

Network writes President of CIHR

Written by Administrator

Thursday, 19 December 2013 00:00 - Last Updated Thursday, 19 December 2013 01:10

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The National ME/FM Action Network sent the following email to the President of the Canadian Institutes of Health Research.

Dr Beaudet

There are several issues the National ME/FM Action Network would like to draw to CIHR's attention. In the absence of operating channels of communication between our organization and CIHR, we are sending this to you directly.

Launching a research program

In November 2012, we sent an email to CIHR asking for help in developing ME/FM research in Canada.

http://mefmaction.com/index.php?option=com_content&view=article&id=448:network-inquiry-to-cihr&catid=69:networknews&Itemid=287 .

In summer 2013, we made a recommendation to pre-budget consultations of the House of Commons Finance Committee that a new Institute be established at CIHR

<http://www.parl.gc.ca/HousePublications/Publication.aspx?DocId=6264805&Language=E&Mode=1&Parl=41&Ses=2>

A ME/CFS research program was just officially launched in Australia. Please take a look at this summary of the opening conference

<https://listserv.nodak.edu/cgi-bin/wa.exe?A2=ind1312b&L=co-cure&F=&S=&>

[p;P=62](#) .

This provides a model for an interesting an important research program.

International Conference

The IACFS/ME is the leading international association for issues around ME/CFS and related conditions, including fibromyalgia. They held their last conference in Ottawa in Sept 2011. The next conference will be in San Francisco in March 2014.

<http://iacfsme.org/Conferences/2014Conference/2014ConferenceAgenda/tabid/534/Default.aspx>

There are 3 points to note:

1.

This is a very important conference and we hope that CIHR sends at least one delegate.

2.

I have been invited to give a presentation on the Public Health Panel chaired by Dr Unger of the CDC. My topic is Canadian statistics. I would like to be able to say that the federal government is responding to the issues raised by the statistics.

3.

Along with the professional conference there will be a “patient conference” during which leading authorities give presentations specifically for patients. It would be very helpful to have recordings of these presentations on our website in both English and French. The cost would be in the range of \$10k, the major expenditure for voice-over translation. Our budget is very small. Would CIHR be willing to support this important knowledge translation project?

Project team – Ontario

With funding from MoHLTC and the Ontario Trillium Foundation, the Myalgic Encephalomyelitis Association of Ontario (MEAO) and the Association of Ontario Health Centres (AOHC) have been reviewing the situation faced by Ontarians with ME/CFS, FM and MCS. Several reports have been produced – one on the social impacts, one on statistics, one on academic and clinical perspectives, and one on architectural considerations. The social impacts report is available on-line at <http://meao.ca/events-dec5.html> . The other reports should be posted soon. Please take a look at the report that is posted. There is so much information that is important to understand. Please do not overlook Chapter 27 which outlines the challenges faced by patient organizations. These reports should be widely circulated within CIHR and publicized by CIHR.

US Case Definition for ME/CFS

About 15 years ago, at the request of the National ME/FM Action Network, Health Canada appointed two expert panels, one for ME/CFS and the other for FM. Your colleague, Dr. Gregory Taylor of PHAC, was very involved. Both panels published diagnostic and treatment protocols.

This fall, the Department of Health and Human Services in the US issued a contract for the development of a case definition for ME/CFS. This has been met with tremendous opposition from clinicians, researchers and patient advocates who argue that there is a very good case definition already in place. They recommend the use of the Canadian Consensus Criteria for ME/CFS. The letter from clinicians and researchers is here:

<https://dl.dropboxusercontent.com/u/89158245/Case%20Definition%20Letter%20Sept%202013%202013.pdf>

Canada should be very proud of its role in developing these guidelines and should be building on this foundation.

Communications from CIHR

CIHR was contacted for clarification of a study that was cited in several pieces of

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correspondence originating from CIHR. Your employee XXX confirmed that the Busse study did not, in fact, apply to ME/CFS as was indicated in the correspondence and said that she had notified the correspondence unit. We then sent her an email discussing broader issues around the correspondence (see below). However, it appears that she was not the proper contact for the additional comments. Would you please share our comments with the appropriate officials.

May I add a further note. The term "chronic fatigue syndrome" is not liked by patients. The terms "myalgic encephalomyelitis" or "myalgic encephalomyelitis/ chronic fatigue syndrome" are preferred. Could you ensure that CIHR does not use the term "chronic fatigue syndrome" alone. If you would like a fuller explanation of this sensitivity, we can provide you with some background.

From: MEFM Action Network [mailto: mefminfo@mefmaction.com]

Sent: Tuesday, November 19, 2013 8:50 AM

To: XXX

Cc:

Subject: RE: Follow up to your phone call and email re Systematic review ME/CFS

Thank you very much for confirming that the Busse study is looking at Fibromyalgia and not ME/CFS as was indicated in several items of government correspondence. And thank you for drawing this to the attention of the staff that prepares the correspondence so that the misinformation is not repeated in the future.

ME/CFS is a terrible illness that reduces a person's ability to function in society. Patients encounter a lack of support from the health system and a lack of understanding from broader society. When people write to you, they are looking for hope for a better future. They want to

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know that scientists are working to unravel the causes and treatments for their illness. When someone asks about ME/CFS and is told about a study that does not exist, there is a feeling of having been deceived. Preventing this from happening in the future is appreciated. Thought could also be given to correcting the misinformation that has been circulated already.

People with ME/CFS want to know that CIHR understands and respects their illness. The correspondence I have seen is not very convincing.

People would like to hear that studies are underway. The decision database which you quote makes it clear that very little research into ME/CFS is being funded by CIHR at the present time, far less than is appropriate for a chronic illness of its prevalence and impact. In the absence of funded research, it would be nice to know that CIHR is implementing strategies to build research capacity in this badly underdeveloped area, in line with the CIHR mandate.

People would like to hear that CIHR understands the complexity and importance of ME/CFS. Assigning ME/CFS to IMHA suggests that CIHR is not familiar with the complex cross-boundary nature of ME/CFS. To quote the IACFS/ME Primer, a core document for ME/CFS, "[t]he pathophysiological consequences of ME/CFS are multi-systemic and may include: immune and neuroendocrine abnormalities; brain dysfunction and neurocognitive defects; cardiovascular and autonomic disturbances; abnormalities in energy production including mitochondrial dysfunction; and changes in the expression of certain genes." This suggests that a number of institutes need to be involved. The failure of CIHR to attend the international conference in Ottawa in September 2011 sends the message that the topic is not considered to be of importance. CIHR might consider sending delegates to San Francisco in March 2014 to learn about ME/CFS and to signal that this topic is on CIHR's radar screen.

Additionally, people would like to know CIHR is consulting on an ongoing basis with the patient community. Our organization has expressed an ongoing willingness to meet with CIHR to move research forward.

Margaret Parlor
President
National ME/FM Action Network

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