

In March of this year, representatives of the Canadian Institutes for Health Research promised a research workshop for the ME/FM community to be held before the end of 2014. That workshop was held on Friday September 26.

I wish I could report that the workshop moved the ME/FM research situation forward, but I cannot.

The proposal put on the table goes as follows: CIHR would fund a research network on “chronic pain and fatigue” at a rate of \$1M per year for five years starting a year or two from now. In preparation, stakeholders with an interest in chronic pain and fatigue would participate in an exercise to identify research priorities. A similar priority setting exercise on a different health condition took a year to complete. Included in the proposal was the possibility of a research fellowship for "chronic pain" and another for "chronic fatigue".

Thus, the ME/FM community is being asked to devote considerable resources to this priority setting exercise along with research heavyweights like the arthritis community. If a ME/FM issue miraculously gets picked as one of the top priorities, then it might get a bit of the \$1M a year funding. In other words, the ME/FM community is being asked to make a major time-commitment and will be rewarded with a small amount of funding in the best case scenario and no funding at all in the worst case scenario. Further we would have to wait a year or two to find out if we get anything. We know that the terms "chronic pain" and "chronic fatigue" are far too vague. All in all, the CIHR proposal does not sound like much of an offer.

It is tempting to walk away. However, the bigger picture is that the ME/FM community needs to develop a strong relationship with CIHR because it is by far the primary source of health research funding, and CIHR needs to develop a strong relationship with the ME/FM community because it has responsibility for spending tax dollars wisely and it cannot ignore a major constituency. We have to learn to work together. But that does not mean we have to be happy with everything offered to us.

As I see it, the next step would be to hold a meeting between senior officials of CIHR and ME/FM community representatives to discuss the state of ME/FM research and to look for ways forward. Senior officials of CIHR need to attend because CIHR is divided into institutes and it not clear how ME and FM fit within the institute structure – they overlap with many of the

institutes.

How can you help? Please remember that many relationships get off to shaky starts but then sort themselves out successfully. This will happen as there is not a choice. In the meantime, it is my sense that a gentle approach is needed here. If you would like to speak up, feel free to contact the president of CIHR, Dr Alain Beaudet asking that the dialogue continue. A draft email is below.

Another way to help is to vote in the Aviva on-line contest (<https://www.avivacommunityfund.org/ideas/acf19712>) and, for those on Facebook, the Fedex contest (https://www.facebook.com/FedExCanada/?sk=app_583141638399233) *Go to* https://www.facebook.com/FedExCanada/?sk=app_583141638399233 , *search for the National ME/FM Action Network and cast your vote - one time only*). If the National ME/FM Action Network is successful, the money will go toward research, and we will be able to demonstrate that the community believes in the importance of research.

Please feel free to share your thoughts with me, and thank you for your support.

CIHR Research Workshop

Written by Administrator

Wednesday, 01 October 2014 09:28 - Last Updated Wednesday, 01 October 2014 09:29

Margaret Parlor

President

Draft email: Feel free to use or adapt...

To alain.beaudet@cihr-irsc.gc.ca

copy to mefminfo@mefmaction.com

Dear Dr Beaudet

CIHR Research Workshop

Written by Administrator

Wednesday, 01 October 2014 09:28 - Last Updated Wednesday, 01 October 2014 09:29

I would like to thank CIHR for organizing a research workshop involving the ME/FM community. ME and FM have a huge impact on patients and their families, as well as on the health system and the economy. It is my understanding that the proposal coming out of the research workshop does not address the needs of the ME/FM community. I hope that you will sit down with the National ME/FM Action Network to work through the issues so that we can have a much-needed ME/FM research program here in Canada.