

IRDiRC SEPTEMBER 2014 UPDATE

for Executive Committee, Scientific Committees, and Working Groups



IRDiRC Conference abstract submission has been extended to October 15, 2014.

New members of IRDiRC

- The European Organisation for Research and Treatment of Cancer (EORTC) has officially been accepted as a new member of IRDiRC. Dr Denis Lacombe will be its corresponding representative. Established in 1968, this non-governmental clinical research organization is dedicated to investigator driven clinical trials and translational research in cancer playing major roles in academic trials, including pediatric cancers, which are all rare. It consists of both a network and a coordinating scientific and operational infrastructure based in Brussels, Belgium.



IRDiRC new documents

- Executive Committee: report of the teleconference held on June 16, 2014.

- **Diagnostics Scientific Committee:** [report](#) of the teleconference held on September 2, 2014.
- **Working Group on Ethics and Governance:** [report](#) of the teleconference held on July 3, 2014.
- **Working Group on Genome/Phenome:** [report](#) of the teleconference held on July 18, 2014.
- **Working Group on Ontologies and Rare Disease Prioritization:** [report](#) of the teleconference held on July 21, 2014.

Upcoming IRDiRC meetings

- October 2, 2014: teleconference of the Executive Committee
- October 6, 2014: teleconference of the Therapies Scientific Committee
- October 7, 2014: teleconference of the Diagnostics Scientific Committee
- October 13, 2014: teleconference of the Working Group on Sequencing
- October 27, 2014: teleconference of the Working Group on Biomarkers for Disease Progression and Therapy Response
- November 6, 2014: Executive Committee meeting in Shenzhen, China

News published on the website

- The FDA issues a [strategic plan](#) to accelerate the development of therapies for children with rare diseases.
- Optimizing research on rare diseases through the [RD-Connect platform](#).
- Launch of the [Open Journal of Bioresources](#).
- [BBMRI-ERIC](#): the European Research Infrastructure Consortium to harmonize biobanking and boost research across Europe.
- NIH's [Rare Diseases Clinical Research Network](#) contributes towards improving research and orphan medicinal products.
- The [Rare Cancer Network](#): purpose, achievements and goals.
- IRDiRC is now acknowledged as contributing to the [Framework for Responsible Sharing of Genomic and Health-Related Data](#) of the Global Alliance for Genomics and Health.

IRDIRC related calls

- The National Institute for Health Research (NIHR, UK) has launched a call on [Improving the mental health of children and young people with long term conditions](#).

Website updates

- The [IRDiRC sessions at conferences section](#) has been updated with the addition of two sessions about IRDiRC during the [IXth ICORD 2014](#) and the [Rare Diseases and Orphan Drug Development Initiatives in India Conference](#).
- The [IRDiRC in the news section](#) has been updated with the addition of one article mentioning IRDiRC from [GacetaMedica.com](#).
- The [Scientific Committees meetings section](#) and the [Working Groups meetings section](#) have been redesigned.

New selected reports and policy documents

- The European Commission [implementation report on the Commission communication on rare diseases](#) is now available.
- The National Institutes of Health (NIH, USA) [Rare Diseases Clinical Research Network's report](#) on its organization and its approach to observational research and health outcomes research is now available.

Other news

- 'IRDiRC Recommended' logo has been created.



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