NATIONAL ME/FM ACTION NETWORK

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Dr. Michael J. Strong
President
Canadian Institutes of Health Research
160 Elgin Street, Address locator 4809 A
Ottawa, ON K1A 0W9

Dear Dr. Strong

Re: Equitable research funding for ME/CFS

The National ME/FM Action Network congratulates you on your new position as President of the Canadian Institutes of Health Research. We know that you will encounter some very important issues during your tenure. We hope that you will give high priority to an issue we have encountered – the lack of equitable research funding for ME/CFS.

The National ME/FM Action Network (the Network) is a Canadian registered charitable organization founded in 1993 to provide support, research and education for the benefit of Canadians with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM). This letter focuses on ME/CFS.

Statistics from the 2014 Canadian Community Health Survey showed over 400,000 Canadians with a diagnosis of Chronic Fatigue Syndrome. These Canadians showed high degrees of disability, unemployment, poverty, food insecurity, social isolation and unmet needs. ME/CFS takes a big bite out of Canadian society and out of the Canadian economy. Scientific research and knowledge translation are needed to address the situation. CIHR is the primary source of research funding in Canada and we understood that it has a mandate to address issues like ME/CFS in an equitable fashion.

Looking at the prevalence and impact of ME/CFS, the Network has estimated that equitable CIHR research funding would be at least $10,000,000 per year. This estimate does not include retroactive entitlement for the years that ME/CFS has received little or no funding. The estimate does not take into account that research into ME/CFS is the gateway to research into Fibromyalgia and Multiple Chemical Sensitivities (MCS). The estimate does not take into account that research into ME/CFS has the potential to provide insights into other health conditions such as Lyme disease, Ehlers-Danlos Syndrome, Alzheimer's, Parkinson's and Autism.

The Network has been asking CIHR for research funding for years. There are world-class Canadian researchers ready, willing and able to get involved. Nevertheless, of the $700,000,000 allocated by CIHR for this fiscal year, not a single penny has been allocated to ME/CFS research. Whenever we ask for more research funding, the reply is invariably – put forward fundable proposals. Our experience shows that this reply is far too simplistic. The attachment summarizes some ME/CFS experiences with the CIHR funding process.

The Network understands that research funding is seen as a zero sum game, that funding to ME/CFS will be seen as a loss to established research areas. Already-in-the-door is hardly a fair criterion for funding. Having said that, we think that this year's funding increase to CIHR was an opportunity to open new research areas. We were truly disappointed that none of the new funding was allocated to ME/CFS.

The Network has assumed that CIHR would provide equitable funding for ME/CFS research within a reasonable time frame, but we no longer have confidence in that assumption.

We hope you will communicate to us very soon what CIHR can offer in the way of help.

Yours truly,

MParlor

Margaret Parlor
President
National ME/FM Action Network

An overview of ME/CFS experiences with research funding.

Shortly after ME/CFS gained prominence in the 1980's, it was suggested that ME/CFS was the fault of the patient, that sympathy and support would exacerbate their condition, and that there was no role for research. The blame-the-patient attitude dominated public policy for decades but has now been discredited. Not only have physical dysfunctions been documented, the studies purporting to prove that cognitive behaviour therapy and exercise fix ME/CFS have been found to be fundamentally flawed. Blaming patients may have been an internationally used standard, but it was never an internationally accepted standard of scientific excellence. Blaming patients explains, but does not excuse, the minimal CIHR funding that ME/CFS research received in years gone by.

Organizations like the US NIH, CDC and IOM (National Academy of Medicine) now recognize ME/CFS as a real illness. Even so, a CIHR grant reviewer wrote in August 2016 that “there is no evidence that CFS is a disease”, “psychosocial factors are strongly associated with the development of CFS” and “research focus on biomarkers is likely to provide limited additional value”. What is shocking is that CIHR allowed that review to stand; CIHR did not fund the grant application under review or even convene another panel.

Not everyone believed the blame-the-patient spiel. Brave researchers, clinicians and advocates from Canada and around the world banded together and continued to support a biomedical approach to ME/CFS. Working behind the scenes with little respect and few resources, these people have shown scientific excellence while addressing many of the issues around ME/CFS. See next page to read about some Canadian accomplishments.

When the blame-the-patient model was discredited, there was a research community and a body of research ready to replace it. Rather than using this as a basis for moving forward, CIHR's response seems to be – we have to stick with our processes because otherwise we would be showing favouritism. Those processes favour incremental change rather than the disruptive change which happened here. Building ME/CFS research under the regular processes will take a very long time. We are legitimately afraid that the good researchers we know will leave the field before the funding arrives.

CIHR seems to be under-estimating the complexity of ME/CFS. The IOM described ME/CFS as “a serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients”. ME/CFS involves neurological, immunological, autonomic and energy metabolism impairments. CIHR competitions seem to be looking for a centralized push, whereas a range of work is needed. CIHR should not worry unduly about coordination of this work. Coordination mechanisms have been well developed thanks to organizations like the IACFS/ME, IiME and Euromene and web groups like Phoenixrising and Healthrising.

Funders and reviewers are used to working in established areas. They can have expectations that are not valid in newer areas and where the illness is not well understood. This came to the ME/CFS community's attention when Dr Ron Davis, a leading US genome scientist who turned his attention to ME/CFS and was working with Nobel Laureates, had several ME/CFS applications rejected by the NIH. Areas of concern that were identified include:

- expecting applicants coming from different fields to already have credentials or publications in ME/CFS
- expecting a hypothesis when the research is observational and exploratory
- expecting proven technologies when the technologies are under development

- expecting detailed methodologies when the methodologies are under development

ME/CFS applicants are disadvantaged by their lack of resources for preparing applications and by the lack of experience that builds up in an area after multiple grant applications have been prepared and reviewed.

We note that people with ME/CFS are largely women of working age, and we suspect that lack of sympathy for this demographic is a factor behind the lack of funding.

Canadian Accomplishments

Canada can take pride in its contributions to the international efforts to learn about ME/CFS including:

- A book compiling studies on ME/CFS published in 1993 by Dr Byron Hyde. Lydia Neilson, the founder and current CEO of our organization had a major role in producing the book.
- The publication of diagnostic and treatment protocols for ME/CFS (commonly referred to as the Canadian Clinical Criteria) in 2003. Ms Neilson spearheaded the project and received an award from the Governor-General for her work. Canadians figured prominently on the expert panel.
- The publication of Canadian statistics on ME/CFS, FM and MCS.
- The conference hosted by Dr Eleanor Stein (Calgary 2008), the international research and clinical conference hosted by the Network (Ottawa 2011) and the collaborative research conference (Montreal, May 2018).
- Specialty clinics for ME/CFS, FM and MCS based in Vancouver, Toronto and Halifax.
- The development of educational material for clinicians and patients by Dr Alison Bested, Dr Eleanor Stein, the Network, and others.
- The report of the Ontario Task Force on Environmental Health which outlined the needs of patients with ME/CFS, FM and MCS and steps needed to move forward. Also very important are the reports that persuaded the Ontario government to establish the Task Force.
- Research at Canadian universities into the pathogenesis of ME/CFS in areas including epigenetics, micro-RNA, and immunology and participation by these researchers in international discussions.