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

IRDiRC new documents

• Executive Committee: report of the meeting held on November 6, 2014 in Shenzhen, China.

• Diagnostics Scientific Committee: report of the teleconference meeting held on October 31, 2014.


• Working Group on Biotechnology-Derived Products including Cell- & Gene-based therapies: report of the teleconference held on November 21, 2014.

Upcoming IRDiRC meetings and teleconferences

• January 26, 2015: Executive Committee teleconference meeting

• March 16, 2015: Executive Committee meeting in Madrid, Spain

• June 5, 2015: Diagnostics Scientific Committee meeting in Glasgow, UK
• June 5, 2015: Interdisciplinary Scientific Committee meeting in Glasgow, UK
• June 5, 2015: Therapies Scientific Committee meeting in Glasgow, UK
• June 6, 2015: Three Scientific Committees joint meeting in Glasgow, UK
• September 7, 2015: Executive Committee meeting in Montreal, Canada

News published on the website

• Challenging patents to diagnose Long QT syndrome in Canada
• Linked2Safety project: secure medical information space to analyze clinical data
• Japan's regulatory agency should accept more surrogate endpoints in clinical trials to increase drug approvals
• State of the Art review of regulatory access and reimbursement options for innovative medicines in the US, the EU, Canada and Singapore
• Publication of the Health Technology Assessment EU strategy paper
• Outcome measures used in Huntington Disease Pharmacological Trials

IRDiRC-related calls

• The ERA-Net “E-Rare” Seventh Joint Transnational Call 2015 has been opened for research programs on rare diseases to further help coordinate research efforts of European countries in the field of rare diseases.

Website updates

• The IRDiRC presence at conferences section has been updated with the addition of a presentations on IRDiRC during the Treat-NMD Global Oversight Committee meeting in Leiden, 4-5 November 2014.
• The IRDiRC in the news section has been updated with the addition of three articles mentioning IRDiRC from Frontiers in Immunology, BHD Foundation and the Action Duchenne 12th International Annual Conference.

New selected reports and policy documents

• The Reports on rare disease research section has been updated with The International Charter of principles for sharing bio-specimens and data, published in the European Journal of Human Genetics, and Current

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