



"Recommendation # 72. Prioritize and fund the development of myalgic encephalomyelitis-specific billing codes for BC clinicians and the development of continuing medical education credits, modules or incentives for BC physicians, medical students, and other medical professionals to attend training about myalgic encephalomyelitis."

Select Standing Committee on Finance and Government Services:
Report on the budget 2022 Consultations; November 2021

June 22, 2022

Dear Minister Dix,

During the recent budget debates, you stated your intention to give British Columbians with Myalgic Encephalitis (ME) "the maximum support we can". The ME community was heartened and grateful to hear your commitment to us. We appreciated the thought and obvious attention to the issues reflected in your responses to Minister Bond's questions about ME in BC. We also heard you identify equity in healthcare as a core value for your work. Equitable access to healthcare is a goal that you share with those living with ME.

There are some issues that we would like to address arising from the budget debates;

1. In your response to Minister Bond's question about billing codes, you stated that there isn't a specific treatment available for ME. This rationale is frequently cited in our discussions with government and the healthcare system as an explanation for the lack of specialized medical programs for ME. This logic is flawed. Specialized care can do much to alleviate patient suffering and improve quality of life. Currently, research shows that patients with ME have the lowest quality of life of any disease group. The lack of a known treatment protocol for ME does not justify failing to provide this patient group with specialized medical care as there is growing international evidence of supportive clinical management approaches that can be offered to patients (e.g., [Clinical Management - U.S. ME/CFS Clinician Coalition](https://mefm.bc.ca/clinical-management) ([mefmcliniciancoalition.org](https://mefm.bc.ca/clinical-management)), [NICE Clinical Guideline ME/CFS | The ME Association](https://www.nice.org.uk/guidance/NG195)). Equity in healthcare means that all patients are entitled to a reduction of suffering and the opportunity for fullest participation in their lives.
2. Throughout the healthcare debates, the Minister referred to the principle of equity in the provision of healthcare services. We are interested in understanding what criteria the Ministry uses to build an

equitable healthcare system. Further, we are interested in the analysis that has been applied to ensuring the healthcare system is equitable for ME patients? We offer the following facts for consideration:

- a. As the province's only medical resource for patients with ME, the Complex Chronic Disease Program (CCDP) sees less than 650 patients of the province's 77,000 people with ME annually. Patients are supported by the self-management program for a year despite the lifelong nature of ME. Is this equitable access to healthcare for a complex chronic incurable condition??
- b. The Minister described in response to Minister Bond a planned redesign of the CCDP. However, he did not identify what, if any, additional resources will support the expanded reach of the program as he described. Without additional funding, the current funding will be spread more thinly and further dilute services. What resources and financial commitments has the Ministry made to ME and the redesign of the CCDP?
- c. The Complex Chronic Diseases Program provides a valuable service to some patients with ME. Services are primarily designed as self management education modules that benefit patients with mild to moderate disease. However, the following patients (often the most ill) are excluded from the program: Patients who are bedridden (estimated: 7700 in BC), individuals unable to use virtual technology, children 18 years of age and younger, those with complex comorbidities (ie. cancer, mental illness) and those who have previously accessed the program but have had a change in their health status. In British Columbia, there are no dedicated healthcare resources to meet the needs of these underserved groups. We ask, what plans are in place to deliver equitable healthcare to the entire spectrum of the ME population in BC for whom there is currently no access to any kind of specialized, ongoing, care?
- d. Equitable healthcare means equitable funding models. During the debates we heard about commitments to resources to other disease groups for specialized care. We look to the funding received by Long Covid clinics, and MS clinics as two examples. We note the current budget includes increased funding for cancer navigators. The healthcare gap in BC is widening: as other serious disease groups receive funding to enhance and increase services, many ME patients languish from neglect by a medical system that fails to meet their needs. ME patients and their families consistently report the challenges of navigating the health care system ([Convene Project Report, February 2021](#) (mefm.bc.ca), yet ME creates a lower quality of life than many other illnesses including cancer. How much longer do ME patients need to persist and navigate in isolation, whilst watching other well funded illness populations receive more and more additional funding?

3. In BC, patients report on average that it takes 7 years to be diagnosed with ME. During this time, symptoms often escalate, jobs are lost and many struggle to qualify for home and disability supports. Families are left to cope alone. These patient issues are a consequence of systemic ignorance and neglect within the medical system. Without coordinated leadership from government and the medical community, working in collaboration with the patient community, this will not change.

The precedent has been set: Equity in healthcare means equity in access to care, equity in funding, equity in support to research, equity in prioritizing the alleviation of suffering.

Equitable access requires a plan and dedicated resources that reflect the population being served, and a commitment to collaboration with the patient community.

It is time for an ME strategy in BC that aims to support the spectrum of all ME patients: One that aims for more than the current limited scope of a single self management program (CCDP), one that aims for equity in the type, intensity and availability of healthcare provided, in the priority given to research, and in the commitment to a decent quality of patient life. We look forward to initial meetings with the Health Ministry to collaborate on plans for achieving an equitable healthcare system for all of BC's ME patients.

Sincerely,

Hilary Robertson and Sue Khazaie, Co-Chairs, ME/FM Society of BC

On behalf of

The Board of Directors of the ME/FM Society of BC

Cc: Shirley Bond

Cc: Maura Parte

Cc: Dr. Luis Nacul, Medical Director, CCDP

Cc: Cheryl Davies