

To.....  
**Parliament Office.**  
**Private Bag 18888.**  
**Parliament Buildings.**

**Wellington 6160.**  
Your address

Date:

Dear .....

I suffer from Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS), a debilitating illness, which affects over 20,000 New Zealanders. This is a serious neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder; international classification code G.93.3. Recent research findings also point to auto-immune/neuro-inflammatory involvement and a biomarker is expected shortly, which will allow a simple blood test to confirm a person has the disease. The Griffith research team in Australia and others in America are very close to releasing biomarkers.

In February 2015, an expert committee was convened by the Institute of Medicine (IoM) to examine the evidence base for ME/CFS. They confirmed "ME/CFS is a serious, chronic, complex, systemic disease that can often profoundly affect the lives of patients." The committee stressed that "health care providers should acknowledge ME/CFS as a serious illness that requires timely diagnosis and appropriate care." Since the IoM report more groundbreaking research findings have been released which confirm the IoM stance that this is an organic or biomedical illness.

ANZMES, the national organization of New Zealand, which represents ME/CFS sufferers, consistently makes representation to government officials on areas of concern such as disability and home help issues.

I want you to know that ME/CFS affects every aspect of my life, from the physical and emotional pain, to my financial position, friendship and relationships. No part of my life or that of my family remains untouched. It costs patients financially in lost income and increased medical care. A recent study Collin (2017) found that people with ME/CFS have nearly 50% more GP consultations, prescriptions, tests and referrals than age-matched controls. ME/CFS also affects the ability to work. Government organisations need to take a flexible approach to supporting these people. It costs society, as many can no longer interact with families and friends. A recent survey commissioned by the New Zealand National Society for ME/CFS "ANZMES" put those with ME/CFS in the lowest 10% of the population for measures such as the NIH PROMIS physical health scale which measures the physical quality of a life. This is lower than those with other neurological illnesses such as Parkinson's disease or Multiple Sclerosis.<sup>1</sup>

I have written to you to raise awareness at a national level of the need for recognition of ME/CFS and support for myself and others affected by this illness. I would like all government agencies to know what ME/CFS is and how it affects people. I would like research into all aspects of the disease to be a priority.

Yours Faithfully,

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