



September 15, 2021

Briefing Note for BC Provincial Treasury Board, Select Standing Committee on Finance

Cc: Premier John Horgan, Minister of Health Adrien Dix, Deputy Minister of Health Stephen Brown, Official Opposition Critic, Shirley Bond, Health Critic Renee Merrifield.

**Subject:** **Equitable Access to Healthcare for ME patients in British Columbia:  
Fund, Develop and Incentivize CME modules on ME for BC physicians**

**Issue:** Myalgic encephalomyelitis (ME), is a devastating, chronic, multi-system disease. Approximately 600,000 individuals in Canada and 77,000 British Columbians suffer from ME. It affects children, adolescents and adults of all ages.<sup>1</sup>

In a recent patient-focussed study in BC (3-page short report [here](#)),<sup>2</sup> 3 of the 4 main issues ME patients identified were: lack of support for disease management, challenges getting a diagnosis, and stigma in the healthcare system. Clinicians noted in the same report that, despite its prevalence, there is a disturbing lack of awareness and misinformation around ME in BC's clinical community. As a result, the average time to a diagnosis is 7 years for this disease, where the first 2 years can be the most critical for a more positive long-term prognosis. Often, patients are mis-diagnosed for years or decades, receiving inappropriate or harmful treatments. Many patients report outright neglect or abuse by the healthcare system.

Currently, BC has one provincial resource for these patients, the Complex Chronic Diseases Program (CCDP) at BC Women's and Children's Hospital. The waitlist for this program has consistently been over 24 - 30 months, since its inception in 2014 and offers a 1-year enrollment for a disease that has only a 5% remission rate, lasts a lifetime with no known cure, and seriously impacts all aspects of life. Program intake excludes children and is not accessible or structured for patients with severe ME. For patients who are lucky enough to be referred to the CCDP and well enough to attend, when they are discharged after only 1 year, they must return to the same ill-informed and often unwilling practitioners they struggled with before.

Both patients and clinicians acknowledge a shocking gap in available clinical care resources, and clinicians are asking directly for improved ME education. Even the leadership of the Complex Chronic Diseases Program (CCDP) acknowledges that relying on one single program cannot be the path forward to improved and acceptable care for the tens of thousands of British Columbians struggling with this debilitating illness.

<sup>1</sup> See [what is ME](#) from the Canadian Institutes of Health Research; and the unpublished 2015 Statistics Canada Community Health Survey.

<sup>2</sup> Full/long report: [M.E. in BC: How the Healthcare System for M.E. Impacts Clinicians and Patients: Report on a preliminary project examining the unmet needs of British Columbians living with Myalgic Encephalomyelitis \(ME\)](#) (2021).

## Myalgic Encephalomyelitis facts:

- ME is a complex chronic disease that presents with a wide range of symptoms, including chronic cycles of debilitating exhaustion, pain, nausea, confusion and “brain fog,” inability to concentrate, powerful light/food/sound sensitivities, lightheadedness and passing out (POTS), and other neurological, physical and cognitive impacts.
- 75% of those affected are unable to work/attend school and 25% are homebound or bedridden.<sup>3</sup>
- ME is triggered by viral infections in the majority of patients. Many scientists speculate that the COVID-19 “long-haulers” may now have ME.<sup>4</sup> The symptoms are very similar. This could add a significant number of new ME patients to our communities, all requiring care.<sup>5</sup>
- People with ME experience a substantial loss of physical and/or cognitive function:
  - Someone with mild ME may be able to work full-time with accommodations
  - Someone with very severe ME may be bedridden, have trouble communicating, and may require: complete darkness, complete silence, complete isolation, a feeding tube and catheter.
- ME presents differently in different people:
  - For many patients, ME is a relapsing-remitting condition, with significant fluctuations in their well-being from day to day, week to week, and month to month.
  - For others, it is progressive with continuous decline. Few patients have stable symptoms.
- Several studies have shown that patients with ME have a suicide rate approximately 5 times higher than national averages due to untreated pain, loss of income and career, loss of independence and the lowest quality of life of any chronic illnesses.
  - The average person with ME scores as more disabled on quality of life surveys than those with multiple sclerosis, stroke, diabetes, renal failure, lung disease, heart failure, and cancer.<sup>6</sup>

## Considerations:

- At this time, ME is unknown or misunderstood by many clinicians in BC. Developing clear Continuing Medical Education (CME) modules specifically for ME is a powerful way to: create general awareness; educate physicians on symptoms, diagnosis, resources, emerging research and safe, effective treatments; increase empathy for patients; and fill the substantial gap in existing care in BC.
- The ME/FM Society of BC, in a patient-led collaboration with BC Women’s Hospital and the CCDP is well-positioned to lead a collaborative, medically-informed and patient-focused effort to develop concise, clear and effective CME modules for BC physicians.

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<sup>3</sup> [A Conversation about Myalgic Encephalomyelitis](#) by Dr. Nina Muirhead of Canadian Institutes of Health Research (2021).

<sup>4</sup> [Working together to understand long-term effects of COVID-19](#) (2021)

<sup>5</sup> Estimates for the U.S. suggest doubling of the numbers of ME/CFS sufferers within a year: [Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?](#) (2021)

<sup>6</sup> [The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome \(ME/CFS\)](#) (2015)

- ME needs elected representatives and key financial and health committee members to stand with BC patients with ME by approving funding for change that will improve the lives of this large, suffering, desperately underserved, and largely invisible population.

### **Conclusion:**

ME patients in BC need medical community awareness and knowledge to help manage living with this debilitating illness.

By supporting and sharing with colleagues the proposals here to fund and develop CME modules and credits for BC doctors, you can substantively help to move ME out of the shadows, provide ME awareness, education and resources to BC's medical community, and give hope to our over 77,000 BC patients and their friends and family members with this debilitating complex disease. With a skilled and knowledgeable medical community, we have the opportunity to reduce the burden of disease and enhance the quality of life for patients throughout the province.

### **Recommendations:**

1. Help prioritize and fund the development of ME-specific CME modules for BC physicians.
2. Argue to fund CME credits to encourage and incent BC physicians to attend ME education.
3. Share and champion the asks in this brief and the related "Diagnosis and Incentivized Billing codes for Myalgic Encephalomyelitis Essential for BC" ME/FM Society of BC brief with colleagues and key ministers and committee members to increase awareness of ME among legislators and begin to provide tangible help to your constituents suffering from ME.

### **Further Information:**

- *Diagnosis and Incentivized Billing codes for Myalgic Encephalomyelitis Essential for BC* - a brief with the ME/FM Society of BC's other proposed actions on improving care for ME patients: [this document is found on the following webpage](#).
- *Backgrounder: The Unmet healthcare needs of British Columbians living with Myalgic Encephalomyelitis (2021)* - ME/FM Society of BC policy brief outlining the current state of ME care in BC: [see here](#).
- *M.E. in BC: how the healthcare system for M.E. impacts clinicians and patients - A preliminary project examining the unmet needs of British Columbians living with Myalgic Encephalomyelitis (ME) (2021)* - ME/FM Society of BC community pilot project report: [short report](#); [long report, including patient stories](#)
- *A Conversation about Myalgic Encephalomyelitis* by Dr. Nina Muirhead, Canadian Institutes of Health Research: <https://cihr-irsc.gc.ca/e/52474.html>

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