



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

Hon Simeon Brown
Minister of Health
Private Bag 18888
Parliament Buildings
Wellington 6160
Email: S.Brown@ministers.govt.nz

30 October 2025

Dear Minister

Thank you for arranging to host a roundtable on the implementation of the Rare Disorders Strategy, now scheduled for 11 November 2025.

Correspondence from your Private Secretary indicates the discussion will focus on progress to-date, identifying issues that need resolving and other relevant matters, and agreeing key next steps. We understand that attendees will include representatives from Rare Disorders NZ (RDNZ) and senior officials from the Ministry of Health, Health New Zealand, and Pharmac.

Ahead of the meeting, Rare Disorders NZ would like to share our perspective on the key issues that need resolving and the next steps that the rare disorder community would like to see to ensure meaningful implementation of the Strategy.

The primary issue we wish to raise is that there has been no cohesive effort to implement the Rare Disorders Strategy and the entities accountable for actioning the Strategy have not developed any form of implementation plan. The Strategy makes it clear that developing implementation plans is an essential step to putting the Strategy into effect. It states that:

"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."

To support progress, RDNZ and the rare disorder community would like the meeting to achieve the following outcomes:

1. **Leadership and Oversight:** Agreement to a senior lead from both the Ministry of Health and Health New Zealand to oversee the implementation of the Strategy for their respective entity. We note Pharmac has already nominated David Hughes.
2. **Implementation Planning:** Agreement that the Ministry of Health, Health New Zealand and Pharmac will each develop implementation plans for the Strategy, with support and coordination from the Ministry of Health (as per the Strategy) as appropriate.
3. **Ongoing Coordination:** Agreement to establish a six-monthly cross-agency forum involving RDNZ, the Ministry of Health, Health New Zealand, and Pharmac to share



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

progress, address challenges, and coordinate implementation. We propose the first meeting occur in May 2026.

4. **Accountability and Reporting:** Agreement that Health New Zealand, the Ministry of Health, and Pharmac will report on progress in implementing the *Rare Disorders Strategy* through their existing performance and accountability reporting mechanisms. Specifically, we propose that reports for the financial year ending 30 June 2026 outline the agreed implementation plan action points, with progress against these reported in subsequent reporting cycles.

We appreciate your continued leadership on this important work and look forward to a constructive discussion at the roundtable.

Yours sincerely

A handwritten signature in dark ink, appearing to read 'Chris Higgins'.

Chris Higgins
Chief Executive
Rare Disorders NZ