



PO Box 7081
Newtown
Wellington 6242
www.raredisorders.org.nz

10 September 2024

Hon Dr Shane Reti
Minister of Health
Private Bag 18888
Parliament Buildings
Wellington 6160

Dear Hon Dr Reti

I am writing to you regarding the implementation of the Rare Disorders Strategy.

Rare Disorders NZ was informed on 14 August 2024 that Health NZ – Te Whatu Ora’s ELT have advised that while the current reset is underway, there is a hold on introducing new substantive programmes of work. Thus, at this time, Health New Zealand will not be initiating any actions in response to the Strategy.

I do not find this acceptable, and it is not open to Te Whatu Ora to opt out of its obligations regarding the implementation of the Strategy for any reason, even temporarily. Much of the content of the Strategy does not introduce “new substantive programmes of work” for Te Whatu Ora – rather, it focuses on ensuring that existing services for people with rare disorders are provided more effectively, as part of a process of continuous improvement.

I have discussed this with Ministry of Health – Manatū Hauora staff, and they have had conversations with their counterparts at Te Whatu Ora regarding the importance of the Rare Disorders Strategy. The message was acknowledged and understood. Manatū Hauora intends to organise a cross-agency meeting to discuss the Strategy in the next month.

On 22 July 2024, you stated: “As a Government, we’ve made it clear that our first and foremost priority in health is improving the delivery and quality of frontline services.... Lester Levy has assured me there will be no adverse impacts on the delivery of care in implementing a turnaround plan....”

With this in mind, **do you and your Government view the implementation of the Rare Disorders Strategy as part of this priority to improve frontline services?** I believe this is a critical question that requires urgent attention. For many people and whānau affected by rare disorders, accessing appropriate and timely healthcare is often a challenge. Implementing the Strategy would not only improve the quality of care for these individuals but also strengthen our healthcare system’s ability to deliver equitable services for all.



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This is not an issue that can 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 to take decisive steps to ensure the Strategy is implemented as a priority and to reaffirm the Government's commitment to supporting the rare disorder community.

I look forward to hearing your thoughts on this matter.

Yours sincerely

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

Chris Higgins
Chief Executive
Rare Disorders NZ