

IRDIRC FEBRUARY 2015 UPDATE

for Executive Committee, Scientific Committees and Working Groups



The [IRDIRC label](#) is now attached to all projects funded by an IRDiRC member highlighted on Orphanet.

IRDIRC new documents

- Executive Committee: [report](#) of the teleconference held on January 26, 2015
- Interdisciplinary Scientific Committee: [report](#) of the teleconference held on February 4, 2015

Upcoming IRDiRC meetings and teleconferences

- March 16, 2015: meeting of the Executive Committee in Madrid, Spain

- 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

- [Orphan drug legislation](#) lacking: pharmas need more to develop orphan drugs
- The President of United States earmarks [US\\$215 million towards 'Precision Medicine'](#)
- The [Japan Prize Foundation](#) awarded to gene therapy pioneers
- How to successfully apply for an [Orphan Designation](#): proving medical plausibility
- [Ten components](#) to navigate the rare disease research roadmap
- PIN for [ranking candidate genes](#)
- [Drugnet](#): a novel drug repurposing webtool
- Guidelines for [diagnostic next generation sequencing](#)
- [Deciphering Developmental Disorders](#) project
- The Institute of Medicine of the United States pushes [companies to share clinical trial data](#): Johnson & Johnson complies
- Public consultation on [application of transparency rules](#) of EU Clinical Trial Regulation

Website updates

- The [IRDIRC in the news section](#) has been updated with the addition of an interview with Prof Paul Lasko published in [International Innovation](#) on how rare disease research drives innovation.

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