

IRDiRC SEPTEMBER 2013 UPDATE

for Executive Committee, Scientific Committees, and Working Groups



IRDiRC new documents

- Reports of the second IRDiRC Diagnostics Scientific Committee meeting and the second IRDiRC Therapies Scientific Committee meeting that took place in Dublin, Ireland, on April 15, 2013.

Read the reports [here](#)

New documents from external sources

- OECD recommendation on the governance of clinical trials.

Read the report [here](#)

- Dr. Draghia-Akli and Dr. Wang have been invited to the show 'BioCentury This Week' for a video interview on IRDiRC.

Watch the video [here](#)

- Article on the saga of the transparency directive which involves the European Federation of the Pharmaceutical Industries and Associations (EFPIA).

Read the article [here](#)

- FDA clarifies aspects of the Orphan Drug Act in the Final Rule document.

Read the article [here](#)

- Cost Action representing European network for congenital imprinting calls for partners to join them.

Read the article [here](#)

- **Pharmacological chaperones to cure genetic diseases – Q&A with G. Andreotti and M.V. Cubellis.**

Read the interview [here](#)

Website update

- **Brand new homepage for IRDiRC website, with information on rare diseases initiatives, and internal and external news.**

Have a look at the new homepage [here](#)

- **All the working groups' teleconferences will now be announced in the 'Upcoming activities' section. The dates of the past working groups' teleconferences and meetings are also available on IRDiRC website.**

Find all the upcoming activities [here](#)

Find the past Working Groups activities [here](#)

- **A complete list of IRDiRC members is now available on IRDiRC website.**

Find the list [here](#)

New lists of research project

- **The list of projects funded by IRDiRC members is now organized by institution/laboratory.**

Find the list [here](#)

- **A list of The National Institute for Health (USA) for 2013 is now available and will be completed in the following months.**

Find the list [here](#)

Other news

- **Interviews of coordinators of the projects funded by IRDiRC members are now regularly published on IRDiRC website. Do not hesitate to make suggestions for interviews or to send articles, interviews, information on conferences, etc. mentioning IRDiRC.**

- **The Academy of Finland, Research Council for Health, has applied to become a member of IRDiRC.**
- **A proposition for the next IRDiRC conference has been made by the BGI. The conference would potentially be held in Sheraton Dameisha Resort hotel (Shenzhen, China), in October or November 2014.**

*Sophie Höhn, Communication manager, IRDiRC Scientific Secretariat IRDiRC,
Plateforme Maladies Rares / Rare Disease Platform, 96 rue Didot, 75014
PARIS, FRANCE, Tel: +33 1 56 53 81 37, Fax: +33 1 56 53 81 38*

<http://www.irdirc.org/>