



NGO COMMITTEE FOR  
**RARE DISEASES**

# The Australian Experience of Rare Disease

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A Committee of **CoNGO**



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



# Rare Voices Australia



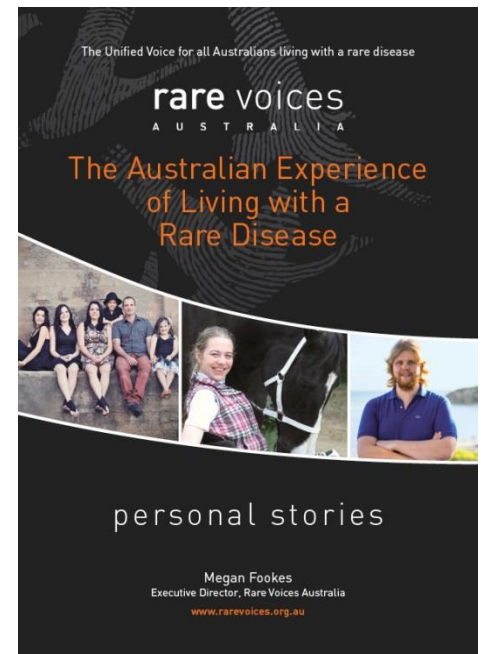
# Rare Disease Facts

- \* Rare Disease patients are located through Australia
- \* Rare Disease Day Movement
- \* WA Rare Diseases Strategic Framework 2015-2018
- \* Orphan Drugs Program
- \* Life Saving Drugs Program
- Rare Disease Summit -2015
- Rare Disease Communique



# Rare Disease Patient Experience

- Diagnosis is often delayed
- Access to coordinated care is fragmented
- Limited data / knowledge
- Expertise is often siloed
- Inequity of health and social services
- Need for clear pathways
- Need for a consistent approach



# Opportunities

- \* National Rare Disease Strategy
- \* A National Rare Disease Registry
- \* Rare Disease Research
- \* **Regulatory/ Reimbursement process – efficiency**
- \* Connect with Oceania countries
- \* Collaborate internationally

