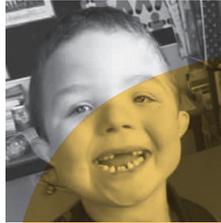




# Fair

FOR RARE

CALL FOR NATIONAL FRAMEWORK  
FOR RARE DISORDERS IN NEW ZEALAND



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

HELEN CLARK, UNITED NATIONS

Statement from UN Development Programme Administrator Helen Clark to the International Conference on Rare Diseases & Orphan Drugs, Cape Town, 20 October 2016

## Rare is Everywhere

People you know, people in your community, are living with a rare disorder. Collectively, rare disorders are not scarce, infrequent or remote with 1 in 17 people (around 300,000 New Zealanders) affected.

Rare Disorders NZ, and the support groups we represent, are calling for recognition and awareness of the common challenges faced by people living with a rare disease, along with a commitment to address these challenges through the development of a New Zealand National Rare Disorder Framework.

Just because a disease is uncommon it shouldn't be dismissed or lead to serious barriers and challenges to wellbeing. Why should a person have a more difficult pathway for needed

support just because of the complexity or rarity of their disease type?

There are excellent models and initiatives already implemented within New Zealand and in other countries that can be integrated or adapted to improve wellbeing for those with rare disorders. Our focus is on making this aspiration a reality.

It's time for New Zealand to take rare diseases seriously to ensure equitable health outcomes for everyone. Rare is part of our communities and deserves a fair go.



**Lisa Foster**  
Chief Executive

OVER  
**6,000**  
distinct rare diseases

Each one affects  
fewer than **1 IN**  
**2,000**  
PEOPLE

Affects  
**6%**  
of the  
population

**72%**  
ARE GENETIC

**300,000** New Zealanders are living  
with a rare disease;  
**300 MILLION** people worldwide

### IMPACT OF LIVING WITH A RARE DISORDER IN NZ

**38%**  
had an emergency hospital visit in the previous six months

**37%**  
often felt unhappy and depressed

**76%**  
have some or a lot of difficulty with seeing, hearing and moving

**32%**  
felt they could not overcome their problems

**73%**  
had to stop work due to their health

**60%**  
felt communication and information exchange between services was bad



# Our Vision

People living with a rare disorder will have improved healthcare and wellbeing through access to diagnosis, medicines and services

## DIAGNOSIS

Early and accurate diagnosis of rare diseases

## PLANNED PATHWAYS FOR CLINICAL CARE

Coordinated and integrated pathways for cohesive healthcare

## ACCESS TO DISABILITY AND SOCIAL SUPPORTS

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

## NATIONAL RARE DISEASE REGISTRY

Capture relevant data on rare disorders in New Zealand

## WORKFORCE DEVELOPMENT

Planned training on rare disorders for health professionals and support staff

“ I feel I am just as sick as any cancer patient but there is no financial support available and even worse, no social support or recognition of my invisible illness. All my issues are considered ‘invisible illnesses’ and that’s exactly how I feel - invisible to our health system.”

“ Because my son’s rare disorder was not well known he did not qualify for funding even with his limitations and behaviour issues. However, now with his additional diagnosis of autism, doors are finally being opened. The supports provided should NOT be based on whether it is a well-known disorder.”

“ We had to leave New Zealand to gain life-saving treatment. I would say the health system completely failed us, despite the best efforts of some people working in it.”



# Our Call For Action

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## Rare Disorders NZ amplifies the collective voice of rare disorders in New Zealand.

The rare disorder community saw real energy, goodwill and impetus for change within Government in 2019. Action and implementation are the next vital steps and the only clear way to reduce barriers to navigating the system for people living with (often complex) rare conditions.

Rare Disorders NZ represents more than 140 rare disease support groups. We have evidence-based data from our 2019 national survey of the challenges faced by people and their whanau living with a rare disorder.

New Zealand needs a health system that's Fair for Rare. We want to work with the Government to co-design a framework that ensures people living with a rare disease are integrated into a society that leaves no one behind.

Our shared vision means implementing effective person-centred care which acknowledges their needs, has room to hear their voice and involves them in the structure of mechanisms for healthcare and social inclusion.

These initiatives would not only benefit those with a rare disorder but have much further-reaching advantages – for example, reducing the burden on the health system and lessening both the time away from work and mental stress for patients and carers.

Rare Disorders NZ is part of the global rare disease community, including Rare Disease International and the Asia Pacific Alliance of Rare Disease Organisations. We want to follow the lead of countries like Australia in establishing a National Rare Disorder Framework and working to ensure equitable health outcomes for everyone.

# New Zealand's International Commitments

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- UN member states now include rare diseases within universal healthcare and affirm the need to address the health of the most vulnerable
- UN 2030 Sustainable Development Goals and New Zealand's 2019 People's Report highlights the vulnerability and unmet needs of 300,000 New Zealanders living with rare diseases
- NZ Public Health and Disability Act 2000 and Statements in the Health and Disability Commission Code of Rights detail expectations to provide comprehensive services for all New Zealanders
- APEC Rare Disease Action Plan provides objectives and pillars to facilitate Asia Pacific alignment and partnerships, with development of policies and regulations for rare disease populations.

**Help us continue to support people living with rare disorders in our communities:**

[givealittle.co.nz/org/nzord](https://givealittle.co.nz/org/nzord)



RARE  
DISEASES  
INTERNATIONAL



Asia Pacific  
Alliance of Rare  
Disease Organisations



[raredisorders.org.nz](http://raredisorders.org.nz)

**1 IN 17**  
PEOPLE  
ARE LIVING  
WITH A RARE  
DISORDER