

Creation of Constituent Committees to advise the IRDiRC Consortium Assembly

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The International Rare Disease Research Consortium (IRDiRC) has grown substantially over the years, since its launch in 2011. In order to better accommodate the growth and diversity of the members, the IRDiRC governance is currently undergoing a number of changes. While the coordination of science and knowledge sharing among the scientists are central to IRDiRC goals, so are the coordination of work and knowledge sharing for the funders, companies, and patient advocacy groups which make up the Consortium Assembly. Until present, no formal forums exist for the latter.

To this end, three Constituent Committees have been created: Funders Committee, Companies Committee, and Patient Advocates Committee. Members of each committee comprise of representative members of the Consortium Assembly. Nonetheless, each committee will meet and discuss independently of the Consortium Assembly, and provide feedback and advice in a similar manner to that of the Scientific Committees.

The Funders Committee will gather IRDiRC public funders to identify and address gaps in rare diseases research funding, including coordination of funding efforts and new network opportunities. The Companies Committee will discuss the collective view from the industry and investigate roadblocks that hold back progress in rare diseases clinical research relative to IRDiRC goals. The Patient Advocates Committee will represent patients' needs and look into patient engagement in rare diseases research. All together, the Constituent Committees will identify common priorities and goals, address roadblocks and coordinate solutions, in order to directly advance IRDiRC objectives.

With the creation of these Constituent Committees, IRDiRC is confident that the consortium will continue to grow and thrive, to not only have the structure to fulfill the original goals and objectives but to build towards new ones continuously and continually, and together, contribute to the next phase of IRDiRC.