Supplementary Notes
to the Letter to
BC Minister of Health
July 2, 2014

1. Current healthcare and social services for ME, FM and Lyme patients were not developed through a coordinated process. Rather, they were developed over the years through a series of decisions by individuals and organizations about whether to serve patients and if so how. The resulting "systems" are incomplete, non-evidence-based, and inequitable.

Among the decisions, Canadian rheumatologists have decided to withdraw from the area of FM, infectious disease doctors have decided to treat chronic Lyme minimally, and no speciality has decided to take on the challenges of ME.

In the current decentralized environment, the process of change is slow. Services lag far behind scientific findings.

2. Ignored "systems" are not cost-free systems. Statistics show that Canadians with ME and FM make frequent visits to health providers. The current approach also has heavy social costs. A new approach is needed for each of these illnesses.

Important statistics about ME/CFS and FM can be found at
http://meao.ca/files/Quantitative_Data_Report.pdf .
Health care utilization is examined in section 2.4 starting on page 26.

An examination of the social consequences of the current systems for ME, FM and Multiple Chemical Sensitivities in Ontario can be found here: http://meao.ca/files/Recognition_Inclusion_Equity-full.pdf
Social issues that were identified include food security, income security, social isolation, support for families, access to homecare, accommodation at school or work, and housing.

3. A new approach is needed for each of these illnesses.

It is imperative to move beyond psychotherapy approaches like Cognitive Behaviour Therapy that at best contribute to coping. Emphasis needs to be put on diagnosis and treatment of the biological abnormalities. One implication of this is the need for better access to laboratory testing.

The Canadian Consensus Criteria (2003) and the International Association for CFS/ME Primer (2014) provide a very good starting point for moving forward on ME.
http://mefmaction.com/index.php?option=com_content&view=article&id=215&Itemid=262
http://iacfsme.org/Home/Primer/tabid/509/Default.aspx

The Lyme community points to the Schmidt report as a basis for dealing with Lyme.
http://canlyme.com/2012/08/14/british-columbia-government-report-on-lyme-disease-schmidt-report/

In 1990, The American College of Rheumatology put forward a definition of FM centred around pain. The Canadian Expert Panel (2003) used this definition but noted that multi-system symptoms often accompanied the condition. The ACR suggested an alternate definition in 2010 (modified in 2011) putting more emphasis on multi-system symptoms. FM is an area in flux.

4. BC is one of the first jurisdictions anywhere to grapple with these problems and deserves great credit for this. The challenges require a pioneering spirit – commitment, creativity, willingness to push boundaries, willingness to do things in new ways, etc.

We are proud of BC for taking this on. BC has a history of pioneering and is well equipped for the challenges.

This could be done through a Centre of Excellence which would "put the diseases under the microscope, provide care and treatment to those affected, educate doctors and healthcare professionals throughout the province, and promote sound social policies". This wording is adapted from the mandate of the BC Centre of Excellence in HIV/AIDS. There are 95,000 British Columbians with a diagnosis of ME, FM or both, and about 13,000 with a diagnosis of HIV. Here is a quote by Dr. Nancy Klimas, AIDS and CFS researcher and clinician, University of Miami taken from the NY Times blog of October 15, 2009. "My H.I.V. patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my C.F.S. patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses (in 2009) I would rather have H.I.V."

5. These illnesses can be severe and the needs of the patient communities are complex.

We know from talking to the community, backed up by the Canadian Community Health Survey statistics, that these can be very devastating illnesses. To give some perspective, a leading US immunologist who treats both ME and AIDS patients said that she would rather be sick with AIDS than with ME. Many people with ME and FM have other medical conditions as well, adding complexity to the medical issues.

Statistics showing the severity of ME and FM can be found in section 2.2, 2.3, 2.6 and 2.7 of the data report at http://meao.ca/files/Quantitative_Data_Report.pdf

The BC patient community includes
- people of all ages, with many of working age
- men and women, with more women than men
- people who are new to the illnesses through to people who have been affected for decades
- people in Vancouver and people in more distant areas
- people who have good medical support through to people who have little or none
- people who have good social support through to people who have little or none
- people who have good financial support through to people who have little or none

A one-size-fits-all approach won't work.

6. There is large pent-up demand in BC for health services for ME, FM and Lyme. While the program's waiting list has about 1,500 people on it, the real waiting list is very much longer.

The Canadian Community Health Survey (CCHS) conducted by Statistics Canada 2010 estimated that there are around 95,000 British Columbians with a diagnosis of ME and/or FM. These illnesses have been under-served for decades. The fact that there is a waiting list for Program services should not come as a surprise. In fact, the 1,500 people on the waiting list can be seen as the tip of an iceberg. There are many other people who want to attend the clinic.

The pent-up demand needs to be addressed. The real solution involves reviewing resourcing, developing best practices and building capacity among health professionals – and managing expectations in the meantime. Patient expectations need to be reasonable, but so do the expectations of the Ministry and those delivering the Program.

7. There is a lot of false information about these illnesses. Real expertise in ME/FM/Lyme is a scarce resource that needs to be carefully managed.

Cancer patients deserve doctors who knows about cancer. Heart disease patients deserve doctors that knows about heart disease. Similarly, ME or FM patients deserve doctors that knows about ME and FM. Unfortunately, ME and FM have received very little attention in medical schools or in the health profession. There are very few doctors anywhere who know a lot about this topic. Doctors have to be trained, and the training needs to come from good sources. This is especially true with ME, FM and Lyme which have been saddled with a lot of misinformation.

The province was extremely lucky to get Dr Bested, one of the world's top ME/FM doctors. Dr Bested has an in-depth understanding of the illnesses, having specialized in the area for over 20 years. She was invited to be a member of the expert panel that developed the highly acclaimed Canadian Consensus Criteria for ME/CFS and the expert panel that developed the International Association's Primer for Clinical Practitioners. She has published a book on ME and and FM. Further, she was a participant at the F/P/T Conference on Lyme disease in 2006.

Losing her is equivalent to losing top cancer or AIDS doctors and having few people in the wings capable of taking her place. And yet officials are treating this as a hiccup. This is much more than a hiccup – it a very serious blow to the program. There still may be the opportunity to keep Dr Bested in BC. Please make an effort to keep her.

8. Not only are patients key stakeholders (nothing about us without us), but patients bring a wealth of experience and knowledge to the table.

Representatives of four patient groups currently sit on the Hospital's Community Advisory Committee. Their role has been limited to commenting on the patient experience. Their hands have been largely tied through the confidentiality agreement they were asked to sign.