**Instructions:** to complete your application, please fill out and sign the attached Letter of Intent. Please also 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?

Additionally, as a condition of membership, the Scientific Secretariat will collect updated information regarding funding commitment toward IRDiRC objectives on an annual basis to ensure that member organizations continue to meet the minimum commitment. Previous, investments if available, since 1 January 2010 contributing to IRDiRC objectives should also be disclosed to enable networking of presently active research teams.

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.

The Consortium Assembly Chair will discuss your application with the IRDIRC Operating Committee during the monthly teleconference meetings and feed the ensuing decision back to you soon afterwards.

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 FUNDING BODY/COMPANY ORGANIZATION]**

**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 funding body/company organisation] from [region/country/countries] would like to join the IRDiRC collaborative effort and is planning to finance future research with an anticipated budget of [xxx (minimum USD 10 million over 5 years)] that is aligned with the IRDiRC scientific objectives, policies and guidelines, and governance structure. In addition, since [date], we have already dedicated [budget] to research projects relevant to the IRDiRC scientific objectives.

To join this initiative, aimed at fostering international research cooperation on rare diseases, our organization 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 funding body/company organization] will support the IRDiRC policies and guidelines, subject to [name of funding body/company organization]’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 funding body/company organization] will also adhere to the roles and responsibilities outlined in the governance document including actively contributing to the Consortium Assembly, the [Funders or Companies – choose which applicable] Constituent Committee, the Scientific Committees and the Task Forces, when appropriate.

We hereby nominate [Mr, Ms, Dr, Prof] [name of the funding body/company organization’s representative] to represent our organization on the IRDiRC Consortium Assembly and [Funders or Companies – choose which applicable] Constituent Committee.

Sincerely,

[Name of applicant]

[Position]

[Name of funding body/company organization]

[Date]