IRDiRCs GOVERNANCE
Consortium Assembly

- Voting members
  - 1 representative per funding body or group of funders
    - Funding agencies, Industry, Research Institutes, Consortium of Funding bodies, Governmental bodies
  - Representatives of patient advocacy groups
  - Chairs of the Scientific Committees

- Non-voting members
  - Members of the Scientific Secretariat
Scientific Committees

- Advising the Executive Committee on research priorities and progress made from a scientific viewpoint
- ~15 members with balanced representation of scientists, patients, industry, etc.
- Memberships on nomination basis
Scientific Committees (Sci Comms)

- **Diagnostics Committee**
  - Advises on research related to the diagnoses of rare diseases

- **Interdisciplinary Committee**
  - Provides expertise on cross-cutting aspects of rare diseases research

- **Therapies Committee**
  - Advising on research related to R&D for therapies for rare diseases
Mandate of the Sci Comms

- Address emerging issues of scientific nature
- Propose research priorities for consideration by research funding agencies
- Propose policies and guidelines for adoption by Exec Comm
- Identify actionable projects and contribute to their implementation
- Organise the scientific programme of IRDiRC conferences
- Encourage exchange of protocols and best practices, and agree on standard operating procedures, quality standards, roadmap to reach IRDiRC goals in their scientific area
Scientific Secretariat

- Based at INSERM US14 – Rare Disease Platform, Paris

- FP7 contract for 6 years, starting October 2012: “Support IRDiRC”

- Organisational support to the implementation of the IRDiRC’s roadmap, tracking of IRDiRC goals

- Management of the website [www.irdirc.org](http://www.irdirc.org) and other communication tools
Governance

Available on www.irdirc.org