



06 July 2020

Our ref: LH20-010

Lisa Foster
Chief Executive
Rare Disorders NZ
lisa.foster@raredisorders.org.nz

Dear Lisa

Letter of Support for Rare Disorders NZ

Thank you for connecting with the Royal New Zealand College of General Practitioners (the College) regarding our support for Rare Disorders NZ (RDNZ).

We recognise that a collective, intersectoral voice is necessary to strengthen advocacy and recognition for people with rare disorders. As an organisation with members involved in caring for individuals with rare disorders, we are aware of the ongoing challenges of diagnosis and the variations in how these disorders present. In saying this, the College supports that more education, awareness, and policy for the rare disorder population is needed, and that this can only be sustainable through wider health system support.

Your recent 50 percent funding cut makes sustainability of your services challenging. Considering the Health and Disability Review final report, your services align with key recommendations of equitable healthcare services and a community-based locality approach to healthcare. These recommendations are considered crucial for the future of our health care system and reinforce the ethos of Te Tiriti o Waitangi in support of Māori with rare disorders.

Further, we consider that the 300,000 people and their whānau impacted by a rare disorder still require the unique and purposeful voice of your organisation, and that such representation and responsibility should not fall through the cracks as the health system is remodelled over the upcoming years.

Thank you for the opportunity to support you at RDNZ. We look forward to connecting again in future.

Sincerely

Lynne Hayman
Chief Executive