IRDiRC JULY 2014 UPDATE
for Executive Committee, Scientific Committees, and Working Groups

IRDiRC new documents

• Executive Committee: report of the meeting held on May 7-8, 2014 in Berlin, Germany.

• Interdisciplinary Scientific Committee: report of the meeting held on May 8, 2014 in Berlin, Germany.

• Working Group on Model systems: report of the teleconference held on March 10, 2014.

Upcoming IRDiRC meetings


• November 6, 2014: Executive Committee meeting in Shenzhen, China.

News published on the website

• PCORI of US announces expert panel on rare disease.

• The promises of stem cell therapy always getting closer.
• In the fast lane to address unmet medical needs: the FDA’s new Expedited Access Program for Medical Devices.

• COST Action project MYO–MRI kicks off in Milan!

• Megafunds to finance orphan drug discovery

Website updates

• The ‘Current results of research’ page has been completely redesigned.

• The ‘List of projects funded by IRDiRC members’ page has been updated with the addition of a section on the number of new research projects funded by IRDiRC funding bodies.

• The IRDiRC website was recently under unauthorized attack. For security measures, all passwords to access the IRDiRC private website have been reset.

• The IRDiRC sessions at conferences section has been updated with the addition of three sessions about IRDiRC during the Global Health Policy Forum, the DIA 2014 50th annual meeting and the European Reference Network Conference.

• The IRDiRC in the news section has been updated with the addition of one article mentioning IRDiRC from EURORDIS.

New selected reports and policy documents

• Report of the FDA on complex issues in developing drugs and biological products for rare diseases and accelerating the development of therapies for pediatric rare diseases.

New lists of research projects funded by IRDiRC members

• The first clinical trials for 2014 under the Orphan Products Grant Program from Food and Drug Administration are now available.

Other news

• A new Working Group of the DSC has been created: the WG on Population Controls Variant Datasets.

• IRDiRC wishes you happy summer holidays!
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