

## Complex Chronic Diseases Program (CCDP) - Fixing Relationships

This message is about the Complex Chronic Diseases Program (CCDP) in British Columbia. It is the story of relationships, including the relationships between:

- BC Women's Hospital and Dr Bested, the medical director they hired
- BC Women's Hospital and the patient representatives on their Community Advisory Committee
- the BC government and BC Women's Hospital
- the BC government and the ME, FM, and Lyme patient communities

The CCDP was announced in 2011 by Christie Clarke very shortly after she became Premier of the province. Some money went for research and some money went for a clinical program – the CCDP. In our vision, the CCDP would sweep away the old ineffective, mythology-based psycho-social models of care and would introduce new models based on best practices and science. The Canadian Consensus Criteria provide new frameworks for ME and FM, while the Schmidt report provides a new framework for Lyme Disease. BC patients would benefit because of improved diagnosis, treatment and support. The BC health system would benefit because of better relationships with patients, better use of resource, and recognition nationally and internationally. Taxpayers would benefit because currently a lot of resources are being spent shuffling ME, FM and Lyme patients around in ineffective ways. Win-win-win.

Funding for the CCDP is administered by the Ministry of Health, which assigned responsibility to the Provincial Health Services Authority (PHSA) who in turn assigned it to BC Women's Hospital. The Hospital advertised for a medical director which led to the hiring of Dr Bested. Her qualifications were outstanding. The future looked bright.

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Written by Administrator

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Unfortunately, the promise of the clinic has not been fulfilled. Dr Bested and the Hospital disagreed over the operation of the program. The Hospital seemed surprised that the program had a waiting list and seemed to attribute it to the fact that the Program's staff was taking time with patients, rather than to the fact that the health system had not been adequately addressing the needs of patients for years. The Hospital demanded that the CCDP process patients in less time than Dr Bested considered professional. Tensions escalated, and Dr Bested left the CCDP in May. The relationship between Dr. Bested and the Hospital is badly broken. Two other doctors left the program around the same time.

There is fear now that the CCDP will stop using Canadian Consensus Criteria principles and will revert to the old ineffective psychosocial model of care.. When asked recently about the Canadian Consensus Criteria, a senior hospital official replied that the question would be considered by the steering leadership group and Clinical Advisory Committee. We thought that the mandate of the CCDP was to implement these Criteria. The Canadian Lyme Disease Foundation has already withdrawn its support for the CCDP based on the restrictions put on the CCDP to implement the Schmidt report. It seems the system is resisting change. That is bad for patients, for the health system, and for taxpayers. Lose-lose-lose.

Five organizations have been represented on the Hospital's CCDP Community Advisory Committee: the National ME/FM Action Network, ME/FM BC, ME Victoria, the Canadian National Lyme and Associated Diseases Society and the Canadian Lyme Diseases Foundation. (As noted, the last organization withdrew its support last year.) These organizations bring a wealth of experience to the table and are trusted sources of information to their communities. I have been extremely impressed with the knowledge, thoughtfulness and dedication of Sherri, Susan, Gloria, Mary and Jim. Unfortunately, the representatives have been provided with little information by the Hospital, are not included on the steering leadership group or the Clinical Advisory Committee, and have not been consulted on important issues. The relationship between the Hospital and patient representatives is not working nearly as well as it should.

To quote the Ministry itself, "The [BC] Ministry of Health provides stewardship for British Columbia's health care system through policies, guidelines and the ongoing monitoring and evaluation of health authority performance against defined expectations". Therefore, it is very appropriate to ask the Minister to define the expectations for the CCDP and to ask how the program is being monitored and evaluated.

In fact, the Ministry has released a document that outlines its expectations of the CCDP. It is an initial document that would benefit from further development in collaboration with patient groups and other stakeholders. But what is clear is that the document recognizes the complexity of the

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illnesses, the need to spend time with patients, and the use of the Canadian Consensus Criteria for ME. The Hospital is not meeting these expectations and the Ministry hasn't intervened. The Hospital is not doing what it was called upon to do by the Ministry, and the Ministry is not calling on the Hospital to fulfil its obligations. The relationship between the Ministry and the Hospital is not functioning as it should.

The National ME/FM Action Network contacted the Minister of Health in May and received a non-committal response. We contacted the Minister (and Premier) over two weeks ago asking for communication and have not received a reply. The Canadian National Lyme and Associated Diseases Society contacted the Minister over 5 weeks ago and has not received a reply.

Patients should be concerned about the lack of communication between patient organizations and the BC government. Taxpayers should be concerned as well. Money is being spent on a health program that isn't doing what it was designed to do.

Effort could be put into fixing the various relationships with BC Women's Hospital, but at this stage moving the CCDP out of the hospital might make more sense.

**The key relationship that needs to be fixed is the relationship between the BC Government and the ME, FM and Lyme communities. The BC government needs to understand that the ME, FM and Lyme communities are being badly served by the health system and that there are serious consequences, not just for patients but for all British Columbians.**

**We invite you to contact the Minister of Health, the Premier, and your local MLA to explain why fixing the healthcare systems for ME, FM and Lyme is important. Please suggest that the Minister and the Premier sit down with the five patient representatives on the Program's Community Advisory Committee to find a way of revitalizing the CCDP, and ask your family, friends and neighbours to support this request as well.**

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One point you might want to emphasize is that Dr. Bruce Carruthers, lead author of the Canadian Consensus Criteria for ME and co-lead author on the Fibromyalgia criteria, is a British Columbia doctor. These documents, which outline the new framework for diagnosis and treatment, are respected world-wide. Having the BC Government lead the implementation of these frameworks would be extremely appropriate.

**Margaret Parlor**

**President**

**National ME/FM Action Network**

**Documentation:**

**Announcement of CCDP, 2011:**

[http://mefmaction.com/index.php?option=com\\_content&view=article&id=290:bc-announces-2-million-to-study-fibromyalgia-lyme-disease-and-mecfs&catid=68:canadiannews&Itemid=293](http://mefmaction.com/index.php?option=com_content&view=article&id=290:bc-announces-2-million-to-study-fibromyalgia-lyme-disease-and-mecfs&catid=68:canadiannews&Itemid=293)

**[Strategic Plan for Clinic:](#)**

**Articles in Vancouver Sun:**

**Jun 15, 2014**

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<http://blogs.vancouversun.com/2014/06/15/a-vancouver-doctor-who-was-paid-about-5000-a-week-but-saw-only-one-patient-a-week-really/>

**May 28, 2014**

<http://blogs.vancouversun.com/2014/05/28/bc-health-minister-terry-lake-wont-intervene-in-dr-alison-bested-controversy-at-vancouver-complex-chronic-disease-clinic/>

**May 22, 2014**

<http://blogs.vancouversun.com/2014/05/22/patients-upset-over-departure-of-top-medical-expert-alison-bested-from-vancouver-hospital-clinic/>

**Sep 11, 2103**

<http://blogs.vancouversun.com/2013/09/11/controversies-continue-over-lyme-disease-diagnosis-treatment-at-canadas-first-complex-chronic-disease-program-clinic/>

**Dec 6, 2011**

<http://blogs.vancouversun.com/2011/12/06/bc-womens-hospital-named-new-medical-centre-for-lyme-chronic-fatigue-and-other-complex-diseases/>

**May 08, 2014 - ME/FM Action Network email to Minister**

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[http://mefmaction.com/index.php?option=com\\_content&view=article&id=492:dr-alison-bested-leaves-bc-program&catid=69:networknews&Itemid=287](http://mefmaction.com/index.php?option=com_content&view=article&id=492:dr-alison-bested-leaves-bc-program&catid=69:networknews&Itemid=287)

### May 28, 2014 - Reply from Ministry

[http://mefmaction.com/index.php?option=com\\_content&view=article&id=492:dr-alison-bested-leaves-bc-program&catid=69:networknews&Itemid=287](http://mefmaction.com/index.php?option=com_content&view=article&id=492:dr-alison-bested-leaves-bc-program&catid=69:networknews&Itemid=287)

### July 2, 2014 - ME/FM Action Network email to Minister and Premier

[http://mefmaction.com/index.php?option=com\\_content&view=article&id=495:email-to-bc-minister-of-health-and-the-premier-of-bc-july-2nd-2014&catid=69:networknews&Itemid=287](http://mefmaction.com/index.php?option=com_content&view=article&id=495:email-to-bc-minister-of-health-and-the-premier-of-bc-july-2nd-2014&catid=69:networknews&Itemid=287)