**[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]

[I/Insert your organisation’s name if relevant] would like to request a meeting with you as our local MP to express the need for a plan to implement the Rare Disorders Strategy.

We would appreciate being able to meet as soon as convenient at your electoral 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.

We are deeply concerned about Te Whatu Ora | Health New Zealand's refusal to engage with Rare Disorders NZ and the rare disorders community to make a plan to implement New Zealand’s first Rare Disorders Strategy.

The rare disorder community has been calling for action for over 20 years to improve services for people living with a rare disorder. The Government has finally delivered a Rare Disorders Strategy, but unless it is implemented it will not be worth the paper it’s written on.

People living with a rare disorder cannot be expected to continue to wait for better health and wellbeing. They have already waited too long.

Rare disorders can be complex, debilitating and life threatening and often require a broad range of services, yet New Zealand has never had pathways in the health system to manage rare disorders. As a result, people affected by a rare disorder are often bounced around in the health system without a clear care pathway, unnecessarily becoming high-need, high-cost patients.

The health system is under a reset, yes, but the health of people living with a rare disorder cannot be put on hold any longer. The reset phase should be used to plan to implement cost-effective approaches to respond to the needs of people living with a rare disorder.

Action can be taken now, beginning with an implementation plan by Te Whatu Ora.

We are hoping that this worthy cause is one you wish to learn more about and may indeed see potential for supporting. Particularly as [insert any personal background/info on the MP that provides a connection to rare disorders].

Together, we can improve healthcare and wellbeing for people and their whānau living with a rare disorder 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]**