Dear [insert their title/name]

I am writing to you as my local MP to encourage you to consider becoming a member of a new cross-party parliamentary group on rare and undiagnosed disorders, which you will have received an invitation to from Rare Disorders New Zealand in December.

People living with a rare disorder are estimated to make up 6% of New Zealand’s population and have for too long experienced substantial unmet need and inequitable access to healthcare. With over 7,000 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. 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.

Advances in genomics and precision medicines mean diagnosis and treatment of rare disorders are at the heart of cutting edge, innovative therapies that could benefit all New Zealanders who become unwell. This is the future of healthcare, and New Zealand, currently lagging far behind other OECD countries in delivering appropriate therapies for rare disorder patients, is at risk of being ill-equipped to meet the growing demand for novel therapies.

We cannot afford to ignore the needs of those affected by rare disorders. By addressing the current challenges and systemic barriers for rare disorder patients, New Zealand will be better placed for a future health system that can deliver individualised healthcare and therapies.

We are hoping that this worthy cause is one you wish to learn more about and may indeed see potential for supporting through membership of the cross-party parliamentary group. You could make a transformational difference to the lives of 300,000 New Zealanders living with a rare disorder by championing their cause.

I look forward to your response.

Yours sincerely,