Dear All,

While the COVID-19 pandemic is spreading through the world, we wish to send a message to the IRDiRC community and express our nearness and encouragement to you all.

The impact of COVID-19 outbreak on rare disease patients cannot be underestimated; not only their condition makes them frailer if infected, but also the exceptional burden hospitals are facing make access to the needed care all the more difficult for them. Research on rare diseases is delayed due to prioritization towards the pandemic, as well as due to work and social distancing restrictions.

On the positive note, we recognize that all of us in the IRDiRC family are engaged at one or more levels in response to the outbreak. Clinicians are on the frontline and are doing all they can to find alternative ways to support patients, including rare disease patients. At the same time, patient organizations continue to play an important role in providing community support and arranging for relevant resources for families. Funding organizations are considering how to take measures to alleviate consequences and ensure research can be sustained.

We would like to call on all stakeholders to maintain research on rare diseases, and be open to new directions the epidemic may offer in terms of scientific questions relevant to rare diseases. The pandemic has brought research at the forefront as the universally acknowledged method to fight the new virus. Sharing of biospecimens, clinical data and clinical translation in concert with regulators are taking place at full speed. Similarly, we are sure IRDiRC principles of collaboration, sharing and transparency will continue to guide us through these challenging times.

Let us stay strong, be creative and make the best use of the resources IRDiRC has contributed to building and sharing for the health of patients. Patients living with rare diseases urgently need access to diagnosis and therapies for their conditions. No single country can face global health issues alone, be it a virus or rare diseases. May this pandemic reinforce our collaborative ties and principles, to ensure no person living with a rare disease is left behind.

Dr. Lucia Monaco, chair and Dr. David Pearce, vice-chair
IRDiRC Consortium Assembly
To read the news on the IRDiRC website click here.
RE(ACT) congress - IRDIRC conference has been postponed to Jan 13 - 16 2021. Please, save the date!

Call for Candidates

IRDiRC is currently assembling a team of experts to populate its new Task Force Chrysalis. Set up by the Funders Constituent Committee (FCC) jointly with the Companies Constituent Committee (CCC) and the Patient Advocates Constituent Committee (PACC), the overarching goal of the Chrysalis Project is to identify key criteria (financial and non-financial) that would make rare diseases research more attractive to industry for research and development, so as to deliver solutions to meet IRDiRC Goal 2. This will be accomplished through several strategies, including identification of diseases that already respond to most criteria (as examples of “success stories”) and identification of criteria that are specific to particular geographic regions (including funding models, social priorities, etc.). The project will therefore maximize the potential of already existing research, reducing barriers and improving the uptake by industry for therapeutic research investments (e.g. via natural history studies, patient registries, epidemiology studies). IRDiRC members and Non-IRDiRC members are encouraged to apply. Deadline: 30 April 2020. For more information on the profile of experts we are looking for, please click here.

Leadership changes

Dr. Adam L. Hartman, Program Director, Division of Clinical Research at the National Institute of Neurological Disorders & Stroke Neuroscience Center, is the new Chair-elect of Funders Constituent Committee (FCC). Under his chairmanship, FCC is launching the Chrysalis Project, which will identify the key components that make RD research more attractive to industry partners. The rare disease funding projects database initiated under the previous FCC leadership in 2018, will remain a top priority and is on schedule to deliver a tool that will enable coordinate funding of all IRDiRC members to reach our collective goals. New efforts will come through gathering new ideas and from strengthening collaborations between FCC and the other Constituencies.

COVID-19 and Rare Diseases: Share your experience

IRDiRC is interested at hearing from you, in the frame of your own engagement in Rare Diseases with COVID-19 crisis:

- How it is affecting your work/practice
- How it is redirecting your activities and
priorities
- What measures are being taken by you/your organizations
- What solutions you envisage
- What you feel IRDiRC could do for and with you.

Please click here for more info.

Social and Humanities Sciences (SHS) research in Rare Diseases

New section on Social and Humanities Sciences on the "IRDiRC Resources and Recommendations" webpage with #2 interesting papers:

- **Capturing Team Dynamics in the Wild: The Communication Analysis Tool** by Klonek et al., that describes the development of a web-based application that helps to better measure and understand teamwork and communication dynamics
- **Diagnosing rare diseases: A sociotechnical approach to the design of complex work systems** by Hay et al., that applies sociotechnical systems theory to understand this new system of social and technical work structures can help to find diagnoses in rare diseases more efficiently and effectively.

A call for global action for rare diseases in Africa

The 11th International Conference on Rare Diseases and Orphan Drugs (ICORD), South Africa, included the Africa-Rare initiative launch and facilitated multi-stakeholder engagement in the challenges facing, and opportunities for, Africans living with rare diseases. The following ICORD Global Call to Action, developed in collaboration with the IRDiRC, synthesizes the outcomes of the deliberations and emphasizes the international collaborative efforts required to address the global effects of rare diseases on public health. The article is under the “Rare Diseases and Society” category.

IRDiRC Members Spotlights

Recently Dr Lucia Monaco, chair of IRDiRC, has been interviewed by #3 magazines to make a stand on where we are in rare disease research, the achievements reached so far, and the challenges faced due to the COVID-19 crisis.

- ALS News Today Global Rare Disease Group’s Focus: 1,000 New Therapies by 2027, Despite COVID-19.
- Horizon Magazine, Interview health with IRDiRC Chair, Dr Lucia Monaco.
- Vita. Malattie rare: «e ora non dimentichiamo la ricerca di base»! -please note that this article is in Italian.

IRDiRC joined the World Health
Day campaign
IRDiRC joined the social media campaign #WorldHealthDay on twitter to thank all the healthcare professionals for their work.

IRDiRC joined the International Women’s Day campaign
This year, IRDiRC joined the International Women Day (#IWD2020) social media campaign together with EU Commission and many other organizations and groups worldwide to support all women in science as well as the institutional initiatives done in this direction. IRDiRC can be an example for many women and organizations.

News Spotlights
New Framework to Provide Global Approach to Solving Rare Diseases
We need a global approach to diagnose and treat rare diseases, according to a new World Economic Forum paper, “Global Access for Solving Rare Disease: A Health Economics Value Framework.” The paper written by health economists from the UK, Australia, Canada and the US, proposes the first global framework illuminating the potential economic benefits of securely sharing genomic data for the purposes of diagnosing and treating rare disease.