

Executive Summary

1st IRDiRC Executive Committee Meeting

**Brussels, Belgium
25-26 January 2012**

The IRDiRC Interim Executive Committee met in Brussels on 25 and 26 January 2012. The main objective of the meeting was to further develop the governance of the initiative in view to meet its ambitious goals to deliver, by 2020, 200 new therapies and means to diagnose most rare diseases.

The Committee welcomed the new members of IRDiRC and noted that, at the time of the meeting, 22 research funding organisations from Europe, Canada, the US and Australia had expressed their commitment to invest a minimum of 10 million USD, over a 5 year period, in research supporting the IRDiRC goals.

At the meeting the Committee, Chaired by Ruxandra Draghia-Akli, took a number of decisions to ensure the effective governance of IRDiRC, including decision making procedures and composition of the Executive Committee. It was also decided that representatives of patient umbrella organisations should be invited to participate as full members of the Committee, and that regulatory organisations should be invited in an advisory capacity. It was agreed that the Chairs of IRDiRC's three Scientific Committees shall also be members of the Executive Committee.

The Executive Committee appointed members to the three Scientific Committees (i.e. the Diagnostics Committee, the Interdisciplinary Committee and the Therapies Committee). Nominations had been received from funding bodies, learnt societies, patient advocacy groups and other nominating organisations. The role of the Scientific Committees will be to: act as scientific coordinating bodies; propose research priorities for consideration by the Executive Committee; propose policies and guidelines for adoption by the Executive Committee; assess and report on progress made by the Working Groups (i.e. projects funded); Address arising issues of scientific nature; Organise the scientific programme for annual meetings of IRDiRC.; Encourage exchange of protocols and best practices, and agree on standard operating procedures, quality standards, etc.

The Executive Committee also discussed the establishment of working groups. An immediate set up was considered premature, and will be reconsidered by the Executive Committee once the Scientific Committees will have expressed their needs for specific working groups.

Highlights from the roundtable of the participating funding bodies included the news from NIH concerning the establishment of the Mendelian Disorders Genome Centers Program, which will invest 48 million USD over the next four years to rapidly and systematically find the genetic underpinnings of rare diseases. Three projects totalling 5.7 million Euros selected from a call specifically dedicated to IRDiRC launched in 2011 by the Spanish Instituto de Salud Carlos III are also expected to bring the field forward.

The next meeting of the Interim Executive Committee will be organised in Paris in September 2012, hosted by the Association Française contre les Myopathies (AFM).

IRDiRC Funding bodies represented at the Executive Committee*

- ▶ Western Australian Department of Health, Australia
- ▶ Canadian Institutes for Health Research*, Canada
- ▶ Genome Canada*, Canada
- ▶ European Commission*, European Union
- ▶ Agence Nationale de la Recherche*, France
- ▶ Association Française contre les Myopathies*, France
- ▶ Bundesministerium für Bildung und Forschung*, Germany
- ▶ Istituto Superiore di Sanita*, Italy
- ▶ Telethon Foundation*, Italy
- ▶ The Netherlands Organisation for Health Research and Development*, the Netherlands
- ▶ Prosensa*, the Netherlands
- ▶ Instituto de Salud Carlos III*, Spain
- ▶ National Institute for Health Research*, UK
- ▶ National Cancer Institute, US
- ▶ National Eye Institute, US
- ▶ National Human Genome Research Institute - Mendelian Disorders Genome Centres*, US
- ▶ National Human Genome Research Institute - National Centre for Translational Therapeutics, Library programme, US
- ▶ National Institute of Arthritis and Musculoskeletal and Skin Diseases, US
- ▶ National Institute of Child Health and Human Development, US
- ▶ National Institute of Neurological Disorders and Stroke, US
- ▶ Office of Rare Diseases Research*, US
- ▶ Sanford Research, US
- ▶ Eurordis (Observer) *

* organisations attending the meeting in Brussels