

October 1, 2021

The Honorable Adrian Dix
Minister of Health
1515 Blanshard Street
Victoria, B.C. V8W 3C8
Via email: HLTH.Minister@gov.bc.ca

Subject: Access to equitable health care for British Columbians with Myalgic Encephalomyelitis (ME)

Dear Minister Dix,

Today we are writing to renew our concerns about the healthcare provided to patients with Myalgic Encephalomyelitis (ME) as discussed during our June 2019 meeting with then ADM David Byres. Additionally, the province's response to the emerging post-viral syndrome that has been named Long-COVID and PASC compels us to comment on the inequities in our current healthcare system.

Following our meeting in 2019, we were assured that BC Women's Hospital would be following up with respect to severe concerns regarding the lack of timely and substantial health care services. Yet these same concerns persist. We deplore the lack of incentives for primary care physicians to care for complex diseases such as ME and the stigma encountered by ME patients in health care. The lack of diagnostic codes for ME prevent rapid access to usable data which allow for epidemiology research and sufficient funding.

It was just a few months following the meeting with David Byres when COVID became a pandemic and rapidly, a state of emergency was declared. Appropriately the BCCDC made COVID a reportable disease and physicians were provided with diagnostic and billing codes. We applaud your timely response and leadership.

A post-Covid clinic was established within 5 or 6 months of the onset of the pandemic, to research the condition and to address the unmet health care needs of patients suffering long-term effects of their post-viral illness, many of whom unfortunately still endure disabling symptoms 12-18 months following their initial infection. As of today, there are 4 clinics for patients living with Long-COVID in British Columbia, and patients are seen 3 months following their first symptoms, and are being followed every 3 months. Once again, we congratulate you for recognizing and responding to the need these patients have for effective and timely medical care.

However, we are concerned that patients suffering with ME are once again being left behind. The similarities between post-COVID patients and those with ME are striking: their needs are similar and

potentially overlapping. Several publications (see articles below) and international experts such as Drs Fauci and Francis Collins (NIH) recognize that many patients who continue to have long lasting symptoms following their COVID infection meet the criteria for Myalgic Encephalomyelitis. A large percentage of patients living with ME have had an infectious onset and never recovered. Additionally, most ME patients do not receive the critical early care that establishes an accurate diagnosis, and prevents harm and an escalation of their disease.

In 2020, the ME/FM Society of BC performed a pilot [needs assessment study](#) (funded by the Vancouver Foundation) in collaboration with the Complex Chronic Disease Program (CCDP) at BC Women's Hospital which found that ME patients felt unsupported by the medical system, stigmatized by medical professionals and are ineffectively and inefficiently navigating the health care system alone. British Columbians with ME report feeling socially isolated and feeling abandoned by the medical community. The results of this project echo the ongoing and persistent voices of patients expressing their unmet needs for years. Additional patient feedback collected by the CCDP itself indicates there are unmet needs of the patients ([CCDP Patient Engagement Findings, Oct 2017](#)). The wait list for the CCDP program remains problematic, along with its limited offerings (ie., predominantly self-education, not individual clinical case management) which are not meeting the needs of the patient population.

In contrast to COVID and Long-COVID care, the single provincial ME-specific program, the Complex Chronic Diseases Program (CCDP) at BC Women's Hospital still maintains a 28-30 month wait for enrollment. The extent of the services include a physician consultation upon entry and at discharge, and choice of self-management education modules. The program does little to address ME's commonly occurring treatable comorbidities.

The CCDP opened in 2013, and services have been essentially unchanged since that time. It's only since the COVID pandemic that they have begun offering virtual appointments, yet patients have been indicating access issues of its Vancouver location for years. Further, the CCDP is only accessible to a small segment of the province's 77,000 ME patients (Statistics Canada CCHS 2015, extrapolated data), excluding children, the more severely ill, and patients requiring disease support beyond 1 year. Overall, the CCDP is insufficient in providing the care, treatment and support that ME patients across BC require.

Patients living with ME have been reporting important gaps in health care for years. There is a dire need for acute care services including inpatient, outpatient, and regular follow-up. Medical education, including entry level and continuing education for physicians and health care professionals, is another desperate need. We are concerned by the fact that the two provincially funded services, CCDP and a post-COVID care network with multiple clinics, both administered by PHSA, are seemingly working independently and with very different models of care. We call on the Health ministry to recognize that they are responding to the current crisis adequately but in doing so, they are creating deep inequalities that leave ME patients desperate for care, and quite frankly falls short of the needs of the patients beyond self-management and education.

The recent [CTV news coverage](#) and the province's response to the COVID pandemic highlight that your Ministry and the health care system can indeed mobilize and provide care for complex diseases. The difference, perhaps for the post-viral ME population, is that our prevalence has been accumulating more slowly, and is not the direct result of a single virus in a recent pandemic.

Nonetheless, our health needs and response from the health care system deserve equity. Recent press statements from the Ministry of Health highlight the inequalities in services and reflect the lack of awareness of the severity of ME.

We are requesting further stakeholder meetings with the province and PHSA to discuss how to achieve equity and improved patient care for ME in BC. We strongly recommend that, at a minimum, the CCDP leadership, the Ministry of Health, ME/FM Society of BC and relevant physician stakeholders convene to address the issues.

We are asking for an improved ME care strategy that includes:

- The province honouring its commitment to healthcare equity
- Moving from a self-management and symptom management model of care to a biomedical model of care
- Addressing the CCDP waitlist
- Diagnostic and incentivized billing coding
- Incentives for physicians to enter the field
- Encouraging relationships with the Long-Covid community, the universities and the research funding bodies that support biomedical research funding and coordinate care strategies that explore the similarities and differences between ME and Long-COVID.

Investment in the health care of British Columbians must be equitable. The Ministry of Health has demonstrated resources can be mobilized when needed. If a 30-month wait time would not be acceptable for Long-COVID patients, it is not acceptable for ME patients.

Partnering with patients has been a value of the Ministry of Health for several years. This value could not be more important when the system is neglecting a group of patients. We hope that you invest in ME patients as well. We look forward to your reply.

Sincerely,
Board of Directors, ME/FM Society of BC

CC:

- John Horgan, Premier
- Teri Collins, Assistant Deputy Minister,
- David Byres, Interim CEO of PHSA
- Cheryl Davies, BC Women's Hospital
- Dr Luis Nacul, Medical Director, CCDP
- Renee Merrifield, Health Critic, Kelowna MLA

Additional reading:

- [How Long COVID Is Forcing a Reckoning with the Neglect of Post-Infectious Chronic Illnesses](#) ●
[The road to addressing Long Covid](#)
- [Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(ME/CFS\)—A Systemic Review and Comparison of Clinical Presentation and Symptomatology](#)

- Articles about Long-COVID patients developing ME/CFS in the media: [CTV](#), [The Scientist](#), [TIME/CFS magazine](#), [New York TIME](#) and [Vox Magazine](#).