NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

www.mefmaction.com
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Including ME/FM in Federal Mandates for 2023/4

Introduction

Dear friends

This is the time of year when Canadians are asked what they would like to see in the next federal budget. This newsletter addresses four questions:

- What do we want the government to do about ME/FM in 2023/4?
- How do we “sell” this request to government?
- How do we submit this request?
- What can people do to help?

For the first two questions, this newsletter goes into quite a bit of detail describing what we are want and why we want it. Here is a short version.

For health care, we want the federal government to recognize that ME/FM is serious and that it is part of the health mandate. We want equitable investments in statistical surveillance, health system design, providing information and awareness, capacity building and of course research. The health system focus is currently on the shortage of family doctors and the overall crisis in health care. One reason for the health system crisis is because health care providers are not getting the support they need. Addressing ME/FM issues would not only help people with ME, FM and related conditions, it would make the work of health care providers more efficient, effective and satisfying.

The disability system deals with issues the health system can’t resolve. Even after treatment, not everyone in a wheelchair can get to stores, so the disability system asks for ramps to be installed. Even after treatment, some people have difficulty participating in the workforce, so the disability system asks employers to accommodate them. Even with accommodations, some people cannot work and support themselves, so the disability system provides income support. And so on.

For disability, we look at the potential for the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to help the ME/FM community. The CRPD sets out a participation-based concept of disability, and we all know that ME and FM can have a major impact on one’s ability to participate in society. We then look at two initiatives the federal government has taken to follow up on the CRPD, the Accessible Canada Act and the Disability Inclusion Action Plan. We find that these initiatives are designed around a pre-CRPD concept of who is disabled. More attention needs to be paid to communities that were previously left out.

We have taken the following actions:.

- We have sent letters to the Minister of Health and the Minister responsible for Disability Inclusion and to the critics from the other parties (see pages 10 and 11).
- We have submitted these letter to the budget consultation website at *https://www.letstalkbudget2023.ca/let-s-talk-budget-2023?tool=survey_tool#tool_tab*.
- We will be attending a pre-budget consultation meeting held by a local Member of Parliament.

Please share this newsletter with anyone who might be interested. If you are comfortable and able to do so, we encourage you to share our letters with your Member of Parliament and to attend any pre-budget consultation meetings your MP might hold.

Margaret Parlor
President

Contents

Abbreviations used in this newsletter:

ACA – Accessible Canada Act (came into effect in 2019)

CIHR – Canadian Institutes of Health Research, the federal department that provides health research funding

CRPD – the United Nations Convention on the Rights of Persons with Disabilities, ratified by Canada in 2010

FM – Fibromyalgia

ME – Myalgic Encephalomyelitis

ME/FM – this is not an official term, but we are using it to refer to ME, FM or both

ICF – World Health Organization International Classification of Functioning, Disability and Health (ICF)

Health and Welfare History

Canada's Department of Health and Welfare split in 1993. Here is some history from Wikipedia's item on Health and Welfare Canada.

Canada's original Department of Health was created in 1919. It would merge with the Department of Soldiers' Civil Re-establishment in 1928 to form the Department of Pensions and National Health. Soon after, the Department of National Health and Welfare would be established in 1944.

In June 1993, Prime Minister Kim Campbell split the department into two separate entities: the portfolio related to health would form Health Canada, while social-development and income-security programs (i.e., the 'welfare' side) would form Human Resources and Labour Canada - which also combined Labour Canada, the employment programs of Employment and Immigration Canada, and the social-development and education programs from the Secretary of State.

It seems that, when the department split, obvious health conditions (infectious diseases, heart disease, diabetes, cancer, etc) went to health, obvious disabling impairments (vision impairment, hearing impairment, etc) went to disability, and what wasn't obvious did not get a home. That would include mental health and poorly understood chronic physical diseases such as ME and FM. Not having a home has had serious consequences for these groups. It is time to fix the situation.

Health Care

Currently making news in Canada is a shortage of family doctors. Many are retiring. Instead of their practices being taking over by younger doctors, their practices are closing. People are turning to walk-in clinics and emergency rooms, bringing stress to the whole health system.

ME and FM have been poorly served by the health system for decades. With the health care system in crisis, this would not seem to be the time to fight for better services. That is an obvious conclusion, but there is another way to look at this.

Why is the family health system in crisis? Here is a letter to the Globe and Mail written by someone who recently qualified as a family doctor. It gives her perspective on why her colleagues are taking niche jobs in family medicine subspecialties rather than entering the broad practice of family medicine.

Globe and Mail
Letters to the Editor
Saturday December 3, 2022

What became of us, the newest cohort of family doctors? We are training in family medicine's numerous subspecialties: palliative care, sports medicine, etc.

There are reasons for the shift away from practice: the inadequate fee-for-services model, high overhead costs and countless hours of uncompensated work. But at the heart of the shortage lies a reason that won't be found in the literature: Family medicine is too difficult.

Medical knowledge has gone up exponentially since the 1950s, currently doubling every 70 days. Family doctors learn an impossible breadth of medicine. Yet patients walk into clinics with every ailment known to humanity, and a good deal that is unknown.

After the typical 10 years required to become a family doctor, and the type-A personality that makes it possible, to sit in the uncertainty that is today's family practice is difficult. Particularly so if patients have their web-informed diagnosis, treatment and referral request.

Shima Shakory, MD Toronto

There are three main messages in this letter.

The first is that the economics of care are important. One recent announcement out of BC was that funding of family clinics in BC would be based on the complexity of the clinic's patient community. For instance, a clinic with a higher proportion of elderly patients should get more that a clinic with a younger clientele. It would follow that clinics with more ME/FM patients should receive more funding. That assumes that the province can identify ME and FM patients, which can happen if ME and FM are coded on administrative records. Even if ME and FM are coded, there needs to be enough additional funding to make ME/FM patients financially desirable. The ME/FM Society of BC is watching this.

The second message is that patients have to be tactful when speaking to health care providers. Some providers may appreciate new information but some may not.

The third message is that health care providers are frustrated. As we know, ME/FM patients are frustrated by the medical system, but the writer is saying that those in the medical system are frustrated when they do not know how to help. ME/FM patients won't be going away. In fact, there will be a surge in ME/FM patients due to long-Covid. The solution is to give the family doctors the structure and tools they need to help these patients. And this is why it is important to address ME and FM now. It is part of solving the family doctor crisis.

What needs to be done?

Statistical Surveillance.

For health system managers to put the needs of the ME/FM community in perspective, they need quantitative and qualitative information.

We have shown health system figures from the Canadian Community Health Survey. The statistics were a factor leading to the establishment of the Complex Chronic Diseases Program in BC and the appointment of the Ontario Task Force on Environmental Health. But, overall, the health system has not yet grasped that ME/FM is an issue that needs a lot more attention. Among other things, management will need to look at the existing CCHS statistics, they will need to create new statistics through administrative systems (notably billing codes), and they will need statistics on system resources and performance and on the economic consequences of illness.

The health system also has to consider the impact of long-Covid. Many (perhaps half ?) of the current long-Covid patients will become ME/FM patients or have done so already.

Health system design.

Management will have to think about how care will be delivered to people with ME/FM.

CareNow Ontario (formerly the Myalgic Encephalomyelitis Association of Ontario or MEAO) convinced the government of Ontario to set up a task force to look at services for ME, FM and Multiple Chemical Sensitivities. The task force reported in 2018. Ontario's Minister of Health then asked Public Health Ontario to put together a plan for implementing the recommendations. PHO hired a very experienced, creative and well-connected former health system manager to write recommendations. He talked to many people in Ontario, in the rest of Canada and elsewhere. That report went to Ontario's Minister of Health in 2021. It has valuable information that people everywhere could use, but it has not been publicly released despite requests, including one through freedom of information. We added our request in November (see page 12).

Even without that report, we know what some two key components to a ME/FM health system are –

- primary care, well informed and appropriately compensated
- specialty clinics with multi-disciplinary staff to support patients, primary care, and research.

One part of health care which receives little attention is helping patients obtain social supports such as educational accommodations, work accommodations, long term disability, CPP-Disability, the Disability Tax Credit, provincial disability, and home care. Very often, health care providers needs to sign administrative forms. The health system should equip health care providers with the expertise and remuneration to carry out these functions or it should negotiate with the disability system for changes to the administrative procedures.

Providing Information and Awareness

Physicians and other health care providers want guidance. There is a lot of very good information that has been compiled by hard-working members of the ME and FM community in Canada and internationally. But it needs to be packaged and approved for official use in Canada. The federal government provides around $4M per year to an organization providing information to the HIV and Hepatitis C health care and community based service providers (see catie.ca). This is a model for ME/FM information provision. Information and awareness are also needed more broadly – for educators, employers, patients, families and friends.

Capacity Building

This is a management function to ensure that there are adequate, trained resources in the right place at the right time.

Research.

While there is a lot that is known about ME and FM, there is a lot that is unknown. Research is needed.

So far in the 2022-23 fiscal year, the federal government's health research funder (Canadian Institutes of Health Research - CIHR) has allocated almost $1B of public money for research. A key-word search of CIHR's funded decisions database shows that only $280k of that is going to ME or chronic fatigue syndrome (to fund a research network), and only $25k is going to FM (to fund a fellowship). A decade ago, the National ME/FM Action Network estimated that ME and FM each should be receiving around $10M per year. More recently, a study of US NIH funding showed that ME was receiving less than 10% of what it would if funding were distributed based on illness burden. FM was not included in the study but would have fared very poorly as well.

ME and FM are caught in a chicken-and-egg situation. The National ME/FM Action Network argues that money will attract researchers. CIHR argues that it is up to ME and FM researchers to attract money. CIHR blinked a little and provided $280k per year for 5 years for a ME research network with the hope that a vibrant research community would emerge. While the funding acknowledged ME, the amount did not signal priority or commitment or confidence.

Shortly after the research network launched, Covid happened. Covid was disruptive to the operations of any organization due to changing priorities and ways of working. The research network was not spared disruptions. For example, presentations had been planned at some universities and these had to be cancelled.

Covid has another implication – the emergence of long-Covid. CIHR recently announced a competition for a long-Covid research network at $4M per year. ME and FM were not even mentioned in the long-Covid grant competition. This means that the long-Covid research network could expend the funding on the non-ME/FM consequences of Covid, ignore ME and FM entirely, and still meet their contractual obligations. Alternately, the research network could look at the ME/FM-type patients without drawing on the ME/FM expertise already available. We emailed the president of CIHR to express our concerns. We later emailed the government's scientific advisor who is mentioned in the CIHR president's response (see pages 13-14).

Disability

ME/FM is languishing in the health care system. It is also languishing in the disability system.

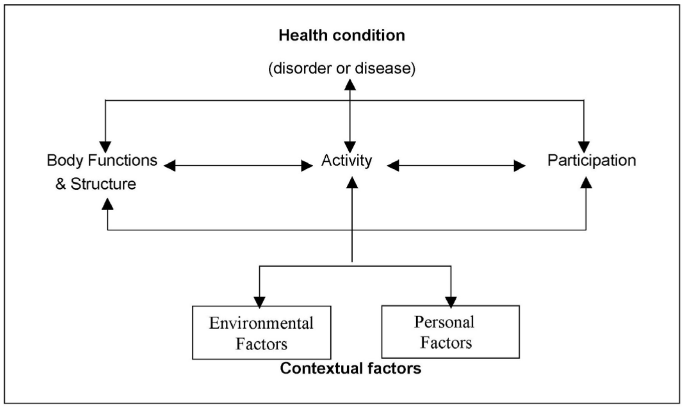
The disability system is complex. There are different rules depending where you live and whether you are young, working-age or a senior. The federal government plays a direct role in the disability system, with programs like the Disability Tax Credit, Canada Pension Plan – Disability, Canadian Survey on Disability, the Office of Disability Issues, Accessibility Standards Canada and the Canadian Human Right Commission. Other players include provinces and territories, municipalities, school boards, employers and insurance companies.

The World Health Organization International Classification of Functioning, Disability and Health (ICF) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) provide a unifying framework for disability.

In Quest 106 (2016), we talked about the ICF. This model presents a chain where body functions & structure affect activity which affects participation. This chain is affected by health conditions and by personal and environmental factors. For a practical application of the ICF model, see Chapter 4 and Appendix A of our CPP-D Applications and Appeal Guide for ME/FM.

While the ICF is an important analytical tool, we run into several issues when using it for ME/FM. As we pointed out in Quest 106, the disease mechanism of ME and FM are not well understood, reduced activity levels affect overall activity rather than specific activities, and personal factors can be used to attribute fault to an individual. But let's set aside those issues for now.

What is important is that some old disability programs are based on problems with selected body functions & structures (impairments) or on selected activity limitations. In contrast, the CRPD calls for disability to be based on participation restrictions.



One program that is based on selected impairments is the Canadian Survey on Disabilities (CSD). You can see their list of impairments on page 7. It would be hard for someone with ME/FM to know how to respond to the survey. Another program that is based on selected impairments is special education Ontario (provincial jurisdiction). They have a category titled "physical disability" but few school boards recognize energy/stamina impairment as a physical impairment and hence few school boards consider part-time and home-bound schooling as special education options. This can leave some young people without access to education.

One program based on selected activity limitations is the Disability Tax Credit (DTC). Many people with ME/FM can technically do all the activities on the list and so don't qualify, don't think they qualify, or have a health care provider who doesn't think they qualify, even when their participation in society is reduced.

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The CRPD is a list of what "states parties" (countries) should do to serve people with disabilities. Here is an example of what the CRPD says:

> *Article 28 Adequate standard of living and social protection*
>
> - *States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.*

Individual countries can ignore, sign or ratify the CRPD. In theory signing means that the country is morally obliged to follow its principles, while ratifying means that the CRPD has legal standing in the country.

Canada signed the CRPD the day it was released in 2007 and ratified it in 2010. The gap between signing and ratification allowed consultation with the provinces because implementation involves both levels of government. Most other countries around the world have ratified the agreement. One country that has not is the United States. There were not enough votes in the US Senate, some senators not wanting international oversight.

The preamble of the CRPD describes disability as follows:

> (*e) Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,*

There are two key messages in this clause.

First, disability happens when there is interaction between people with impairments and barriers, the result being problems participating in society. Impairments are medical problems, but when the symptoms spill over and disrupt someone's participation in society, they become societal problems. The CRPD applies when there are participation problems caused by impairments and there are barriers which governments can address. Government could take actions like sponsoring awareness campaigns or ensuring access to part time school, workplace accommodation, income support, or home care, Overall, it is important to recognize that the CRPD does not base disability on certain kinds of impairments or on specific functions that someone can't do. The CRPD test for disability is based on participation. The social goal is greater participation.

Second, disability is an evolving concept. The CRPD changes the concept of disability from impairment-based or activity-based to participation-based. The CRPD concept of participation has tremendous significance for people with ME/FM. Their impairments include reduced available energy. Reduced available energy often or usually leads to reduced participation in economic, social or civic life, meaning that many or most people with ME and/or FM are entitled to the rights outlined in the CRPD even if they don't fit traditional thinking of what disability is.

*

Soon after the Liberals came to power in 2015, they announced their intention to pass a Canada Disability Act. By the time the Act became law in 2019, the name had changed to the **Accessible Canada Act**. The definition of disability in the ACA is not identical to the CRPD wording but it uses the concepts of impairment, barriers, and hindered participation and is therefore aligned with the CRPD.

The ACA has two thrusts. First, the ACA creates an Accessibility Standards Council which oversees the development of guidelines, standards and regulations. Second, the ACA requires each federal department and agency to publish an accessibility plan. The first set of plans was due December 31, 2022. The plans are posted on the department or agency's website and will be updated every 3 years. Federally regulated organizations will also have to develop accessibility plans but they have a later deadline.

If you look at the ACA closely, you will see that it focuses on federal responsibilities and it picks up only a small part of the CRPD.

We generally talk about access to justice, access to health care or access to an adequate standard of living. Article 9 of the CRPD is titled "Accessibility" and talks only about access "to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public". The ACA standards being developed focus heavily on Article 9 (Accessibility) and Article 27 (Work and employment).

The accessibility plans we have looked at focus on people with disabilities as employees or as people directly interacting with existing programs and services. For example, CIHR's accessibility plan discusses employees, researchers and peer reviewers. It sees its programs as giving out grants to researchers. It does not see its role in improving the lives of Canadians with health issues. Thus, while the ME/FM community sees the lack of funding for research as a barrier to their participation in society and want equitable access to research funding, CIHR does not see accessibility that way.

There is a word used in the ACA that we want to see addressed in the next round. Accessibility plans have to examine "the design and delivery of programs and services". Currently, this is being interpreted as the "design of the delivery", so departments and agencies are not questioning the actual design of their program or service. They should be.

...continued on page 9

MEASURING DISABILITY IN CANADA

The 2017 Canadian Survey on Disability (CSD)[1] collected data on experiences of persons with disabilities.

The CSD is based on a social model of disabilities, which considers disability to be the result of the interaction between a person's functional limitations and barriers in the environment, including social and physical barriers that make it harder to function day to day. Data from the 2022 CSD will provide updated information on persons with disabilities in Canada; results will be available in 2023.

In 2017, 6.2 million (22%) Canadians aged 15 and older had a disability.

24% Women

20% Men

13% Youth aged 15 to 24

20% Working-age adults aged 25 to 64

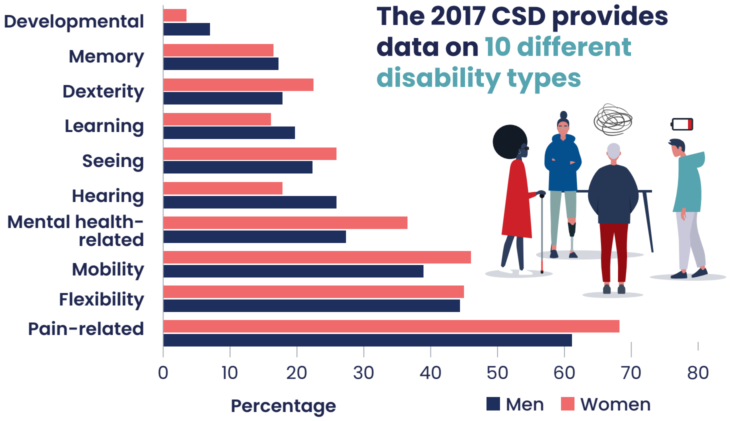
38% Seniors aged 65 and older

The majority of people have **two or more** types of disabilities:

29% One disability type

71% Two or more types of disabilities

The 2017 CSD provides data on 10 different disability types



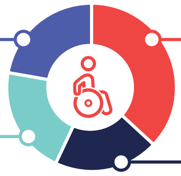
The CSD used the Disability Screening Questions to identify **four classes of disability severity.** The severity score is determined by both the **intensity** and **frequency of activity limitations.**

The name assigned to each class is intended to facilitate use of the severity score and is not a label or judgment about the person's level of disability.

Proportion of people with a disability, by disability severity

Very severe 22%

Severe 21%



Mild 37%

Moderate 20%

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[1] For more information, see the *Canadian Survey on Disability, 2017: Concepts and Methods Guide* on the Statistics Canada website.

Source: Statistics Canada, 2017 Canadian Survey on Disability.

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Canada's Disability Inclusion Action Plan

OBJECTIVES

- **Improve** the social and economic inclusion of persons with disabilities
- **Reduce poverty** among persons with disabilities
- **Achieve** the *Accessible Canada Act* goal of a barrier-free Canada by 2040
- **Develop** a consistent approach to disability inclusion across the Government of Canada and make it easier for persons with disabilities to access federal programs and services
- **Foster** a culture of disability inclusion

PILLAR 1: Financial Security

- improve the immediate and long-term financial security of persons with disabilities
- address long-standing financial exclusion and systemic inequities

PILLAR 2: Employment

- support more persons with disabilities to find and keep good quality jobs, advance their careers, or become entrepreneurs
- help employers make workplaces more inclusive and accessible
- increase the capacity of individuals and organizations that work to support disability inclusion and accessibility

PILLAR 3: Accessible and Inclusive Communities

- address physical, communication, and attitudinal barriers that prevent persons with disabilities from fully participating in our communities and the economy

PILLAR 4: Modern Approach to Disability

- address the challenges that persons with disabilities face in accessing federal programs and benefits
- ensure that the needs and perspective of persons with disabilities are reflected in the Government's policies and programs

Grounded in the **United Nations Convention on the Rights of Persons with Disabilities**

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The government recently announced a **Disability Inclusion Action Plan (DIAP)** with four “pillars” (see page 8).

We have been looking at the plan to see if it provides opportunities for the ME/FM community. From what we have seen so far, the focus is on the needs of the traditional disability community even when it comes to the pillar on modernization. We don’t begrudge the traditional disability community the items listed in the plan, Some of these actions could benefit ME/FM, but we do want more attention paid to the specific needs of the ME/FM community.

What does modernization look like for ME/FM? It means reaching out to ME/FM community and ensuring people are included to the extent possible in economic, social and civic life. Three variables on the Canadian Community Health Survey are indicators of lack of participation – poverty, food insecurity and social isolation. Bringing these rates down would demonstrate progress.

For the whole disability community, poverty problem needs to be addressed, but the ME/FM community encounters two huge barriers when applying for income supports that established disabilities do not encounter - non-inclusive program criteria and serious gaps in medical support to complete the application form.

Food insecurity is tied to income but also to the energy required to shop for food and prepare meals. Better access to home care would be one strategy. Food intolerances are common, so nutritional support may be helpful.

The impact of ME/FM on social life can be profound. Lack of understanding by others can be hurtful. Awareness could go a long way. So could building a social infrastructure.

Employment should be mentioned. The unemployment rate for ME/FM is high, but we don’t know what it should be. On one hand, there may be people not working who could be working. On the other hand, we have heard from people who are really struggling at work, putting their health at risk. It is important to research this area.

Overall, we need the same actions on the disability side that we are requesting on the health side - investments in statistical surveillance, disability system design, information and awareness, capacity building and research.

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Several years ago, a senior public servant in the disability area told me that ME/FM would be recognized when the rest of the disability community decided to recognize it. That is completely ridiculous. The Supreme Court of Canada recognized ME and FM years ago in two cases – Fidler v Sun Life (2006) and Honda v Keays (2008). By ratifying the CRPD, Canada committed “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.

Correspondence

On page 10, you will find the letter we sent to Canada’s Minister of Health, Jean-Yves Duclos, with copies to the opposition health critics, asking that the federal government’s upcoming budget recognize ME and FM health concerns. We would like to meet with government staff to work out an action plan and the amounts involved. You can reinforce our message by contacting your Member of Parliament.

On page 11, you will find the letter we sent to Canada’s Minister for Disability Inclusion, Carla Qualtrough, with copies to the opposition critics, asking that the federal government’s upcoming budget include funding to look at the disability needs of the ME/FM community and to fix what needs to be fixed. Again, you can reinforce our message by contacting your Member of Parliament.

On page 12, you will find a letter we sent to Ontario’s Minister of Health asking for the release of the Action Plan for Environmental Health. On page 4 of this newsletter, we mentioned that there had been a freedom of information request for this document. That request was made by Ms France Gelenas, the NDP health critic. The request was sent to mediation. As a result of mediation, the government released a very heavily redacted version of the report which is posted on our website. About all that is left is the cover page and some background we knew already. MPP France Gélinas office continues their appeal of a freedom of information request that started in February of 2022. You can reinforce the need for the full document by writing the Minister, sylvia.jones@ontario.ca and gelinas-qp@ndp.on.ca.

On page 13 and 14, you will find email correspondence with the President of CIHR and the Chief Science Advisor of Canada. As of today (2023-01-17), we do not know who will be leading the long-Covid research network and we have not seen the final report on long Covid being prepared by the Chief Science Officer’s task force.

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Jan 18, 2023
The Honourable Jean-Yves Duclos
Minister of Health, Canada
email: hcminister-ministresc@hc-sc.gc.ca

Please include ME/FM in the Health portfolio's 2023/4 plans

We are asking that the 2023/4 plans of the health portfolio include substantial funding to address the inadequate health care provided to Canadians with Myalgic Encephalomyelitis and Fibromyalgia.

According to Statistics Canada's Canadian Community Health Survey, around one million Canadians have a diagnosis of chronic fatigue syndrome (an old name for ME), FM or both. There are few health care providers knowledgeable about these conditions. Waiting lists at the three small clinics in Canada are years long. There have been great strides in recent years in understanding ME but these strides have not been built into the Canadian health system.

A federal investment in ME and FM would benefit Canadians with these conditions and the people around them. This investment would also benefit many people with overlapping conditions like Multiple Chemical Sensitivities, Ehlers-Danlos Syndrome, and Dysautonomia.

The investment would benefit many people with long-Covid. Many long-Covid cases are expected to turn into ME or FM. Long-Covid can learn much from ME and FM about both health and social issues.

The investment would benefit the health system. People with ME and FM have frequent contact with the health system. Despite these frequent contacts, many people report unmet health care needs. Health care providers have little access to research, information, training, referral routes or compensation for ME and FM. Fixing these gaps would improve efficiency, effectiveness and morale.

With so many benefits, we hope that equitable funding for ME/FM statistical surveillance,health system design, information, awareness, capacity building, and research will be included in the 2023/4 budget.

Yours truly,

MParlor

Margaret Parlor
President

cc.
Conservative Health Critic – Dr Stephen Ellis stephen.ellis@parl.gc.ca
Bloc Quebecois Health Critic - Luc Thériault luc.theriault@parl.gc.ca
NDP Health Critic Don Davies don.davies@parl.gc.ca

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Jan 18, 2023
The Honourable Carla Qualtrough,
Minister of Employment, Workforce Development and Disbility Inclusion
email: Carla.Qualtrough@hrsdc-rhdcc.gc.ca

Please include ME/FM in the 2023/4 plans for Disability

We are asking that the 2023/4 plans for disability include actions to address the inadequate attention currently being paid to Canadians disabled by Myalgic Encephalomyelitis and Fibromyalgia.

According to Statistics Canada's Canadian Community Health Survey, around one million Canadians have a diagnosis of chronic fatigue syndrome (an old name for ME), FM or both. A wave of new ME/FM cases is coming as a result of Long-Covid.

The survey shows that the ME/FM community experiences high levels of poverty, food insecurity and social isolation. These important indicators of social distress are a result of gaps in the health and disability systems.

Despite meeting the concept of disability found in the United Nations Convention on the Rights of Persons with Disabilities and in the Accessible Canada Act, many laws, policies, programs, services and structures still do not consider the type of disability experienced by people with ME and FM.

We hope that the government's disability plans for 2023/4 will include an examination of the disability needs of this overlooked segment of the disability community and that this leads to corrective action.

Yours truly

MParlor

Margaret Parlor
President

cc
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Bloc Quebecois people withdisability critic Louise Chabot Louise.Chabot@parl.gc.ca
NDP disability inclusion critic Bonita Zarrillo bonita.zarrillo@parl.gc.ca

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November 9, 2022
The Honourable Sylvia Jones
Minister of Health, Ontario
sylvia.jones@ontario.ca

Dear Minister Jones:

Re: Release of Action Plan for Environmental Health

In December 2018, the Minister of Health received a report entitled "Care Now" from the Task Force on Environmental Health. The Task Force looked at health care needs and services for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and Environmental Sensitivities/Multiple Chemical Sensitivities in Ontario. That report is available on the Ontario government website.

In the letter to the Minister that accompanied the 2018 report, the Task Force stated:

The need for action is urgent. About three-quarters of a million Ontarians are suffering with these debilitating conditions, and they and their families deserve effective care and support now.

In January 2020, the Minister of Health, acknowledging the need for action, asked Public Health Ontario to put together an action plan to implement the Task force recommendations. The action plan document, which we think is called "Laying the Groundwork", was submitted to the Minister of Health in July 2021. This important action plan document has not been made public.

When the Task Force wrote the accompanying letter, they did not know that a pandemic would arrive and result in many more Ontarians developing these debilitating conditions. (Many long-COVID cases meet the criteria of ME/CFS or FM.) They also did not mention in the letter that the issues raised in the 2018 report affect jurisdictions outside Ontario, although the report itself did indicate that Ontario could become a global leader in the management of ME/CFS, FM and ES/MCS.

Planning for the 2023-24 fiscal year is underway in Ontario and elsewhere. This is an opportunity to include measures that will improve care and support for this very underserved population in next year's plans. Having the action plan document would provide ideas and insights on how to proceed.

We ask that the action plan document developed by Public Health Ontario be released immediately.

Margaret Parlor

MParlor

President

Note: This letter is being delivered in person by my MPP, Chandra Pasma.

Email Correspondence with CIHR and Science Advisor re Long-Covid

CIHR Announces a Competition for a Post-Covid Research Network

Email sent to Dr Strong, President, CIHR
Subject: ME/FM and post-Covid should be working together
2022-10-25

Dr Strong:

The National ME/FM Action Network is a patient-based organization that has been serving Canadians with Myalgic Encephalomyelits, Fibromyalgia or both since 1993.

We are requesting that CIHR take another look at its proposal to launch a post-Covid research network.

The proposal seems to assume that post-Covid is a unique phenomenon. Our community has a more nuanced view. ME and FM are acquired chronic diseases, with infections being a frequent trigger. Covid is undoubtedly a new infectious agent, but the concept of post-infection damage is not new. The experience and expertise of the ME/FM community would be invaluable to understanding post-Covid, while post-Covid research would be invaluable to understanding ME and FM. The problem is that ME and FM are not even mentioned in the proposal so ME/FM-post-Covid collaboration is optional rather than fundamental.

On top of this, ME/FM research is seriously under-resourced. While Statistics Canada's Canadian Community Health Survey shows nearly a million Canadians with one or both diagnoses, together they are receiving only $305,000 in CIHR funding this year. Low research funding is an ongoing source of frustration in the ME/FM community. The message to ME/FM patients is that they are unimportant. The message to researchers is that they should work elsewhere. The size of post-Covid proposal ($4,000,000 per year) reinforces these messages.

We are not suggesting that the amount of the proposal be reduced. We believe that post-infection research is badly needed. What we are asking is that the proposal be written in a way that benefits both the ME/FM and post-Covid communities and that they are set up to work together as colleagues.

Margaret Parlor

President
National ME/FM Action Network

www.mefmaction.com

Second email to Dr Strong, this time with a copy to the Minister of Health
Subject: ME/FM and post-Covid should be working together
2022-10-26

Dr Strong

We were hoping to have an acknowledgement of yesterday's email and our follow-up attempt to contact you by phone.

We repeat our urgent request that CIHR rethink the post-Covid proposal, both from the point of view of good science and from the point of view of the negative messages it sends to the ME/FM community.

When it comes to science, be aware that many groups, including NIH, have connected post-Covid with ME. An example can be found here: *https://covid19.nih.gov/news-and-stories/studying-long-covid-might-help-others-post-viral-fatigue-ailments*

Margaret Parlor
President
National ME/FM Action Network
www.mefmaction.com

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Reply from Dr Strong

Subject: ME/FM and post-Covid should be working together
2022-10-26

Hello, and thank you for your note received yesterday afternoon.

I appreciate your comments regarding the intersection between SARS-CoV-2, FM/ME and the much broader rubric of chronic post-infectious diseases. Internationally, there is a considerable movement to ensure that these are not dealt with as discrete entities, but rather to recognize that SARS-CoV-2 is but one infection, albeit in real time, that can be associated with residual chronic disease states, including but not limited to FM/ME. Your comments and reminder are thus timely.

Dr Nemer's task force on the post COVID condition (PCC) has completed their deliberations and are preparing their final report which we anticipate receiving in the near future. I know that the intersection of FM/ME with the infection has been clearly delineated, but more importantly to recognize that the association is not new and thus to ensure that the framing of any research questions recognize this. Our research programs going forward will draw heavily on this. Like you, I fully anticipate that any research on PCC will only help to further inform our understanding and treatment of FM/ME; and vice versa.

Having said that, the current funding opportunity is but the beginning with respect to PCC. We recognize that it is limited, but it is what we were provided with at this moment in time. It is meant to be foundational and not restrictive in any way. There are active discussions ongoing to frame the next steps.

In the meantime, Dr Karim Kahn as the Scientific Director of the CIHR Institute of Musculoskeletal Health and Arthritis has been a very strong voice of your community and has also been very clear in ensuring that we understand the issues that you have raised. Ditto for Dr Charu Kaushic who is our Scientific Director of the CIHR Institute of Infection and Immunity . So FM/ME has been raised at multiple levels, not as a passing notion but rather as a critical chronic post-infectious condition.

Thank you again for taking the time to forward your concerns

With best regards
Michael J Strong, MD, FRCP, FCAHS, FAAN
President, Canadian Institutes of Health Research
Michael J Strong, MD, FRCPC, FAAN, MACSS
Président, Instituts de recherche en santé du Canada

Email sent to Dr Mona Nemer, Chief Science Advisor of Canada
Subject: ME/FM and post-Covid should be working together
2022-11-16

Dr Nemer

Without going into detail, ME and FM have been trying for years, even decades, to break into the research system. There has been little success. The lack of respect from the research area has adversely affected health and social care.

Our people have been hoping that the overlap between ME/FM and PCC would be recognized and that a mutually beneficial approach would be developed. However, CIHR just announced a PCC research network funding opportunity without mentioning ME or FM, so it looks as if ME and FM will be left behind yet again.

We wrote Dr Strong with our concerns and have received a reply (see correspondence below). He acknowledges the overlap but offers no concrete action around ME or FM. His reply does mention that your task force on PCC is preparing a report.

The ME/FM community will be just as interested in the report as the PCC community.

If the report is not finalized, would you take a look at it from the ME/FM perspective? If it is finalized, could we have a copy asap so we can consider its implications?

We are available for discussions any time.

Margaret Parlor
President
National ME/FM Action Network
mefmaction.com

We have not received a reply from Dr Nemer. In December, her post-Covid task force released a "pre-report" entitled Post-COVID-19 Condition in Canada: What We Know, What We Don't Know and a Framework for Action. A Preview of the Chief Science Advisor's Upcoming Report on post-COVID-19 condition. The pre-report says that post-Covid can turn into chronic illness, but does not mention Myalgic Encephalomyelitis or Fibromyalgia by name.

https://science.gc.ca/site/science/en/office-chief-science-advisor/initiatives-covid-19/post-covid-19-condition-canada-what-we-know-what-we-dont-know-and-framework-action-pre-report

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