

# 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 Biotechnology-derived products including cell- & gene-based therapies: [report](#) of the teleconference held on December 20, 2013.
- Working Group on Orphan drug-development and regulatory processes: [report](#) of the teleconference held on December 20, 2013.
- Working Group on Biomarkers for disease progression and therapy response: [report](#) of the teleconference held on January 9, 2014.
- Working Group on Chemically-derived products including repurposing: [report](#) of the teleconference held on January 16, 2014.
- 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

- 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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