**[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 the lack of data being collected on rare disorders in New Zealand and the barrier this imposes on seeing any progress on health outcomes for this community.

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].

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.

A recent report by BERL found that it is not possible to accurately estimate the prevalence of rare disorders in New Zealand due to the low quantity of data available. The primary reason for this is that the classification system for diseases that New Zealand uses does not include most rare disorders.

How can the Government measure the need, estimate the demand for services and make evidence-based decisions for this population group without any data?

While we are delighted that Manatū Hauora is in the process of developing a National Strategy for Rare Disorders, a significant and persistent problem hindering any meaningful change to improve the health outcomes for our community is the lack of systematic data collection on rare disorders in New Zealand.

Without data, rare disorders and the needs of this population group remain invisible to the Government and its officials, and will not be allocated sufficient priority and funding. It is a significant concern to have such a community of scale’s health needs ignored.

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 by championing this cause.

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]**