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]ejprarediseases.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
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 click here.

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
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.

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.