



IRDiRC HIGHLIGHTS

Nomination Call: Therapies Scientific Committee

IRDiRC
Nomination
Call

Therapies Scientific Committee (TSC)

TSC has two openings for new members who are from the following regions: Africa, Asia, Australasia or South America.

Apply before **June 15th**

IRDiRC
INTERNATIONAL
RARE DISEASES RESEARCH
CONSORTIUM

To best represent the worldwide rare diseases community in its full width and complement the current membership, the **IRDiRC Therapies Scientific Committee (TSC)** has two openings for new members who are from the following regions: **Africa, Asia, Australasia or South**

America. Interested candidates are invited to send their resume, biosketch and letter of motivation to **scisec-irdirc[at]leiprarediseases.org before the 15th of June 2021.**

As such, we are looking for rare disease experts from these regions with the following qualities:

- Expertise in medicines or medical devices (experience in Advanced Therapy Medicinal Products (ATMPs), or artificial intelligence and/ or machine learning as applied to medical research)
- Expertise from an industry, regulatory or Health Technology Appraisal fields
- Able to commit to monthly teleconferences, a yearly meeting and regular committee activities and email correspondence

22nd Meeting of the IRDiRC Consortium Assembly - Scientific Committees

22nd Meeting of the IRDiRC Consortium Assembly- Scientific Committees

Monday, 15 March 2021
Teleconference



click [here](#).

Members and experts from all over the world gathered on March 15 for a meeting of the **IRDiRC Consortium Assembly and Scientific Committees**. The goal of the meeting was to provide members with an update on ongoing activities and present the 2021 roadmap of activities.

To see the available Consortium Assembly meeting reports (up to 2020), please

Leadership and Membership Changes

- We would like to thank **Dr. Sarah Bowdin** and **Mrs. Yukiko Nishimura** for serving as **Vice Chairs** of the **Diagnostics Scientific Committee** and **Patient Advocates Constituent Committee**, respectively.

Therapies Scientific Committee Nominations

We warmly welcome **Dr. Anneline Jonker** (University of Twente, the Netherlands), who was elected **Vice Chair** of the **Therapies Scientific Committee**.

IRDiRC IN EVENTS

IRDiRC held the following meetings:

- 15 March 2021: **22nd IRDiRC Consortium Assembly meeting**

[More Information](#)

OTHER NEWS

Heritable Human Genome Editing Rare Disease Week Discussion

On February 26, 2021, members of the **International Commission on the Clinical Use of Human Germline Genome Editing** participated in an online discussion of the implications of this technology for genetic disease and disability communities.

[More Information](#)

ORD India Organizes Events for International Pompe Day

To mark International Pompe Day (April 15, 2021) and commemorate **15 years of the treatment of Pompe disease in India**, **ORD India** conducted the following events: a webinar series on infantile-onset Pompe disease and late-onset Pompe disease; an interview with various stakeholders **broadcast on Indian television**; and an **ongoing webinar series on rare diseases in pediatric neurology**.

[More Information](#)
