

## **IRDiRC Consortium Assembly at the center of IRDiRC's governance**

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The International Rare Disease Research Consortium (IRDiRC) was started in 2010 with the objective to accelerate medical breakthroughs for people affected by rare diseases. Initially conceived as a consortium of rare disease research funders following a joint discussion of the European Commission and the US National Institutes of Health, IRDiRC has experienced substantial growth in the number and diversity of its members over the last five years. Current Consortium members include funding agencies, industry, institutes, ministries and patient organizations.

For the Consortium to continue to function efficiently, IRDiRC governance needs to adapt to the growth in size and diversity of its members and functions. The first of these adaptations is the renaming of IRDiRC's largest representative body, formerly the Executive Committee, as the Consortium Assembly. The new name more accurately reflects this group's function as a gathering of all the consortium's members, focused on information exchange and efforts to develop and coordinate scientific and policy efforts that will advance IRDiRC goals.