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.

  Sign the petition here

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

  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.
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