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: pharma 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 web tool

• 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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