NATIONAL ME/FM ACTION NETWORK
SINCE 1993

# Quest
## Newsletter

www.mefmaction.com
Quest 125, Fall 2020
mefminfo@mefmaction.com

In recent months, we are seeing the emergence of people who are supposedly over their COVID but are still experiencing symptoms. From their point of view, their COVID related health issues have been a long-haul, having lasted a few weeks or a few months. They call themselves "long-haulers". They have been featured in many media stories in Canada and internationally.

This very likely represents a new wave of people with ME and/or FM though we have to be cautious about jumping to that conclusion. Firstly, not all people with lingering symptoms will turn out to have ME or FM. For some, the lingering symptoms will fade away and for others the lingering symptoms might be something like lung damage. Secondly, we are not quite sure what causes ME or FM, and we can't be sure that COVID will trigger the same mechanisms.

There is currently a tension between the new "long-haulers" and the long-time ME/FM community. Long-haulers see themselves as new and unique. They identify with other COVID people, not with the ME/FM world. They probably don't want to know how long their symptoms could last. The existing ME/FM community sees attention is going to go to the newcomers.

It is important to focus on the synergies between the two groups. The existing ME/FM community has a lot of understanding and experience that it can share while the new attention is positive for everyone.

In this newsletter, we have compiled a fact-sheet for people struggling to recover from COVID-19. It focuses on how to describe their symptoms to their health-care providers. Another item in this newsletter focuses on what is happening with ME and FM research.

In other news, Statistics Canada has now released some data from the 2019 Canadian Community Health Survey. It shows a 10% increase in diagnosed FM cases since 2016 and a 20% drop in diagnosed CFS cases. You can see the figures and discussion in this newsletter.

We have been asked when the special disability payment (discussed in Quest 124) will arrive. The latest information we have is sometime this fall.

## Contents

## CCHS 2019 data on CFS and FM

Statistics Canada has now provided us with prevalence figures for Chronic Fatigue Syndrome and Fibromyalgia from the 2019 Canadian Community Health Survey (CCHS). For more information about the CCHS see the Quest 112 special issue on statistics.

**In 2019, there were an estimated 572,200 Canadians with a diagnosis of Fibromyalgia. An estimated 462,700 Canadians had a diagnosis of Chronic Fatigue Syndrome. An estimated 902,800 Canadians had a diagnosis of one or both of these conditions.**

CFS and FM have been included on the CCHS in selected years. The most recent years were 2010, 2014, 2015, 2016 and 2019. Multiple Chemical Sensitivities was included in those earlier years but not in 2019.

The prevalence figures for CFS and FM are shown in the following table. As you can see, the figures for CFS were relatively steady in between 2010 and 2014, jumped upwards in 2015 and 2016, then fell back in 2019. The figures for FM stayed relatively steady between 2014 and 2016, then showed an increase in 2019.

We asked Statistics Canada if they could provide insight into the dramatic drop in CFS cases in 2019. They said that there were no changes to the way that they conducted the survey that would explain the movement. They did raise the issue of sampling. Because an individual respondent can be used to represent hundreds of Canadians, the estimates are far from precise. A key piece of information is the confidence interval. Statistics Canada provided 95% confidence intervals for 2015, 2016 and 2019. We are including the three tables that STC provided to us.

Even if CFS was over-sampled in 2015 and 2016 and under-sampled in 2019, the intervals don't overlap, which means that sampling is very unlikely to explain the drop that occurred though it could be a contributing factor.

It is critical to keep in mind that the survey asks ordinary Canadians to report chronic conditions that have been diagnosed by a health professional. The survey does not check whether the information provided is correct. The health professional could miss cases or could make a diagnosis when CFS or FM was not present. This means that the prevalence figures can reflect how thoroughly and carefully diagnoses are made. People could report cases that hadn't been diagnosed or fail to report cases that have. This means that prevalence figures can reflect how willing people are to report cases. Overall, this means that changes in attitudes or practices among health providers and patients can lead to an increase or decrease in the number of diagnosed cases even without a change in the number of true cases.

|  | Fibromyalgia | Chronic Fatigue Syndrome | CFS and/or FM |
|---|---|---|---|
| 2005 | 389,800 | 333,800 | 628,500 |
| 2006 |  |  |  |
| 2007 |  |  |  |
| 2008 |  |  |  |
| 2009 |  |  |  |
| 2010 | 438,800 | 411,500 | 755,900 |
| 2011 |  |  |  |
| 2012 |  |  |  |
| 2013 |  |  |  |
| 2014 | 518,800 | 407,600 | 808,700 |
| 2015 | 493,600 | 561,500 | 916,700 |
| 2016 | 522,000 | 581,600 | 964,600 |
| 2017 |  |  |  |
| 2018 |  |  |  |
| 2019 | 572,200 | 462,700 | 902,800 |

| | **2015** | | | | | |
|---|---|---|---|---|---|---|
| | **Number** | **Number, low CI** | **Number, high CI** | **Percent** | **Percent, low CI** | **Percent, high CI** |
| **Fibromyalgia** | | | | | | |
| Total, by sex | 493,600 | 445,200 | 542,000 | 1.6% | 1.5% | 1.8% |
| Males | 97,200 | 69,500 | 125,000 | 0.7% | 0.5% | 0.8% |
| Females | 396,400 | 357,800 | 434,900 | 2.6% | 2.3% | 2.8% |
| Total, by age | 493,600 | 445,200 | 542,000 | 1.6% | 1.5% | 1.8% |
| Less than 65 | 335,800 | 294,800 | 376,900 | 1.4% | 1.2% | 1.5% |
| 65 or older | 157,800 | 133,900 | 181,600 | 2.9% | 2.4% | 3.3% |
| **Chronic fatigue syndrome** | | | | | | |
| Total, by sex | 561,500 | 506,800 | 616,100 | 1.9% | 1.7% | 2.0% |
| Males | 195,100 | 160,900 | 229,200 | 1.3% | 1.1% | 1.5% |
| Females | 366,400 | 322,000 | 410,800 | 2.4% | 2.1% | 2.7% |
| Total, by age | 561,500 | 506,800 | 616,100 | 1.9% | 1.7% | 2.0% |
| Less than 65 | 404,500 | 356,400 | 452,600 | 1.6% | 1.4% | 1.8% |
| 65 or older | 156,900 | 132,500 | 181,400 | 2.9% | 2.4% | 3.3% |
| **Both conditions** | | | | | | |
| Total, by sex | 138,400 | 107,700 | 169,200 | 0.5% | 0.4% | 0.6% |
| Males | 23,400 | 1,700 | 45,000 | 0.2% | 0.0% | 0.3% |
| Females | 115,100 | 92,900 | 137,200 | 0.8% | 0.6% | 0.9% |
| Total, by age | 138,400 | 107,700 | 169,200 | 0.5% | 0.4% | 0.6% |

| | 2016 | | | | | |
|---|---|---|---|---|---|---|
| | Number | Number, low CI | Number, high CI | Percent | Percent, low CI | Percent, high CI |
| Fibromyalgia | | | | | | |
| Total, by sex | 522,000 | 473,700 | 570,300 | 1.7% | 1.5% | 1.9% |
| Males | 106,300 | 83,500 | 129,100 | 0.7% | 0.6% | 0.9% |
| Females | 415,700 | 372,900 | 458,500 | 2.7% | 2.4% | 3.0% |
| Total, by age | 522,000 | 473,700 | 570,300 | 1.7% | 1.5% | 1.9% |
| Less than 65 | 317,500 | 279,000 | 356,100 | 1.3% | 1.1% | 1.4% |
| 65 or older | 204,500 | 174,600 | 234,300 | 3.6% | 3.1% | 4.1% |
| Chronic fatigue syndrome | | | | | | |
| Total, by sex | 581,600 | 525,300 | 637,900 | 1.9% | 1.7% | 2.1% |
| Males | 208,300 | 175,000 | 241,600 | 1.4% | 1.2% | 1.6% |
| Females | 373,400 | 326,300 | 420,400 | 2.4% | 2.1% | 2.7% |
| Total, by age | 581,600 | 525,300 | 637,900 | 1.9% | 1.7% | 2.1% |
| Less than 65 | 434,700 | 383,200 | 486,300 | 1.7% | 1.5% | 2.0% |
| 65 or older | 146,900 | 124,100 | 169,600 | 2.6% | 2.2% | 3.0% |
| Both conditions | | | | | | |
| Total, by sex | 139,000 | 114,400 | 163,600 | 0.5% | 0.4% | 0.5% |
| Males | 20,200 | 11,500 | 28,900 | 0.1% | 0.1% | 0.2% |
| Females | 118,900 | 96,500 | 141,200 | 0.8% | 0.6% | 0.9% |
| Total, by age | 139,000 | 114,400 | 163,600 | 0.5% | 0.4% | 0.5% |
| Less than 65 | 93,600 | 74,700 | 112,500 | 0.4% | 0.3% | 0.5% |
| 65 or older | 45,400 | 30,300 | 60,600 | 0.8% | 0.5% | 1.1% |

| | 2019 | | | | | |
|---|---|---|---|---|---|---|
| | Number | Number, low CI | Number, high CI | Percent | Percent, low CI | Percent, high CI |
| **Fibromyalgia** | | | | | | |
| Total, by sex | 572,200 | 521,500 | 622,800 | 1.8% | 1.6% | 2.0% |
| Males | 114,800 | 88,000 | 141,600 | 0.7% | 0.6% | 0.9% |
| Females | 457,400 | 415,900 | 498,800 | 2.8% | 2.6% | 3.1% |
| Total, by age | 572,200 | 521,500 | 622,800 | 1.8% | 1.6% | 2.0% |
| Less than 65 | 377,300 | 331,900 | 422,700 | 1.5% | 1.3% | 1.7% |
| 65 or older | 194,800 | 171,300 | 218,400 | 3.1% | 2.7% | 3.4% |
| **Chronic fatigue syndrome** | | | | | | |
| Total, by sex | 462,700 | 418,500 | 507,000 | 1.5% | 1.3% | 1.6% |
| Males | 153,000 | 126,800 | 179,100 | 1.0% | 0.8% | 1.1% |
| Females | 309,800 | 274,400 | 345,200 | 1.9% | 1.7% | 2.1% |
| Total, by age | 462,700 | 418,500 | 507,000 | 1.5% | 1.3% | 1.6% |
| Less than 65 | 325,400 | 286,100 | 364,700 | 1.3% | 1.1% | 1.4% |
| 65 or older | 137,300 | 117,600 | 157,000 | 2.2% | 1.9% | 2.5% |
| **Both conditions** | | | | | | |
| Total, by sex | 132,100 | 110,200 | 154,100 | 0.4% | 0.3% | 0.5% |
| Males | 18,300 | 10,600 | 26,000 | 0.1% | 0.1% | 0.2% |
| Females | 113,800 | 93,600 | 134,100 | 0.7% | 0.6% | 0.8% |
| Total, by age | 132,100 | 110,200 | 154,100 | 0.4% | 0.3% | 0.5% |

In early 2015, the US Institute of Medicine (IOM) released a report on ME/CFS. This was a statement by top doctors that ME/CFS is real. It provided a quick way of identifying potential cases. The report would have come to the attention of Canadian doctors. It would have given them more confidence to make a diagnosis of CFS. It could also have given patients more confidence to report their diagnosis. This could explain the big jump in 2015 and sustained level in 2016.

It is very unlikely that the 2019 decline represents widespread recovery. Some of the decline in cases appears to have been CFS cases re-diagnosed as FM. It is not obvious where other cases went. If increased respect for CFS explains the 2015/16 increase, then it could be that decreased respect for CFS explains the 2019 decline.

We simply don't know what happened between 2016 and 2019. We know that almost a million people reported a diagnosis of CFS, FM or both. We know from previous surveys that these cohort are under-served and in great need. The prevalence figures should not bounce around like this without explanation. There is a need for more discipline, quality assurance and surveillance in this segment of the medical system. This is especially true with an expected surge in CFS and FM cases over the next months and years as a result of the pandemic.

Looking forward, the 2019 CCHS public use microdata file (PUMF) is not expected until late 2021. The 2020 CCHS survey includes CFS and FM. CCHS collection for 2020 was suspended in March and there are plans to collect nine months worth of data this autumn - the collection disruption could affect comparability between 2019 and 2020 data. CFS, FM and MCS are all expected to be on the 2021 survey. A major survey design is likely for 2022.

As can be seen, there are delays and gaps in our understanding of what is happening. A more comprehensive surveillance system for ME/FM is needed.

Note: The survey asks about "Chronic Fatigue Syndrome", so that is the term used throughout this section.

# Information for People Struggling to Recover from COVID-19

Even though your COVID-19 is officially gone, your health is not bouncing back the way you think it should. This is having an impact on your overall life. One possible reason for your slow recovery is that you are developing Myalgic Encephalomyelitis (ME), Fibromyalgia (FM) or both. We cannot provide medical advice. You will need a health care professional to help you sort out your medical issues. However, as patients and caregivers who have experience with ME and FM, we can share with you some of what we have learned.

Many people with existing ME or FM found that their health problems started after having a virus. Continuing infection does not seem to explain the ongoing symptoms. One possible explanation is that the virus turned on the immune system, the virus left, and the immune system couldn't turn itself off. (When you feel bad with a virus, you are feeling your immune system response rather than the virus itself.) Another possible explanation is that the virus damaged the autonomic nervous system which controls many bodily functions.

ME (formerly referred to as chronic fatigue syndrome) and FM are complex chronic disabling diseases. At last count, around 900,000 Canadians had been diagnosed with one or both conditions. They are more prevalent in women than men. They can affect young and old but are most often found in people of working age.

## Diagnosing ME and FM

Two decades ago, there was little guidance to clinicians on how to diagnose and treat ME and FM. Our organization found doctors to draft guidelines. We worked with Health Canada to appoint panels of Canadian and international experts to review the drafts. We facilitated the work of the two panels. The results were published in peer review journals in 2003. The ME diagnostic criteria have become the world standard. The FM guideline changed thinking about FM, moving the focus from pain to a broader range of symptoms.

In the absence of known biomarkers, ME and FM are diagnosed based on a pattern of symptoms. These include reduced activity levels, cognitive problems, sleep problems, and pain. The main difference is that ME requires post-exertional malaise (referred to as PEM) while FM does not.

Most people can push themselves, and the next day they are able to push themselves as far or farther. Their bodies respond to challenges by become fitter. People with PEM do worse the second day, suggesting that exertion actually harms their aerobic energy system. If you have PEM, exertion can be harmful. It can be hard to convince patients with PEM and those around them that backing away from activity can be a better strategy than pushing forward. You will see advice to people with ME to try Graded Exercise Therapy (GET) which is about trying to do a little more every day. Be aware that this therapy has been discredited for ME patients.

The leading organization for US clinicians is the Institute of Medicine (now called the National Academy of Medicine). In a 2015 report on ME, they addressed a specific problem. Many people with ME were undiagnosed and health care providers had limited time to meet with patients. How could potential cases of ME be recognized in a few minutes? They recommended that the health care provider look for reduced activity levels, PEM, sleep disorders, and either cognitive problems or orthostatic intolerance. These are some of the elements in the 2003 clinical guidelines for ME, so think of the IOM report as a useful screening tool for ME cases.

# Diagnosing ME and FM (continued)

Most people can look after themselves and their home, participate in school or work, maintain a social life and do some physical activity. When chronic illness intervenes, they find themselves cutting back on these activities a little or a lot, depending on the severity of the chronic illness To discuss activity levels with your health care provider, it is very helpful to keep a diary and then apply the functional capacity scale (FCS) which is shown on the next page. The FCS runs from zero (completely bedbound) though 7 (can do some part time work) to 10 (athlete). Your level of function can vary from day to day, but you are trying to find a level that you can sustain and build from. A diary is also useful in identifying PEM and in documenting disability applications if required.

Orthostatic Intolerance (OI) has to do with getting blood to your brain. If you are lying down, you are pumping along the flat. If you are walking around, the movement helps you pump. If your body (ortho) is standing still (static), then you have to rely on your pulse and blood pressure. If these aren't working properly you may feel faint or dizzy and you may lose concentration (intolerance). People with OI might be able to walk around a grocery story but have trouble waiting in line to pay. People with OI  have trouble taking showers, especially washing hair where they have to pump blood up to their arms and head. People with OI have trouble standing at a stove to stir food. One measure to use when describing OI is HUA – hours of upright activity. Count how much of the day you are standing or sitting with your feet on the floor, versus sitting with your feet raised or lying down.

Cognitive problems are very common with ME and FM and this can be the most frustrating symptom. They may be related to OI or to running out of energy. Be aware that you have limited energy reserves that are shared between physical, mental and emotional activity.

If you discuss a FM diagnosis, your health provider has choices on what criteria to use. We suggest looking at the Overview of the 2003 FM report. In that report, the FM criteria is based on widespread pain and the existence of tenderpoints, and then health providers are asked to consider additional related symptoms like reduced activity levels, sleep problems and cognitive difficulties. Nowadays, some health providers are inclined to give less attention to tenderpoints and more attention to additional symptoms.

## Pacing

If you are experiencing Post Exertional Malaise (PEM), it is important to manage your activity levels. It will take some time, but you can figure out what level of exertion will cause an exacerbation of symptoms. Remember that exertion can be mental, physical or emotional. If you do too much you may not feel the effect right away. It may be the next day and it could last for days or weeks. People often find it better to do activities in short stints with breaks rather than all at once.

# FUNCTIONAL CAPACITY SCALE:

The Functional Capacity Scale incorporates energy rating, symptom severity, and activity level. The description after each scale number should help you to rate your functional capacity at the beginning and end of each day.

0. No energy, severe symptoms including very poor concentration; bed ridden all day; cannot do self-care (e.g. need bed bath to be given).
1. Severe symptoms at rest, including very poor concentration; in bed most of the day; need assistance with self-care activities (bathing).
2. Severe symptoms at rest, including poor concentration; frequent rests or naps; need some assistance with limited self-care activities (can wash face at the sink) and need rest afterwards for severe post exertional fatigue.
3. Moderate symptoms at rest, including poor concentration; need frequent rests or naps; can do independent self-care (can wash standing at the sink for a few minutes) but have severe post exertion fatigue and need rest.
4. Moderate symptoms at rest, including some difficulty concentrating; need frequent rests throughout the day; can do independent self-care (can take a shower) and limited activities of daily living (e.g. light housework, laundry); can walk for a few minutes per day.
5. Mild symptoms at rest with fairly good concentration for short periods (15 minutes); need a.m. and p.m. rest; can do independent self-care and moderate activities of daily living, but have slight post exertion fatigue; can walk 10-20 minutes per day.
6. Mild or no symptoms at rest with fairly good concentration for up to 45 minutes; cannot multitask; need afternoon rest; can do most activities of daily living except vacuuming; can walk 20-30 minutes per day; can do volunteer work – maximum total time 4 hours per week, with flexible hours.
7. Mild or no symptoms at rest with good concentration for up to ½ day; can do more intense activities of daily living (e.g. grocery shopping, vacuuming), but may get post exertion fatigue if 'overdo'; can walk 30 minutes per day; can work limited hours, less than 25 hours per week; no or minimal social life.
8. Mild intermittent symptoms with good concentration; can do full self-care, work 40 hours per week, enjoy a social life, do moderate vigorous exercise three times per week.
9. No symptoms; very good concentration; full work and social life; can do vigorous exercise three to five times a week.
10. No symptoms; excellent concentration; over achiever (sometimes may require less sleep than average person).

NUMBER OF USABLE HOURS / DAY = Number of hours NOT asleep or resting/meditating with eyes closed.

# Talking to Your Health Care Provider

Now we come to a delicate but important topic. As you go through the health system, we hope you are treated seriously and with respect, but, unfortunately, this doesn't always happen. ME and FM are complex diseases that the health system has difficult explaining and treating. The health system has not confronted this challenge; instead it has set it aside.  You may encounter health care providers who step forward and offer support, others who ignore ME and FM and others who will blame you. Don't take the negative reactions personally. They say more about the health care providers and their training than they say about you. But it does leave you in the difficult situation of figuring out how to get the help you need.

Focus on your priorities. This will include understanding what is wrong with you and how you can protect and rebuild your health. It may also include dealing with difficulties at work or school and financial stress. Let us also raise another priority, so obvious it is often overlooked. Be aware that your ongoing heath issues affect your relationships with family and friends.

Spend time at the diagnostic stage so that you understand fully what you are dealing with. Be sure to check for overlapping and differential diagnoses.

We cannot see what your health will be in the future, but we do know that, regardless of your health condition, you can still have a beautiful and meaningful life.

**Resources to get started:**

For overviews of the Canadian Consensus Documents

*Myalgic Encephalomyelitis (available in English, French, Spanish, German, Italian and Dutch)*
http://mefmaction.com/index.php?option=com_content&view=article&id=214&Itemid=263

*Fibromyalgia (available in English, French and Spanish)*
http://mefmaction.com/index.php?option=com_content&view=article&id=214&Itemid=263

For clinical guidance on how to diagnose ME (including a discussion of differential and overlapping diagnoses) and how to treat ME:

*The International Association Primer (available in English and French)*
http://mefmaction.com/index.php?option=com_content&view=article&id=508:mecfs-primer-for-clinicalpractitioners-2014-revision&catid=88

*The Pediatric Primer (available in English and French)*
http://mefmaction.com/index.php?option=com_content&view=article&id=541:mecfs-diagnosis-and-management-inyoung-people&catid=67&Itemid=376

*For the Institute of Medicine Clinicians Guide  which confirms the medical basis of ME and provides screening criteria (available in English only)*
https://www.nap.edu/resource/19012/MECFScliniciansguide.pdf

Many more resources are available on our website at www.mefmaction.com

## ME/FM Research Update

There have been a lot of on-line meetings and presentations recently relating to ME research and to the issue of people with continuing symptoms after contracting COVID-19.

The IACFS/ME (the International Association for CFS/ME) has been organizing conferences every two or three years for thirty years. They had a conference scheduled for Long Island New York in June but ended up moving it on-line in August.

The first speaker was Toronto doctor and researcher Harvey Moldofsky speaking on a study he published in 2011. He looked at people with chronic symptoms following the SARS virus, and compared their symptoms with FM and CFS. After he gave his presentation, people in the audience asked how the patients are now. His very sobering answer was that they could not find funding to follow-up on the study. Wouldn't it be helpful for health and disability planning if the follow-up had been done!

SolveME invited Dr Anthony Komaroff, long-time ME clinician from Harvard, to talk about whether post-COVID could develop into ME. Dr Komaroff is a very careful presenter. He noted that there were no documented cases of post-COVID ME, COVID being so new. But he pointed to other viruses that have been associated with ME and he noted the symptoms post-COVID patients are experiencing. He suggested it was only a matter of time until ME cases were diagnosed.

Dr Komaroff noted along the way that the coronavirus attacks the brain, the lungs, the heart and the kidneys, so post-COVID may have a range of symptoms, some covered by ME and some not. Another long-time ME physician told me that he believes that different viruses do different damage, so post-viral syndromes may be virus-specific. This emphasizes the importance of research. It also emphasize the importance of each patient having a careful and thorough diagnosis since not all post-viral cases might present the same way.

This brings us to the first US inter-agency on-line meeting. The meeting was attended by representatives of a number of US agencies, including the CDC, NIH, Department of Defence and Department of Veterans Affairs. Also participating were the US groups SolveME, Open Medicine Foundation and #MEAction. It was exciting to hear the different organizations discuss research studies they were planning, especially with the opportunity to study how COVID might trigger cases. #MEAction brought a dose of reality to the session by pointing out that half a dozen or a dozen new studies would not make up for the extreme deficit in ME research. This ties in with an update to a US article comparing, for a range of medical conditions, their Disability Adjusted Life Years with their NIH funding. Disability Adjusted Life Years combines mortality (early death) with morbidity (reduced quality of life). According to these calculations, ME research is receiving only 7.3% of what it should be receiving from NIH.

There are two studies on post-COVID that deserve special attention.

One involves long-time ME researcher Dr Leonard Jason. He wanted to study young people developing ME following mononucleosis which is associated with the Epstein-Barr virus. He enrolled a large group of healthy young people. He anticipated that some of them would develop mono and some of those would go on to develop ME. Having health information and bio-samples before the virus would provide a baseline to study how the ME developed. Now he hopes to use the same group of young people to study post-COVID. This post-COVID study would not have been possible without the study group being in existence. This really illustrates the advantage of having a broad research/surveillance infrastructure in place for ME (and FM of course).

The other study has been funded by the Open Medicine Foundation which raises money for ME research. In May, OMF announced "the initiation of a study of patients with COVID-19 to monitor the course of their disease and its sequelae (the medical term for chronic conditions after an illness) to ascertain whether they convert to ME/CFS and if it occurs, to study the molecular transformation. This will involve the collection of body fluid samples at frequent intervals, continuous health monitoring via wearables, and symptom data recorded at many separate time points over two years." A key partner in this research is Dr Alain Moreau of Montreal. His research team is one of the four collaborative centers in the OMF chain.

The OMF held an on-line conference for researchers in September and will be holding an information webinar for the Canadians public on Saturday October 3rd. Check their website for information.

CIHR is Canada's health research funding agency. It has a funded decisions database. Of the $1.2 billion allocated so far this fiscal year, $309k has gone for the ME research, specifically to the new ME research network. (It was supposed to be $280k – the extra $29k is possibly a special COVID supplement). Only $62k has been allocated to FM research. Why haven't Disability Adjusted Life Years been calculated for medical conditions in Canada to line up against CIHR allocations? Public money should be allocated to public priorities.

Speaking of the Canadian ME research network announced a year ago, they have had a bit of a bumpy start as they try to stretch their small funding as far as they can and as they deal with the disruption that came with COVID-19. .

# Pointers from your colleagues

Thanks to the individuals who drew these issues to our attention.

## Aging and dementia

In the future, ME, FM and MCS will be more understood and respected. In the meantime be aware that health providers may simply assume that cognitive difficulties in older individuals are dementia without taking ME, FM or MCS into account. Here are two examples.

An older gentleman in hospital was assessed as having dementia . The family argued that this wasn't dementia but was instead a temporary bout of cognitive dysfunction related to MCS. The doctors stubbornly stuck to the dementia diagnosis for days. They only reconsidered when they noticed him reading and understanding the Economist magazine.

A women with ME/FM/MCS took her elderly mother to a dementia assessment. The mother was told the name of three items. After having an unrelated discussion, the mother was asked to recall the three items, which she couldn't. The daughter casually commented that she couldn't recall the items either, and the assessor suggested that the daughter sign up for the dementia program.

## ME/FM and serious health issues

We have heard from several people recently with serious health issues (cancer, heart problems etc.). Their question was how this health issue interacts with their ME or FM. Maybe someday down the road there will be studies into the questions, but for now we suggest concentrating on the health issue that needs the most attention.

## Powdered meal replacement

Someone told us that the easiest way to prepare and consume meal replacement was to use a baby bottle with a liner. There are two advantages. Firstly, you can shake the bottle thoroughly so the powder dissolves. Secondly, you just throw out the liner so you just have the nipple to clean. The liner may qualify for recycling.

## Screening questions for Covid

Some screening questions for Covid-19 ask if you have fatigue or breathing difficulties. These symptoms of course exist if you have ME, FM or asthma. The question should ask whether you have these symptoms not related to a pre-existing condition.

## Milk Intolerance

The writer developed a milk intolerance. She found that any use of ordinary cows milk, or cheese made from such milk, resulted in worsening of her symptoms. Lactose free milk was no better.  But she could tolerate goat milk products as well as french cheeses. She speculates that the problem might result from cows milk with casein A1. Cattle with this milk protein is prevalent in northern Europe, UK, and North America. But in the south of France, Eastern Europe, and Asia cows milk has casein A2, which for her appears to be better tolerated and less likely to trigger inflammation. She also observed that milk products show up in a number of processed foods.

## Toothbrushes

It was reported that an electric toothbrush is easier to use than a manual toothbrush because the electric toothbrush does some of the motion for you.

## Voting

If an election is called in your jurisdiction and you are concerned about going to the polls, check out the different ways to vote. Voting by mail is offered in many places. B.C. even has an option of voting by telephone in special circumstances.  .

## Speech From the Throne

The speech from the Throne is the government's opportunity to announce its priorities. There were several items in the September 23 speech that should be of interest to people in the ME/FM community including the following statement:

*COVID-19 has disproportionately affected Canadians with disabilities, and highlighted long-standing challenges. The Government will bring forward a Disability Inclusion Plan, which will have:*

- *A new Canadian Disability Benefit modelled after the Guaranteed Income Supplement for seniors;*
- *A robust employment strategy for Canadians with disabilities;*
- *And a better process to determine eligibility for Government disability programs and benefits.*

Other topics in the Speech included dealing with the opioid epidemic, homelessness and food insecurity.

One topic not mentioned in the Speech was the long-term effects of COVID.

http://mefmaction.com

http://www.facebook.com/MEFMActionNetwork

NATIONAL
ME/FM
ACTION NETWORK
SINCE 1993

# MEMBERSHIP APPLICATION or RENEWAL FORM

## NEW MEMBERSHIP or RENEWAL fees

**ANNUAL MEMBERSHIP FEE :**
$30.00 per year including quarterly newsletter Quest

**IN ADDITION**, I would like to donate *$______________
to help with the many projects of the National ME/FM Action Network.
**Tax Receipt issued for all donations*

## TOTAL PAYMENT:

$_________________________

## PAYMENT OPTIONS

☐ Cheque
*Please make Cheque Payable to the:*
NATIONAL ME/FM ACTION NETWORK

☐ VISA

☐ Master Card

☐ Other ___________________

Card Number:

__________________________

Expiry Date:

month ______ year ________

CVV________ (3 digit code on back of card)

Name on Card:

__________________________

Signature:

__________________________

*For online application and renewals goto to MEFMaction.com*

Date: _____________________

Name / Organization

__________________________________________________

Contact Name ____________________________________

Address _________________________________________

_________________________________________

City _________________________________________

Province/State ___________Postal Code/Zip ___________

Country _________________________________________

Email _________________________________________

Phone _________________________________________

Website _________________________________________

☐ Please send news updates to my email address
☐ **Do not** send news updates to my email address

______________________________________

☐ Please send an electronic version of the Quest newsletter
☐ Please send the Quest newsletter to my mailing address

## *MAIL FORM & PAYMENT TO:*

**NATIONAL ME/FM ACTION NETWORK**
**512-33 Banner Road**
**Nepean, ON K2H 8V7**

## THANK YOU FOR YOUR SUPPORT!

*CREDIT CARD TRANSACTIONS CAN BE FAXED TO 613-829-8518*