

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





Ehlers-Danlos Syndromes
New Zealand



Friedreich Ataxia Research Association
New Zealand



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

Hereditary haemorrhagic telangiectasia Support Group

Hirschsprung's Support Group

Intracranial Hypertension New Zealand

Immune Thrombocytopenia Purpura (ITP) NZ

Myasthenia Gravis Support Group

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