

RDNZ Budget Policy Statement oral presentation

Thanks for the opportunity to present in person Rare Disorders New Zealand's submission on the Budget Policy Statement.

To recap:

- About 300,000 New Zealanders have a rare disorder
- There are about 7000 rare disorders prevalent in New Zealand.
- Approximately 50% are children
- 72% of rare disorders are genetic in origin.
- 78% experience difficulty with seeing, hearing and/or moving which is related to their disorder

They're very high users of health and disability services in large part because of:

- a) the diagnostic odysseys they experience in their quest to find out what's wrong with them, or their child
- b) the treatment odysseys they experience in their quest to access evidence based best practice standards of care for themselves or their children
- c) the need to treat and respond to symptoms which could have been prevented or ameliorated with earlier diagnosis and treatment
- d) the need to treat and respond to symptoms because they can't access treatments that are available internationally but not in New Zealand
- e) the need to treat and respond to symptoms simply because effective treatments are yet to be identified anywhere – let alone in New Zealand

We at Rare Disorders New Zealand therefore advocate for people with rare disorders to have access to world class and world leading health, disability,

education and other services and experience the same rights as every other New Zealander to have best possible health and wellbeing – to live well to a ripe old age.

Our expectation is that the 2024/24 Budget will include allocations which are sufficient to address the issues which are preventing people living with rare disorders from living their best lives, and in turn we expect this to be mandated by the associated Budget Policy Statement.

This is why it's so important to us that the Budget Policy Statement includes clear, standalone, commitments to furthering New Zealanders' wellbeing, including an affirmation that it is a basic duty of the New Zealand government to support its citizens to live well for as long as possible.

This is the first time that Rare Disorders New Zealand has made a Budget Policy Statement submission.

We're doing so now because we understand that New Zealand's first ever Rare Disorders Strategy is soon to be confirmed and released. Our expectation is that its implementation will be resourced to address preferably all of the following issues which we've identified in successive surveys of people living with rare disorders and reported on in our White Papers:

- An underdeveloped approach to rare disorders prevention
- Anachronistic new born screening arrangements
- Misalignment between availability of screening tests and availability of treatment
- Life saving, life extending and life enhancing medicines being

denied to those who would benefit

- Demand for modern genetic testing technology and expertise is outstripping supply and availability, resulting in delayed diagnoses and access to effective treatment
- Clinicians, including both general practitioners and specialists are often not sufficiently equipped or resourced to accurately diagnose rare disorders
- Clinical responses to rare disorders are often based on inaccurate diagnoses which means that patients' health outcomes either fail to improve or become worse because they receive inappropriate, harmful or no treatment
- A dearth of coordination services to support people to navigate the complexities of the health system
- Disability support which is experienced as discriminatory, insufficient, difficult to access and not enabling people with rare disorders to live good lives
- New Zealand underinvests in the health research including rare disorders research, which could identify new and better interventions, treatments and cures.

I want to now turn to our submission's comments on investment. There are huge costs to society and to our health and disability services in supporting people living with the debilitating effects of having a rare disorder. Yet if we invest in doing everything we can to improve their health, wellbeing and quality of life we can both mitigate many of these costs and allow people to

function well as productive members of society and net contributors to the New Zealand economy and overall living standards.

One case in point is how allocations are made to New Zealand's medicine's budget. Over the last couple of days I've been participating in an access to medicines "valuing life" conference where the Associate Minister Hon David Seymour was the opening speaker.

He told us that his aspiration was for New Zealand to be a world leader in giving our citizens access to the medicines they need, and then made the pre-budget announcement that despite the fiscal cliff that had resulted from the previous government's commitments to increase expenditure on pharmaceuticals, the 2024/25 Budget would continue to fund medicines at those new levels.

That was good news.

However, the announcement also indicated that those same levels would prevail for the next three years. If we're to achieve the Minister's aspiration to be world leaders then the size of the allocations needs to continue to significantly increase. It's likely that this will only occur if we shift from a capped budget approach to purchasing medicines to an approach which is based both on their overall return on investment and reflects this country's overall notions of fairness and decency.

If this were to happen then this creates opportunities for people with rare disorders to be treated fairly and equitably and benefit from medicines that are currently out of reach for them.

Thanks again for the opportunity to present.

