What is IRDiRC?
International Rare Diseases Research Consortium (IRDiRC)

Co-operation at international level to stimulate, better coordinate & maximize output of rare disease research efforts around the world
Enable all people living with a rare disease to receive an accurate diagnosis, care, and available therapy within one year of coming to medical attention.
All patients coming to medical attention with a suspected rare disease will be diagnosed within one year if their disorder is known in the medical literature; all currently undiagnosable individuals will enter a globally coordinated diagnostic and research pipeline.

1000 new therapies for rare diseases will be approved, the majority of which will focus on diseases without approved options.

Methodologies will be developed to assess the impact of diagnoses and therapies on rare diseases patients.
IRDiRC’s history

- **2010-2011 – Building period**
  - 3 workshops to define and adopt goals and governance structure

- **2012-2014 – Set up period**
  - Implementation of Scientific committees
  - Definition of IRDiRC’s road map
  - Funding and set-up of Scientific Secretariat

- **2015-2018 – Implementation period**
  - Implementation of road map through Task Forces
  - IRDiRC recommended process
IRDiRC – basic principles

- International level co-operation to stimulate, better coordinate & maximize output of rare disease research efforts around the world
- Teams up public and private organizations investing in rare diseases research
- Research funders with relevant programs >$10 million US over a 5-year period can join & work together
- Each organization funds research its own way
- Funded projects adhere to a common framework
58 IRDiRC members
- 31 funders
- 14 companies
- 13 patient advocates organizations
IRDiRC’s Members are located in 22 countries

North America
- Canadian Institutes of Health Research
- Canadian Organization for Rare Disorders
- Cydan II
- Food and Drug Administration
- Genetic Alliance
- Genome Canada
- Genzyme
- Global Genes
- Ionis Pharmaceuticals
- NIH/National Cancer Institute
- NIH/National Center for Advancing Translational Sciences
- NIH/National Eye Institute
- NIH/National Human Genome Research Institute
- NIH/National Institute of Arthritis and Musculoskeletal and Skin Diseases
- NIH/National Institute of Child Health and Human Development
- NIH/National Institute of Neurological Disorders and Stroke
- National Organization for Rare Disorders
- NKT Therapeutics
- Pfizer
- PTC Therapeutics
- Recursion Pharmaceuticals, Inc
- Sanford Research

Europe
- Academy of Finland
- Agence Nationale de la Recherche
- Chiesi Farmaceutici S.p.A.
- Children’s New Hospitals Management Group
- E-Rare Consortium
- European Commission
- European Organisation for Research and Treatment on Cancer
- EURORDIS-Rare Diseases Europe
- Federal Ministry of Education and Research
- French Foundation for Rare Diseases
- French Muscular Dystrophy Association
- Istituto Superiore di Sanità
- Loulou Foundation
- Lysogene
- National Institute for Health Research
- National Institute of Health Carlos III
- Rare Diseases International
- Roche
- Shire
- Teletton Foundation
- The Netherlands Organisation for Health Research and Development
- Ultragenyx

Asia
- Advocacy Service for Rare and Intractable Diseases
- BGI
- Chinese Organization for Rare Disorders
- Chinese Rare Disease Research Consortium
- Japan Agency for Medical Research and Development
- Indian Organization for Rare Diseases
- Korean National Institute of Health
- National Institutes of Biomedical Innovation, Health and Nutrition
- Organization for Rare Diseases India
- Saudi Human Genome Project
- WuXi AppTec Co., Ltd

Africa
- Rare Diseases South Africa
- Botswana Organization for Rare Diseases

Australia
- Western Australian Department of Health
- Rare Voices Australia