




# 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**



# IRDIRC Goals, by 2027

- ▶ 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**

INTERNATIONAL  
RARE DISEASES RESEARCH  
CONSORTIUM

# IRDiRC – basic principles

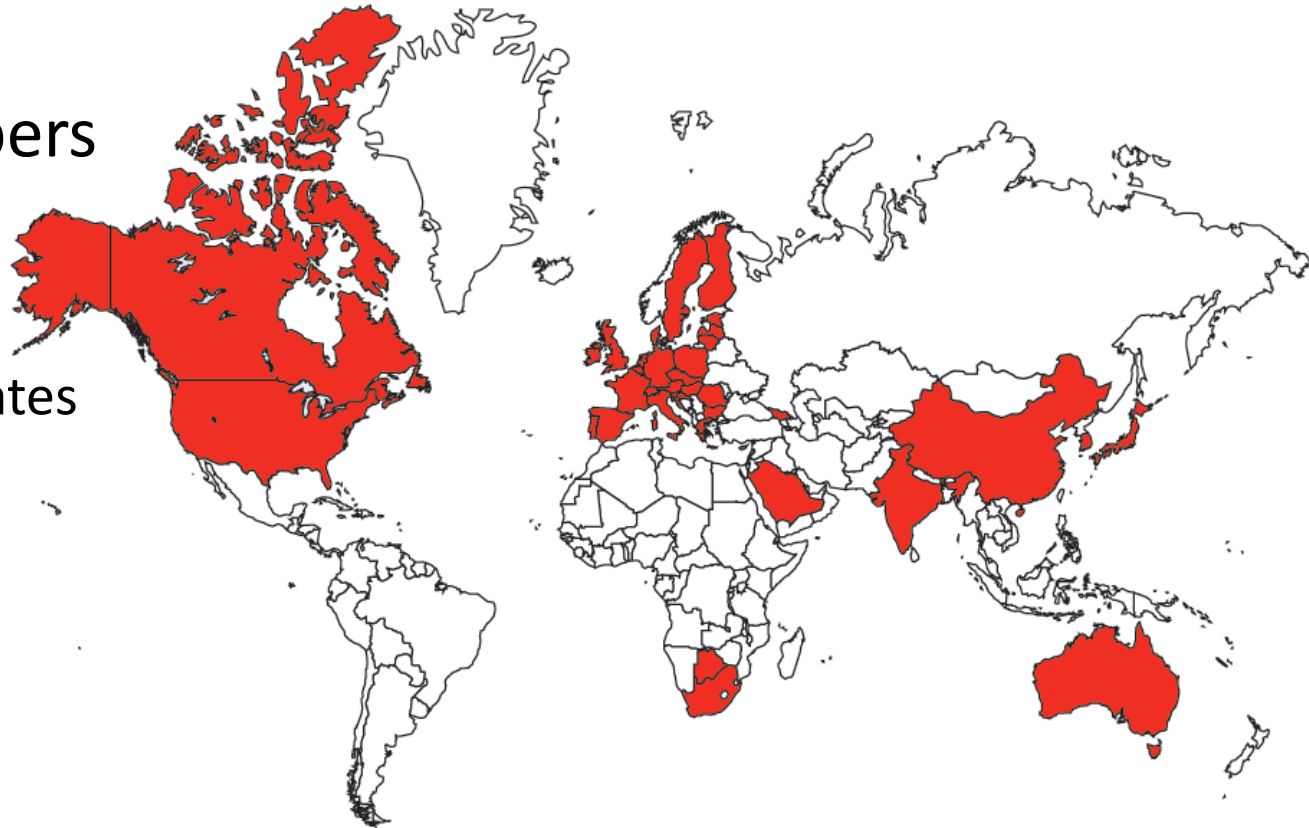
- ▶ International level co-operation to stimulate, better coordinate & maximize output of rare disease research efforts around the world
- ▶ Teams up public and private organizations investing in rare diseases research
- ▶ Research funders with relevant programs >\$10 million US over a 5-year period can join & work together
- ▶ Each organization funds research its own way
- ▶ Funded projects adhere to a common framework



# IRDiRC's Members

## ► 58 IRDiRC members

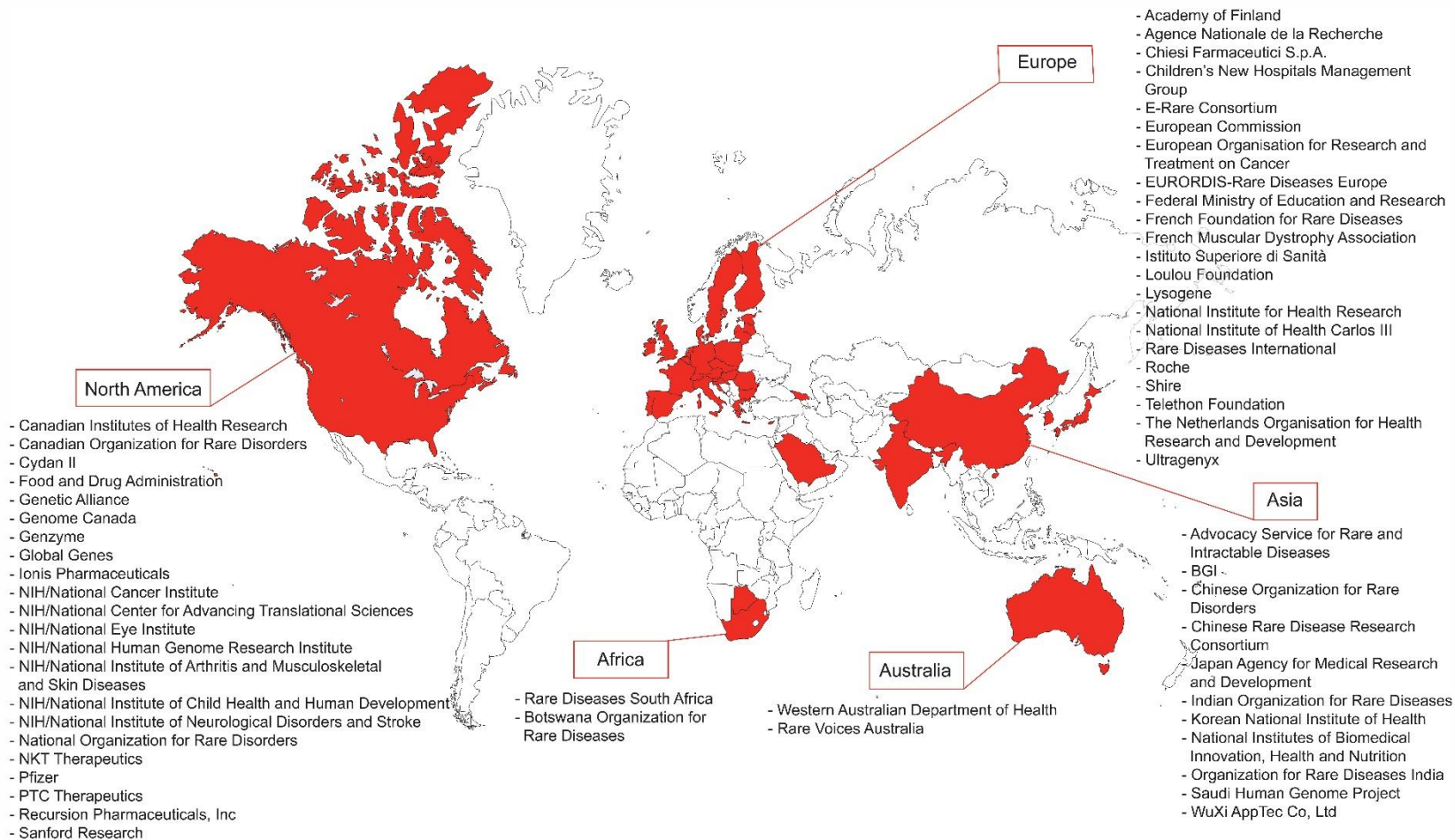
- 31 funders
- 14 companies
- 13 patient advocates organizations



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# IRDiRC's Members are located in 22 countries



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