

IRDiRC DECEMBER 2013 UPDATE

for Executive Committee, Scientific Committees, and Working Groups



IRDiRC new documents

- The 5th IRDiRC Executive Committee meeting report and the 6th IRDiRC Executive Committee report are available.

Access the reports [here](#)

- An updated version of the governance document is available on the IRDiRC website following the changes requested during the 5th Executive Committee meeting in Miami.

Access the updated governance document [here](#)

- The following Scientific Committee reports are now available:

** Diagnostics Scientific Committee:*

September 10, 2013 – 3rd IRDiRC Diagnostics Scientific Committee meeting

May 10, 2012 - 1st IRDiRC Diagnostics Scientific Committee meeting

** Interdisciplinary Scientific Committee:*

May 30-31, 2012 - 1st IRDiRC Interdisciplinary Scientific Committee meeting

November 9-10, 2012 - 2nd IRDiRC Interdisciplinary Scientific Committee meeting

** Therapies Scientific Committee:*

October 29, 2013 - 2nd teleconference of IRDiRC Therapies Scientific Committee

July 19, 2012 - 1st IRDiRC Therapies Scientific Committee meeting

Access the reports [here](#)

Highlights on research projects

- ACMG recommendations on incidental findings earns criticism in an article; another article recommends a decision tree approach to disclosing incidental findings.

Read the article [here](#)

- Ségolène Aymé (2013 European Leadership Award ; IRDiRC project coordinator), Shire (Best Pharma Pipeline ; IRDiRC member) and Prosensa (Best SME Biotech Pipeline ; IRDiRC member) have won the 2013 ROAR Awards.

Read the article [here](#)

- Regulatory and scientific issues regarding use of foreign data in support of new orphan drug applications for approval by the FDA.

Read the article [here](#)

- Telethon Network of Genetic Biobanks: a key service for diagnosis and research on rare diseases.

Read the article [here](#)

- FDA awards USD 14 million to 15 rare disease projects.

Read the article [here](#)

IRDiRC related calls

- The 6th joint call for European research projects on rare diseases has been launched by E-Rare.

Access the call [here](#)

- The Canadian Institutes for Health Research in partnership with Genome Canada is actually proposing a call named “Research Catalyst Network: expediting collaboration between basic and clinician scientists in functional studies of novel rare disease genes”.

Access the call [here](#)

Website update

- The Therapies Scientific Committee Working Groups' composition is available on IRDiRC members' page.

Access the member's page [here](#)

- Related rare diseases initiatives section has been updated with the addition of the Korean Organization for Rare Diseases helpful link.

Access the related rare diseases initiatives section [here](#)

New lists of research projects funded by IRDiRC members

- The data collection of the projects funded during 2013 by the NIH institutes are available.

Find the different NIH lists of projects [here](#)

- The Orphan product grants program from the FDA are online from 2010 to 2013.

Find the FDA list of projects [here](#)

- The mutation database for rare diseases (2011) and the Korean patient registries (2010) from the Korean National Institute of Health are online

Find the list of projects [here](#)

Other news

- The 7th IRDiRC Executive Committee meeting will take place on May 7-8, 2014 in Berlin, Germany.
- Genzyme has officially sent a letter of intent of application to join IRDiRC.



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