

January 2021

Tēnā koutou,

I am writing a submission on behalf of Rare Disorders NZ in support of the Holidays (Increasing Sick Leave) Amendment Bill, in particular clause 4 which extends the annual entitlement of sick leave from 5 to 10 days' paid sick leave.

Rare Disorders NZ are the connector hub and collective voice of rare disorders in New Zealand. We have more than 140 different support groups under our umbrella and multi-sectoral links with government, community medical practitioners and researchers. A rare disorder is defined by the EU as having a prevalence of less than 1 in 2,000 and there are 6,000+ different types, affecting an estimated 300,000 New Zealanders. Fifty percent of rare disorder patients are children, which places a great burden of care on families and, in particular, women.

Financial hardship is a common theme within our collective with costs of health needs and rehabilitation often being paid for privately. The situation for Māori and Pasifika may be more extreme although New Zealand currently has no data being collected on the rare disorder population to evidence this summation.

Increasing paid sick leave entitlement is important to our collective of people living with, or caring for those with, rare disorders because it means that:

- The vulnerable population of New Zealanders living with, or caring for someone with, a rare disorder will be entitled to increased availability of employer-funded sick leave
- Due to the high level of uncertainty and complexity of rare disorders, there is often increased need for sick leave. This is evidenced in our NZ Voice of Rare Disorders survey from 2019 and detailed in the accompanying White Paper, included with this submission:
 - Rare disorders lead to high utilisation of healthcare services including specialist and GP visits (81-88% utilisation rate by respondents over the last 70 days) and diagnostic tests. One in three people presented at the hospital in the last year. One in twenty people were in ICU for an average of eight days per year.
 - This is also evidenced within the National Strategic Action Plan for Rare Diseases by Australian Government, Department of Health <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases>
- The financial burden and detrimental impact on wellbeing for this population will be reduced by enabling increased financial support when unwell and ensuring there is not enforced use of annual leave or unpaid leave to cover medical appointments. This will allow annual leave/unpaid leave to be utilised for quality time with families.
- Job security will be improved as it will allow employees to take sick leave without feeling undue pressure from employers, who may not appreciate the difficulty of the situation facing those living with rare disorders.
- This bill will reduce mental distress and illness related to the pressure of having to always choose between using available sick leave for themselves or the person cared for

Feedback from our collective on increasing sick leave entitlement:

- *“Being able to take sick leave for myself and not get even more sick would be amazing!”*
- *“Both my partner and I being able to be at the hospital with my girl without worrying about not being paid.”*
- *“I could finally take on a career and still be able to be home for my daughter during a flare.”*

Increasing sick leave entitlements is one small step that the Government can take to support people living with a rare disorder, but there is so much more to be done to support the one in 17 New Zealanders living with a rare disorder and their carers.

As detailed in this quote by Helen Clark:

“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

Most developed nations have a clear plan for this vulnerable population, for example, the Australian National Strategic Action Plan for Rare Diseases is a nationally coordinated effort to address rare diseases in Australia. Rare diseases are complex but share countless commonalities and this action plan addresses this common ground to outline a comprehensive, collaborative and evidence-based approach built on three principles:

- person-centred
- equity of access
- sustainable systems and workforce

Our call is for a New Zealand National Rare Disorder Framework to be established in line with Treaty of Waitangi and UN expectations. Simply indicating this vulnerable population is covered within other health action plans or reviews is not acceptable without consultation, awareness of specific needs and related policy.

Therefore, we call on the Government to adopt:

- The seven strategic priorities that make up a National Rare Disorder Framework for rare disorders to be embedded in current health strategies and implemented in New Zealand: details www.raredisorders.org.nz/fair-for-rare-nz/fair-for-rare/
- Rare Disorders New Zealand (RDNZ) having our government funding reinstated. We have had our funding sliced from \$120,000 per year, to \$60,000 this year with an end date of 2023. RDNZ represents an important and sizable population that deserves and needs recognition.

I wish to make an oral submission in support of my written submission on behalf of RDNZ's collective.



Lisa Foster
Chief Executive, Rare Disorders NZ

¹ Statement from UN Development Programme Administrator Helen Clark to the International Conference on Rare Diseases & Orphan Drugs, Cape Town, 20 October 2016.