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

11 September 2024

Dr Lester Levy  
Commissioner  
Health New Zealand/Te Whatu Ora  
PO Box 793  
Wellington 6140

Dear Dr Levy

**Implementation of New Zealand’s Rare Disorders Strategy (RDS).**

As you may be aware on 25<sup>th</sup> July 2024 Manatū Hauora/Ministry of Health published New Zealand’s first ever [Rare Disorders Strategy](#) . This is something that Rare Disorders New Zealand has long campaigned for, follows a recommendation of the 2022 final report of the [Pharmac Review](#), and was written in consultation with New Zealanders who live with rare disorders.

The RDS states that “the Ministry of Health – Manatū Hauora, Health New Zealand – Te Whatu Ora, Pharmac – Te Pātaka Whaioranga and the Health Quality & Safety Commission - Te Tāhū Hauora will be accountable for implementing and monitoring the strategy. The Ministry of Health will support entities to make plans for actioning strategy priorities. Entities will report progress against these plans in their performance reports and annual reports”.

In anticipation of the imminent release of the RDS Rare Disorders New Zealand (RDNZ) had been constructively engaging with Health New Zealand (HNZ)/Te Whatu Ora personnel, which culminated in submission of a set of recommendations to HNZ’s Executive Leadership Team (ELT) for initiating the Strategy’s implementation.

RDNZ was therefore astonished to learn on 14 August 2024 that the ELT’s response was that while the current reset is underway, there is a hold on introducing new substantive programmes of work and that Health New Zealand will not therefore be initiating any actions in response to the Strategy.

I do not find this acceptable. It is not open to Health New Zealand to opt out of its obligations regarding the implementation of the RDS for any reason, even temporarily. In any case much of the content of the Strategy does not introduce “new substantive programmes of work” for Health New Zealand – on the contrary it focuses on ensuring that existing services for people with rare disorders are provided more effectively and efficiently as part of processes of continuous improvement. As such implementation of the RDS is consistent with rather than separate from your intentions for the reset insofar as it will support enhanced delivery of front line clinical services to patients.

It is also supports your assurances to the Minister of Health that will be no adverse impacts on the delivery of care in implementing a turnaround plan.



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This is not an issue that should be delayed or sidelined. The estimated 300,000 New Zealanders living with rare disorders, as well as their families, deserve action and attention. I urge you therefore to assure me, and New Zealanders living with rare disorders, that HNZ will prioritise implementation of the Rare Disorders Strategy as part of the reset which you have been charged with leading.

Yours sincerely

A handwritten signature in black ink, appearing to read "Chris Higgins".

Chris Higgins  
**Chief Executive**  
**Rare Disorders NZ**