LEADERSHIP & COORDINATION MECHANISM FOR RARE

PRIORITY 1 OF THE AOTEAROA NEW ZEALAND RARE DISORDERS STRATEGY

In 2024, the Ministry of Health released the Aotearoa New Zealand Rare Disorders Strategy (RDS). It sets the direction and long-term priorities that will guide health entities over the next 10 years to better support all people and their whānau living with rare disorders.

Priority 1 of the RDS outlines the need to establish **leadership and coordination** mechanisms in the health system to spearhead responsiveness to rare disorders.

WHY IS THIS NEEDED?

People living with rare disorders often have complex health needs and require services from a wide range of disciplines.

Patients and practitioners alike have called for a more connected system, and support coordinating the on-going care across disciplines.

The RDS sees these mechanisms supporting:

- diagnostic, referral, navigation and care standards, guidelines and pathways
- capability development reports and initiatives
- recommendations for service and system enhancements.

CHOOSING THE RIGHT MECHANISMS

A number of countries around the world have mechanisms in place to lead their responsiveness to rare disorders. These mechanisms include:

- Centres of Excellence
- Reference networks
- Information hubs

A mechanism chosen for the New Zealand context must, according to the RDS, easily and sustainably integrate across the system and have the resourcing support it needs to ensure continuous improvement.

PRIORITIES IDENTIFIED BY RD COMMUNITY

DIAGNOSIS

Early and accurate diagnosis of rare disorders

PLANNED PATHWAYS FOR CLINICAL CARE

Coordinated and integrated pathways for cohesive healthcare

ACCESS TO DISABILITY & SOCIAL SUPPORTS, INCLUDING SUPPORT FOR CARERS

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

DATA COLLECTION

Code and capture relevant data on rare disorders in New Zealand

WORKFORCE DEVELOPMENT

Planned training on rare disorders for health professionals and support staff

www.raredisorders.org.nz