

# BE RARE AWARE



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

### 1 Diagnosis

Early and accurate diagnosis of rare diseases

### 2 Planned pathways for clinical care

Coordinated and integrated pathways for cohesive healthcare

### 3 Access to disability and social supports

Implement simple mechanisms to ensure appropriate access to disability and social supports

### 4 Rare disorder medicines

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

### 5 Research

Coordinated and funded programme of research for rare disorders

### 6 National rare disease registry

Capture relevant data on rare disorders in New Zealand

### 7 Workforce development

Planned training on rare disorders for health professionals and support staff

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