

## **Email to BC Minister of Health and the Premier of BC, July 2nd, 2014**

Dear Mr Lake:

The National ME/FM Action Network is a registered charity that has been supporting Canadians with Myalgic Encephalomyelitis (ME) and/or Fibromyalgia (FM) for over 20 years. According to Statistic Canada's 2010 Canadian Community Health Survey, there were 95,000 people in BC with one or both of these serious conditions.

We have been watching with great interest the establishment of the Complex Chronic Diseases Program (CCPD). The program is intended to address the needs of British Columbians with ME, FM and/or Lyme disease. Individuals and organizations from around the world have been watching as well. The BC Government initiated the program and assigned it to the BC Women's Hospital. The Ministry of Health provides direction, resources, and oversight for the program.

The CCDP has encountered a serious setback with the departure of its medical director, Dr. Alison Bested, and two additional members of the program's medical staff. While we are told by Hospital authorities that they will overcome this setback, we are very concerned about the future of the program. We see these departures and that of the Canadian Lyme Disease Foundation a year ago as serious losses to the program and as symptoms of serious underlying issues.

The following principles are basic to the success of the CCDP. These are complex principles which are discussed further in the notes attached.

**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.**

**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.**

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

**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.**

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

**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.**

**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.**

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

The CCDP was designed around the \$1M/year allocated to it for clinical services. The project plan that launched the program was deceptively complex. It talks about “a clinical program”, “provide a model of assessment”, “provide leadership”, “work in partnership with the health care community to embrace best practices in state of the art management” and “leverage scientific infrastructure in BC to optimize the probability of identifying clearer causes”. An investment of \$1M a year is insufficient to accomplish these objectives.

With such an ambitious mandate and with few resources (and no apparent commitment to increase funding over time), the stresses within the program came quickly to the surface. Hospital management chose to focus on reducing the waiting list and chose to do this by diverting resources from other priorities and by cutting the appointment times. The choices were made by administrators against the advice of medical experts. The decisions offended both the program staff (3 resignations) and the patient community.

An appropriate response by the hospital would have been to seek direction and resources from the Ministry. Perhaps the hospital did. We don't know. The process has not been transparent.

There are many unanswered questions and the patient community deserves answers. Here are some questions to start with:

**What is the Ministry's vision for the CCDP in the long run, recognizing that British Columbians with ME, FM and Lyme have a right to services that are comprehensive, evidence-based and equitable?**

**What is the Ministry's strategic plan for achieving this vision?**

**Recognizing that expertise is a scarce resource, what action has the Ministry taken to retain the services of Dr Bested?**

**What processes are in place to consult with and inform the patient community?**

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Written by Administrator

Sunday, 20 July 2014 16:28 - Last Updated Sunday, 20 July 2014 16:58

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We are planning to send a bulletin to our community in two weeks. The community is very concerned about recent events. We would like to be able to say that the Minister has given the community cause for hope. One possibility would be the announcement of a senior Ministry team reporting to the Minister to investigate the situation, to consult with stakeholders including patient groups and former program staff members, and to report back to you this summer with recommendations on moving forward.

It will take a pioneering spirit to build a new system, but the benefits will be enormous – better health and quality of life for the many patients in the province, better use of system resources, and national and international prestige. We believe that BC has the ability to meet this challenge.

The National ME/FM Action Network wants the CCDP to succeed. We will assist you in any way we can. Please let us know how we can help.

*Margaret Parlor*

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[Supplementary Notes - Letter to Minister.pdf](#)