Prime Minister Jacinda Ardern
Parliament Buildings
Wellington 6160

**[Insert date]**

Dear Prime Minister,

**[Insert your organisation’s name if relevant]** is writing to you to highlight the issues being faced by those living with rare disorders in our electorate.

As you may be aware, over 300,000 New Zealanders live with a rare disorder in New Zealand (1 in 17 people, or 6% of the population) – half of whom are children. The impact of living with a rare disorder is significant, affecting not only the individual, but extending to affect families and carers, the health system and society.

Regrettably, in New Zealand there is very little support for those living with a rare disorder and no recognition. They face inequitable access to diagnosis, treatment and care – particularly when compared to countries such as Australia. We know what needs to change to improve the quality of life of those with rare disorders, but it requires commitment from the highest level to happen.

**[Insert your story/experience and the issues important to you/your group]**

[Insert your organisation’s name], as one of the 138 support groups that constitute Rare Disorders NZ, is seeking to:

1. gain official recognition of the very existence of this group of people;
2. secure the Government’s commitment to implement a National Rare Disorder Framework;
3. secure sustainable funding for Rare Disorders NZ, the ONLY organisation representing all people living with a rare disorder.

As Helen Clark said at the United Nations in 2016, “No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases.”

We know you value kindness and are focused on the wellbeing of all New Zealanders, so we hope you will commit to improving healthcare and wellbeing for people and their whānau living with a rare disorder in New Zealand.

Yours sincerely,

**[INSERT SIGN OFF/CONTACT DETAILS AS WELL AS LINK TO ORGANISATION’S WEBSITE]**