Genetic Alliance at the United Nations

Jenny Rollo OAM
Rare Diseases International
New York, February 2019
Members of Rare Disease International - AGM @ Microsoft.
Including Rare Diseases in the Disability agenda using the UN Convention on the Rights of Persons with Disabilities

Lieven Bauwens
Secretary General, International Federation for Spina Bifida and Hydrocephalus
Board member, Eurordis
20 February 2019
Some history

- **Decades of prior (policy / UN) activity**
  70 years of human rights history, from the Declaration on Human rights over the decade on Disabilities to the CRPD

- **Adopted 13 December 2006**, open for signature: 30 March 2007

- **Paradigm shift:** “**nothing about us, without us**”
  (article 4.3: “In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations”)
  (article 33.3: “Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.”)

- **Almost reaching universal ratification**
Australia represented in APARDO,
Asia-Pacific Economic Cooperation (APEC)

- 21 Member Countries
- 2.8 billion people
- Facilitates economic growth in region
- 59% of the world's GDP
- Responsible for 49% of world trade
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https://www.un.org/development/desa/disabilities/wp-
Walking home in the snow
Policy Event at the United Nations
Hosted by the permanent Mission of Estonia
The UN Building
Rare Diseases International reps
Why?

• Raise awareness amongst the **general public, stakeholders and decision-makers**

• **Break isolation** of people living with a rare disease and their families

• Create a **sense of community** across the different rare diseases

• Generate an **international momentum** and a **common identity**
Improving the lives of people with rare diseases
Standing room only for the all-day meeting
A UN RESOLUTION FOR RARE DISEASES WOULD BE A BIG STEP TOWARDS A BRIGHTER TOMORROW
Action Plan Pillars

1. Define rare disease and orphan products with policies and processes
2. Raise public and political awareness of rare disease issues
3. Promote innovative research and development
4. Build human resource capacity in medical and non-medical sectors
5. Facilitate early, accurate, and systematic diagnosis
6. Coordinate patient-centred care across medical speciality, life course and location
7. Deliver new and accessible treatments to patients
8. Support financial and social needs of patients and their families
9. Manage pooling and usage of patient data securely and effectively
10. Prioritize comprehensive domestic rare disease policy
The importance of secure data collection

Registry should be a dynamic platform that captures and interrogates data

- Registry time-scales
  - Short-term, medium-term, Long-term time-frames

- Registries system should capture data required by all stakeholders and make outcomes accessible and useful for decision making

- It should have the capacity to add additional conditions/data collection centres as required

Bellgard M. Embracing digital disruption to advance clinical research, 2017 ACS Distinguished Citation.
Ooh, look! A squirrel!
Thank you

Genetic Alliance Australia
www.geneticalliance.org.au

Rare Diseases International
www.rarediseasesinternational.org