

National ME/FM Action Network at the Montreal Conference on ME/CFS May 3-5, 2018

Four of us officially represented the National ME/FM Action Network at the ME/CFS conference in Montreal last week – Lydia Neilson (founder and CEO), Sherri Todd (director), Anne Marie MacIsaac (director) and me. There were 250 researchers, clinicians and patient/caregivers attending in person. There were people from Canada, the US, the UK, Sweden, Germany, Australia and Finland. Another 70+ people signed up to listen to day 2 on line.

On the morning of May 3, the four of us met with Dr Karim Khan, Scientific Director of the Institute of Musculoskeletal Health and Arthritis of the Canadian Institute of Health Research, along with Tanya Gallant his acting assistant director and Marilyn Desrosiers a manager in CIHR's external affairs group. People from Millions Missing Canada and MEFM BC were in the room already. We talked about unmet needs and the consequences of the poor science that has plagued ME/CFS. We stated the position of the National ME/FM Action Network – that CIHR should be funding ME/CFS research at the level of at least \$10M/year not counting retroactive entitlement. (We think that FM research should receive that much also!) We noted that seed funding for networks, followed by project funding, appears to be a workable method to launch research. We asked ourselves if there were enough topics for networks, and had no trouble suggesting a substantial number of topics. Dr Khan showed keen interest in our ideas and talked about meeting with us again soon. You can see our speaking notes [here: #1](#)

On the afternoon of May 3, the National ME/FM Action Network organized a workshop on meeting unmet needs. We were fortunate to have patient representatives from six provinces in the room. We were also fortunate that professionals from three provinces joined us since they have important perspectives on the issues. You can view the powerpoint slides used in the workshop [here: #2](#) A big thank you to Margaret Soden who helped organize, run and follow-up from the workshop, all on a volunteer basis.

Our launching point for the workshop was the interim report of the Ontario Task Force on Environmental Health. We were fortunate that Dr Ray Copes, the Ontario Task Force chair, was able to attend. Prior to the workshop, we had offered people the opportunity to comment on the interim report. Over 20 written comments were received and a document compiling them was passed to Dr Copes at the workshop. You can see the written comments [here: #3](#) Generally, people found that the report did a very good job of listing the steps needed to improve services

and then the people added suggestions and observations. The workshop discussion followed the same positive lines.

The interim report talked about the importance of agreeing on diagnostic and treatment protocols and of having a model of care for Ontario. These are indeed needed for all provinces and territories. There was general discussion of diagnostic and treatment protocols and then the workshop split into three groups to discuss care pathways. The groups were each given a flipchart to record their thoughts. You can read their notes [here: #4](#) At the end of the workshop, people were quickly asked to identify next steps with were recorded on another flipchart and you can read those notes

[here: #5](#)

Dr Copes had planned to leave at 4 pm, but he was so interested he delayed his flight home so he could stay to the end.

In the evening, Lisa Schneiderman organized a screening of Unrest with the double goal of raising awareness and raising money. She raised over \$10,000, with some going to Millions Missing Canada, some to Dr Moreau's research, and some to the National ME/FM Action Network. We would really like to thank Lisa for her initiative.

Friday May 4th started with welcoming statements. The lead speaker was Jennifer Brea (via video). Nobody from the Canadian federal government provided opening remarks, indicating that the federal government is still not comfortable with ME/CFS. Special awards were given to two leading Montreal doctors, Dr Denis Phaneuf and Dr Richard Morisset who have worked in the ME/CFS area for years. This was followed by presentations by Dr Byron Hyde and Dr Ron Davis.

The groups then split into professional and patient/caregiver sessions. The latter session had a range of presentations including mine on meeting unmet needs (using the same slide deck as for the CIHR meeting) and another by Dr Stein and a patient-based team talking about patient education. At the end of the day, we heard patient/caregiver representatives from the Victoria, BC, Edmonton, Manitoba and Quebec ME groups along with Millions Mission Canada, Action CIND, the Open Medicine Foundation (US) and Solve CFS/ME (US).

Written by Administrator

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On the morning of Saturday May 5th, there was a session bringing together patients/caregivers, clinicians and researchers to discuss how to move research forward together. I gave a presentation describing how Lydia was able to bring people together to create the consensus criteria for ME/CFS and FM and then describing how the network is trying to open up conversations around health services, around CIHR funding and around supporting researchers. You can see my slide deck [here: #6](#)

As could be expected with a topic as broad as moving research forward, the discussion was stimulating but scattered so there will be a need to draw it together. There seemed to be great interest in the European model Euromene, the European ME research network <http://www.euromene.eu/> | I suspect it will be a model for a Canada/US collaboration. Time will tell.

I asked several attendees coming away from the conference what had surprised them. One said that she was surprised by the breadth of the issues, another said that he was surprised by how much cause there is for hope, and a third said that she was surprised by how much is already known about ME/CFS.

All in all, the conference was high quality and exciting. Many thanks to Dr Moreau and his organizing committee for their fantastic work.

Margaret Parlor

President