NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

www.mefmaction.com
Quest 131, Winter 2022
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New Cabinet, New Mandates 2021

On September 20, 2021, Canada held a federal election and the Liberal party was returned to power with a minority government. On October 26, 2021, the Prime Minister appointed his new cabinet. On November 23, 2021, the Governor-General read the Speech from the Throne, outlining generally what the new government hoped to accomplish. On December 16, 2021, the Prime Minister released the Mandate Letters which articulate detailed expectations for each of his cabinet ministers.

All the Mandate Letters start with standard text describing government-wide priorities and values. Next there is a paragraph that summarizes the objectives for the particular minister. This is followed by some detailed objectives for the minister. The final section is standard and describes how ministers are expected to operate. *https://pm.gc.ca/en/mandate-letters*

We have now reviewed the Mandate Letters to see how they might affect the ME/FM community in Canada. The news is very good. The Minister of Health is asked to "strengthen the universal public health care system" and to look at long-Covid. The Minister for disability inclusion is asked to undertake "a comprehensive review of access to federal disability programs". She is also asked to work toward greater financial support for low-income working-age people with disabilities. A Minister has been appointed to focus on mental health and substance use. These mandates provide openings to discuss healthcare and disability services for ME and FM.

Contents

Minister of Health: Jean-Yves Duclos

Background: Minister Duclos has a PhD in Economics with his thesis focusing on social programs. He was a professor at Laval University before being elected as the MP for Quebec City in 2015. He was Minister for Social Development and President of Treasury Board prior to being assigned to Health.

Mandate Letter

As Minister of Health, your immediate priority is to help finish the fight against COVID-19, working in close cooperation with provinces and territories. As we emerge from this pandemic, I expect you to work in partnership with provinces and territories to strengthen our universal public health care system and public health supports, backed by an early increase of investments in primary and virtual care and mental health services so all Canadians can get the care they need no matter where they live. Collaboration with provinces and territories will be key to ensuring the primary care system is positioned for the future, including accessible health system data, as well as working to improve the quality and availability of long-term care.

The Minister is specifically asked to study the long-term health impacts of Covid.

Minister of Mental Health and Addictions and Associate Minister of Health: Carolyn Bennett

Background: Minister Bennett was a family physician in Toronto for two decades before being elected to Parliament in 1997. She has been reelected ever since. She served as minister for public health under Paul Martin and minister for indigenous affairs since 2015.

Mandate letter:

As Minister of Mental Health and Addictions and Associate Minister of Health, you will work with the Minister of Health to build a healthier future, with a particular focus on ensuring that health inequities are understood and addressed, including for Indigenous Peoples, Black Canadians and vulnerable Canadians. You will work to ensure that mental health care is treated as a full and equal part of our universal health care system, working in close collaboration with provinces and territories, and lead a whole-of-society approach to address problematic substance use in Canada.

Minister of Employment, Workforce Development and Disability Inclusion: Carla Qualtrough

Background: Minister Qualtrough studied political science and law. She worked as a lawyer specializing in human rights. She was elected as a MP in the Vancouver area in 2015. Since then she has held several cabinet positions. She has a strong background in disability issues, but note that disability issues are only part of her responsibilities.

Mandate letter:

As Minister of Employment, Workforce Development and Disability Inclusion, your immediate priority is to support workers whose work has been interrupted by public health measures. I also expect you to build a better, more inclusive employment insurance system, complete and advance early and significant actions under Canada's Disability Inclusion Action Plan, and help workers and communities prosper as we move to net-zero, including through the launch of a Clean Jobs Training Centre.

The Minister is asked specifically to:

- *Move forward with the design, introduction and implementation of a Canada Disability Benefit Act and Canada Disability Benefit for low-income working age persons with disabilities.*
- *Finalize and release Canada's Disability Inclusion Action Plan, in consultation with the disability community, with early actions in key areas of financial security and employment, creating disability-inclusive spaces and adopting a modern approach to and common definition of disability across the Government of Canada. In addition to measures to be implemented by other ministers, actions will include:*
    - *Launching an employment strategy for Canadians with disabilities;*
    - *Undertaking a comprehensive review of access to federal disability programs, including for Canadians*

with mental health challenges;
- *Supporting national disability organizations to build capacity and partner in efforts to eliminate systemic barriers;*
- *Advancing our commitment to permanently fund support services that ensure equitable access to reading and other published works for Canadians with print disabilities; and*
- *Proceeding with the implementation of the Accessible Canada Act and the harmonization of accessibility standards across Canada.*

New NICE Guidelines for ME

Message: The idea that patients are to blame for ME is not supported by evidence.

The new NICE guidelines for ME were released on October 29, 2021. NICE is the agency that is responsible for developing guidelines for medical professionals in the UK. The special committee looking at the ME guidelines was essentially a tribunal being asked to examine evidence and make a decision. The fundamental issue was whether exertion helped or hurt ME patients. The previous guidelines, released 17 years before, said that exertion helped patients. Patients claimed that exertion hurt them, citing personal experience and research studies.

The stakes were high. If exertion made ME better, then patients were responsible for fixing their own health situation; they did not deserve healthcare or disability supports because they were not pushing themselves enough. If exertion made people worse, then they could not fix their health situation themselves and would be deserving of healthcare and disability supports.

Despite some last minute interference from the pro-exertion side, the new guidelines came down squarely on the side of exertion doing harm. This was a very strong statement considering that the UK has pushed the exertion theory more than anyplace else. This is the same conclusion that a US government-appointed expert committee reached in 2015 after examining the evidence. The issue whether exertion hurts or helps should now be considered fully resolved.

In fact, the issue should have been resolved years ago but the health system was not listening and was not believing what patients were saying. This failure to listen, the disbelief and the failure to respond have caused a lot of suffering among existing patients, many of whom have been receiving wrong services or no services. It has also left the health system unprepared for long-Covid.

Are there other related conditions where patients are being ignored and disbelieved and hence poorly served? The answer is yes – with FM being an important example. There is a gap in Canada's "universal" health care system for this family of conditions, with ME being the one that has been most able to expose the gap.

Long-Covid

Message: There are major overlaps between ME, FM and long-Covid and together they constitute a major challenge for Canada's health and social systems.

At the present time, there is a wary attitude between the long-Covid community and the existing ME/FM community. The existing ME/FM community, whose symptoms have lasted years or decades, find it ironic that the long-Covid patients, whose symptoms have lasted for weeks or months, are considered "long-haulers" and are getting considerable attention. Meanwhile, long-Covid patients are wary of associating with ME and FM, due to lack of awareness and stigma. Working together is ideal, but to do so these sensitivities have to be understood and acknowledged.

Overlap with ME

The article "Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of acute COVID-19 syndrome" is by Dr Komaroff, a leading ME clinician from Harvard and Dr Lipkin, a leading researcher from Columbia University. It appeared in the September 2021 issues of Trends in Molecular Medicine.

The authors observe that some people have chronic organ injury following Covid, but some people experience lingering illness with fatigue and cognitive defects not explained by obvious organ injury. This long-Covid syndrome is similar to ME which is often preceded by an infectious-like illness. It is currently unclear whether the same abnormalities happen in long-Covid as in ME, but it is likely that the same mechanisms are at play. It has long been known that ME and FM can be triggered by assaults to the immune system, including viruses. Would it matter what the particular immune system trigger was? To try an analogy, if someone is hit by a car, would it matter what particular make the car is?

The article sets out observations and theories around ME, thinking that it is better for long-Covid researchers to learn from work that has already been done than to reinvent the wheel.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8180841/

Disaster, Long Shadow, Catastrophe

The New England Journal of Medicine published a "perspective" on long-haul Covid in the summer of 2021. The article was co-authored by a public health consultant and by the Dean of the Harvard School of Public Health. It had the powerful title: "Confronting Our Next National Health Disaster – Long-Haul Covid".

The authors estimated that the pandemic will result in at least 15 million cases of long-haul Covid in the US with the people affected being relatively young, meaning that there will likely be "a long shadow on our health care system and economic recovery". They also described long Covid as "a looming catastrophe" even though the long-Covid catastrophe has already arrived.

Based on attitudes toward other post-infection conditions like ME and FM, the authors anticipate that the medical community will have "ambivalence about recognizing long Covid as a legitimate disease or syndrome" with some in the medical community seeing long Covid as a pathophysiological syndrome and others seeing long Covid as a mental illness The authors expect that patients will be "disbelieved, marginalized and shunned by many members of the medical community". The fact that long Covid disproportionately affects women is a factor in the disbelief.

The authors also pointed out that the health system is organ-focused while long Covid may affect a number of organ systems. Adding to the challenge, long Covid may occur in diverse patterns, the pathophysiology is unknown and there are no objective diagnostic tests or biomarkers.

They state the need for a coordinated health system response that is based on five "pillars":

- encourage vaccines to reduce number and severity of long-hauler cases,
- build research into causes and mechanisms which will lead to prevention and treatments,
- learn from other post-infection syndromes,
- apply an integrative (cross-disciplinary) patient care model, and
- believe and support patients.

The article can be found here:
https://pubmed.ncbi.nlm.nih.gov/34192429/

The "Missing Worker" Reality

This following article appeared in the Business section of the January 1, 2022 issue of the Globe and Mail. It points out that long-Covid has significant workforce and disability implications. ME and FM do also.

When we talk about labour shortages, we shouldn't overlook the direct health impacts of the pandemic on labour supply. Given what we're learning about the long-term effects of COVID-19, a disease that just keeps on giving, the projections are worrisome. First, let's recall that some so-called missing workers are dead. Among working-age adults in Canada, 1,181 have died since the start of the pandemic. Another 6,480 have survived an ICU admission and will very likely have long-term disability related to COVID-19 and necessary medical interventions, while another 18,810 have survived a hospital admission (but not ICU) and are at heightened risk for disability, relative to the general population of COVID-19 survivors. Nearly 1.1 million working-age adults in Canada have been infected by COVID-19 and between one-quarter and one-half could have or develop post-COVID symptoms that may limit their health or activity, whether for a few months or maybe even permanently. These estimates are all up to the start of December and before the effects of Omicron.

We should be thinking about our readiness to respond to more workers with disabilities. Disability too often means reduced labour-market attachment and inadequate access to supports. In a normal year, only about 3,500 working-age Canadians receive disability benefits from the Canada Pension Plan for long-term illness related to an infectious disease. According to Statistics Canada, less than half of workers reported having long-term disability coverage at work at the start of the pandemic. The federal government has passed legislation promising a new Canada Disability Benefit, but the design process and details are still being determined. Will this pandemic finally force policy makers, employers and insurance providers to respond to the challenges faced by working-age adults with disabilities?

Jennifer Robson, associate professor of political management, Carleton University (@JenniferRobson8)

Action Needed for ME and FM

Our organization focuses on ME and FM. This section has implications for long-Covid as well.

Research

What the ME/FM community wants: An appropriately funded research program asap to unravel the mysteries of ME and FM, leading to better prevention, diagnosis, treatment and support.

Advances have been made in understanding ME. In a published commentary, ME specialist Dr Komaroff of Harvard describes the abnormalities that have been found under five categories:

- *First, there are anatomic, physiologic and electrical abnormalities in the brain.*
- *Second, various elements of the immune system are chronically activated and in some people those elements are exhausted—perhaps secondary to years of chronic activation. This includes chronic activation of the brain's innate immune system—neuroinflammation. It also includes evidence of autoimmunity, including autoantibodies directed at targets in the central and autonomic nervous system.*
- *Third, there also is evidence of impaired energy metabolism: the person with ME/CFS feels he or she lacks "energy" because his or her cells have a reduced ability to generate energy molecules (adenosine triphosphate, or ATP). Along with the abnormalities in energy metabolism, there is associated oxidative stress, or redox imbalance.*
- *Fourth, the autonomic nervous system is dysregulated, one consequence of which appears to be impaired blood flow to the brain.*
- *Fifth, there are characteristic abnormalities of the gut microbiome, with increased numbers of pro-inflammatory bacterial species and decreased numbers of butyrate-producing antiinflammatory species.*

While abnormalities have been described, he states that "*What remains unclear are the mechanistic details as to how the abnormalities in each of these five categories affect each other, and whether one of them is the initial and primary abnormality.*"

The author thus emphasizes the need for more research. He speculates that understanding ME will help understand many other diseases.

The article "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: When Suffering Is Multiplied" appeared in July 2021 in the journal Healthcare.
https://www.mdpi.com/2227-9032/9/7/919

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In 2012, the National ME/FM Action Network met with the Canadian Institutes of Health Research and suggested that, considering their prevalence and seriousness, ME and FM should be receiving $10M/year each in research funding. That did not include funding of projects that mentioned ME or FM peripherally, and that did not include retroactive entitlement. CIHR has never challenged our target figures.
http://mefmaction.com/index.php?option=com_content&id=448&catid=69&Itemid=287

CIHR posts the research summaries of approved applications in a public data base with a key word search function.

In the nine fiscal years since, ME and FM should have received $90M each.

A word search for ME for the 9 year period show a grand total of $2.3M.

A word search for FM for the 9 year period show a grand total of $2.6M.

As of January 1, 2022, CIHR has awarded $1Billion in research grants for the 2021-22 fiscal year. A search for ME brings up 3 projects totalling $1M. There is $17k funding for a masters student. There is $280k funding for the research network that is supposed to fix the research gap but is struggling with so little funding. There is $742k for a clinical trial. A search for FM brings up 4 projects totalling $816k. There is funding for two masters students ($5k+$17k), a fellowship ($50k), and the same clinical trial ($742k). The clinical trial is looking at a medication (low dose naltrexone) for long-Covid. The application's summary notes that LDN has been tried with some success on ME and FM patients and that this study may have implications for ME and FM patients. This is why this study gets picked up in the ME and FM word searches.

ME and FM have been chronically underfunded in other countries as well. A study of 74 conditions found that ME was the most underfunded by the US National Institutes of Health. (FM wasn't included in the study.) Gender and stigma were seen as factors.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8290307/

Information and Awareness

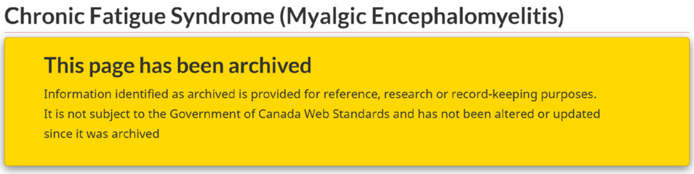
What the ME/FM community wants: An appropriately funded program asap to raise awareness and share information about ME and FM, leading to better prevention, diagnosis, treatment and support. The program should provide good information in a manner that is respectful of people with ME and/or FM.

In the published commentary just mentioned, Dr Komaroff of Harvard describes how unawareness of the basis of ME can lead to skepticism about its reality which leads to patient suffering. “Unfortunately,” he notes “many physicians are unaware of the new discoveries about ME/CFS.”

This article emphasizes the importance of information sharing to physicians. Information sharing is also needed for patients, family, friends, nurses, physiotherapists, occupational therapists, pharmacists, psychologists, social workers, employers, educators and so on.

The Public Health Agency of Canada website provides information on chronic diseases. For ME and FM, it gets a failing grade.

- For ME, the information is labelled “archived”, signifying that it is out of date and unimportant.
- For FM, the PHAC website shows a 2005 publication. It is very good information, but the absence of more current information shows how little attention is being paid to disseminating FM information.



Chronic Fatigue Syndrome (Myalgic Encephalomyelitis)

This page has been archived

Information identified as archived is provided for reference, research or record-keeping purposes. It is not subject to the Government of Canada Web Standards and has not been altered or updated since it was archived

From the Public Health Agency of Canada website

Health Canada’s website also gets a failing grade. If you go to Health Canada’s home page, click on health concerns, click on diseases and conditions, click on more diseases, and then click on chronic diseases, you arrive at an error page without finding anything to do with ME or FM.

The Government of Canada is sending out the message that ME and FM are non-existent or unworthy of attention.

We know the challenges of developing informational material. Our organization was instrumental in developing some key documents including diagnostic and treatment protocols for ME and FM, a Sourcebook for Educators, and a Guide for applying for CPP-D. We also keep the community informed through our newsletter, website and information service. It is important to get the information right. It is also important that the information be respectful of patients. Considering the troubled histories of ME and FM, that cannot be taken for granted.

We understand that the Public Health Agency of Canada provides funding to a charity focused on information sharing for HIV/AIDS/HCV to the tune of several million dollars a year. That should be a benchmark for discussions.
https://www.canada.ca/en/public-health/services/chronic-diseases/chronic-fatique-syndrome-myaligic-encephalomyelitis.html

Health System Design

What the ME/FM community wants: Timely access to diagnosis and treatment based on the best information available.

The public health article on long-Covid recommends an integrative patient care model. It is pointed out that the current specialist system is designed around organs or systems. ME and FM are complex and multi-system. Multi-system patients default to family doctors. Family doctors are not trained or financed to deal with ME or FM cases.

Integrative care should be looked at in at least two ways. One is bringing together medical specialists such a neurologist, immunologists, sleep specialists, pain specialists, etc. The other is bringing together allied health professionals like physiotherapists, occupational therapists and social workers. The value of patient support groups should not be forgotten.

There are three clinics in Canada (Vancouver, Toronto and Halifax) that deal with ME and FM. They are small with limited services and waiting lists that are years long. Barriers to growth include financing and staffing. They could provide a foundation for moving forward.

There has been work on this question in Ontario, with a business case, a task force report and, most recently, a report to the Minister from Public Health Ontario (PHO). This report, which has not been made public, could have valuable insight for action. The Ontario Ministry of Health provided the following statement in September 2021 to The Myalgic Encephalomyelitis Association of Ontario (MEAO):

The Ministry of Health has reviewed the PHO recommendations and is currently exploring options for implementation that will directly benefit Ontarians. We remain committed to working with MEAO and health partners across the province to better support individuals affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and Environmental Sensitivities/ Multiple Chemical Sensitivity, and acknowledge the impact of these illnesses on Ontarians.

Mental Health

What the ME/FM community wants: Access to mental health support where appropriate, but not the kind that thinks that ME and FM are caused by poor mental health.

In the past, we have been focused on trying to convince people that ME and FM are physical health issues, not mental health issues. With the 2015 US IOM report and the 2021 UK NICE guidelines, the idea that ME and FM are mental health issues should be completely discarded. So we can now send a more nuanced message - ME and FM are physical health issues, but they can have mental health aspects or implications.

- Having any chronic physical illness can have mental health consequences.
- The health system has not grappled adequately with the nature and seriousness of ME and FM, leaving patients feeling disbelieved, blamed, under-served and stressed.
- ME and FM are associated with reduced activity levels, which lead to reductions in social contact and thus to social isolation. The social isolation started before the pandemic and won't end when the pandemic ends.
- People with ME and/or FM can have comorbid mental health conditions.

A very good document on the topic is Assessment and Treatment of Patients with ME/CFS: Clinical Guidelines for Psychiatrists by Dr Eleanor Stein (2005), available at *http://mefmaction.com/images/stories/Legal/guidelines_psychiatrists.pdf*

Dr Stein writes "The best antidepressant for patients with ME/CFS is improved physical health & quality of life." That is why we will continue to emphasize the need for better services overall while recognizing that mental health supports can have value if provided appropriately.

Opioids

What the ME/FM community wants: A health system that balances the benefits of opioids with the harms of opioids.

A Canadian physician gave a presentation entitled "Why opioids should not be used to treat Fibromyalgia" at the 2021 international Fibromyalgia conference. This was mentioned in Quest 130. Here is what one of our member wrote to the presenter. We have heard the similar messages from other people.

Hello,

For more than 30 years, I have suffered with the pure misery of FM/ME.

Unable to work for 20 years, nor to marry, nor to have children.

Now, housebound, often bedridden. I'm 56 years old.

Hydomorphone 1mg OD is necessary for my survival in basic activities for daily living.

i.e. showering, making meals, physio exercises

It gives me pain relief as well as ENERGY.

I have been on it for 4 years. I have never abused it.

But doctors like you are causing me more pain. Your lectures on how opioids should not be prescribed to people with FM is misinformed. Your message is causing so much more harm to us sufferers. It is so difficult to find a doctor who is willing to write me a prescription for morphine.

I am considering MAID because of this lack of access.

I, and many others like me, are suffering Needlessly when there is relief out there but doctors who have limited expertise on FM/ME are robbing us of any quality of life.

Please reconsider your position on this matter.

Sincerely,

(name)

Disability Inclusion

What the ME/FM community wants: A decent quality of life including social inclusion.

In 2016, the Government of Canada held consultations around what should be in new disability legislation. The National ME/FM Action Network made a submission on September 29, 2016 from the perspective of a disability that was not well established. See pages 11-14.

New legislation, called the Accessible Canada Act, was proclaimed in 2019. It responded to requests of the established disability community to build standards around issues like employment, communications and the built environment. It could be considered step 1 in disability inclusion.

The new mandate letter to the minister responsible for disability inclusion asks her to continue implementing the ACA. It also asks for "a modern approach to and common definition of disability across the Government of Canada" and "a comprehensive review of access to federal disability programs".

This is an opening to go back to the ideas in our 2016 submission and move to step 2 of disability inclusion. Our recommendations include reviewing disability programs, amending the requirements for the Disability Tax Credit, increasing disability literacy in the public service, building a comprehensive statistical program and recognizing the role of organizations like ours.

The Government has also expressed the intention to introduce a new financial support program for low-income working-age Canadians with disabilities. We know how badly this is needed and will be watching closely to ensure fair access for people with ME and/or FM.

Responsibility for Action

Message: It is unfair that the burden of responsibility for change continues to be placed on the sick and disabled.

Many times in the past, the research, health or disability system has failed to get involved. This leaves it up the the patient community to try to sort things out without the resources that these systems have access to. This situation arose again in the long-Covid context. On November 19, 2021, when the Harvard School of Public Health hosted an hour-long webinar on the topic of long Covid with a broad panel of speakers.

The patient representatives talked about the frustrations of dealing with the health system. The clinicians talked about the challenges they face due to lack of information and a health system that is designed around specific organs and designed for quick visits. The patients and clinicians described what needs to be done.

The NIH representative spoke of the study that has been started to follow long Covid patients through time. He talked about doing science "at the speed of science". This was roughly equivalent to having a massive snowstorm underway in a municipality which does not have the resources to handle it, and the municipality saying that the problem will be studied in the fullness of time.

Using AIDS activism as a precedent, the public health consultant advised the long Covid patient community to focus its frustration and anger on understanding the research mindset and then to use this understanding to push research in useful directions. He said that what he is currently hearing from patients is noise and that noise has to be turned into signal.

This advice makes some very questionable assumptions, such as:

- the patients aren't sending a clear signal,
- the onus is on patients, not the health system, to initiate needed changes,
- the health system has no responsibility to learn from the AIDS experience, and
- any patient community can succeed just as the AIDS community succeeded.

No doubt the consultant meant well when he gave the advice, but he excuses the systems inaction and leaves the patient community feeling abandoned.

For links to the webinar and to a transcript of the webinar, go to: *http://mefmaction.com/index.php?option=com_content&id=567&catid=70&Itemid=294*

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Back in 2012, our organization proposed to CIHR that fair funding for ME and FM would be $10M each annually (see page 5).

CIHR said they would fund ME and FM projects when they got good applications. That makes questionable assumptions such as:

- there is infrastructure to put together ME and FM applications,
- researchers will put together applications when they

know that ME and FM are not areas of CIHR interest,

- CIHR will indeed fund good applications, and
- there is no public need for ME/FM research.

In 2016, a ME grant application that would have launched a ME research was turned down. The peer review process gave the application low scores using phrases including “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”. CIHR could have overridden the peer review decision or sent the application to a new panel. Instead, CIHR allowed this peer review to stand. The ME community felt betrayed.

Finally in 2019, CIHR approved a grant for a ME research network. Funding was set by CIHR at $280k each year for 5 years.

The ME patient view is that $280k per year is very small funding considering that ME is a serious health issue that casts a long shadow, that research is very necessary for explaining it, and that the research could lead to better prevention, diagnosis, treatment and support.

So why did CIHR offer so little? Let’s go back to the long-Covid webinar where the NIH representative stated that science “moves at the speed of science”. We all know that science may not be able to provide all the answers, but that science can respond very quickly when it wants to. So the slowness of science does not explain the low funding.

The NIH representative then added a very important concept. Science, he said, “moves at the speed of trust”. What trust? He didn’t say. But it could be trust that they wouldn’t be criticized by their bosses or peers or patients or the public for where they were investing their research resources. And that would explain their reluctance to fund ME and FM research. They don’t want to stick their necks out. And they are not factoring in the consequences of their reluctance.

According to the CIHR’s governing legislation:
“The objective of the CIHR is to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system”.

In the view of the ME/FM community, CIHR is not striving for scientific excellence. It is striving for scientific conformity.

Emails to Ministers

Sent Jan 10, 2022

To The Honourable Jean-Yves Duclos, Minister of Health

email: hcminister.ministresc@hc-sc.gc.ca
phone: 613 957-0200

Re: Health Issues affecting the ME/FM Community

The National ME/FM Action Network would like to welcome you as Minister of Health.

Your mandate letter calls on you to strengthen the health care system and to look at long-Covid. These issues are very relevant to Canadians with Myalgic Encephalomyelitis, Fibromyalgia or both.

According to the Canadian Community Health Survey, nearly a million Canadians have been diagnosed with ME (called Chronic Fatigue Syndrome on the survey) and/or FM. Nevertheless, there are minimal health services available across the country. There is minimal research funding from CIHR. There is minimal information available on the PHAC or HC websites. Many people are suffering as a result of these gaps.

ME and FM are acquired chronic conditions. Infection is a frequent trigger. Fatigue, pain, and cognitive difficulties are frequent symptoms. These are some of the symptoms of long-Covid. We see this part of long-Covid as being in the same family of illnesses as ME and FM.

We would like to see three things happen moving forward:

- An immediate review of the CIHR funding for ME and FM. They have not been fairly funded and this needs to be discussed and fixed.
- An immediate review of ME and FM information on the HC and PHAC websites. The information is inadequate and needs to be discussed and fixed.
- Inclusion of the ME/FM family of illnesses when working with the provinces and territories to strengthen the health care system. The redesign that is called for in your mandate letter is a perfect opportunity to address ME/FM services

We are attaching a copy of our latest newsletter where we delve into these issues in more detail.

We hope that you will use the information we have provided as you develop your budgets and plans for the coming year.

To The Honourable Carolyn Bennett, Minister of Mental Health and Addictions and Associate Minister of Health

email: mhaminister.ministresmd@hc-sc.gc.ca
phone: 613 948-3265

Re: Health Issues affecting the ME/FM Community

The National ME/FM Action Network would like to welcome you back to the Health Portfolio. We appreciate your interest in ME and FM over the years and we remember your attempt to provide research funding for ME and FM when you were in the Health Portfolio previously.

Progress for ME and FM have been slow over the years, but today Canada has the perfect opportunity to leap forward. The ME community has just put to rest the idea that people can simply exercise their way to health. This means that the health and disability systems have to think of ME and related conditions more seriously. The emergence of long-Covid, which is in the same family as ME and FM, adds numbers and urgency to this. Meanwhile, the Health Portfolio is called upon to strengthen the health system which positions them for action.

We know that you have been asked to focus on mental health and addictions. For years we have been fighting the perception that ME and FM are mental health issues. It should now be clear that they are physical health issues. However, like any physical health issue, they can have mental health aspects. For opioids, we want to make sure that people dealing with pain have access where appropriate and do not have to turn to less desirable alternatives.

All these issues are discussed in our latest newsletter (attached).

To The Honourable Carla Qualtrough, Minister of Employment, Workforce Development and Disbility Inclusion

email: Carla.Qualtrough@hrsdc-rhdcc.gc.ca

Re: Disability Issues affecting the ME/FM Community

The National ME/FM Action Network would like to welcome you back as Minister for Disability Inclusion.

We know that progress has been made on disability issues over the last few years. This progress aimed primarily at established disabilities. Coming from the non-established disability side of the disability community, we see the progress that was not made.

We went back to the submission we made on September 29, 2016 for the public consultations on the proposed new disability legislation and found that our ideas were not incorporated. We asked for a review of disability programs. We asked for amendments to the Disability Tax Credit eligibility criteria because they are selective and non-inclusive. This became highly visible when the attempt was made to base Covid disability payments on the DTC. We asked for increased disability literacy in the public service since we rarely feel that our conversations with government get beyond a beginner level. We asked for a more holistic disability statistics program. And we asked that the government think about the value of organizations like ours.

We are very glad that your mandate letter and the disability inclusion plan provide the opportunity to take on this next generation of disability issues.

We would like to share with you our latest newsletter which includes our 2016 submission.

NATIONAL ME/FM ACTION NETWORK

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Submission to the public consultation on inclusion and accessibility leading to a Canada Disability Act

on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM)

September 2016

The Government of Canada has announced its commitment to promoting equality of opportunity and increasing the inclusion and participation in society for Canadians who have disabilities or functional limitations. The government has announced a public consultation process leading to the introduction of new legislation.

The National ME/FM Action Network is very familiar with disability issues.

The National ME/FM Action Network is a registered charity that has been working on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM) since 1993. We have many accomplishments to our credit including spearheading the development of diagnostic and treatment protocols for ME/CFS and FM, publishing a guide to applying for CPP-Disability, publishing a sourcebook for teachers of young people with ME/CFS or FM, and publishing statistics on the illnesses. We keep in contact with the ME/FM community by newsletter, website, email, facebook, twitter, phone and personal contact.

ME/CFS and FM are chronic disabling illnesses that impact many Canadians.

We know from our contacts with the ME/CFS and FM community that people are experiencing very serious issues. This has been confirmed by Statistics Canada's Canadian Community Health Survey. The 2014 cycle found over 800,000 Canadians with a diagnosis of ME/CFS, FM or both. These Canadians are predominantly female and of working age. Among people with ME/CFS and FM, the survey found:

- high rates of disability,
- high rates of unmet health care and home care needs,
- high rates of poverty,
- high rate of food insecurity.

Very importantly for this consultation, the survey found <u>a weak sense of community belonging</u>. This is a key measure of the lack of inclusion and needs to be addressed

The ME/FM community brings an important perspective to disability discussions – having a disability that is not well-established.

Our community experiences many of the same barriers that the traditional disability community experiences. There are, however three interrelated barriers which strongly affect the ME/FM community:

- lack of health services and supporting research
- lack of awareness and understanding of the conditions and, often, misinformation and stigma
- incomplete incorporation into disability programs.

Other groups have been in this situation in recent times - autism and mental illness jump to mind.

People should not be disadvantaged because their disability is not a traditional or well-established one. The new disability legislation should address the needs of traditional, well-established disabilities, but the needs of people with non-traditional disabilities must be addressed as well.

The CRPD provides a definition of disability, but putting too little emphasis on participation restrictions and too much emphasis on impairments can be exclusionary.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) describes disability as resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

While people with ME/CFS and FM often encounter major participation restrictions, the physical mechanisms causing ME/CFS and FM are not well understood. In the absence of a biological explanation, society tends to downplay the disability or to blame the person for the problems. Health professionals shy away from helping, disability benefits are hard to obtain, and even friends and families can be judgmental.

The obvious solution is for research to find an explanation. Unfortunately, the research system is uncomfortable in less-established stigmatized areas like this and is not aggressively searching for answers. The disability system needs to recognize this phenomenon and focus less on medical explanations and more on observational evidence of the restrictions in participation.

The discussion paper uses other disability legislation as the main models for moving forward. Much can be learned from experiences around building inclusion for other excluded groups.

The discussion paper looks to previous disability experience for models of moving forward. The Americans with Disability Act and the Accessibility for Ontarians with Disabilities Act are two models suggested. Our suggestion is to look more widely at inclusion initiatives. Examples include minority official languages, women, visible minority groups, indigenous people, and the LGBTQ community. Many initiatives have been undertaken to overcome the outsider status experienced by these groups.

The discussion paper seems to be defining accessibility in a very narrow sense, the way it is used in article 9 of the CRPD. All rights within the CRPD need to be considered, not just article 9.

Section 9 of the CRPD states that people with disabilities have the right of access, on an equal basis with others, 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. Other provisions within the CRPD are extremely important to our community such as Article 8 awareness-raising, Article 24 education, Article 25 health, and Article 28 adequate standard of living and social protection.

Our experience is that federal government employees know little about disability issues. A key priority of the new legislation should be building federal competency.

I have personally been bringing forward issues to the federal and Ontario governments for 15 years. I find that I am giving the introductory speech over and over and over. Conversations rarely get beyond a very basic level. Federal government employees need to know much more about disabilities and disability issues.

Every government job has a linguistic profile – saying what language skills the incumbent is required to have. Every government job should have a disability profile. Senior management jobs, jobs in the disability area, and certain human resource jobs should require a high level of disability competency. Supervisory jobs, policy jobs and public contact jobs should require a reasonable level of disability competency. All employees should receive basic training.

Further, there should be a disability coordinator in every federal department and agency to facilitate the government/public interface, and the disability coordinators should be meeting at regular intervals to ensure up-to-date information.

The federal government should be taking leadership on disability issues as there are many stakeholders.

People with ME/CFS and FM have very poor access to health care, one of the rights in the CRPD. Stakeholders include several federal departments and agencies, the provinces and territories, and numerous professional groups. When we discuss our issues with government, the attitude is typically "Thank you for telling us about it. You should be talking to someone else. Good luck sorting it out." One senior government official commented to us on how hard it would be to sort out the health care issue with so many players involved. If it is hard for government, think how much harder it is for a little-known all-volunteer organization dependent on memberships and donations, with donations hard to raise because the cause is unknown and stigmatized. A better answer would be "Thank you for telling us about it. There is obviously a public issue here. We need to be part of sorting it out. How can we work together? Who else do we need to bring into this discussion?"

The federal government needs to understand the value of disability organizations like ours.

The National ME/FM Action Network is providing a very valuable service to Canadians, as are ME/FM organizations at the provincial and local levels. We understand the problems in the community. have knowledge, credibility and infrastructure to connect to the community. We understand the culture and sensitivities.

We have seen what happens when government ignores the needs of the community. We have seen what happens when government jumps in without understanding the culture or sensitivities.

Amendments to the Disability Tax Credit provisions should be included in the new legislation.

In a February meeting with the Minister, we focused on five existing federal programs – Canada Pension Plan-Disability, Disability Tax Credit (which is a benefit but also a gateway to other benefits), home care, accommodation at work and voting in elections from home.

It appears that most issues in these programs can be sorted out within the current legislative framework. In the case of the DTC, legislative change is needed because the eligibility criteria spelled out in the Income Tax Act are selective and non-inclusive.

Statistics and evaluation are extremely important.

We will know that the new legislation is working when our communication with government improves and our community reports improved experiences. We will be looking to the Canadian Community Health Survey for confirmation. In particular, we will be looking for the ME/CFS and FM communities to have:

- greater sense of community belonging
- lower rates of unmet health care needs
- lower rates of unmet home care needs
- lower rates of poverty
- lower rates of food insecurity

Note that many of these indicators are not included on the Canadian Survey on Disability. The survey needs to be reviewed.

We see the need for a holistic disability statistical program rather than a single survey. There needs to be surveys on participation, experiences and attitudes. There need to be evaluations of the various programs. There need to be studies of issues like the adequacy of disability benefits.

**

Thank you for this opportunity to contribute to the dialogue around accessibility and inclusion. <u>We hope to be invited for more discussions as the consultations progress.</u>

We will be sharing this document with our community and making it available on our website. We give you full permission to post and share this document.

Margaret Parlor
President
National ME/FM Action Network

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