What is IRDiRC?



International Rare Disease Research Consortium (IRDiRC)

Cooperation at international level to stimulate, better coordinate and maximize output of rare disease research efforts around the world



IRDiRC – basic principles

 Co-operation at international level to stimulate, better coordinate & maximise output of rare disease research efforts around the world



- Teams up public and private organisations investing in rare diseases research
- Research funders with relevant programmes >\$10 million US over a 5-year period can join & work together
- Each organisation funds research its own way
- Funded projects adhere to a common framework



Goals of IRDiRC by 2020

200 new therapies for rare diseases



Means to diagnose most rare diseases





Intruments to reach the goals

- Increase research volume
- Boost cooperation between researchers
- Speed up R&D





Governance structure

- 1 representative per funding body - 1 representative per group of funders **Executive Committee** (accumulative funding) - representatives of umbrella organizations of patient advocacy groups Scientific - the chairs of the Scientific Committees Secretariat Scientific Committees 15 members with balanced Diagnostics Interdisciplinary Therapies representation of scientists, patients, industry, etc. **Working Groups** Ontologies and Model systems Genome/Phenome Sequencing diseases prioritization Representatives of funded Registries and Bioinformatics Ethics and Biobanks projects or patients Natural history Governance and data sharing organisations, experts, etc. Biotechnology-derived Biomarkers for Chemically-derived Orphan drugdisease progression products including products including celldevelopment and & gene-based therapies and therapies responses repurposing regulatory processes



IRDiRC Scientific Secretariat

- ▶ In place at Inserm US14, at the Rare Disease Platform, Paris, France
- ► FP7 contract for 6 years since October 2012: « Support IRDiRC »
- Management of the network / assistance
 - to Executive Committee, Scientific Committees and Working Groups



Management of the website: http://www.irdirc.org/

Expansion of the consortium on four continents





IRDiRC Conferences

- ► First IRDiRC Conference
 - ublin, Ireland
 - \$April 16-17, 2013
 - Organized by the European Commission



- Second IRDiRC Conference
 - ∜in Shenzhen, China
 - ♥ November 7-9, 2014
 - Organized by Beijing Genomics Institute (BGI)





All documents are accesssible at www.irdirc.org





