

NEW ZEALAND NATIONAL RARE DISORDER FRAMEWORK

“No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases.”¹

Rare Disorders NZ (RDNZ), and the support groups they represent, are calling for the development of a National Rare Disorder Framework in New Zealand. RDNZ offers a strong common voice for inclusive health policy and a healthcare system that is fair for people with rare disorders.

While individual rare disorders may be rare, collectively they are common with over 300,000 New Zealanders living with a rare disorder in New Zealand (1 in 17 people or 6% of the population) – more than those diagnosed with diabetes. This collective deserves recognition.

Those living with a rare disorder in New Zealand face inequitable access to diagnosis, treatment, and care – particularly when compared to countries such as Australia. With visionary leadership, and building back better, the opportunity now exists for substantial changes in our health policy to improve lives. New Zealand’s current wellbeing budget and living standards framework means these changes make economic, ethical and social sense.

Rare disorders, like many other chronic diseases, are often serious and progressive. A National Rare Disorder Framework would not only benefit those with a rare disorder but have much further-reaching advantages for wellbeing and contribution to society.

Rare disorders need to be recognised as a national health priority.

People living with a rare disorder have common challenges and barriers that deserve governmental recognition and action. A National Rare Disorder Framework should focus on these priority areas:

1. DIAGNOSIS

Early and accurate diagnosis of rare disorders

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 fair and specific assessment pathway

5. RESEARCH

Coordinated and funded programme of research for rare disorders

6. NATIONAL RARE DISORDER REGISTRY

Capture relevant data on rare disorders in New Zealand

7. WORKFORCE DEVELOPMENT

Planned training on rare disorders for health professionals and support staff

¹ Helen Clark, United Nations, 2016

ORGANISATION ENDORSEMENT OF THE CALL FOR A NATIONAL RARE DISORDER FRAMEWORK





RARE DISORDER SUPPORT GROUPS WITHOUT LOGOS

ALD Foundation Trust
 Alpha-1 Association New Zealand
 Arnold Chiari Malformation Support Group
 Congenital Cytomegalovirus Support Group
 Cornelia de Lange Syndrome Support Group
 Cri du Chat Support Group of New Zealand
 Cystinosis Support Group
 Foetal Anti-Convulsant Syndrome New Zealand
 FOXG1 New Zealand Support Group
 Hereditary haemorrhagic telangiectasia Support Group
 Hirschsprung's Support Group
 Intracranial Hypertension New Zealand
 Immune Thrombocytopenia Purpura (ITP) NZ
 Myasthenia Gravis Support Group

Mal De embarquement Syndrome Support
 New Zealand Williams Syndrome Association
 Occulo Dento Digital Dysplasia Support Group
 Orthostatic Tremor Support Group
 Osteogenesis Imperfect Support Group
 Perthes Support Group
 Perry Syndrome Support Group
 Porphyria Support Group (NZ)
 Restless Legs Syndrome Support Group
 Sarcoidosis New Zealand
 Tarlov Cyst New Zealand