

IRDiRC APRIL 2014 UPDATE

for Executive Committee, Scientific Committees, and Working Groups



IRDiRC new documents

- Executive Committee: [report](#) of the teleconference held on February 3, 2014.
- Interdisciplinary Scientific Committee: [report](#) of the teleconference held on March 28, 2014.
- Working Group on Ontologies and rare disease prioritization: [report](#) of the teleconference held on January 29, 2014.
- Working Group on Biotechnology-derived products including cell- & gene-based therapies: [report](#) of the teleconference held on January 30, 2014.
- Working Group on Chemically-derived products including repurposing: [report](#) of the teleconference held on February 19, 2014.
- Working Group on Orphan-drug development and regulatory processes: [report](#) of the teleconference held on February 28, 2014.

News published on the website

- [PhenomeCentral](#): a new matchmaking web portal launched on Rare Disease Day which matches patients with similar genotypes and phenotypes.
- China's Food and Drug Administration (CFDA) has acted to impose [regulatory constraints on the provision of clinical genetic tests](#).
- [FDA's drives towards increasing dialogue](#) with the public to help patients with rare diseases.

IRDiRC related calls

- The Federal Ministry of Education and Research (BMBF, Germany) has launched the [translational consortia for rare diseases research funding initiative](#).

Website updates

- The [IRDiRC in the news section](#) has been updated with the addition of five articles mentioning IRDiRC from the [Irish Medical Times](#), [EURORDIS](#), [Rare Diseases](#), [European Commission](#) and [EL GLOBAL.net](#).
- The [IRDiRC sessions at conferences section](#) has been updated with the addition of three sessions mentioning IRDiRC during the [EU-LAC health 2nd roadmapping workshop](#), the [Seminaris VIHR](#) and the [Worldwide Orphan Medicinal Designation Workshop](#).

New lists of research projects funded by IRDiRC members

- The 'Agence Nationale de La Recherche' [list of research projects](#) for 2013 has been updated.

Other news

- [Isis Pharmaceuticals](#) has officially been accepted as a new member of IRDiRC. Brett Monia is its representative.



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