NATIONAL ME/FM ACTION NETWORK

Quest Newsletter

www.mefmaction.com Quest 119, Summer 2019 mefminfo@mefmaction.com

Speaking up and Being Heard

As I neared the end of putting together this newsletter, I realized that there was an underlying theme – Speaking up and Being heard.

May 12th ME/FM Awareness Day is a wonderful opportunity to speak up. Activities take place in Canada and around the world ranging from proclamations to lighting of landmarks to public events to on-line events. Thanks to everyone who participated!

Awareness events do make a difference. There are many examples but let me mention two:

- MEAO holds an annual awareness event at the Ontario legislature (Queen's Park) to draw ME, FM and MCS to the attention of Ontario MPP's in a non-partisan way. MEAO has been pressing for the public release of the Final Report of the Ontario Task Force on Environmental Health which was submitted to the Minister in December or January. The report was released on the day of the Queen's Park event, certainly suggesting that the event triggered the report's release.
- US ME organizations hold an annual Capital Hill event in May, meaning that people come from across the US to meet with Congressmen and Senators. Several weeks later, the US Senate passed a resolution recognizing ME and the need for research and awareness. This resolution will reverberate across the US and into Canada.

Many people have spoken up about the lack of research funding provided by the Canadian government's health research funding agency CIHR. This message has been heard. In April, CIHR announced a targeted competition for a ME research network. A group came together and has made a submission. The research network will focus on the etiology and pathophysiology of ME. The results of the competition are expected in late August. If the submission scores enough points to receive funding, we will launch the network. If the submission does not score enough points to receive funding, we will carefully assess what to do next. Either way, we are well aware that the amount CIHR is currently offering ($355k/year for 5 years) is far less than equitable funding.

Last winter, many people spoke up, sending messages to the Ministers of Health and Finance and to local MP's asking for recognition of ME and FM in the federal budget. Despite the messages, there was no mention of ME or FM in the federal budget released in March. It was ambitious to think it could happen, but the absence of ME and FM from the budget was still a disappointment. The Network has written the Minister of Health expressing this disappointment, but also pointing out ways that the needs of the ME/FM community can be included in initiatives that are underway. We do know that ME is now on the Minister's radar screen because she talked about it at a town-hall meeting in Toronto. Your messages have been heard.

Another disappointment was to learn that the Government of Canada organized a national disability summit and did not invite the Network. We cannot accept that this was an innocent oversight. The Network qualified as a national disability organization, we let officials know when we were left out of a consultation leading up to the introduction of the Accessibility Act and we let officials know when we were not invited to the Minister's annual reception in December 2018. The purpose of the summit was to plan implement the new Accessibility legislation. We want your voices to be heard as that work proceeds.

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Joyce George

It is with sadness that we pass on word that Joyce George, a former director of the National ME/FM Action Network, passed away in March in Battleford Saskatchewan two days before her 89th birthday. Joyce was a vivacious and caring person who threw herself into family and outside activities.

One of her major activities was working on behalf of people with fibromyalgia which she had herself. She formed the Fibromyalgia Association of Saskatchewan. As president and editor of their newsletter she worked hard to build awareness, distribute information and provide support. She later joined the National ME/FM Action network and servered as a director for almost twenty years.

We would like to thank Joyce for her years of service and offer our sympathy to her four children and and their families.

Left Out of the Budget

Email from the National ME/FM Action Network to the Office of the Minister of Health: April 18, 2019

There is a Myalgic Encephalomyelitis/Fibromyalgia crisis in Canada. Unmet health care needs, unmet home care needs, social isolation, food insecurity, poverty, suicidal thoughts...

ME and FM could have been specifically addressed in the 2019-20 federal budget documents. That did not happen.

CIHR could have offered an aggressive approach to developing ME and FM research. That did not happen.

The Minister is now paying attention. Please look at a video taken at a town hall meeting on health care in Toronto last Sunday. The video starts with a statement by Scott Simpson of Millions Missing Canada which advocates for ME research funding and treatment access. Mr Simpson was one of several speakers who raised ME issues at the town hall meeting. At the 2 minute mark, the Minister acknowledges that ME is a concern and asks for a meeting in Ottawa to learn more about ME. *https://www.facebook.com/MillionsMissingCanada/videos/403798790452868/*

Here are some suggestions for moving forward that can be done very quickly while longer-term strategies are being developed.

- Hold the meeting that the Minister refers to in her town hall statement as soon as possible.
- Request public servants to brief you on ME and FM issues. Currently, the public service pays scant attention to ME or FM and, as a result, the Minister is not being adequately briefed and the community feels ignored and frustrated.
- Follow through on the Minister sponsored round-table which was proposed at our meeting of February 4, 2019.
- Set up the task force that Mr Simpson proposed at the town hall meeting.
- Introduce the ME/FM perspective into current health initiatives.

Here are some health initiatives identified in budget documents that could and should be expanded to incorporate ME and FM perspectives:

Food insecurity: According to the Canadian Community Health Survey 2015-16, 11% of the approximately half million Canadians with severe household food insecurity had a diagnosis of Chronic Fatigue Syndrome (the term used in the survey), FM or both. That jumped to 18% when Multiple Chemical Sensitivities was included. People with ME, FM and MCS deal with limited funds to buy food, limited energy to purchase and prepare food, and food sensitivities. These topics are important to food security discussions.

Suicide prevention: According to the CCHS 2014, 9% of the almost three quarters of a million people who said that they had seriously considered suicide in the past year reported a diagnosis of CFS, FM or both. Many volunteers in our community are drawn into discussions about suicide and Medical Assistance in Dying. We need support and our contribution to suicide prevention needs to be recognized. Stanford University will be hosting a webinar on suicide and ME on April 30, 2019 which could provide an introduction for Canadian officials.

Chronic Pain: According to the CCHS 2014, 21% of Canadians who reported that pain prevents most activities also reported a diagnosis of CFS, FM or both. Not only is the ME/FM community a stakeholder in chronic pain discussions, it is a stakeholder in related discussions around opioids and cannabis.

Physical Activity: The Public Health Agency of Canada wants to encourage less active Canadians to become more active. People with ME and FM have reduced physical (and mental) activity levels. They would fall into the less active group and would therefore be encouraged to do more activities. Being more physically active could cause harm to their health. Encouraging them to be more active when they can't would bring shame and guilt. The messaging around physical activity MUST recognize that health factors have to be taken into account when establishing activity levels and MUST not punish people for having reduced activity levels.

Home care: The budget documents targets a reduction in unmet home care needs. CCHS consistently shows that people with CFS and FM have high rates of unmet home care needs, indicating systemic bias that needs to be explored and addressed.

The ME/FM crisis in Canada has gone on for far too long. Please let us know what action will be taken to address the crisis and how the National ME/FM Action Network can be of assistance.

Postscript: The Minister's office has not responded to this email. We contacted the secretariat of the chronic pain task force directly and have had a discussion with them.

Chronic Pain Task Force

In the latest budget, the government set up a Task Force to look at chronic pain. Over the next 3 years, the Task Force will assess how chronic pain is currently dealt with in Canada, consult on how to improve the situation, and work with governments, health professionals and other stakeholders to share best practices.

The Network sent around an email asking people what issues or best practices should be brought forward. People gave very thoughtful replies. They talked about the need for early and good diagnosis. They talked about the need for health providers to listen and believe and have courage. They talked about treatments, both pharmaceutical and non-pharmaceutical. For pharmaceuticals, cost can be an issue and so can side effects. For non-pharmaceutical treatments, costs and access are issues. People talked about the stigma and blaming that comes with chronic pain. Special populations were noted – young people with pain, seniors with pain, homebound people with pain. The need to recognize caregivers was raised.

The Network had a phone conversation with an official at the secretariat to outline the range of interests of the ME/FM community. She advised us that there will be regional meetings across the country sometime next winter and spring (2019-2020). These meeting will provide members of the public with the opportunity to provide direct input. We will keep you posted.

Left Out of Disability

Correspondence between the National ME/FM Action Network and the Office of the Minister responsible for persons with disabilities. We saw an article in a newspaper that a National Disability Summit was underway in Ottawa just as the two-day summit was wrapping up.

From the National ME/FM Action Network: May 10, 2019

We understand that a National Disability Summit is being held in Ottawa. Could you tell us if people disabled by ME, FM or MCS are represented at the summit? This group is often forgotten.

From the Office of the Minister: May 10, 2019

Its great to hear from you.

The summit was just for disability organizations. Not the disabled public. The summit was by invitation only. You should have received an invitation. My apologies if you did not.

From the National ME/FM Action Network: May 13, 2019

This is the third time recently that the National ME/FM Action Network has been excluded from a major national disability activity, even though we have been recognized as a national disability organization. This should never have happened even once.

The National Disability Summit would have been an opportunity for us to develop partnerships with other organizations to tackle accessibility issues. We were not given this opportunity.

We don’t want to have to tell the ME/FM community that they are sitting ignored on the sidelines.

Steps need to be taken to fix this immediately. Please let us know what will be done to correct this situation.

From the Office of the Minister: May 14, 2019

I want to apologize for the miss in terms of your inclusion in the summit last week. I agree that it shouldn’t have happened, and I have resent your contact details to our officials who manage the stakeholder lists. It certainly wasn’t intentional, but I can appreciate your frustration.

Given that we have National Access Ability Week coming up at the end of the month, I wanted to make sure you had

the link to the main website that includes info for stakeholders:
https://www.canada.ca/en/employment-social-development/campaigns/national-accessability-week/

From the National ME/FM Action Network: May 15, 2019

Thank you for reminding us that AccessAbility Week is coming soon.

AccessAbility Week provides a golden opportunity for the Minister to reflect publicly on the breadth and complexity of disability. As the UNCRPD says, "disability is an evolving concept". That means that the old stereotypes around who is disabled need to be questioned.

When my sister was young, the challenges that comes with autism were not recognized as disability issues. I saw what she and our family went through contending with the autism itself but also with the lack of supports and protections that come with recognition. Today, the concept of disability has evolved to include autism. As a result, many more supports and protections are available to people with autism, allowing them to participate more fully in society.

Today, the challenges that come with ME and FM are not recognized as disability issues. We at the National ME/FM Action Network see, not only in our own families but also in the broader ME/FM community, the disabling effects of ME and FM plus the harm and isolation that result from the lack of supports and protections that would come with recognition. The concept of disability needs to evolve once again.

It is important for the public to be aware of the full scope of disability because the interactions between the members of the public and individuals with disabilities contribute to societal inclusion.

It is now also very evident that public servants and the disability community itself need to consider the scope of disability. The absence of representation of hundreds of thousands of Canadians with disabilities at the National Disability Summit should not have gone unnoticed and unchallenged.

We hope that the Minister will use AccessAbility Week as an opportunity to open up discussion about the scope of disability. It's an important part of changing the way we think, talk and act about accessibility and inclusion*!*

Postscript: There has been no follow-up and we saw no public mention of the scope of disability during Access Ability Week. This issue still has to be resolved.

Re: Health Research Priorities - Request for Meeting

Correspondence between the National ME/FM Action Network and the Canadian Institutes of Health research.

From the National ME/FM Action Network, May 31, 2019

The National ME/FM Action Network is pleased that CIHR has opened a conversation about how CIHR can contribute to the goal of ensuring that Canadians are as healthy as possible in the next 10, 20, and 30 years. As part of this conversation, CIHR is conducting a survey and is holding meetings with stakeholders. We are requesting a meeting.

The National ME/FM Action Network can bring a special perspective to this conversation. We have been working on behalf of Canadians with Myalgic Encephalomyelitis (ME) and/or Fibromyalgia (FM) for over 25 years. Current estimates suggest that nearly one million Canadians are affected by one or both of these conditions. These are conditions that have been subject to stigma and misinformation. They have little clinical, social or research infrastructure. Most of the people affected are women of working age, a group that society expects to be supporting others and not needing support themselves. The lack of research has serious consequences not only for patients but also for their families, for the economy and for society. Despite the public need for research, CIHR has provided very little funding in this area.

We have identified five questions around funding allocation and priorities that we ask CIHR to consider in developing its strategic plan.

1. How can CIHR ensure that research funding allocation is not influenced by stigma?
2. How can CIHR ensure that research funding allocation is not biased by gender or age?
3. What does scientific excellence look like in an emerging area?
4. What is CIHR's role in combating health misinformation?
5. How can CIHR ensure that the public money directed to health research addresses public needs?

It is hard to do justice to these issues using the on-line survey. We think that a stakeholder meeting would be a better way to explore them. .

We look forward to sitting down together to talk about addressing health research priorities.

From CIHR, June 10, 2019

Thank you for your interest in the CIHR Strategic Plan. We are pleased to note that many of the areas highlighted in your document align closely with the priorities highlighted for discussion to inform CIHR's next Strategic Plan. While an in-person consultation session will not be possible, we encourage you to kindly submit these comments across the relevant survey instruments within the www.letstalk-cihr.ca website.

Postscript: The Network is considering how to proceed. Note that the Network also made a submission to the consultation about research and development statistics in Canada. We noted that the proposal to describe the type of research being done was far better developed than the proposal to describe the purpose of the research, suggesting that officials have difficulty articulating the purpose of investing in research and development.

Functional Assessments

The National Academy of Medicine has released a report on assessing functionality for employment in adults. It was requested by the the US organizations roughly equivalent to the Canadian CPP-Disability program and the provincial/territorial disability programs.

The report's conclusion reads as follows:

Determinations about a person's ability to perform and sustain full-time work are more complicated than can be indicated by an assessment of individual body structures, functions, or impairments. Functional assessments provide important information for disability determinations, and many validated instruments are available to assess work-related physical and mental functions. Since no single tool or source is likely to provide all of the information needed to evaluate an individual's ability to work, it is important to combine and evaluate the consistency of information from different sources when evaluating an individual's ability to work.

Along the way, the report says:

For instance, someone who is capable of performing a set of activities separately may not be able to coordinate and sequence them effectively. A person may be able to perform work tasks successfully during a single assessment but be unable to perform those tasks on a day-to-day basis.

Factors related to a health condition (e.g., side effects of a medication) or work environment (e.g., noise levels, temperatures) may limit the ability to participate in work on a regular and continuing basis, even if the person is able to perform each of the tasks associated with a job. The controlled, quiet testing environment may also differ from the actual work environment in a way that may negatively affect the ability to perform the work tasks. Moreover, the capacity to perform work requirements successfully in one specific work environment does not necessarily indicate the ability to perform the same work in a different setting.

The concept that a person's ability to perform activities in one environment does not guarantee his/her ability to work in an employment environment could be very useful to anyone with ME or FM applying for disability supports.

To read the report, please visit *nationalacademies.org/FunctionalAssessment*

Stairlifts

Sent by a person with ME whose elderly mother moved in with her.

One of the home modifications I installed was a stair lift. My Mom was having difficulty climbing the stairs. I was surprised at how (relatively) reasonable a basic stair lift is!! As I'm sure you can understand, there have been many days when I've also had difficulty managing the stairs given my ME. I am using the stair lift all the time and its made a HUGE difference for me!!! We are even using it to send the laundry up and down! It was only $3,200 (no tax on this item). I had been expecting $15,000 or more before looking into it, so was very pleasantly surprised! My staircase is one straight line. They are more expensive if your staircase is curved or if you have landings/turns. But, please let anyone struggling know that this may be a great option for them. If anyone wants the contact information for the company I used in Toronto, I'd be happy to provide it. The service was exceptional!!!

“The Blues” Spiral

by Liana Brittain

This article was written by a person homebound with chronic pain to share some of her experiences with others in the same situation. We can all learn from her wisdom.

Many of us are facing a major crisis. The medical system and the pharmaceutical industry have developed treatments that allow us to live longer. While this has extended our lives, it has not addressed our quality of daily living. In fact, it has doomed some of us to years of suffering and agony, ultimately leading to a miserable quality of life. Now, they appear to be abandoning us when we need them the most by cutting back availability of treatments, medications and supports!

Their actions rob us of alternatives. They take away our choices and leave us at the mercy of a system that is ill equipped to meet our needs. Our bodies have become fragile. They are riddled with multiple comorbid conditions which are robbing us of the life we once knew and cherished. We’re getting hit from both sides - the inability of our bodies to function properly and the withdrawal of critical services from those that should be there to help and support us.

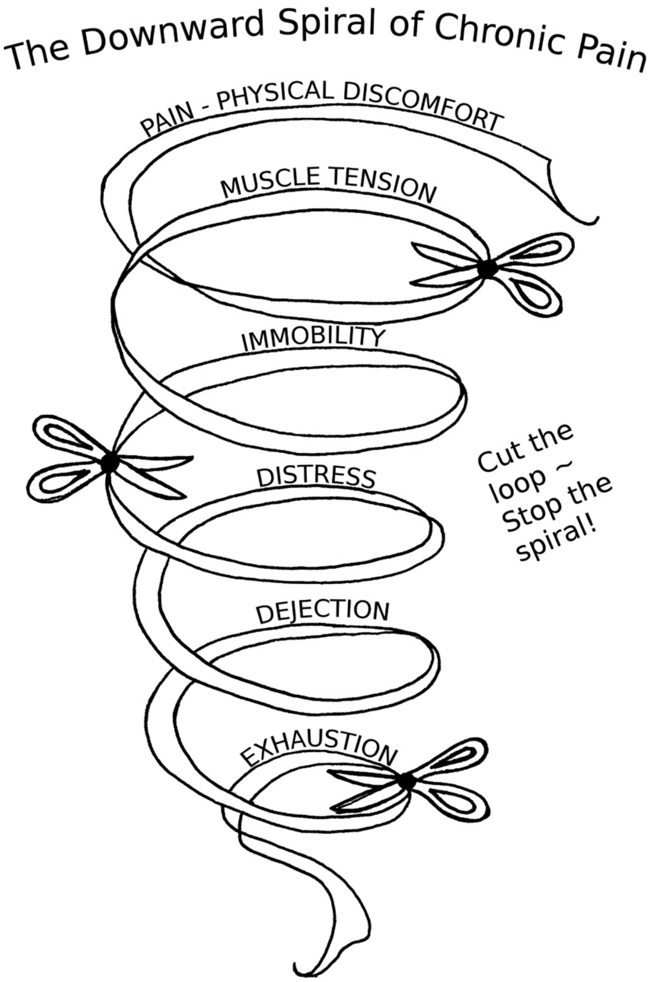
So many times, I have had medical specialists turn to me and tell me that science hasn’t yet caught up to the physical challenges I’m facing. My body has become so hypersensitive that it rejects the alternatives that the medical system can provide for me at this time.

Prolonged, excruciating, uncontrollable, mind numbing pain - I feel abandoned. Useless, unlovable, a burden, without hope, I am dragged downward into the pit of despair. At my lowest point, I wrote the poem on the following page.

So, now, trapped in this destructive mental space, I face the fight of my life. What alternatives are left for me in this situation?!

Just like the poem says: reach out to anyone, anywhere. Find what works for you. Cut the loop. Break the downward cycle of chronic pain.

It’s easy to say reach out, but it’s not as easy to do. So much depends on the individual’s resources – physical, mental and monetary. I watched the documentary done by Lady Gaga about her battle with Fibromyalgia and chronic pain created by Netflix – “Gaga: Five Foot Two”. While I applauded her courage and candor in sharing this very private part of her life, I couldn’t help feeling envious of the resources at her fingertips that were provided by her wealth. My quality of life would improve dramatically if I had a private massage therapist, a therapeutic pool, someone to do all my cooking and cleaning just for a start! However, I have to live in my world, alone, in isolation, on a pension. My realities are vastly different.



Having said that, there are things I can do to improve my quality of life as a shut-in with meager financial resources. Life in chronic pain takes courage and strength. Sometimes, it requires every ounce of my being to find those qualities.

The Pit

the darkest web
of deepest night
binds me helpless,
holds me fast
within the pit.

my heart is cold,
shrivelled,
dry as dust,
aching with
the crushing
need which burns
my soul
to blackened ash.

i scream in anguish,
paralysed with
fear and doubt.
my body,
racked with
heaving sobs,
aches beyond
the ragged edge
of my reality

lost in the
roiling ooze
and slime
of bleak despair,
my fetal essence
curls within itself
seeking shelter
from the brutal lash
that rakes it raw.

imprisoned here,
shackled by
my wretched thoughts,
i know the pain
futility inflicts
upon the dying mind.
i claw and scratch
to find my way...
there is no light,

only the velvet glove
which smothers
as i fight to breathe.

help me!
i plead with
acid tears,
into the dark morass
of nothingness...
crumpled,
laying deep
within her womb,
my fingers
reach in silent prayers
like the spectral bones
of those long dead,
searching for a loving hand
to touch my soul
and pull me free.

> *"No Matter how bad things get, something good is out there just over the horizon"*
>
> *The Green Hornet*

The first thing I have done to break my downward spiral is to cultivate a new relationship with myself. Like a garden, this cultivation takes time, patience and nurturing. I have come to believe that I am worth the effort. Just because my body is struggling to cope with these physical realities, doesn't mean that the other parts of me should be abandoned. My life no longer resembles the one I had before. Everything is strange, constantly changing and not easy to understand or accept.

In recognition of that, I turn to a very powerful tool - distraction. It's just one of the strategies and techniques I've learned over the past 22 years as I've battled Fibromyalgia, multiple other forms of arthritis and numerous comorbid conditions, all of which generate chronic pain.

> *It's a widely accepted fact that the human brain can only truly focus on one thing at a time. When it is distracted, pain fades into the background of our consciousness.*

Distraction can literally be anything that engages the mind completely, allowing you to take a rest from the pain. Here are just a few…

1. Breathing: I'm not talking about the unconscious type of breathing that we do without thinking. When I say breathing, I'm talking about a focused, deliberate type of breathing that can flood our bodies with oxygen and help ease our pain, tension and anxiety. There are many different approaches used to enhance breathing such as the techniques offered by Yoga. This is called diaphragmatic breathing. It can be done anywhere, anytime without anyone else realizing you're managing your pain – in a meeting, in a car, waiting in the doctor's office. You can find videos and directions on the internet by doing a search.
2. Meditation: I'm self taught and I use this strategy to manage pain break-throughs several times a day. There's always that awkward stretch between when a dose of pain killers wears off and when the next dose kicks in. I find meditation a very helpful tool to manage that problem. There are two basic types of meditation – one done with your eyes closed and the other done with your eyes open. Some examples of the latter are - allowing your mind to wander and become still as you gaze into the flames of a fire, watching the gentle movements of a water feature or fountain

or watching the bubbling and fish in an aquarium, to name but a few. Videos about both open and closed eye meditations can be found by doing a search on the internet.

3. Music: Listening to music can set the mood or tone in any environment. That's why they play it in elevators! It helps to calm and sooth people who might find the experience distressing – medical waiting rooms, technical help calls and being put on hold during service calls are all examples used in our daily environments. I have music playing quietly in the background all day and night. It helps me prevent tensing up as I deal with everyday tasks that generate pain. It also helps me relax and stay relaxed as I go to sleep. If you can sing so much the better! You get the added benefit of the oxygen from the deep breathing as you belt out your favourite tune. Fibromyalgia has done permanent damage to my vocal cords, so my days of singing with a band or in a choir are over, but that doesn't stop me from indulging myself when no one's around and the music stirs me to join in on an old favourite. If you play an instrument, you have an added bonus!
4. Laughter: Dr. Patch Adams proved that there is tremendous power and healing in the simple act of laughing. Watch a movie, listen to a comedian or catch that crazy sitcom. Do whatever it takes to become so absorbed in the moment that you laugh out loud. It will release tension and endorphins to sooth your brain and body.
5. Arts, crafts and hobbies: Whether you truly have a talent, or you just enjoy dabbling, do something which distracts your mind from the pain and brings you pleasure. If you can do it in a group, so much the better because you have added the element of socialization and camaraderie. You can paint, draw, colour from a colouring book, knit, crochet, scrapbook, garden, bird watch, collect stamps, research your family history through genealogy, make jewelry, decorate cakes, or anything else that appeals to you – the list is absolutely limitless.
6. Keep Moving: It's so tempting for me to sit very still and hope that the pain will pass soon, but in reality, that approach causes me more harm than good. No matter what the cost, I must stay active physically. I use a Fitbit to track the number of steps I take every day. I push myself, on the bad days, to hit a minimum number of steps. Every week I check my charted progress to make sure I'm not sitting too much. Some days I have to truly fight my negative self to just get up and walk to the kitchen, but I know how important it is and what will happen if I don't! It's a challenge every day, but somehow, somewhere I find the strength to keep going. For those of you who still have a level of mobility, your options are much greater than mine. Just choose something that works for you but be sure to check with your health care provider to make sure it's safe for you.

I have shared six forms of distraction with you. This is just the tip of the iceberg. I haven't mentioned opportunities to combine a variety of these distractions with social interaction. If you have the capacity to spend time with others, it will greatly enhance the impact of the distraction on your pain management. I'm a shut-in and so that's more difficult, but I still make the effort to interact with others by inviting people over for a visit or video conferencing and phone calls.

Above all else, be patient with yourself as you develop a new relationship with you. Tackling any new technique or skill takes time and practice. It will require two weeks of consistent daily effort before any strategy for pain management feels comfortable. In six to eight weeks of constant and persistent use it will become a part of the natural rhythm of your life. Only try one new thing at a time so as not to get overwhelmed, which will of course, cause you to give up and go back to what's old, comfortable and familiar.

Keep reaching out. It may seem, in the moment, that no one cares… no one is listening… but there are those of us who do care, and we are listening.

* * *

"You are braver than you believe, stronger than you seem, and smarter than you think"

Spoken by Christopher Robin to his friend, Pooh Bear, in one of the delightful children's stories written by A. A. Milne.

* * *

From the New PEI Association

Dolores Griffin

I am excited to officially announce the name of our provincial ME/FM chapter which is "ME/FM Coalition of Prince Edward Island". Formed in 2019, the Coalition is a non-profit organization consisting of volunteers, dedicated to promoting awareness of ME/FM issues on P.E.I. through advocacy and the organization of awareness events.

Vision Statement

One day, ME and FM will be recognized and understood by all as the physical debilitating chronic illnesses they are, and be a funding priority for both research and patient services.

Mission Statement

To increase awareness of ME and FM on P.E.I. through information and educational activities targeted to patients, the general public, health professionals and organizations, educators, and government.

One of the priorities this year was to improve the quality of our promotional material and to increase visibility. To this end, a poster (shown at right) and banner were designed. I am indebted to Murphys Pharmacies who have been a loyal supporter of our PEI awareness activities over the years and to their partner Revolution Media for the design work, as well as to Red Shores Racetrack and Casino for the printing and banner hardware.

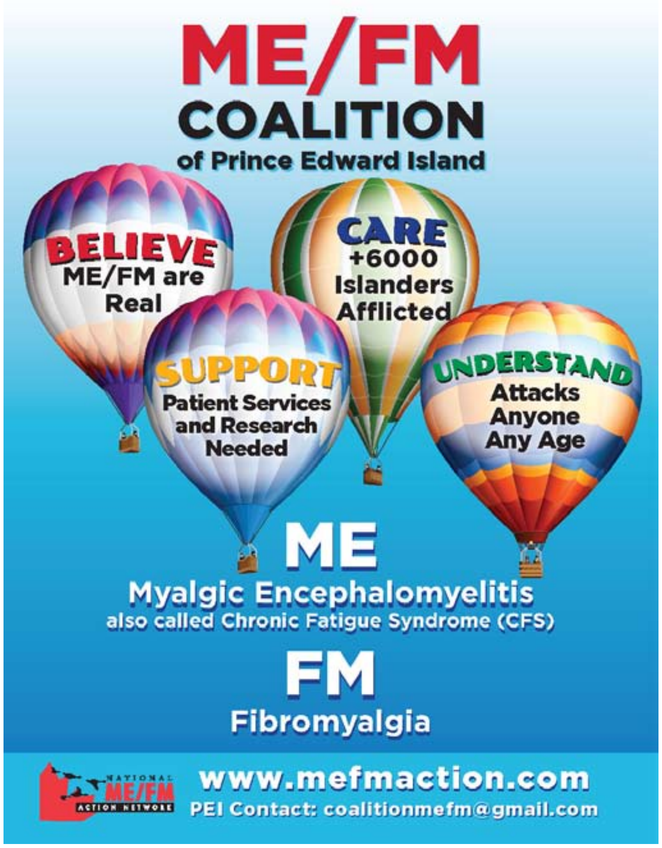
Activities for May 12 Awareness Day included:

- Lighting of the City of Charlottetown bell tower in blue and purple lights from May 9-13 and press release in local newspaper and statement by the Major to City Council.
- Notice re: May 12 Awareness Day on the City of Charlottetown, Town of Cornwall and Town of Stratford websites and on Eastlink Community channel notice board

The main awareness event for 2019 will be an evening at the races sponsored by Red Shores Racetrack and Casino. There will be an ME/FM pace on the evening of August 3rd with a cooler presented to the driver of the winning horse at trackside. There will also be an information booth set up inside the casino lobby and the unveiling of the new ME/FM banner for PEI.

Other awareness activities include:

- An online ME/FM trivia contest (participants will go to the ME/FM Action Network website to find the answers to questions to win a prize valued at $50) Just send an email to *coalitionmefm@gmail.com* for contest details
- Call to local artists to design a provincial ME/FM logo



Disability Tax Credit

The Minister of National Revenue appointed a committee in late 2017 to provide advice on the Disability Tax Credit. The committee's first report was released in May 2019. It will be discussed in the next newsletter.

https://www.canada.ca/en/revenue-agency/corporate/about-canada-revenue-agency-cra/disability-advisory-committee.html (English)

https://www.canada.ca/fr/agence-revenu/organisation/a-propos-agence-revenu-canada-arc/comite-consultatif-personnes-handicapees.html (French)

Ontario Task Force report

Several years ago, the Ontario Liberal government appointed a Task Force on Environmental Health to look at services for ME, FM and MCS in Ontario and report back by January 2019. The Task Force produced an interim report in 2017. Their activities were suspended when the Ontario election was called in the spring of 2018. (This is standard for Minister-appointed committees.) The Task Force was restarted by the new provincial health minister in the late autumn of 2018. It submitted its final report to the new minister before its mandate ran out. The report was released on May 15, 2019, the day of MEAO's Queen's Park event.

A back-bench member of the governing party made the following statement in the Legislature: "... Today I want to reiterate our government's commitment to work with MEAO to ensure no Ontarians feel like their government isn't taking their medical issues seriously. To that end, our government today released the final report of the Task Force on Environmental Health. We will work to shine a light on these challenges and advance real, meaningful solutions as part of our work to build a health care system that truly works for the people of Ontario and is centred around the patient..."

The main section of the report focuses on the recommendations. The recommendations are a very good list of the challenges that will need to be worked through - raise awareness, develop clinical tools, support a cadre of health care providers, and so on. The report recommends that the most severe cases be seen at a provincial centre of excellence. For everyone else, the report recommends that they have access to interdisciplinary primary care teams with a special interest in ME/CFS, FM and ES/MCS. These teams are expected to have the expertise to diagnose these conditions and provide integrated multidisciplinary treatment and management plans. Before being designated as a primary care site, a team would be called upon to demonstrate clinical understanding of the three conditions, access to an interdisciplinary care team, environmentally safe clinic space and the ability to deliver deliver care by telemedicine or equivalent.

There are eight appendices to the report. The first three (list of members, statistics from the Canadian Community Health Survey) are straightforward.

Appendix D lists the recommendations from the interim report and the follow-up that has occurred. The relative lack of action combined with the delayed and quiet release of the final report tell us that, while patients see a crisis, the Ontario government still needs to be convinced that action is needed.

Appendix E calculates the costs of ME/FM health services using data from provincial billing systems. Appendix F summarizes conversations with 15 physicians about their views on ME/FM/MCS. Appendix G proposes diagnostic criteria for ME, FM and MCS. Appendix H summarizes the experiences of the specialty clinics in Vancouver and Halifax (but not Toronto). These appendices could leave a reader with the impressions that patients are costly and uncoopoerative, that case definitions can be developed on the fly and don't need validating, and that clinics are primarily to support patient self-management.

The impressions that were created by the last four appendices are not challenged in the main report. Please remember that the Task Force had very little time to review the appendices when the Task Force was reinstated in the late autumn.

The ME/FM community should be aware that the report's recommendations could be interpreted to create a system of health clinics which lacks a theoretical foundation and is simply there to provide moral support to patients with complex but vague complaints. Patients want medical services - good, timely diagnosis (including recognition of overlapping and differential conditions), good medical advice, appropriate medical treatments, access to social supports, and ongoing monitoring.

As the report states, "[w]ith this proposed action plan, Ontario has the opportunity to become a global leader in the management of ME/CFS, FM and ES/MCS." This is indeed true. The challenges now are:

- to convince officials (in Ontario and across the country) that there is a major gap in services, and
- to ensure that the new services are medically substantive and not just token or generic.

As a final note, the services for young people are not considered in the report. This oversight needs to be addressed.

You can find the report here:
http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/default.aspx (English)

http://www.health.gov.on.ca/fr/common/ministry/publications/reports/environmental_health_2018/default.aspx (French)

We welcome your comments and questions.

Issues around diagnosis

We are calling for better diagnosis of ME and FM.

Many people have experienced delays in diagnosis, leaving them without proper guidance on how to manage their health. But the problems of diagnosis go beyond that. Even if people meet the criteria for ME or FM, it is very important to consider the possibility of co-morbidities and differential/exclusionary diagnoses, and to do this on an ongoing basis.

Cort Johnson of Health Rising reported on a meeting with Dr Nath of the US National Institutes of Health. Dr Nath is leading a study of ME patients. According to Dr Nath, of the first 19 ME patients who were intensively investigated, 6 were found to have diseases that excluded them from the study.

Jennifer Brea, the producer of the documentary Unrest and the founder of #MEAction and Millions Missing, has announced that she had surgery for Craniocervical Instability and her ME symptoms have disappeared. These two example emphasize how important it is to look for alternative diagnoses.

The Network was talking to someone with ME and FM. She shared with us that several doctors overlooked warning signs of a different serious health issue for several years, brushing off the symptoms as ME or FM. This emphasizes the importance of checking for comordibities and checking on an ongoing basis.

The Lady with the Lamp

May 12th was chosen as International ME/FM Awareness Day because it is Florence Nightingale’s date of birth.

Florence Nightingale was born on May 12, 1820 in Florence Italy and died on August 13, 1910. She was a British nurse, statistician, and social reformer who was put in charge of nursing British and allied soldiers in Turkey during the Crimean War. Nightingale wandered the wards at night with a lamp and became known as The Lady with the Lamp as she provided support and personal care to the wounded soldiers.

In May 1855 Florence Nightingale began the first of several excursions to Crimea. However, shortly after arriving, she fell ill and experienced a slow recovery. It was thought she had brucellosis. She experienced some recovery but suffered the lingering effects for 25 years, confining her mostly to her bed because of severe chronic pain as well as suffering from exhaustion.

Florence Nightingale’s greatest achievements are centred around creating social reform in health care and nursing. Due to Nightingale’s statistical data and analysis, a Royal Commission was established on her findings which resulted in marked reform in the military medical and purveyance systems. Her Notes on Nursing: What It Is and What It Is Not has been continuously published since 1859.

Lydia

(Lydia Neilson and the late Tom Hennessy started May 12th International Awareness Day back in the early 1990’s).

Federal Election

The next federal election is expected in October 2019. While the campaign is not officially underway, candidates will be knocking on doors over the summer. This is an opportunity to speak up about the importance of addressing the shortage of research funding for ME and FM, the need for better recognition of ME and FM in the health system, and the need for better recognition of how disabling ME and FM can be. These are non-partisan public issues.

For those who are homebound, please remember that election officials can come to your home to register you, give you a ballot to fill in, and take the ballot back to the office to be counted. To take advantage of this option, contact the returning officer in your riding as soon as the election is announced.

Dr Luis Nacul

BC Women's hospital welcomes Dr. Luis Nacul as the new medical director and research director of the Complex Chronic Diseases Program (CCDP).

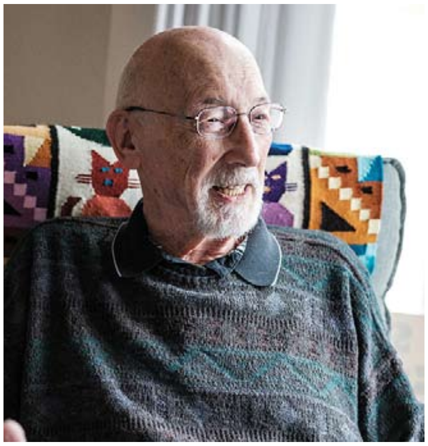
Dr. Nacul is an internationally renowned leading clinician and researcher in his field with a broad understanding of complex chronic diseases treated at CCDP from medical, health services and research perspectives.

"It is a privilege for me to join such a dedicated team at one of a few centres in the world that specifically treats complex chronic diseases," says Dr. Nacul. "I look forward to starting my new role and the opportunity to work in a collaborative environment that involves patient and community groups that are most affected."

One of the challenges in treating complex chronic diseases is that their causes are unclear. In his capacity as CCDP research director, Dr. Nacul will leverage an established clinical program to expand research into complex chronic diseases. This is an important gain for the program, as CCDP patients with myalgic encephalomyelitis /chronic fatigue syndrome (ME/CFS), fibromyalgia syndrome and symptoms attributed to chronic Lyme-like disease will be able to benefit directly from research discoveries.

Dr John Wodak

John Wodak of Edmonton is, with some reluctance, retiring a second time. His first retirement was from government. At that time, he started volunteering in the disability area. Over the last 20 years or so, John has helped individuals deal with their applications for disability supports at every stage from initial application to hearings. He has served for about 15 years on the CPP-Disability Roundtable, a federal government group that provides input into the CPP-D program. He was one of the authors of the Network's CPP-Disability Guide.



John has stepped down from the CPP-D Roundtable and he has told ME Edmonton that he is no longer taking new cases. The ME Society of Edmonton is desperately looking for cloning technology. John has indicated that he is still working on some ongoing cases and may be available to help with updates to the ME/FM CPP-Disability Guide. ME Edmonton held a special event in May to honour John.

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