

IRDIRC DECEMBER 2016 UPDATE



Less than 35 days until the 3rd IRDiRC Conference

The countdown has started towards the 3rd International Rare Diseases Research Consortium (IRDIRC) Conference, that will be held on February 8-9, 2017, in Paris, France. Less than 35 days separate us between now and a conference that will bring together various stakeholders in the rare diseases community. The [program](#), that is now finalized, will bring together a wide spectrum of invited speakers from around the globe, as well as speakers selected for their high-quality abstracts.

There are still places available for the conference! Register [now](#) and join us in determining the future for rare diseases research. We look forward to welcoming you in Paris, France, in February 2017!

IRDIRC new documents

- Consortium Assembly – [report](#) of the face-to face meeting, Catania, Italy of September 23, 2016
- Patient Advocacy Committee – [report](#) of the teleconference of August 22, 2016
- Funders Committee – [report](#) of the teleconference of August 22, 2016
- Companies Committee – [report](#) of the teleconference of August 30, 2016

Upcoming IRDiRC teleconferences and meetings

- January 4, 2017 – Operating Committee – Teleconference
- January 9, 2017 – Conference Planning Committee – Teleconference
- January 13, 2017 – Interdisciplinary Scientific Committee – Teleconference
- February 6-7, 2017 – Consortium Assembly and Scientific Committees – Face-to-face meeting, Paris, France
- February 8-9, 2017 – 3rd IRDiRC Conference - Paris, France

Events for your calendar

4th International Clinical Trials Methodology & 38th Society for Clinical Trials Conference 2017

The Society for Clinical Trials and the MRC Network of Hubs for Trials Methodology Research, jointly organize the 4th International Clinical Trials Methodology Conference. This event promises to be a unique opportunity for those working in clinical trials to collaborate at a world leading conference venue to discuss the issues pertinent in trials today.

4th International Clinical Trials Methodology Conference, May 7-10, 2017, Arena and Convention Centre (ACC) - Liverpool, UK

More details and registration: <http://www.ictmc2017.com/>

Rare disease research published on the website

- The challenges of rare diseases in the [United Nations](#) program
- [Priority review voucher](#) of the United States: should it be expanded to all orphan drugs?

Research highlights from IRDiRC members

- "This 30th Telethon launches a generation of finders!"
- The [21st Century Cures Act](#): a landmark piece of legislation
- Countdown to [Rare Disease Day 2017](#)
- [Genetic Alliance](#) 30th anniversary celebration
- President signs [21st Century Cures Medical Innovation bill](#) into law
- Blood brain barrier on a [chip](#)

Research highlights

Workshop on Privacy-Preserving Record Linkage

The first face-to-face meeting of the Privacy-Preserving Record Linkage (PPRL) task force, a joint initiative of the Global Alliance for Health and Genomics (GA4GH) and IRDiRC, took place on December 8-9, 2016. The meeting began with the task force's two committees each presenting a brief primer they had drafted on the relevant considerations in their two respective areas of inquiry, namely the ethico-legal and technical aspects of PPRL. In the discussion that followed, the task force quickly gravitated toward the existing European Unified Patient Identifier (EUPID) approach as providing a sound basis for PPRL. A number of implementation issues would, however, need to be addressed. At least some of the elements it envisions as centralized would likely need to function on a federated basis. An optimal set of immutable linkage data will also need to be identified. These types of questions are being further explored by the task force, which will then draft recommendations to the GA4GH and IRDiRC that outline the relevant considerations and identifying the outstanding technical questions that will need to be resolved.



IRDiRC-related calls

The French Foundation for rare diseases, together with the French National Infrastructure PHENOMIN, have launched the [3rd joint call for the creation and exploration of mouse models for rare diseases](#). This call aims to boost the development of mouse model, in order to gain a better understanding of the pathophysiological mechanisms involved in rare diseases and validate therapeutic proofs of concept, at the pre-clinical in vivo level. Application deadline: February 9, 2017.

Other news

If you are presenting in a meeting or a conference, and you would like to show some information about IRDiRC, standard slides are available on the IRDiRC private website; additional slides can be made

available upon request. Please also email the Scientific Secretariat when and where you will be presenting, so we can keep track of "IRDiRC presence at conferences."

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