

IRDiRC MARCH 2015 UPDATE

for Executive Committee, Scientific Committees and Working Groups



Application for [IRDiRC Recommended](#) is now open.

IRDiRC Recommended has been launched as a quality indicator, based on a specific set of criteria. Any platform, tool, standard or guideline compliant with the criteria set forth is entitled to the label.

“IRDiRC Recommended” is a public label to be made visible on and by the resource, giving users a guarantee of its quality/appropriateness.

IRDiRC encourages long-term sustainability of tools, standards and guidelines, and their societal value.

IRDiRC new documents

- Executive Committee: [report](#) of the teleconference held on January 26, 2015

Upcoming IRDiRC meetings and teleconferences

- May 11, 2015: teleconference of the Executive Committee

- **June 5, 2015: meeting of the Diagnostics Scientific Committee in Glasgow, UK (full day)**
- **June 5, 2015: meeting of the Interdisciplinary Scientific Committee in Glasgow, UK (full day)**
- **June 5, 2015: meeting of the Therapies Scientific Committee in Glasgow, UK (afternoon)**
- **June 6, 2015: meeting of the three Scientific Committees in Glasgow, UK (morning)**
- **September 11, 2015: Executive Committee meeting in Montreal, Canada**

Research highlights published on the website

- The [megafund model](#) to finance development of orphan drugs: analysing the NCATS portfolio
- [Orphanet Report Series](#) update on Registries and Research Infrastructures useful to Rare Diseases in Europe
- Uncovering disease-disease relationships through the [incomplete interactome](#)
- [GeneYenta](#): matchmaking for rare disease patients
- Should NIH rethink the [2014 Genomic Data Sharing policy](#)?

IRDiRC-related calls

- The [Recherche Hospitalo-Universitaire en santé \(RHU\)](#) call for projects aims to support research projects with a strong potential for rapid transfer into industry or to society.
- [Validation of Pediatric Patient Reported Outcomes in Chronic Diseases \(PEPR\) Consortium \(U19\)](#). The aim of this call is to capitalise on recent advances in the science of Patient Reported Outcomes (PROs) to measure patient experience in clinical care and research in children with a variety of chronic diseases and conditions.
- [PhD fellowships from Kindness for Kids foundation](#) in collaboration with EuroBioBank and RD-Connect. Kindness for kids is looking for a PhD project that develops or tests a new treatment, identifies therapeutic targets or employs a screening platform in the area of rare paediatric diseases using in vitro experiments.

- **AFM Telethon Research Grants** open to Researchers or clinical Investigators with a permanent position in an academic, governmental or private institution.
- **Clinical Studies of Safety and Effectiveness of Orphan Products** Research Project Grant (R01) to support the clinical development of products for use in rare diseases or conditions where no current therapy exists or where the product being developed will be superior to the existing therapy.

Website updates

- The **IRDiRC website** is in the process of being reorganised to improve clarity and highlight essential documents.
- The IRDiRC **Governance/Structure diagram** has been updated to reflect the completion of the Working Groups' brainstorming phase and the composition of several Task Forces to implement identified projects.
- The **IRDiRC presence at conferences section** has been updated with the addition of a session on IRDiRC during the conference on **Raising awareness for Rare Diseases**, organised by the Indian Organisation for Rare Diseases and which took place in Hyderabad, India, on March 20, 2015. The conference aimed to raise awareness on rare diseases at all levels, particularly at government level. A white paper on rare diseases was presented to the former president of India, Dr. APJ Abdul Kalam, who inaugurated the conference and acknowledged the need to coordinate efforts on rare diseases at a national level.

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