Briefing to the Incoming Minister of Health, Hon. Andrew Little

Congratulations and Introductions

Congratulations on your appointment as the Minister of Health! We have seen your success with a new approach and strategic thinking in the Justice portfolio, and look forward to working with you to make similar inroads in the health sector.

Rare Disorders NZ is the connector hub and collective voice of rare disorders, with more than 140 rare disorder support groups under our umbrella, plus multi-sectoral links including community medical practitioners and researchers. With 6,000 different types of disorders, our organisation represents an important and sizable population that needs recognition.

1 IN 17 NEW ZEALANDERS HAVE A RARE DISORDER

What we need: A National Rare Disorder Framework

There are seven key elements of a rare disorder framework to ensure equity and inclusion:

- **Diagnosis**: Early and accurate diagnosis of rare disorders
- **Planned pathway for critical care:** Coordinated and integrated pathways for cohesive healthcare
- **Access to disability and social support**: Implement simple mechanisms to ensure appropriate access to disability and social supports
- **Rare disorder medicine**: 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

Why it matters

The current system has barriers that lead to inequities for people living with a rare disorder. This impacts the living standards of over 300,000 people with a disorder and their whanau/carers. These barriers are contributing to child poverty in New Zealand, and we know that this vulnerable group have been disproportionately impacted by COVID-19[1].

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[1] https://www.rarediseasesinternational.org/wp-content/uploads/2020/07/RDI-STATEMENT-Not-leaving-behind-RDs-in-COVID-19_Final.pdf

A rare disorder framework for New Zealand will:

- Help ensure that people living with a rare disorder are included and have improved healthcare/wellbeing through access to diagnosis, medicines and services. This is universal healthcare in action.
- Mean that the wellbeing of people with rare disorders is acknowledged and factored into government policy - including health, education, employment, and welfare/social services. This would incorporate preventative health economy policies.
- Provide vital support for carers of people with rare disorders - disproportionately women, who may also be suffering from rare disorders themselves (e.g. genetic conditions).
- Support the Government with meeting its goal of eliminating child poverty, and embed a living standards framework for some of New Zealand's most vulnerable people.
- Ensure this vulnerable group receives the vital mental health support they need at every stage of their health journey.
- Help New Zealand meet its international obligations (UN Declaration of Human Rights, CEDAW, UNCROC, Disability Convention, SDGs).
- Ensure New Zealand aligns with international standards to reduce inequity so people living with rare disorders are supported like in other OECD countries, such as the UK, Australia and the USA.

What is a rare disorder?

Unlike the US or EU, New Zealand has no official definition of what constitutes a rare disorder, however they are considered to be life-threatening or chronically debilitating disorders, which are statistically rare – and have an estimated prevalence of less than 1 in 2,000, and have a high level of complexity and uncertainty.

Examples of rare disorders include some well-known conditions such as cystic fibrosis, Batten's disease, Ehlers-Danlos syndrome, muscular dystrophy, and also rare cancers - plus other conditions with no formal diagnosis.

Key Statistics

- **Over 300,000 people in New Zealand have a rare disorder (this is higher than the number of people diagnosed with diabetes).**
- **Approximately 50% of rare disorder patients are children,** 30% of whom will not live to celebrate their 5th birthday [2].

Next steps

We would like to meet with you to discuss the issues raised in this briefing and how we can work together to progress a national framework for people living with a rare disorder.

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[2] https://globalgenes.org/rare-diseases-facts-statistics/