

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



Season's Greetings  
with all good wishes for the New Year

## 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 Orphan-Drug Development and Regulatory Processes: [report](#) of the teleconference held on December 3, 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](#)

**trends in biobanking for rare diseases: a review, published in the *Journal of Biorepository Science for Applied Medicine*.**

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