

## 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.”<sup>1</sup>

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

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<sup>1</sup> 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  
Pemphigus New Zealand  
aHUS New Zealand  
New Zealand EoE Support group  
Te Whānau Kōtuku – Rare Disorders NZ Maori support  
Ladybug Foundation  
SCN2A Australia Asia Pacific  
Myositis NZ  
New Zealand EoE Support  
Marfan NZ and related Connective Tissue Disorders  
Aortic Dissection Support Group