

IRDiRC MARCH 2014 UPDATE

for Executive Committee, Scientific Committees, and Working Groups



IRDiRC new documents

- Interdisciplinary Scientific Committee: [report](#) of the teleconference held on February 13, 2014.
- Therapies Scientific Committee: [report](#) of the teleconference held on January 24, 2014.
- Working Group on Genome/Phenome: [report](#) of the teleconference held on December 10, 2013.
- Working Group on Model systems: [report](#) of the teleconference held on December 16, 2013.

News published on the website

- The international conference on “[Translational Science of Rare Diseases – From Rare to Care 2](#)” organized by Research For Rare will take place on October 8-10, 2014 in Herrenchiemsee, Germany.
- Stephen Groft has been a strong voice in rare diseases. He has now retired and [an article](#) has been realized about his achievements.
- [Lessons on data sharing](#) from ENGAGE, a large research consortium.

IRDiRC related calls

- Dates have been changed for the [call for proposals AFM-TELETHON 2014](#) (AFM, France).
- The French Foundation For Rare Diseases (France) has launched the Call 2014 [‘Preclinical Research in rare diseases: translational steps in](#)

large animals'.

Website updates

- The IRDIRC in the news section has been updated with the addition of three articles mentioning IRDiRC.

New selected reports and policy documents

- "Data sharing in large research consortia: experiences and recommendations from ENGAGE" has been added to the list of recommendations available on the IRDiRC website.

New lists of research projects funded by IRDiRC members

- The E-Rare list of research projects for 2013 has been updated.
- The European Commission list of research projects for 2013 has been updated.

Other news

- Pamela McInnes is the new representative of the Office of Rare Disease (NIH) following the retirement of Stephen Groft.
- Pedro Cortegoso Fernández, Secretary General of the Institute of Health Carlos III, is the new Delegate representing Spain in the Executive Committee of IRDiRC, replacing Antonio Luis Andreu Pérez.
- The Phenotype day, an initiative developed jointly with the Bio-Ontologies and BioLINK Special Interest Groups will take place on July 12, 2014, in Boston, USA. It will trigger a comprehensive approach to studying the process of knowledge acquisition and support for deep phenotyping.

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