to antitrust.

[Name of patient advocacy organisation] will also adhere to the roles and responsibilities outlined in the governance document including actively contributing to the Consortium Assembly, the Patient Advocates Constituent Committee, the Scientific Committees and the Task Forces, when appropriate. In particular, [Name of patient advocacy organisation] will support the Patient Advocates Constituent Committee (PACC) in its purview and mission described below:

*The role of the PACC, and hence each Patient Advocacy Group IRDiRC member, is to actively contribute to the IRDiRC global vision, goals, and set of actions that will accelerate diagnostic and therapeutic development and deployment for all rare diseases. The PACC addresses systemic issues that apply to all members and all rare diseases, articulates points in the diagnostic and therapeutic development process where patient involvement is crucial, measures the success and impact of that patient involvement (particularly in areas contributory to the IRDiRC goals), and focuses on patient group deliverables that demonstrably advance the goals and activities of the other IRDiRC constituencies and the Consortium as a whole. Example topics that the PACC tackles: the science of patient engagement, registries, access, cross-stakeholder interactions, and the development of tangible tools, paradigms and approaches to advance the IRDiRC goals from a patient involvement perspective. The PACC aims to harness the successes of member groups, improve the playing field for all, and work together to reach equity across the world.*

Generally, support for travel to meetings will be covered by the [name of patient advocacy organisation] itself.

We hereby nominate [Mr, Ms, Dr, Prof] [name of the patient advocacy organisation’s representative] to represent our organisation on the IRDiRC Consortium Assembly and Patient Advocates Constituent Committee.

Sincerely,

[Name of applicant]

[Position]

[Name of patient advocacy organisation]

[Date]