

Dr Liz Craig  
Chair  
Health Committee

By email: [Health@parliament.govt.nz](mailto:Health@parliament.govt.nz)

Dear Dr Liz Craig

**Re: Petition 2020/38 of Sue Haldane and 3,472 others**

Thank you for the opportunity to provide a written submission on the petition of Sue Haldane, requesting:

*"That the House of Representatives urge the Government to acknowledge the universal challenges faced by people living with a rare disease, and the unfairness within the current system, by committing to the development of a New Zealand National Rare Disorder Framework, and note that 3,472 people have signed an online petition to this effect."*

The Ministry of Health (the Ministry) has considered Sue Haldane's submission and the information provided in support.

**Impact of rare disorders**

The Ministry is committed to ensuring that all people have equitable access to the best possible health care and support in New Zealand.

We acknowledge that rare disorders have a significant effect on the quality of life and wellbeing of those diagnosed with the disorders. We also appreciate that the whānau, aiga<sup>1</sup> and carers of those with rare disorders carry a considerable responsibility in caring for and supporting their loved ones in these situations.

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<sup>1</sup> family

## **Ministry of Health recommendation**

The Ministry does not recommend the development of a national framework for rare disorders at this stage.

The Government has a significant work programme in health, which includes work that will help improve health outcomes for those affected by rare disorders. For this reason, the Ministry does not support prioritising the development of a national framework above existing initiatives at this time.

Developing a national rare disorders framework (including the work required for comprehensive data collection) would require substantial resourcing which we are unable to provide at this time.

## **Other programmes and initiatives**

There is a range of work underway to improve the health and disability system and improve health outcomes.

The Health and Disability System Reforms<sup>2</sup> have a strategic aim to ensure national consistency in service delivery, to make healthcare accessible to everyone, regardless of where they live, and to improve the health and wellbeing of all New Zealanders, including those who live with or support people with rare disorders.

As part of these reforms, the Māori Health Authority will be responsible for ensuring the health system provides more equitable outcomes for Māori.

The Ministry also has five-year strategic frameworks to address Māori and Pacific health equity concerns and achieve better health outcomes: Whakamaua: Māori Health Action Plan 2020–2025<sup>3</sup> and Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025<sup>4</sup>.

As noted above, carers play a significant role in supporting people who have rare disorders. The cross-government Carers' Strategy<sup>5</sup> and associated Mahi Aroha Carers' Strategy Action Plan 2019-2023<sup>6</sup> acknowledge this role and aim to improve the wellbeing of this group. The New Zealand Disability Strategy 2016-2026<sup>7</sup> and the Disability Action Plan 2019-2023 will also support improved health outcomes for people with rare disorders. Other initiatives include the ongoing programme delivery of our newborn metabolic screening programme, to ensure that those twenty-three disorders

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<sup>2</sup> <https://dpmc.govt.nz/our-business-units/transition-unit/response-health-and-disability-system-review/information>

<sup>3</sup> <https://www.health.govt.nz/publication/whakamaua-maori-health-action-plan-2020-2025>

<sup>4</sup> <https://www.health.govt.nz/publication/ola-manuia-pacific-health-and-wellbeing-action-plan-2020-2025>

<sup>5</sup> <https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/index.html>

<sup>6</sup> <https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/index.html#MahiArohanbspCarersStrategyActionPlan201920234>

<sup>7</sup> <https://www.odi.govt.nz/nz-disability-strategy/>

we screen for are detected early. There are also a wide range of mental health and wellbeing initiatives that all New Zealanders can access.

The Government has also commissioned an Independent Review of PHARMAC. The review committee will report to the Minister of Health in December 2021.<sup>8</sup>

PHARMAC has specific funding avenues for people with rare disorders. Further information is available on the PHARMAC website.<sup>9</sup>

The Ministry will continue to host quarterly meetings with Rare Disorders NZ, which focus on a particular topic each time. This provides an opportunity for the organisation to connect and collaborate with teams across the Ministry and other external stakeholders.

In conclusion, I hope my response demonstrates that while we do not recommend the development of a rare disorders framework at this time, the many other initiatives underway will be of benefit to those living with and supporting people with rare disorders.

Yours sincerely



Deborah Woodley  
Deputy Director-General  
Population Health and Prevention  
**Ministry of Health**

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<sup>8</sup> <https://pharmac.govt.nz/news-and-resources/news/independent-review-of-pharmac/>

<sup>9</sup> <https://pharmac.govt.nz/medicine-funding-and-supply/the-funding-process/from-application-to-funded-medicine-how-we-fund-a-medicine/medicines-for-rare-disorders/>

