

IRDiRC JANUARY 2015 UPDATE

for Executive Committee, Scientific Committees, and Working Groups



Upcoming IRDiRC meetings and teleconferences

- **March 16, 2015: Executive Committee meeting in Madrid, Spain**
- **June 5, 2015: Diagnostics Scientific Committee meeting in Glasgow, UK (full day)**
- **June 5, 2015: Interdisciplinary Scientific Committee meeting in Glasgow, UK (full day)**
- **June 5, 2015: Therapies Scientific Committee meeting in Glasgow, UK (afternoon)**
- **June 6, 2015: Three Scientific Committees joint meeting in Glasgow, UK (morning)**
- **September 11, 2015: Executive Committee meeting in Montreal, Canada**

Research highlights published on the website

- EMA chooses six medicines in the [first phase of the adaptive pathways pilot project](#)
- [IRDiRC label](#) to highlight research projects funded by an IRDiRC member
- Clinical trial designs for rare diseases: [International Rare Cancers Initiative portfolio](#)
- [Drug repurposing](#) based on a new concept: Homopharma
- Eleven centers designated as [Genomic Medicine Centers to decode 100,000 genomes in the UK](#)
- [Telethon 2014](#) collects a record € 82,353,996 in France
- [OPEN Act](#): legislation introduced in US congress to encourage research on drug repurposing for rare diseases
- [Rethinking drug development for rare diseases](#): a combinatorial approach to treat Charcot-Marie Tooth disease
- [The Canadian Rare Diseases Models and Mechanisms network](#) has been awarded CAD 2.3 million by the Canadian Institutes of Health Research
- [International Charter of principles](#) for sharing bio-specimens and data
- [ClinRegs](#): an online database of clinical research regulatory information
- [Clinic-developed software](#) to support NIH/NCATS global rare diseases registry
- HHS and NIH take steps to modify [clinical trial rules to improve transparency](#), following initiatives from the WHO and EMA
- The 204th ENMC International Workshop on [Biomarkers in Duchenne Muscular Dystrophy](#)

IRDiRC-related calls

- The [‘JPco-fuND’ Joint Transnational call](#) for European research projects on neurodegenerative diseases (risk and protective factors, longitudinal cohort approaches and advanced experimental models) was launched on 8 January 2015, in partnership with the European Commission under the

ERA-NET Co-fund scheme, and will be open for pre-proposals until 10 March 2015.

Website updates

- The [IRDiRC in the news section](#) has been updated with the addition of three articles mentioning IRDiRC from [Life Sciences Connect](#), [Federal Telemedicine News](#) and the [International Society for Neonatal Screening](#).

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