

The International Rare Diseases Research Consortium (IRDiRC)

Today, the diagnosis for most patients affected by rare diseases remains a challenge and most are lacking dedicated therapies. Recent progress in human genomics and other scientific advances increases the prospect for developing effective interventions. Progress will require increased coordination and renewed efforts among multiple stakeholders across the world.

Over the last days a group of research funders, patient advocacy groups, researchers, industry and regulatory agencies continued their work at the second meeting of the International Rare Disease Research Consortium, IRDiRC. The success of this meeting was the endorsement by many stakeholders of the objectives to deliver by 2020 diagnostic tests for most rare diseases and 200 new therapies for patients affected by rare diseases.

This ambitious vision will be realised through an unprecedented cooperation at the international level. The International Rare Disease Research Consortium invites public and private partners with shared commitments from across the globe, to join our efforts and alleviate the suffering of individuals affected by diseases for which today there are no treatments available.

The group will next develop the scientific and policy framework to guide the research activities and foster collaboration among the stakeholders to systematically explore all the opportunities to accelerate the development of diagnostics and therapies for rare diseases. The next meeting of IRDiRC will take place in Montreal, Canada in October 2011. Continued efforts until the next meeting will include strengthening the cooperation among the consortium members and to reach out for new partners.

More information will be forthcoming.