

Dr Alison Bested leaves BC Program

Written by Administrator

Friday, 16 May 2014 23:08 - Last Updated Sunday, 20 July 2014 23:48

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The British Columbia Women's Hospital and Health Centre has announced that Dr. Alison Bested is leaving the Complex Chronic Diseases Program (CCDP). You can read the announcement here:

<http://www.bcwomens.ca/Services/HealthServices/complex-chronic-disease-program/default.htm>

Dr Bested was hired by the Program as its first medical director. She brought with her many years of experience in this difficult and underdeveloped area of medicine. She was a member of the expert panel that developed the Canadian Consensus Criteria for ME/CFS. She was also a member of the expert panel that developed the IACFS/ME Primer. She has been a medical adviser to the National ME/FM Action Network for many years. Prior to joining the CCDP she ran a very busy clinical practice in Toronto Ontario specializing in ME/CFS and FM. Her Ontario patients were sorely disappointed when she left for BC and established a medical student scholarship fund to recognize her work.

The National ME/FM Action Network has heard from a number of patients who are upset by the changes. We consider the departure of Dr Bested to be a serious setback for the Program. We contacted both the Minister of Health and the President of the Hospital urging them to consider the consequences of Dr Bested's departure. (See below).

Nothing ever seems to come easily in the ME/FM world. This is another challenge we will have to work through.

Margaret Parlor
President
National ME/FM Action Network

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Email to BC Minister of Health: hlth.minister@gov.bc.ca

On 2014-05-08 18:11, MEFM Action Network wrote:

I am very disappointed that I have not been contacted by an official in the Minister's office in response to my phone call early Mondayafternoon. I did receive a call from a Ministry official responsible for patient and client relations who quickly recognized that my question was not in her domain. I also received a call from Dr David Patrick of BCCDC and UBC but there was no indication that he was representing the Minister's office.

I believe that

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the Chronic Complex Diseases Program is on the verge of collapse

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the collapse of the CCDP would be devastating to patients in BC and would be noticed by the ME/FM community around the world

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the collapse of the CCDP would reflect badly on the Minister and on the government of BC who established the program in the first place

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there was a window of opportunity to save the program

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the Minister's office has an important role to play in saving the program.

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I am not sure how long that window of opportunity will stay open, or even if it is still open. Valuable time has been lost. I hope that the Minister's office steps forward while there is still the opportunity to save the program.

Margaret Parlor

President

National ME/FM Action Network

Email Response:

1009812

Ms. Margaret Parlor

mefminfo@mefmaction.com

Dear Ms. Parlor:

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The email you sent to the Ministry of Health email on May 8, 2014 regarding the Complex Chronic Diseases Program has been forwarded to me for response.

I appreciate your concern for this program.

The 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. The regional health authorities are responsible for planning, managing and delivering publicly funded health care services within their jurisdictions.

BC Women's Hospital (BCWH), which falls under the Provincial Health Services Authority, recently conducted a review of the Complex Chronic Diseases Program to assess its strengths and areas for improvement. As a result of the review, a number of changes were made. While it was hoped that all clinicians who were participating in the program would support the changes, Dr. Bested made the decision to depart.

BCWH is committed to ensuring the continuity and the highest standards of on-going care to their patients and families. A transition plan is in place and Dr. Stephanie Rhone, Senior Medical Director, Ambulatory Programs and Dr. Wee-Shian Chan, Head, Department of Medicine have been appointed as interim co-leads of the Complex Chronic Diseases Program.

I appreciate the opportunity to respond to your concerns. If you have further questions, I encourage you to contact Ms. Cheryl Davies, Vice-President, Patient Care Services, by email at: cdavies2@cw.bc.ca or by telephone at: 604 875-2856.

Sincerely,

Michele Lane

Executive Director

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pc: Ms. Cheryl Davies

Email to Hospital President Dr Jan Christilaw:

On 2014-05-14 11:10, President National ME/FM Action Network wrote:

To: Dr Jan Christilaw, President, BC Women's Hospital & Health Centre

In our opinion, it is a terrible mistake to let Dr Alison Bested leave the Complex Chronic Diseases Program.

The National ME/FM Action Network is a registered Charity founded in 1993 to support Canadians with ME/CFS and/or FM. We work closely with provincial and local groups, as well as with international organizations. We take a great interest in Lyme issues because the symptoms of Lyme overlap significantly. Our organization was involved in the establishment of the CCDP. Several of us worked with Dr Patrick in setting up the clinic and one of our directors, Sherri Todd, sits on the Community Advisory Board.

ME/CFS and FM are complex diseases. ME/CFS is associated with immune system abnormalities, neuroendocrine dysregulation, brain abnormalities, cognitive impairment, autonomic dysfunction, cardiovascular abnormalities, and mitochondrial/energy production abnormalities. There appears to be a genetic predisposition. (This information is cited from the IACFS/ME Primer for Clinical Practitioners.) FM is not as well documented but may share many or all these issues.

A valuable source of information about ME/CFS and FM in Canada is the Canadian Community Health Survey conducted by Statistics Canada. The 2010 survey showed that there were 95,000 British Columbians with the diagnosis of Chronic Fatigue Syndrome, Fibromyalgia or both. The survey shows that people with CFS and FM experience a high degree of disability and disadvantage and that these conditions are associated with a high number of co-morbidities. It also shows that CFS and FM patients make numerous visits to family doctors, specialists and alternate care providers and yet their needs are still not being met. The survey confirms what our organization had learned through our contact with the ME/FM community over the years.

Health system capacity is a serious issue for ME/CFS and FM. There is no official speciality for ME/CFS and very few doctors have chosen to focus on the area. FM was served by rheumatologists but they are withdrawing services. Patients everywhere often encounter health professionals who are uninformed or are misinformed. ME/CFS and FM patients need services but they are hard to find. Services are important. As a recent Ontario study noted,

where study participants did find expert health professionals who were familiar with their conditions, they had exceptional, life-changing, often life-saving positive support which raised their quality of life, and in significant cases, restored productivity and ability to function in many social spheres.

We were therefore very pleased when the government of British Columbia announced the establishment of the Complex Chronic Diseases Program to serve patients with ME/CFS, FM and Lyme Disease. BC was taking a leadership role to address very important issues. The announcement was welcomed in BC, in Canada and internationally. We were also very pleased when the Program hired Dr Alison Bested as medical director. Dr Bested has an excellent reputation in the ME/FM world. She was a member of the expert panel that developed the highly respected Canadian Consensus Criteria. She was a member of the panel that developed the highly respected IACFS/ME Primer for Clinical Practitioners. She had a busy practice in Toronto and her patients were very distressed when she left. With her experience and wisdom, Dr Bested is a very rare and valuable resource.

The source of stress seems to be the waiting list for the program. The waiting list is no surprise considering that there are 95,000 British Columbians with CFS and/or FM and this area is poorly served. The problem won't be solved quickly. Imagine that there was a waiting list for AIDS services. The solution wouldn't be to let the AIDS expert leave, to put specialists from

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other areas in charge of the program, to have complex patients managed by a nurse-practitioner, and to cut appointment times below what is standard practice for these patients. Yet these are the types of solutions being proposed for the CCDP. 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 of Hospital management. The health system seems to be assuming that issues will disappear as soon as Dr Bested does. This won't happen. This is a classic situation of shooting the messenger.

We suspect that there is a window of opportunity to ask Dr Bested to stay. For the sake of British Columbians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and/or Fibromyalgia, we request that you contact Dr Bested and work through the issues that are leading to her departure.

Margaret Parlor

President

National ME/FM Action Network

www.mefmaction.com

[Reply from Hospital President Dr Jan Christilaw:](#)