



NGO COMMITTEE FOR  
**RARE DISEASES**

# The NGO Committee for Rare Diseases

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The International Conference on Rare Diseases and Orphan Drugs

A Committee of **CoNGO**



CoNGO  
The Conference of NGOs  
in Consultative Relationship  
with the United Nations



# ICORD – in 1 slide

- \* Multi-stakeholder, Formed in 2005, 11 annual meetings
- \* Including US, Europe, Japan, Russia, Latin America, South Africa
- \* Engaging governments, health systems, professionals, patients
- \* Yukiwariso declaration on RD policy and action plans
- \* Emphasis on right to health and universal healthcare
- \* Seeding policy responses in countries visited
- \* Focus on developing nations
- \* Statement from Helen Clark, UNDP, on RD in Sustainable Development Goals and Universal Healthcare – October 2016



# The future for Rare Diseases

- \* An issue whose time has come
- \* Now an unstoppable momentum
- \* Need for close collaboration among all stakeholders
- \* Many dimensions – HTA, drug discovery and regulation, ethics and human rights, better clinical care, faster diagnosis, screening, prevention, patient information and empowerment, education, social support
- \* All are important. Neglect any at our peril
- \* Working together for a better future for rare



# Why it matters to me

