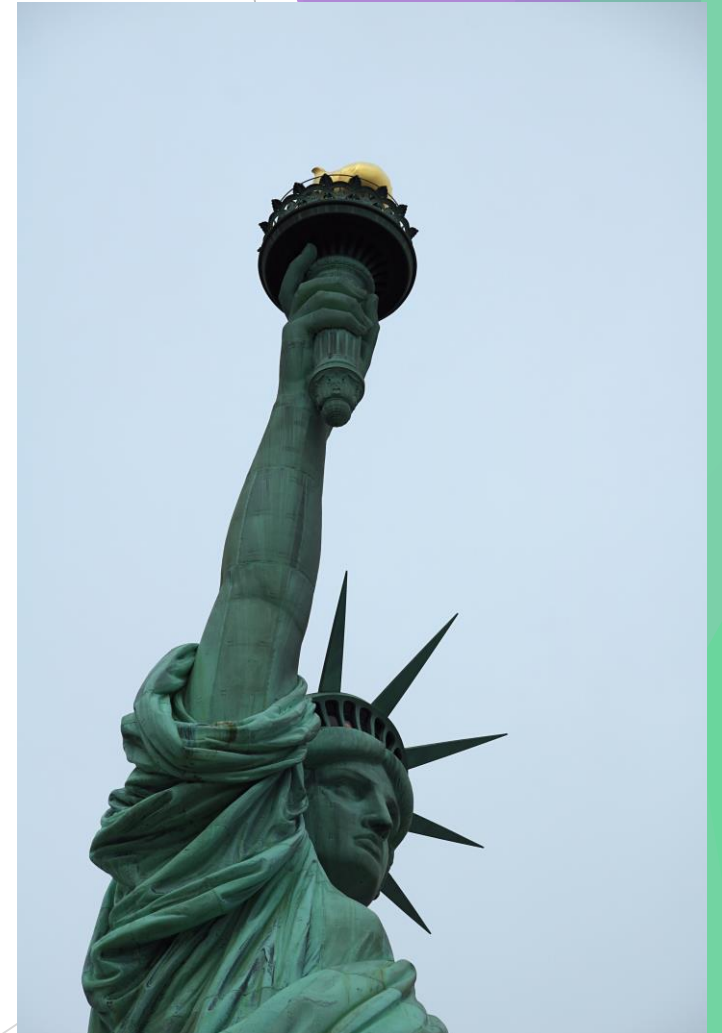


Genetic Alliance at the United Nations

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**



RARE
DISEASES
INTERNATIONAL

https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2018/01/History_Disability-in-the-UN_jan23.18-Clean.pdf

Australia represented in APARDO,



Asia Pacific
Alliance of Rare
Disease Organisations

APARDO's Vision

- To be a strong united voice in the Asia Pacific region on behalf of patients and families living with/affected by rare diseases

APARDO's Mission and Mandate

- To help member organizations improve treatment outcomes for those affected by rare diseases (including rare cancers) in Asia-Pacific

APARDO's Objectives

- Larger voice on rare diseases by integrating regional voices
- Sharing information through active communications
- Policy development for regional and national policies
- Conduit for developing rare disease national alliances by connecting groups

APARDO Members

Members

- Canadian Organization for Rare Disorders
- Chinese Organization for Rare Disorders
- Dakshayani And Amaravati Health and Education
- Hong Kong Alliance for Rare Diseases
- Indian Organisation for Rare Diseases
- Lysosomal Storage Disorders Support Society
- Rare Voices Australia Ltd

Affiliates Members

- Carcinoid & Neuroendocrine Tumor Society
- DEBRA Singapore

Asia-Pacific Economic Cooperation

21 Member Countries

2.8 billion people

Facilitates economic growth in region

59% of the world's GDP

Responsible for 49% of world trade



APEC

APEC Action Plan

Some history

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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



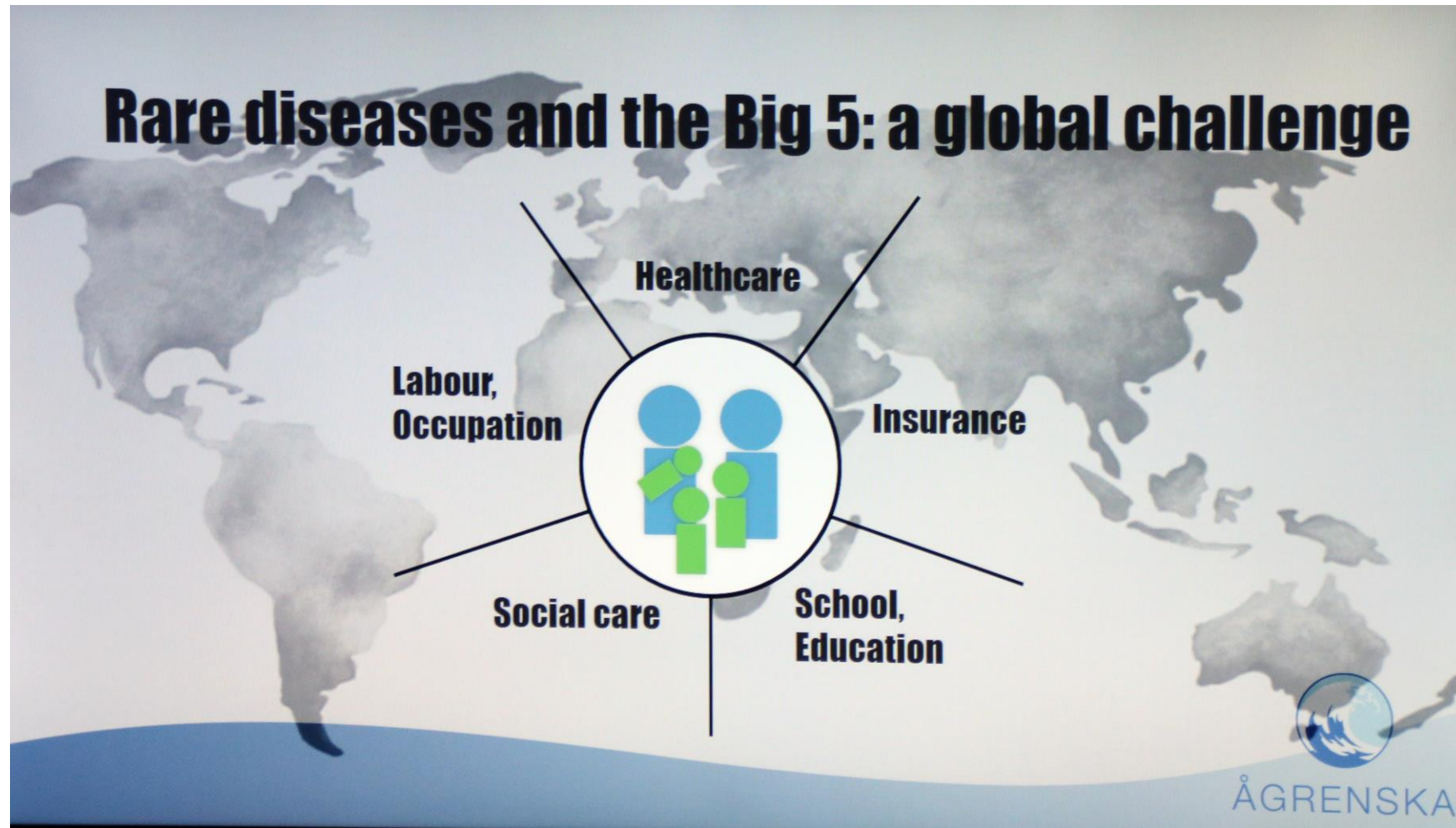
Why?

- 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**



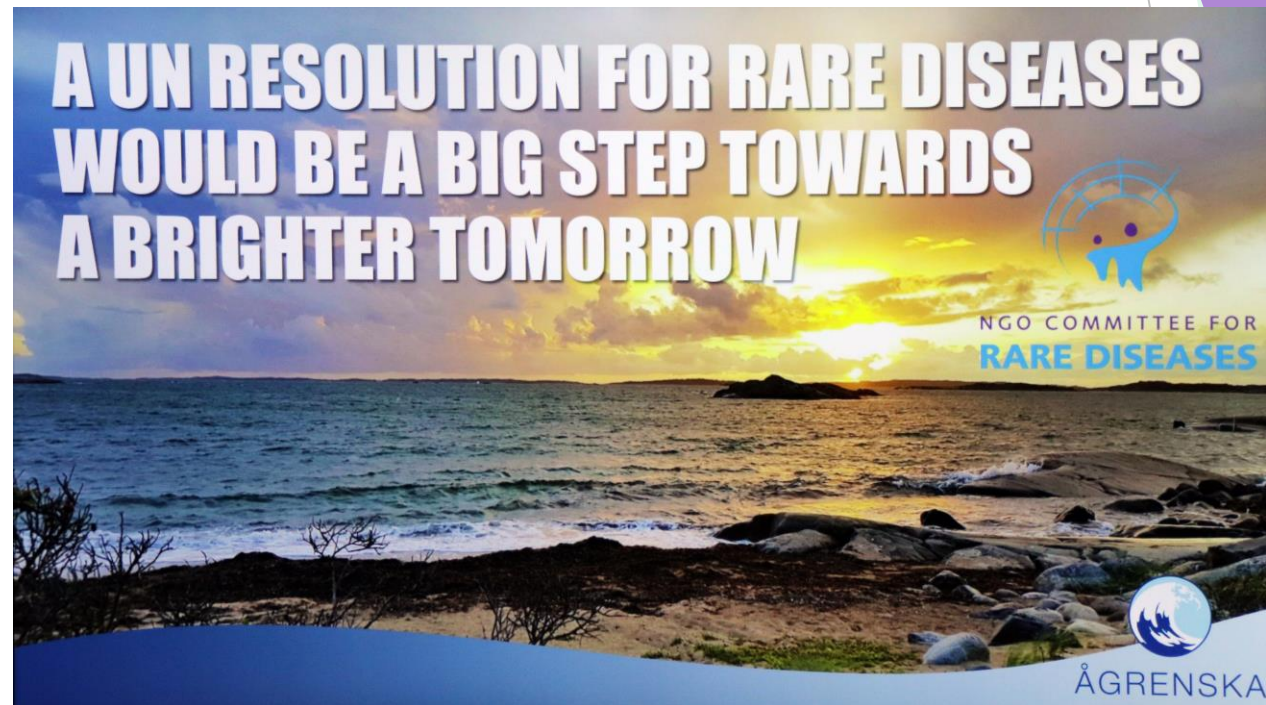
NGO COMMITTEE FOR
RARE DISEASES

Improving the lives of people with rare diseases



Standing room only for the all-day meeting





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

Prioritize comprehensive domestic rare disease policy

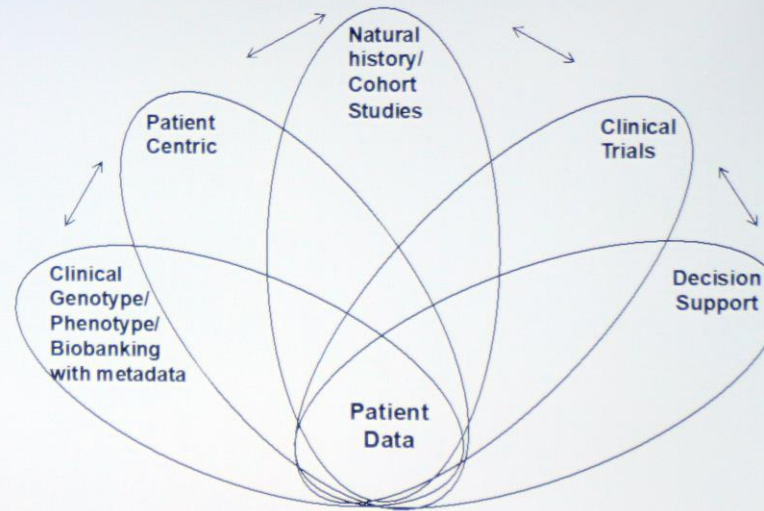
10



The importance of secure data collection

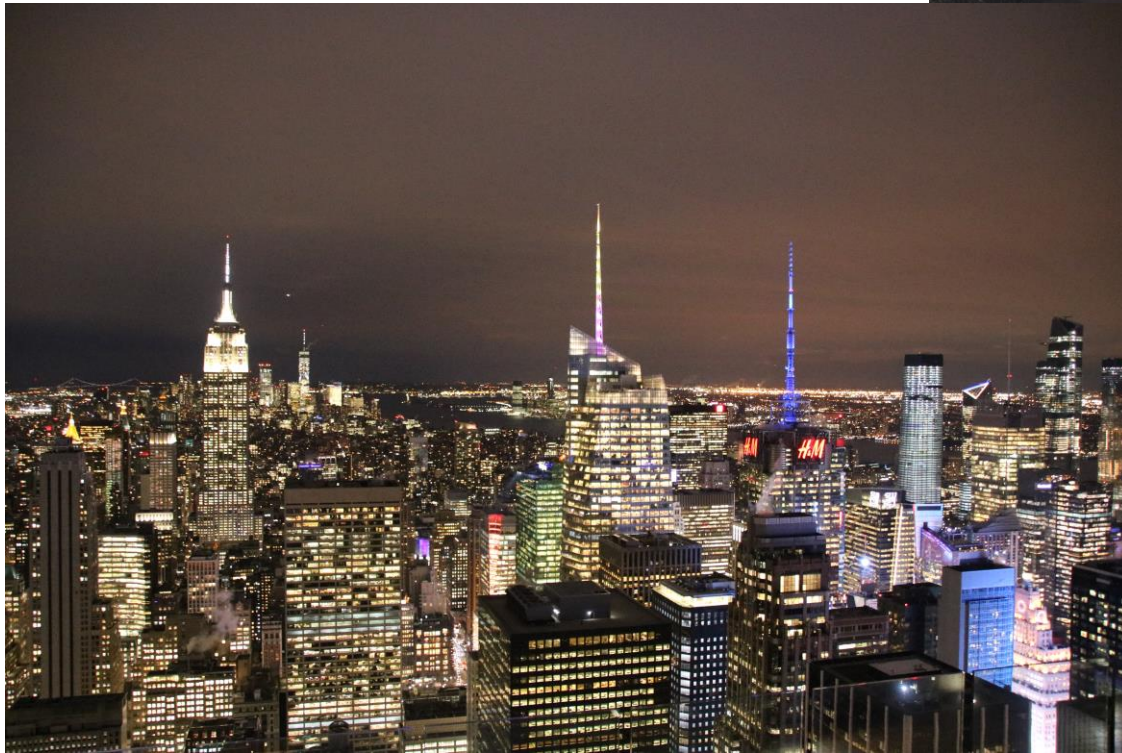
Registry should be a dynamic platform that captures and interrogates data

- 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 Oration.

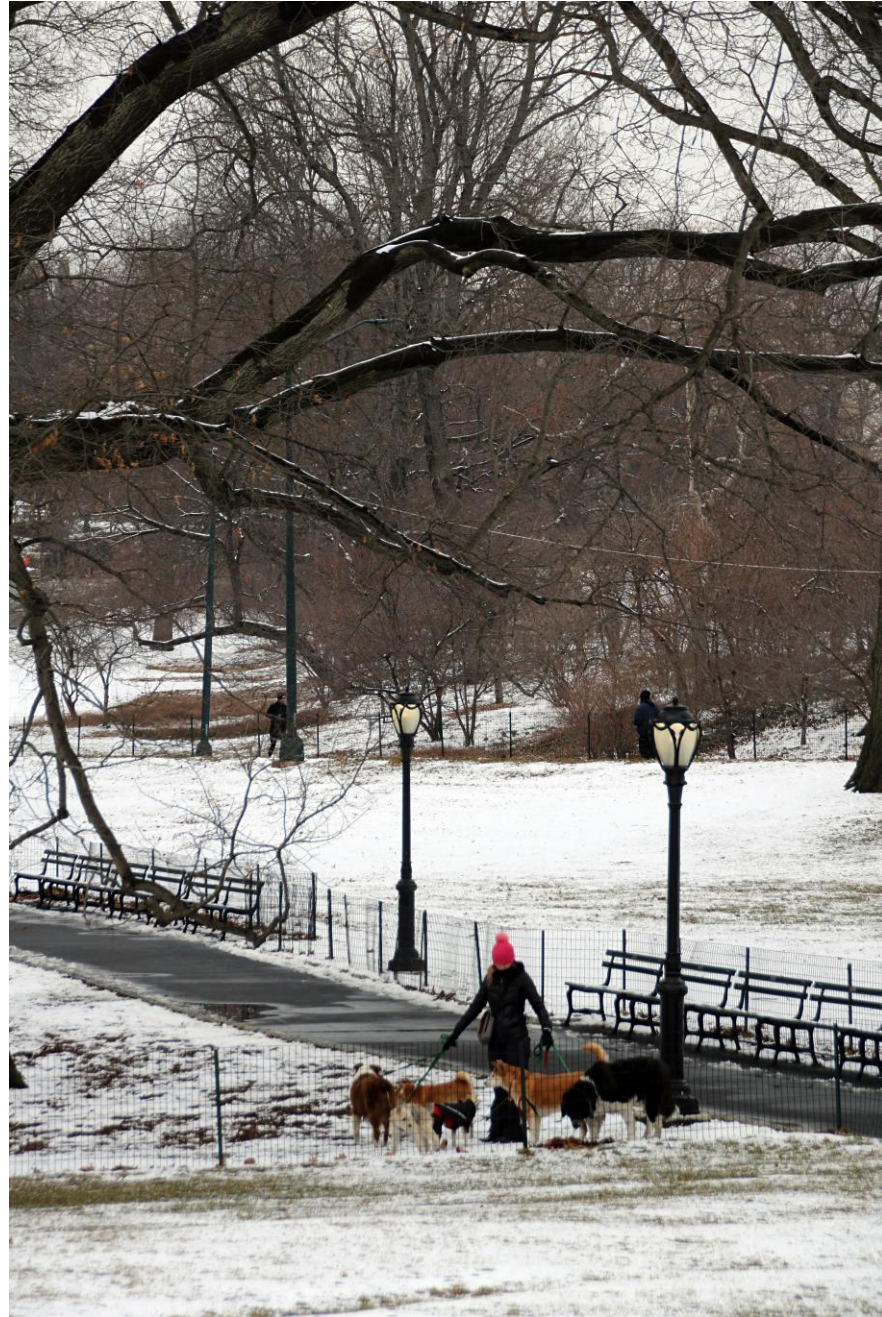






Ooh, look! A squirrel!









Thank you

Genetic Alliance Australia

www.geneticalliance.org.au

Rare Diseases International

www.rarediseasesinternational.org

