



Prime Minister Jacinda Ardern  
Private Bag  
Parliament Buildings  
Wellington

26 March 2020

Dear Prime Minister,

Rare Disorders NZ, and the 140 support groups we represent, commends you on the strong government response to the many challenges arising from COVID-19 virus. In these disruptive and uncertain times, we wholeheartedly support the view you have repeatedly expressed of the importance of New Zealanders being the best they can be and caring for the most vulnerable, as we have done so well in the past.

People living with uncommon or rare disorders are some of the most vulnerable in our society. There are an estimated 300,000 New Zealanders living with a rare disorder and around half of those are children, so our collective involves thousands of carers, support workers and extended whānau.

RDNZ is currently developing an online forum for our support groups, caregivers and others to share strategies for mental health, wellbeing and resilience techniques for those living with a rare disorder and their whānau. During this crisis, RDNZ welcomes working with Government to utilise our expertise and connections with clinicians, specialists and rare disorder support groups to facilitate responsive communication. As many people with rare disorders have challenges accessing disability and social services, it is likely those in real need may fall through the gaps.

We are already offering our support groups all current links to Ministry of Health information. Having a key contact person within the Ministry of Health would make this process more effective and responsive. I have attached a letter sent to Deborah Woodley outlining this request and we would welcome any specific updates we can send to our groups, especially during this time of great risk and stress within this vulnerable community.

We are committed to the need to work together as a nation to ensure that those with unique health challenges are supported during this drastic time of change and upheaval. We sincerely hope that in the development of ongoing support for our communities, from the financial through to the psychological, that the rare disorder community will be included.

Ngā mihi,

A handwritten signature in black ink, appearing to read 'Lisa Foster', written in a cursive style.

Lisa Foster  
Chief Executive

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