

# IRDiRC AUGUST 2014 UPDATE

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



[IRDiRC Conference](#) early registration deadline has been extended to September 15, 2014.

### New members of IRDiRC

- [Chiesi Farmaceutici S.p.A.](#) (Parma, Italy) has officially been accepted as a new member of IRDiRC. Dr Andrea Chiesi will be its corresponding representative. Established in 1935, this international pharmaceutical company operates in all 5 continents and has shown strong commitment to develop therapies for rare diseases.
- [WuXi AppTec Co., Ltd.](#) (Shanghai, China) has officially been accepted as a new member of IRDiRC. Dr Mao Mao will be its corresponding representative. Established in 2000, this leading global pharmaceutical and medical device outsourcing company, with operations in China and USA, aims to facilitate the R&D efforts for new therapies with well-established partnership with pharmaceutical companies and to develop clinical diagnostics kits for rare diseases.



## IRDiRC new documents

- Working Group on Registries and Natural History: [report](#) of the teleconference held on July 9, 2014.
- Working Group on Data Sharing and Bioinformatics: [report](#) of the teleconference held on July 21, 2014.
- Working Group on Chemically-Derived Products Including Repurposing: [report](#) of the teleconference held on July 23, 2014.
- Working Group on Biobanks: [report](#) of the teleconference held on July 24, 2014.

## Upcoming IRDiRC meetings

- September 2, 2014: teleconference of the Diagnostics Scientific Committee.
- September 16, 2014: teleconference of the Working Group on Population Controls Variant Datasets.
- October 6, 2014: teleconference of the Therapies Scientific Committee.
- November 6, 2014: Executive Committee meeting in Shenzhen, China.

## News published on the website

- Scouting for rare disease causing genes: [results from Canada's FORGE](#).
- [Early escape crossover trials for rare diseases](#) are better adapted to patient needs and preferences.
- Not just a number: [the benefits of putting patients at the heart of clinical trials](#).
- [Proposal for international guidelines](#) on conducting research and sharing genomic data.
- Fostering orphan medicine research and development: the success of the FDA's [Orphan Products Grants Program](#).
- [New standardized protocols](#) to conduct research on congenital muscular dystrophy in mouse models.

## Website updates

- The [IRDIRC sessions at conferences section](#) has been updated with the addition of 1 session about IRDiRC during the International Conference on Rare and Undiagnosed Diseases that will be held in September 29-30 in Rome, Italy.
- The [IRDIRC in the news section](#) has been updated with the addition of three articles mentioning IRDiRC from the [Journal of General Internal Medicine](#), the [Western Australian Department of Health](#) and [BioClub](#).

## New selected reports and policy documents

- The 2014 annual EUCERD report on the [State of the Art of Rare Disease Activities in Europe](#) is now available.

## New lists of research projects funded by IRDiRC members

- The [French Foundation for Rare Diseases list of research projects](#) is now available for 2012 and 2013.
- The [list of clinical trials for 2014](#) under the Orphan Products Grant Program from Food and Drug Administration has been updated.

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