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To: The Honourable Mark Holland, Minister of Health hcminister.ministresc@hc-sc.gc.ca

Re: Addressing Long-COVID

The joint Statistics Canada / Public Health Agency of Canada report cited below made a number of findings about the long-term effects of COVID-19. As of June 2023:

- 2.1M Canadian age 18+ were experiencing long-term symptoms following COVID-19.
- 49.7% of them said that they had not seen any improvement in symptoms over time.
- Fatigue and brain fog were the most reported symptoms.
- About 14.5M days of work or school have been missed by Canadians age 18+ due to long-term symptoms following COVID-19.
- About 100k Canadians age 18+ have been unable to return to work or school because of their symptoms.
- Only 1 in 8 Canadians age 18+ who sought help for their long-term symptoms felt they received adequate care.

The report concludes that: "Considering these findings, protection against COVID-19 infections including reinfections and the development of long-term symptoms is paramount."

That is a good suggestion but it does not help people who already have long-term symptoms or the people who will develop long-term symptoms in the future. These people need help and Canada needs their contributions.

Our organization has been working on the topic of post-infectious illnesses for three decades. Our advice is to build on the work currently being done around Myalgic Encephalomyelitis.

ME (which is often referred to as chronic fatigue syndrome) is often acquired following infection. A number of different infectious agents have been found to trigger ME. Symptoms of ME include fatigue and brain fog - the two most reported long term symptoms following COVID infections.

Despite a lack of support from the health and disability systems over recent decades, a top-class international ME community has formed with expertise in research, clinical care and disability issues. It is from this community that many of the long-COVID answers are likely to emerge. But the ME community needs your support to make this happen.

We would be pleased to meet with you or your staff to discuss how to move forward. We would like to see these ideas reflected in the 2024-25 plans and priorities of the health portfolio.

Margaret Parlor President

c.c Stephen Lucas, Deputy Minister, Health Canada, <u>Stephen.Lucas@hc-sc.gc.ca</u>
Heather Jeffrey, President, Public Health Agency of Canada, <u>Heather.Jeffrey@phac.aspc.gc.ca</u>
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See "Experiences of Canadians with long-term symptoms following COVID-19" published December 2023 by Statistics Canada and the Public Health Agency of Canada. https://www150.statcan.gc.ca/n1/pub/75-006-x/2023001/article/00015-eng.htm

For a short history of ME and Fibromyalgia in Canada, see our organization's 30th anniversary newsletter here: https://mefmaction.com/images/stories/quest_newsletters/Quest137.pdf