

May 2023

From: _____

To:

Parliament Office
Private Bag 18888
Parliament Buildings
Wellington 6160

World ME Day, 12th May 2023

Will you advocate for patient safety and adequate support for people with ME/CFS and long COVID?

Dear

May 12th is World ME Day, a day to raise awareness about Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS). It is estimated that this serious and debilitating illness affects between 25,000 - 45,000 people in Aotearoa/New Zealand. How debilitating is it? Research¹ indicates that people with ME/CFS have the lowest Health Related Quality of Life index score of the common diseases studied: ME/CFS – 0.47, Depression - 0.62, Multiple Sclerosis – 0.67, Breast Cancer – 0.75, General Population – 0.85.

ME/CFS most often develops following an immune challenge such as a viral infection. The global COVID-19 pandemic has put a spotlight on post-viral diseases with many people developing long COVID²; and some meet the internationally accepted diagnostic criteria^{3,4} for ME/CFS.

The New Zealand government is overdue in ensuring that people with ME/CFS have access to appropriate clinical and practical support - currently, we do not. Changes are needed to improve patient safety and to lift our quality of life.

As someone who is directly affected by ME/CFS, I urge you to advocate for:

1. Alignment of all-of-government and medical bodies with one clear message: ME/CFS is a serious multi-systemic disorder with a biological basis, significant disability, and long-lasting economic and social effects.
2. Increased funding for Te Whatu Ora to ensure that people with ME/CFS and long COVID have access to knowledgeable health practitioners, home help, and other support. In 2023, the Health Select Committee has considered a petition⁵ for improved access.
3. Funding the regional ME/CFS charities who provide support, connection and advocacy for individuals with ME/CFS.
4. Funding the New Zealand-based and world-leading biomedical researchers in ME/CFS and long COVID, who struggle to fund their projects: Professor Warren Tate, Dr Lynette Hodges, Dr Anna Brooks, and others.
Please help to improve my quality of life and the lives of the thousands of New Zealanders who are impacted by this debilitating illness.

Yours faithfully, Ngā mihi

¹ Research Article on HRQoL for ME/CFS <https://doi.org/10.1371/journal.pone.0132421>

² Nature Long Covid Review Article <https://www.nature.com/articles/s41579-022-00846-2>

³ CDC Diagnostic Criteria and guidelines for ME/CFS <https://www.cdc.gov/me-cfs/about/index.html>

⁴ NICE Guidelines for ME/CFS <https://www.nice.org.uk/guidance/ng206>

⁵ ANZMES Petition to reclassify ME/CFS as a Disability https://www.parliament.nz/en/pb/sc/submissions-and-advice/all?custom=PET_125649

This letter was provided by ANZMES, the national advisory and support body for ME/CFS in Aotearoa/NZ. For more information, please contact: www.anzmes.org.nz / info@anzmes.org.nz