IRDiRC FEBRUARY 2014 UPDATE
for Executive Committee, Scientific Committees, and Working Groups

IRDiRC new documents

- Diagnostics Scientific Committee: report of the meeting that took place in Prague, Czech Republic on December 2, 2013.

- Article and report of a workshop held in Prague, Czech Republic, following the meeting of the Diagnostics Scientific Committee, on December 3, 2013.

- Interdisciplinary Scientific Committee: report of the meeting that took place in Montreal, Canada, on October 17-18, 2013.

- Working Group on Registries and natural history: report of the teleconference held on October 2, 2013.


- Working Group on Orphan drug-development and regulatory processes: report of the teleconference held on December 20, 2013.


- New version of the letter of intent to address the concern of organizations from the private sector regarding the intellectual property, data sharing, etc.

News published on the website

http://www.irdirc.org/?wysija-page=1&controller=email&action=view&email_id=9&wysijap=subscriptions
• The Rare Disease Day will take place on February 28, 2014.

• The much awaited ontology of rare diseases of Orphanet has just been released.

• A valuable resource for drug developers has been established by the FDA: the Rare Disease Repurposing Database.

• Guidelines on pharmacogenomics have been drafted by the EMA.

Website updates

• A sitemap has been added to the IRDiRC website.

• The upcoming activities section has been updated with the creation of two categories of upcoming activities: “Public conferences” and “Internal meetings”.

• The conferences section has been updated with the creation of three categories of conferences: “IRDiRC conferences”, “IRDiRC workshops”, and “IRDiRC sessions at conferences”.

• The IRDiRC in the news section has been updated with the addition of three articles mentioning IRDiRC. A weekly survey of the news from the media mentioning IRDiRC will now be realized in order to update regularly the IRDiRC in the news section.

New selected reports and policy documents

• ACMG clinical laboratory standards for next-generation sequencing and ACMG recommendations for reporting of incidental findings in clinical exome and genome sequencing have been added to the list of recommendations available on IRDiRC website.

• EMA guideline on the use of pharmacogenetic methodologies in the pharmacokinetic evaluation of medicinal products has been added to the list of recommendations available on IRDiRC website.

• EMA guideline on key aspects for the use of pharmacogenomic methodologies in the pharmacovigilance evaluation of medicinal products has been added to the list of recommendations available on IRDiRC website.
New lists of research projects funded by IRDiRC members

- The Academy of Finland list of research projects for 2010 to 2013 has been updated.

- The National Institute for Health Research (UK) list of research project has been updated for the years 2012 and 2013.

Other news

- The dates for the 2nd IRDiRC Conference that will take place in Shenzhen, China, have changed. This conference will take place on November 7-9, 2014, in Shenzhen, China.

- The French Foundation for Rare Diseases has officially been accepted as a new member of IRDiRC.

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