BE RARE AWARE



SEVEN PRIORITIES TO IMPROVE HEALTH AND WELLBEING FOR PEOPLE LIVING WITH A RARE DISORDER

- Diagnosis
 Early and accurate diagnosis
 of rare diseases
- Planned pathways for clinical care
 Coordinated and integrated pathways for cohesive healthcare
- Access to disability and social supports
 Implement simple mechanisms to ensure appropriate access to disability and social supports
- Rare disorder medicines

 Equitable access to modern rare disorder medicines through a specific assessment pathway

- Research
 Coordinated and funded programme of research for rare disorders
- 6 National rare disease registry
 Capture relevant data on rare disorders in New Zealand
- Workforce
 development
 Planned training on rare disorders
 for health professionals and
 support staff