

# IRDIRC NOVEMBER 2013 UPDATE

## for Executive Committee, Scientific Committees, and Working Groups



### IRDIRC new documents

- Report of the first teleconference of the working group on Ontologies and disease prioritization.

Read the report [here](#)

### New documents from external sources

- China celebrates the founding of the Chinese Rare Disease Research Consortium.

Read the article [here](#)

- IDEAL: international project to explore new methods for design and analysis of clinical studies in rare diseases.

Read the article [here](#)

- Petition requesting amendments to the draft on Data Protection Regulation.

Sign the petition [here](#)

- Draft NIH Genomic Data Sharing Policy Request for Public Comments (before November 15, 2013).

Read the draft [here](#)

- ISPOR (International Society for Pharmacoeconomics and Outcomes Research) is implementing a rare disease Special Interest Group (SIG).

Read the article [here](#)

- **StaR Child Health: improving global standards for child health research.**

Read the article [here](#)

- **Rare diseases – How Europe is meeting the challenges.**

Read the report [here](#)

## Website update

- IRDiRC governance structure has been updated.

Access to the new governance structure [here](#)

- Research news section has been updated and organized per month.

Have a look at the research news section [here](#)

- Related rare diseases initiatives section has been updated with the addition of the Rare Diseases portal of the European Commission.

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

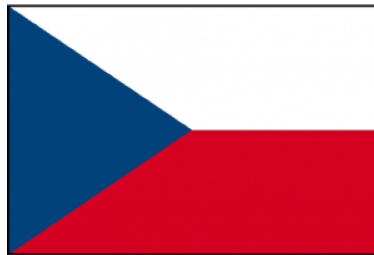
## New lists of research project

- The list of projects funded by the National Institute of Health (NIH) has been updated (April 2013 – July 2013).

Find the list [here](#)

## Other news

- The Executive Committee members will have a teleconference on November 25, 2013, from 2 PM to 4 PM CET.
- The third IRDiRC Diagnostics Scientific Committee meeting will take place on December 2, 2013 in Prague, Czech Republic.



*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*

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