IRDiRC Membership Application

Thank you for your interest in joining the International Rare Diseases Research Consortium (IRDiRC). We look forward to learning more about you and your organization, as well as information on your potential participation as an IRDiRC member and in IRDiRC activities.

**Instructions:** To complete your application, please fill out and sign the attached Letter of Intent (LOI), including the Supporting Document page stating your organization’s reasons and motivation for joining IRDiRC. We ask that you answer the following questions:

1. Your organization’s motivation for joining IRDiRC.
2. How does your organization contribute to research on rare diseases?
3. How will your organization contribute to advance IRDiRC’s vision, goals, and activities? Which focus do you resonate with most?

**IRDiRC’s 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.***

In order to work towards this bold and ambitious vision, IRDiRC has set three goals for the next decade:

**Goal 1**: All patients coming to medical attention with a suspected rare disease will be diagnosed within one year if their disorder is known in the medical literature; all currently undiagnosable individuals will enter a globally coordinated diagnostic and research pipeline

**Goal 2**: 1000 new therapies for rare diseases will be approved, the majority of which will focus on diseases without approved options

**Goal 3**: Methodologies will be developed to assess the impact of diagnoses and therapies on rare disease patients

IRDiRC recommends that you nominate someone in your organization as your representative who has knowledge of the strategic priorities of your organization, has the willingness and subject matter expertise to actively participate in IRDiRC Constituent Committee activities, has a reach into your organization to nominate candidates for participation in other IRDiRC activities, and who has a demonstrated commitment to the rare disease community. In situations where your official representative cannot attend some of the IRDiRC meetings, a substitute should be designated and an official letter from your organization be sent to the IRDiRC Scientific Secretariat minimum of two weeks in advance by email.

The Consortium Assembly Chair will discuss your application with the IRDIRC Operating Committee and present it to the Consortium Assembly for consideration.

Dr. David Pearce

Chair of IRDiRC Consortium Assembly

Attention to: IRDiRC Scientific Secretariat

IRDiRC – INSERM

Hôpital Charles-Foix

7 Avenue de la Republique

94200 Ivry-sur-Seine

France

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**LETTER OF INTENT (LOI)**

**NAME OF 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 diagnostics and treatments 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 organization from region/country/countries would like to join the IRDiRC collaborative effort and can confirm that the organization invests or will invest in rare disease research and development (R&D) for minimum USD 10 million over a five-year period (investment includes expenses associated with the organization’s internal and/or third-party RD innovation and improvements). This investment disclosure is in ‘good faith’, as organizations are not asked to disclose specific investments to IRDiRC. Nor are organizations obligated to provide direct financial support to IRDiRC or its projects, beyond what is voluntarily shared. The organization ensures that activities are aligned with the IRDiRC scientific objectives, policies and guidelines, and governance structure.

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 minimize unnecessary redundancy,
* Harmonization and standardization 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 organization will support the IRDiRC policies and guidelines, subject to name of organization’s obligation to act in accordance with name of organization’s 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 organization will also adhere to the roles and responsibilities outlined in the governance document including actively contributing to the Consortium Assembly, the  Constituent Committee, the Scientific Committees, and the Task Forces, when appropriate.

We hereby nominate name of organization's representative to represent our organization on the IRDiRC Consortium Assembly and in the Constituent Committee.

Sincerely,

Name of applicant

Position

Name of organization

Date

**SUPPORTING DOCUMENT**

**NAME OF ORGANIZATION**

**TO JOIN THE**

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

1. Your organization’s motivation for joining IRDiRC.
2. How does your organization contribute to research on rare diseases?
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Sincerely,

Name of applicant

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