To celebrate the 2020 Rare Disease Day, the Chair and vice-Chair of IRDiRC wish to send a message to the community on unique value of collaboration and are pleased to announce the exciting new activities from IRDiRC.

“There is no greater mission that trying to develop improved diagnosis and treatments for rare diseases. Millions of individuals are afflicted with complicated and debilitating symptoms as a result of having a rare disease. Through coordinated efforts, such as IRDiRC, we can expedite reducing the suffering for these individuals.”

Dr. David Pearce – Vice-Chair of IRDiRC Consortium Assembly

“The IRDiRC community is gearing up to a
challenging 2020. Our ambitious roadmap for year 2020 tackles key questions with four new task forces. Gaps in the development path towards new therapies for neglected rare diseases will be addressed; an innovative clinical trial design will be studied to maximize inclusion of the rarest patients; the most advanced omics technologies will be promoted to help solve difficult undiagnosed cases; and finally hurdles preventing access to therapies will be addressed to enhance impact of available medicines. Top level experts form the research, enterprise and patient advocacy fields are joining competences and skills to move forward and meet our vision.”

Read more about the new IRDiRC activities:

- Chrysalis Project
- Integrating new technologies for the diagnosis of rare disease
- Shared Molecular Etiologies
- Rare Disease Treatment Access Working Group

Join major event on rare diseases in 2020: The RE(ACT) Congress and IRDiRC Conference
11-14 March 2020, Berlin - Germany

There is still time to register to this exceptional joint event to learn about newest updates on orphan drug development, on innovations in rare disease diagnosis, therapies and societal inclusiveness. It will be a unique occasion to network and meet high-profile scientific leaders, experts as well as young scientists from a variety of breakthrough scientific fields and patients/patient advocacy organizations. IRDiRC members have special fees for the registration. IRDiRC and Blackswan Foundation look forward to welcome you in Berlin! Deadline for Standard Registration is 21 February. Free registration to students from Berlin institutions/universities will also be offered. They can register to the congress via the following link!
New IRDiRC Recognized Resource. Human Pluripotent Stem Cell Registry (hPSCreg)

The hPSCreg is a database that provides an overview of human pluripotent stem cell lines available for research. The Registry contains some human induced pluripotent stem cell lines from patients with rare diseases.

New IRDiRC Members

IRDiRC is pleased to announce two new members in the Consortium that will be joining the IRDiRC - PACC committee:

- Rare Disease Ghana Initiative (RDGI) with Samuel Agyei Wiafe as its Founder and Executive Director
- Iberoamerican Alliance for Rare Diseases (ALIBER) with Alba Ancochea as its Advocacy Advisor

IRDiRC Spotlights

IRDiRC on the “Orientations” EU document

IRDiRC is mentioned in the EU document “Orientations towards the first Strategic Plan for Horizon Europe” document that presents suggestions for key impacts to be targeted in the first four years of Horizon Europe (2021-2024), including the Health cluster for Rare Diseases under the European Partnerships umbrella (pg. 43).
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