**[INSERT RESPECTIVE TO/FROM ADDRESS DETAILS (NOTING WE ARE TARGETING THE MP’S ELECTORATE ADDRESS) AND DATE – USE ORGANISATIONAL LETTERHEAD IF ONE EXISTS]**

Dear [insert their title/name]

[Insert your organisation’s name if relevant] would like to request a meeting with you as our local MP to express our concern over New Zealand’s poor record of managing rare disorder cases in the health system and to recommend to you the establishment of a Rare Disease Centre of Excellence similar to other countries as a solution.

We would appreciate being able to meet as soon as convenient at your electorate office (or via a virtual meeting) and propose that in attendance from our organisation would be [list name/s] as well as local constituent [insert name]. [Insert sentence briefly outlining the rare disorder details of that local constituent].

People living with a rare disorder are estimated to make up 6% of New Zealand’s population, yet this large community experiences substantial unmet need and inequitable access to healthcare. With over 6,000 known rare disorders, individually these disorders occur in very small numbers in the population, but collectively, rare disorders are estimated to affect 300,000 people in New Zealand.

Rare disorders can be complex, debilitating and life threatening, and often require a broad range of services. Rare Disorders NZ’s survey of the rare disorder community in 2021 found that regardless of their specific disorder, those affected share the same challenges and systemic barriers - lack of timely diagnosis, poor treatment access, lack of access to modern medicines, lack of coordinated care, isolation, significant carer impact and for many, being lost in the system.

Among the alarming results, the survey found:

* Over half took longer than one year to get a diagnosis, and for one in five, it took over 10 years.
* High utilisation of healthcare services, with 81-87% having seen a specialist or GP in the 70 days prior to survey
* There were few accessible, effective modern medicines available for the majority of people, with most being used to relieve pain and inflammation.
* The majority felt that communication and information exchange between different service providers was poor and that professionals are poorly prepared to support them.

These issues have been addressed in other countries by establishing Rare Disease Centres of Excellence that act as hubs of expertise and promote best practice, bringing together experts from multiple specialities to reduce the time to diagnosis and improve the availability and coordination of multi-specialty clinical care, improving medical and family education, creating safe and effective referral pathways, and driving innovation around new treatments, therapies, and research.

There is an opportunity to establish such a centre in New Zealand by looking to international best practice, developing regional partnerships and applying a Te Tiriti lens to such work.

We are hoping that this worthy cause is one you wish to learn more about and may indeed see potential for supporting. You could make a transformational difference to the lives of 300,000 New Zealanders living with a rare disorder by championing the call for the establishment of a Rare Disease Centre of Excellence in New Zealand.

We appreciate that your time is valuable, so we will ensure to keep our meeting brief.

We would look forward to your response.

Yours sincerely,

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