NATIONAL ME/FM ACTION NETWORK
SINCE 1993

# Quest
## Newsletter

www.mefmaction.com
Quest 129, Summer 2021
mefminfo@mefmaction.com

## Introduction

Several members of the ME/FM community in BC were invited to speak to UBC health science students on Awareness Day. One of the speakers chose the topic of stigma. The speaker has given us permission to use the speech in this newsletter (see page 4).

Hopefully, ME/FM stigma will become an issue of the past. Stigma is about assigning responsibility for dealing with ME/FM to the individual, and avoiding assigning responsibility to the health and social systems. We are seeing signs that health system attitudes toward ME and FM are changing for the better. Factors leading to this attitude change are the seriousness of ME and FM which cannot be denied, the hard work of the ME/FM community and the emergence of long-Covid.

We see signs of the new positive attitude in a study done by the MEFM Society of BC. We see signs in a presentation made at the MEAO annual awareness day event. We also see these signs coming out of the US. We at the National ME/FM Action Network will be encouraging and supporting the health system as it moves forward.

While the health system is coming to recognize that it has to do things differently, it has not sorted out what it should be doing. This is where clinical diagnostic and treatment protocols become important. The health system is going to find good foundation documents for ME, not as good documents for FM, and serious gaps around MCS. This will take time to sort out. Therefore, it may be a while before patients notice changes in their interactions with health professionals. In the interim, the speech on stigma is very relevant.

## Updates

### US developments

There has been a lot of movement in the US since the publication of the IOM report Beyond Myalgic Encephalomyelitis in 2015. This report led both the Centers for Disease Control (CDC) and the National Institute of Health (NIH) to consider ME with much more respect. Long-Covid is providing support for the importance of looking at post-infectious conditions.

This spring, a bill was introduced in the US House of Representatives which, if approved, would allocate $30M each for research into the long-term symptoms of Covid, for research into the health care system’s response to long-Covid, and for education and dissemination of information with respect to long-term symptoms of Covid.

The last category lists, specifically,

- ME/CFS and FM,
- POTS and other forms of dysautonomia,
- autoimmune diseases associated with viral triggers,
- connective tissue diseases exacerbated or triggered by infections, and
- mast cell activation syndrome (MCAS).

This gives an indication that the health system could treat these conditions together in the future.

Another very important initiative in the US is the ME/CFS Clinicians Coalition. Around 20 top ME specialists have come together with the following goals:

- Improve clinical care for patients with ME/CFS by promoting and advancing best clinical practices and

## Contents

**Introduction** 1

**Updates** 1

by providing medical education and evidence-based recommendations

- Expand the pool of medical providers with strong expertise in ME/CFS
- Provide clinical insights to scientists to accelerate and promote advances in research

They have a website with valuable information on it: *https://mecfscliniciancoalition.org/*

### BC Developments

A study on the health care system was published by the ME/FM Society of BC. The study included some very interesting illustrations which the Society has given us permission to reprint. They are featured on pages 7-10 of this newsletter.

Going on separately in BC are discussions with the BC College of Physicians and Surgeons. The discussions are based on an individual's complaint against several physicians. Over 100 patients and caregivers sent supporting letters to the College, Human Rights Commission and provincial elected representatives describing the ignorance and stigma they encountered when turning to physicians for help with ME/FM.

### Ontario Developments

In December 2018, a Task Force appointed by Ontario's Minister of Health submitted recommendations to improve services for people with ME, FM and/or MCS. In 2020, the Minister asked Public Health Ontario (PHO) to advise her on how the recommendations would best be implemented. It makes perfect sense to assign responsibility to PHO because what is happening around ME, FM and MCS (unmet needs, poverty, isolation etc) constitutes a public health problem.

For a number of years, the Ontario ME Association MEAO has held an annual awareness event at Queen's Park. The 2021 event was held over Zoom and the featured speaker was the head of PHO.

The meeting was frustrating in one sense. The role of PHO is to advise the minister, not to announce what she might do. The speaker was therefore limited in what he could say. The challenge for the audience was to try to figure out what will be recommended and what might come to pass.

People came away with a certain optimism. PHO has explored the challenges of increasing services in Ontario. The MPP who assists the Minister of Health gave a recorded message expressing a desire to help. The health critic for the NDP and Liberal parties were in attendance. The speaker mentioned that PHO has found some willingness in the health system to deal with these issues. Long-Covid is drawing more attention to this area. And there is an Ontario election due around spring 2022 which means that the Minister will want to find action items.

Also occurring in Ontario this spring was a consultation by the College of Physicians and Surgeons of Ontario (CPSO) as they review their policy around Complementary and Alternative Medicine. CPSO wants to protect patients from inappropriate or unsubstantiated health practices. The problem for the ME/FM/MCS community is that clinical practices and procedures are not strongly established or supported by evidence. While this leaves patients open to inappropriate or unsubstantiated practices, it also means that clinicians who enter this area have to document and defend what they do and this leaves them open to disciplinary action. A big fear is that clinicians will avoid practicing in areas like ME, FM and MCS because of diagnostic and treatment uncertainties.

The solution is, of course, to have conversations around practices and procedures and to do the research necessary. That will take time, money and commitment. In the meantime, we hope that the CPSO will be sensitive to the vulnerable situation for both clients and clinicians in the ME/FM/MCS area.

It is our prediction that PHO's advice to the Minister will emphasize the importance of consolidating practices and procedures around ME, FM and MCS. This will benefit both patients and the clinicians who want to practice in this area. It is also our prediction that inter-provincial discussions will happen. As can be seen, the Ontario and BC health systems are facing the same issues. BC and Ontario will talk to each other, and other provinces will be very interested in their discussions.

## ICanCME Research Network

The Research Network has announced a grant competition for graduate students (the deadline has passed) and a grant competition for research projects (deadline July 15). You can read the details here:

*http://www.icancme.ca/page.asp?ID=143* (graduate students)

*http://www.icancme.ca/page.asp?ID=138* (research projects)

## Federal Chronic Pain Task Force

Several years ago, the federal government appointed a task force to explore issues around chronic pain. The final report of the task force was released this spring. It is a very, thorough, polished, high level report.

It is interesting to compare the chronic pain report with the report of the Ontario Task Force on Environmental Health of December 2019. The environmental health report was much more specific about what should be done. Nevertheless, it was not specific enough for the Ontario government to take action. The government turned it over to PHO to suggest an implementation plan.

The question is whether the Chronic Pain Task Force report is too high level. There are two things that make chronic pain different. The first is infrastructure. There is a Canadian Pain Society whose mission is to bring together scientists, educators, health care professionals, and patients to foster education and research on pain mechanisms and management and to improve access to high-quality care with the goal of preventing and treating pain more effectively. The second is government recognition and support. This includes the chronic pain research network, a research network that received $12M from CIHR over the past 5 years and the Chronic Pain Task Force which received government funding and had a government secretariat.

## Disability Advisory Committee

Several years ago, the federal government appointed a disability advisory committee reporting to the Minister of National Revenue. The Canada Revenue Agency is the department that administers the Disability Tax Credit. The legislation governing the DTC is the responsibility of the Department of Finance.

The committee released its second report this spring. It is an excellent report, recommending many important changes in the administration of the legislation.

The problem is that the legislation is itself flawed and the committee felt bound by the legislation. We have written the committee suggesting that they look deeper into the purpose of the program. (See page 13.)

## Disability Inclusion Action Plan

A new group called Accessible Canada that is part of Economic and Social Development Canada has been given responsibility for developing a "Disability Inclusion Action Plan". Keeping in mind the disability theme of "Nothing about us without us", the group sent around a survey for organizations and individuals to complete.

The National ME/FM Action Network struggled to understand the questions on the survey. In the end, we did not follow their format but instead wrote comments about each section. You can see the email we submitted on page 12.

We invite you to make your own submission. You can find the consultation document at *https://www.canada.ca/en/employment-social-development/programs/accessible-canada/consultation-disability-inclusion-action-plan.html*

The deadline is Aug 31, 2021

## French study on Pandemic Coping

A survey of people with chronic illnesses was carried out in France near the beginning of the pandemic. People were asked to identify their chronic illness(es) and to describe how they were coping with the pandemic. The study looked at three coping strategies

- emotion focused coping (adjusting one's attitudes)
- seek social supporting (asking for help from others)
- problem-focused coping (adjusting one's situation)

The study compared people with ME and with a control group consisting of people with recognized disabling diseases (arthritis, heart disease...) The study found that people with ME used social supports and problem-focused coping significantly less than the control group.

This should not be a big surprise. People with ME have likely experienced difficulty finding techniques that work or finding people to help them.

What is important is to recognize that "the squeaky wheel gets the grease", meaning that if people don't reach out, those around them may not realize the extent of their problems.

# ME/FM and Stigma - The Damage Done

*Speech given by RD Tailleur to UBC students in health sciences.*

M.E./F.M. bring devastation to the lives of those among us unfortunate enough to suffer from one or both of these diseases. That is a reality that cannot be denied. Yet, there is still a mindset that this devastation is not clearly (or sufficiently) "visible" (or real), to: politicians; public health administrators; medical practitioners; and, to society as a whole, when compared to other diseases and the hardships and disabilities they cause. That mindset has no basis in reality, and is not acceptable in modern society.

I think that - in large part - it is the long-standing stigma that has become attached to M.E./F.M. that has made these diseases less visible, and therefore somehow less worthy of attention. I believe that by reducing the stigma associated with M.E./F.M., sufferers will become more visible to society. And I believe that greater visibility will bring about more attention and focus on these diseases - in the much needed form of funding for research and disease management. It's simply an application of the same formula that we've used to solve many diseases or serious problems facing humankind.

It would be hard for anyone to objectively argue that people with such high levels of unmet health care needs are somehow less worthy, because they are not yet clearly 'visible' (acceptable) to society. The sophisticated diagnostic tools now available to modern western medicine make the invisible visible. It's not the technology that is lacking. The obvious challenge, of course, is getting to the point where society begins to shift sufficiently - to the point where the decision makers are forced to see these so called invisible illnesses for what they are: causes of human suffering. Suffering does not discriminate - and is never really invisible - if we are willing to look for it, discuss it, and take action to alleviate it. It really is that simple.

The stigma attached to these diseases has added insult to injury - for decades - and continues to this day. Those who have been devastated by M.E./F.M. know how much damage has been caused by the stigma: the shame, guilt, and diminishment of self esteem. Not to mention the lost decades of potential progress that could have been made - if it were not for stigma diminishing the importance of these diseases - resulting in very limited funding for research and management, to this day.

The Merriam-Webster Dictionary defines stigma as “a mark of shame or discredit.” Those of us with M.E./F.M. are all too familiar with the mark of shame that comes with having one (or both) of these diseases. We have come to understand that - like it or not - we must learn to live with the stigma that has been imposed upon us. We are forced to deal with: shame; dismissal; disbelief; disrespect; and, lack of acceptance.

These complex chronic diseases have been discredited - tainted really - for many decades now. In the case of the illness that became known as Chronic Fatigue Syndrome (now called M.E.), the seeds of doubt and dismissal were planted early. And they were spread by news media, talk show hosts and comedians making jokes about the yuppie flu, and, by society in general. At least they weren’t discrediting M.E. with taxpayer dollars. In contrast, some: politicians; administrators of medical research facilities and teaching institutes; health care professionals; and, some public health agencies have been spreading doubt and misinformation … for decades. And they - shamelessly - have been doing it with taxpayer dollars.

It is good science we need … not long-ago debunked beliefs, still being perpetuated by uninformed individuals, who undeniably - for whatever reasons - continue to malign these diseases. With a little examination, I think you will generally discover their reasons are ideological and personal, and have little to do with science. Science by its very nature does not cling to long-held beliefs that have been - over time - gradually, and repeatedly proven to be false.

When sharing that I have M.E. with friends and family, I have come to expect common responses, such as: “Yeah, I was tired all the time too … until - I started making a protein smoothie every morning. It works wonders. You should try it.” After such responses, where could I take the conversation?

The dynamic is different when I seek medical care. I see the patient/practitioner relationship as being unique and vital. While I can dismiss a friend who tells me I just need to make myself a smoothie every morning, I want and need, to work with medical professionals. And I know from personal experience that my best hope is when a practitioner is willing to work cooperatively with me, and truly listens to what I have to say.

First appointments are the most stressful, given the stigma associated with M.E./F.M. I know that I will often have to deal with incorrect beliefs - or disbelief - while still putting across my situation, in order that I may be helped. I often experience a familiar feeling of apprehension - in my mind, along with knots in my gut. I try to arrive prepared, with my thoughts organized (often in the form of written notes) in the hope that I will speak clearly and concisely, as I know I do not have much time. But often the stress combined with the brain fog results in my forgetting much of what I want to express.

I have the well-founded fear that the practitioner may not “believe” in these diseases, and so will dismiss me. And during any health care appointment: I am always aware … that my long-term livelihood - whether I will be able to financially support myself - depends in large part on my medical appointments and the notes and reports on my file. Most of us will - at least for periods of time - be completely unable to work. And the reality is, that many of us will never be able to work again.

Thank you for listening. I am grateful for the opportunity to share my thoughts concerning the devastating effects of stigma. If you are moved by my words, please take whatever action you can, so that we may - in time - put the stigma attached to M.E./F.M. behind us. Only then will be become more visible to society. With your help we can - in time - sever the malignant stigma attached to these diseases. I believe that will take Respect and Recognition - along with much more Research - plus a healthy dose of humility … in the face of the unknown.

## The Disability Tax Credit, Your Doctor and You

*by Coral Hetherington*

*The following article appeared in the newsletter of Fibromyalgia Support Group of Winnipeg Inc, 825 Sherbrook Street, Winnipeg, MB, R3A 1M5*

*Phone 204 975-3037*
*Fax 204 975 3027*
*Website: www.fmswinnipeg.com*
*Email: info@fmswinnipeg.com*

*We thank both Fibromyalgia Winnipeg and the author, Ms Hetherington, who gave us permission to reprint.*

Have you wondered why some people have been approved for the Disability Tax Credit (DTC), but you have not? Have you encountered resistance from your doctor to even attempt to apply for the DTC

Persons with Fibromyalgia can be approved for the credit, yet many are denied. It is not only the lack of information, but the type of information provided on the application that can result in a denial.

Imagine for a moment that you are an agent of the Canada Revenue Agency (CRA) and you are responsible for reviewing applications and determining eligibility for the tax credit. You do not have a medical background, but you have been extensively trained on the legislation for the credit. The legislation states that working, housekeeping, managing a bank account, and social or recreational activities are not considered basic activities of daily living so you cannot consider those aspects when determining eligibility. You must base your decision on how the impairment affects the applicant's ability to perform the functions of one or more of the specified categories that the doctor has certified on the application. You must determine if the effects of the applicant's impairment, even with therapy and the use of appropriate devices and medication, cause the person to be restricted all or substantially all of the time. You cannot make a decision based on the diagnosis as some conditions are progressive and at the early stages may not meet the criteria. Eligibility for the DTC is based on the effects of the impairment, not on the medical condition itself.

Also keep in mind you cannot see, nor will you ever meet the applicant. The application specifically states that it is mandatory for the doctor to describe and provide examples of the impairment so you must make the decision based solely on the information provided.

Imagine receiving an application where the doctor has certified an impairment in the category walking and entered the following information:

“Patient has Fibromyalgia. Has not been able to work for the past three years. Has difficulty doing house and yard work. Has stopped doing many activities which she used to enjoy. Sometimes is forgetful and has trouble concentrating. Medication helps somewhat. Can be slow when walking for more that 10 minutes. Cannot carry anything heavy. Can only remain sitting or standing for 10-15 minutes at a time.

Although the doctor seems to have provided good information, if you were the CRA agent you would probably deny the application simply because most of the information provided cannot be considered. There is no information or examples that describe why the patient has difficulty walking nor does it address the criteria.

For individuals with Fibromyalgia, it is typical to have widespread musculoskeletal pain accompanied by fatigue, sleep, memory and mood issues. They may also have joint disorders, irritable bowel syndrome, anxiety and depression. If none of that information is provided, then how can the CRA approve the credit?

Now imagine that you are at an appointment with your doctor. “How are you?” asks the doctor. To which you reply, “I'm fine.” We Canadians don't like to complain, do we?

The doctor is aware of your diagnosis and knows that you have pain but how does the doctor know how your symptoms affect you on a day-to-day basis? When you have your appointment, you are probably already sitting in the examination room before the doctor enters the room. The doctor does not see you walking into the clinic, has no idea that it took two hours that morning to get out of bed, shower, wash your hair and get dressed. The doctor does not know how exhausted you were in that process and that you had to rest before you were able to get out the door to be at the appointment on time .

The doctor rarely has the time to chat with you and would be unaware of how difficult it is for you to do many of the small tasks we do everyday. Generally, persons with Fibro should apply for the credit in the categories Walking, Dressing, Feeding and possibly Mental Functions. There are two ways of completing the application to specify these categories: EITHER one or more as a Marked Restriction OR two or more as a Significant Restriction.

The CRA uses the term “markedly restricted” and defines it in the following way: “A person is markedly restricted if, they are unable or takes an inordinate amount of time to do one or more of the basic activities…”

An “inordinate amount of time” is not specifically defined in the legislation, however, there has been an attempt by CRA to describe the term to mean that “Usually, this equals 3 times the average time needed to complete the activity by a person of the same age who does not have the impairment.” The main problem with the concept of 3 times longer is that “the average” time is not stated so there is really no substantial way to measure this.

The Marked Restriction categories are listed on page 2 and 3 of the application. The Significant Restrictions

*Continues on page 11*

# M.E. in B.C.

## HOW THE HEALTHCARE SYSTEM FOR M.E. IMPACTS CLINICIANS AND PATIENTS

### PILOT PROJECT PURPOSE

BEGIN TO:

- EXPLORE M.E. **CARE** IN BC
- UNDERSTAND THE **NEEDS** OF M.E. PATIENTS IN BC

### BACKGROUND

Feb-Aug 2020

PATIENT LED COMMUNITY ENGAGEMENT

ME/FM Society of BC | COMPLEX CHRONIC DISEASE PROGRAM – BC WOMEN'S HOSPITAL | CONVENE GRANT – VANCOUVER FOUNDATION

### METHODS

8 INTERVIEWS

4 FOCUS GROUPS

25 PATIENTS

79 DOCTORS

42 NURSES

SURVEY

173 CLINICIANS/ADMIN

### FINDINGS

- SOCIAL ISOLATION IS PROFOUND

- STIGMA FROM THE HEALTHCARE SYSTEM

- GETTING DIAGNOSED IS COMPLICATED, LENGTHY, AND CHALLENGING

> "M.E. TOOK AWAY EVERY SINGLE THING, EVERY CONSTRUCT I WAS AS A HUMAN BEING."
>
> – PATIENT

> "I FEEL EXTREMELY SORRY FOR THEM BECAUSE BC HAS ALMOST NOTHING FOR THEM."
>
> – CLINICIAN

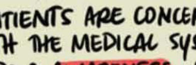
### CLINICIANS & PATIENTS AGREE:

- WE NEED IMPROVED COMMUNITY REFERRALS
- WE NEED BETTER DIAGNOSIS PATHWAYS & CLINICAL GUIDELINES
- WE NEED MORE **EDUCATION** ON M.E.
- THERE IS A LACK OF **KNOWLEDGE** & **EDUCATION**

### CONCLUSION

PATIENTS' EXPERIENCES OF LIVING WITH M.E. IS

**DIRE, ALARMING & URGENT**



PATIENTS ARE CONCERNED WITH THE MEDICAL SYSTEM'S POOR **AWARENESS** OF M.E.

BOTH PATIENTS AND CLINICIANS ACKNOWLEDGE A PAUCITY OF AVAILABLE CLINICAL CARE **RESOURCES**

CLINICIANS EXPRESSED A DESIRE FOR IMPROVED **EDUCATION** FOR M.E. CARE

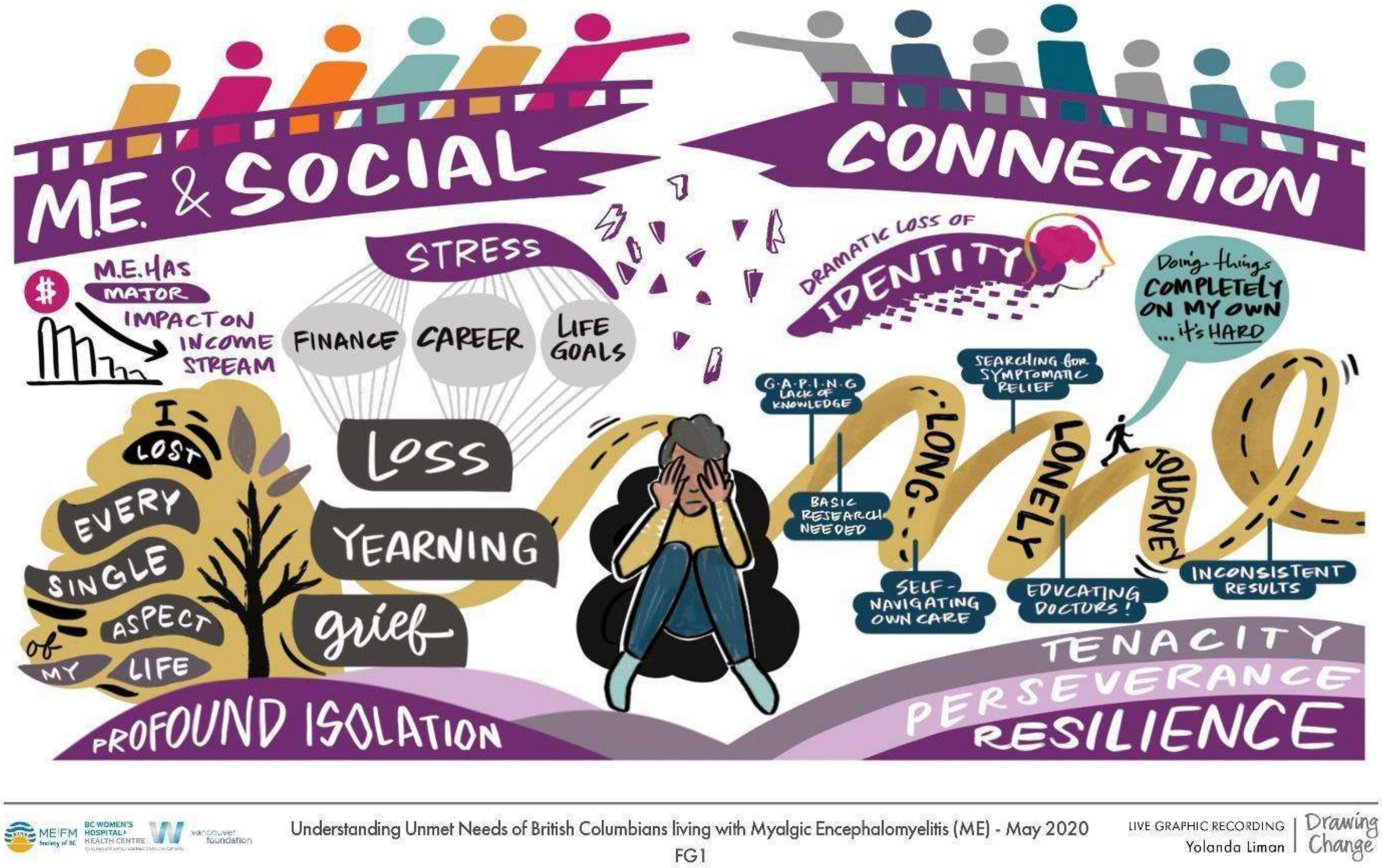
LARGE SCALE PROVINCIAL NEEDS ASSESSMENT IS NEEDED. **FULL REPORT** AVAILABLE AT WWW.MEFM.BC.CA

·DRAWING CHANGE 2021·

ME|FM Society of BC

BC WOMEN'S HOSPITAL + HEALTH CENTRE

vancouver foundation



Understanding Unmet Needs of British Columbians living with Myalgic Encephalomyelitis (ME) - May 2020
FG1

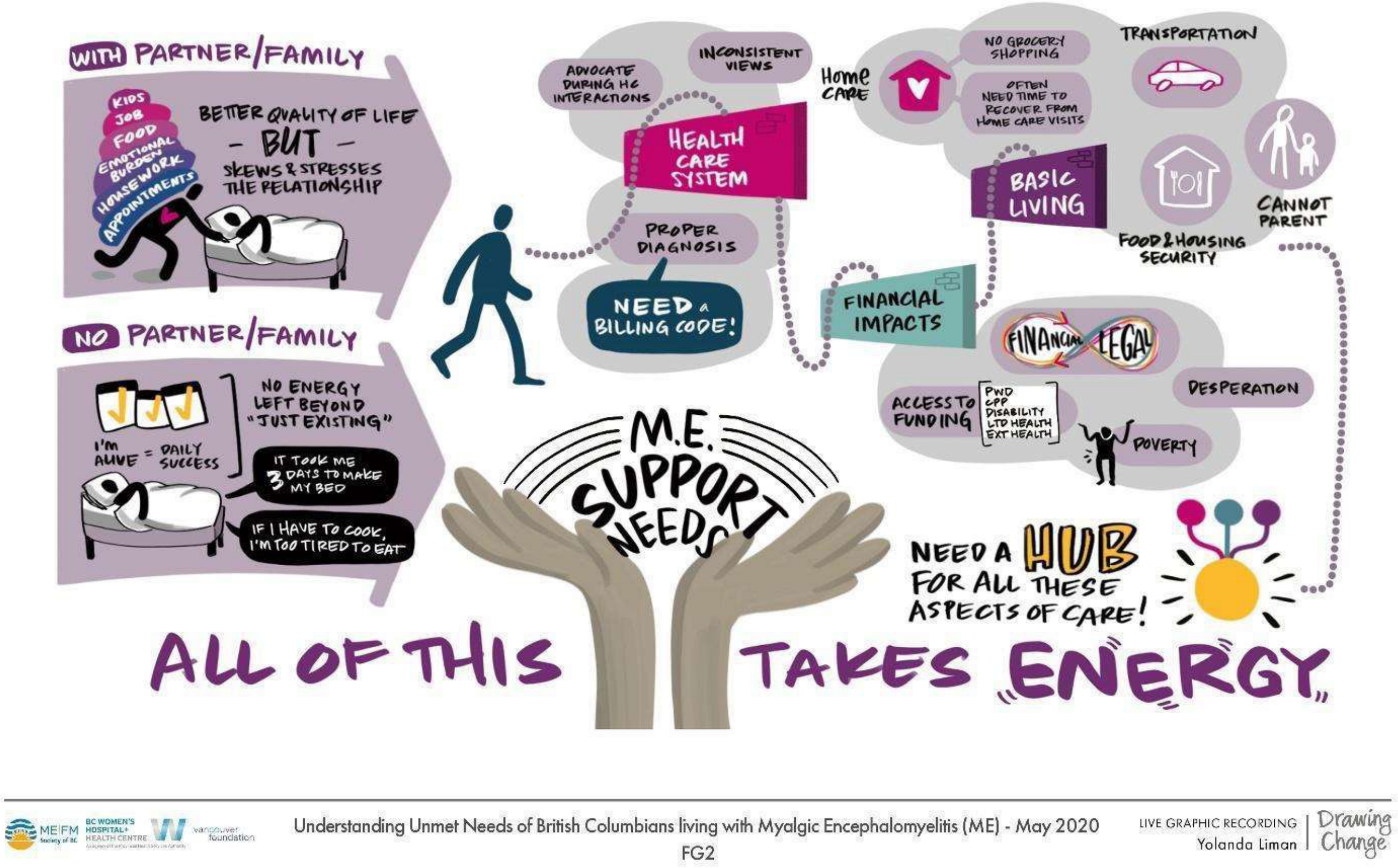
LIVE GRAPHIC RECORDING Yolanda Liman | Drawing Change

## ME/FM BC Study

This patient led community inquiry project was conducted through a partnership between the ME/FM Society of BC, the Complex Chronic Diseases Program at BC Women's Hospital + Health Centre, and the Women's Health Research Institute. The project was funded by the Vancouver Foundation through the Convene competition. The patient interviews highlighted four key themes to the ME experience in BC:

- Social isolation, loss of identity and the need for emotional support
- Supports for disease management and how to live with ME
- Challenges to diagnosis
- Stigma in the healthcare system

*The project is summarized on the preceding page. The four themes are illustrated on this page and the two subsequent pages.*



The clinician survey identified parallel challenges noting the need for:

- ❖ Increased awareness of ME within the clinical community
- ❖ Improved clinical resources (e.g. diagnosis pathways and clinical guidelines)
- ❖ Improved community referral resources including more options for patients
- ❖ Improved empathy for the patient experience/lack of options for patients

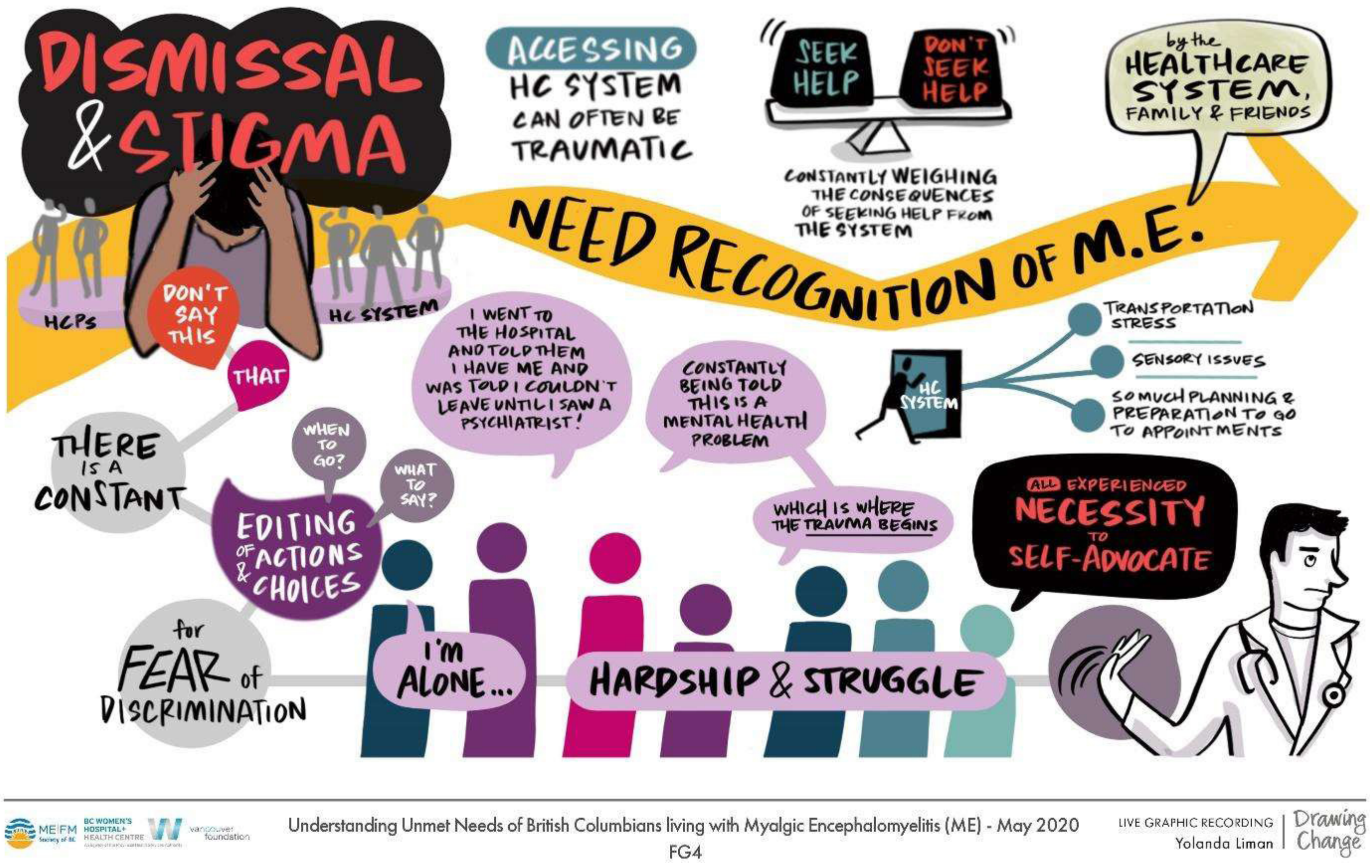
Overall, key findings presented from this project have been defined:

1. Patients' experiences of living with ME is dire, alarming, and urgent
2. Patients are concerned with the medical system's poor awareness of ME
3. Both patients and clinicians acknowledge a paucity of available clinical care resources
4. Clinicians expressed a desire for improved education for ME care

*You can find the full and summary reports at https://www.mefm.bc.ca/our-research*

Understanding Unmet Needs of British Columbians living with Myalgic Encephalomyelitis (ME) - May 2020
FG3

LIVE GRAPHIC RECORDING | Drawing Change
Yolanda Liman



Understanding Unmet Needs of British Columbians living with Myalgic Encephalomyelitis (ME) - May 2020
FG4

LIVE GRAPHIC RECORDING | Drawing Change
Yolanda Liman

*continued from page 6*

are listed under the Cumulative Effect of Significant Restrictions on page 4.

The legislation changed in 2005 to include the Cumulative Category. Although more that 15 years has passed since it was introduced it remains one of the most mis-understood aspects of the application process. Theoretically it should have made the application process easier. But very rarely do doctors understand how to complete this section for their patients. The premise of the category was that there are many people who did not meet the criteria for a single Marked Restriction but because they had Significant Restrictions in more than one category, they could be deemed eligible under the Cumulative Category.

The Cumulative Category could actually work very well for persons with Fibro. As mentioned earlier, areas of difficulty are in walking, dressing feeding and mental functions.

How can you help your doctor to complete the application for a positive outcome?

Start with understanding how you are affected daily in one or more of the categories as defined by the criteria for the DTC. Think about how you would describe those issues to that CRA agent who is reviewing your application.

Often when we have pain, we try to compensate by shifting our weight to the “good side” and either avoid certain movements or do them very slowly.

Ask your spouse or a friend to walk at their normal pace and see if you can keep up with them. Do you have to slow down or even stop because of the pain? When going up or down stairs do you have to hold onto the handrail and pause at each step? Are you afraid of falling because of issues with balance?

When getting dressed do you have to sit or hold onto something? Do you have trouble with buttons or zippers? When dressing your lower extremities is it difficult to bend your knees or to bend over because of pain? Can you lift your arm above your shoulder or behind your back when putting on a top, jacket or coat? Do you need help with putting on socks, shoes or boots? Does washing and dressing increase the pain so that you find it necessary to change your way of doing it? Do you have to rest during or after dressing?

The category of Feeding includes preparing a meal. Do you have difficulty with holding or using knife for cutting, chopping or slicing food, opening a jar or using a can opener? Difficulty standing working at the sink or worktop? Difficulty lifting a saucepan to drain the contents? Carrying a pot from the stove to the table or removing items from the oven?

If the answer is yes, tell your doctor. A good way to do this is to write it all down to give to the doctor at an appointment. Be specific about what you can and cannot do and how much longer it takes. Do not ramble on – be precise when you make your list. That way it will not take up time during the appointment and you won’t forget all the things you wanted to say.

Which leads us to the final category – Mental Functions. Fibro fog can make you forgetful, make it difficult to concentrate and stay focused on the subject at hand.

The criteria for this category as a Marked Restriction is very difficult to meet. However, it can be considered when added to the Significant Restrictions in walking, dressing and or feeding in the Cumulative Category. Constant pain and the inability to live a normal life often leads to depression. If the depression is so severe that the person has difficulty getting out of bed and neglects or abandons self-care for days at a time this aspect would be considered in the Markedly Restricted category.

If your doctor is hesitant to complete the application form it could be that they are unaware of how your limitations fit the criteria or perhaps, they have not been successful when completing it in the past and are frustrated with their dealings with the CRA.

Approaching the doctor with candid and clear information of how you do meet the criteria; how you struggle with these issues on a daily basis along with a respectful request that you would like to at least try for the DTC might be met more favourably. When your doctor has a better understanding of your situation that also might lead to better medical care for you.

For more information, contact:

Coral Hetherington
Hetherington & Hodson, Your Disability Tax Credit Advisors
Phone: (204) 299-9414
Email: coral@DisabilityCredits.com
Website: *www.disabilitycredits.com*

# Network Correspondence

The federal government has recently released:

- a survey asking Canadians for advice on a new Disability Inclusion Action Plan (see page 4)
- an advisory committee report on the Disability Tax Credit program (see page 3)
- a bill before parliament to create a new “Canada Disability Benefit” similar to the Guaranteed Income Supplement for seniors. This bill would authorize the government to establish the eligibility criteria, application process and payment amounts through regulations.

These releases have led the National ME/FM Action Network to write three emails to the federal government. There is some repetition between the emails because they are going to different areas of government.

## Disability Inclusion Action Plan Survey

To: ACCESSIBLE-CANADA@hrsdc-rhdcc.gc.ca

The National ME/FM Action Network welcomes any initiative to better the lives of Canadians with disabilities. However, we have two fundamental problems with the Disability Inclusion Action Plan survey. Firstly, we are very uncomfortable with the idea of voting on options when we know that all the options have important roles to play. Secondly, the proposed action plan does not cover many of the ME/FM disability issues.

Myalgic Encephalomyelitis (aka Chronic Fatigue Syndrome) and Fibromyalgia are acquired, chronic, disabling conditions. At last count, there were nearly a million Canadians diagnosed with one or both. This number is expected to surge since many COVID “long-haulers” have ME/FM-type symptoms. The existing ME/FM community is predominantly female and predominantly of working age. It is poorly served and in distress. You can find statistics demonstrating this at *http://mefmaction.com/docs/CCHS_Stats_2014.pdf*. These statistics use the Canadian Community Health Survey conducted by Statistics Canada. The data was extracted and analyzed by our organization.

In very simple terms, people with ME and/or FM have reduced energy available for participating in society. The extent to which participation is affected indicates how severe the condition is. The mechanisms that lead to the reduction in available energy have not been adequately explained. The lack of explanation is due to the complexity of the mechanisms combined with a lack of support for research. The health system has tended to brush aside these conditions rather than to confront them. An individual with reduced energy has a choice of how to use the available energy and therefore the effect is not specific to a particular activity. Therefore, disability eligibility criteria that are based on impairments or activity limitations do a poor job of identifying ME/FM disability cases.

The proposed disability inclusion action plan was designed around well-recognized disability groups. The issues for under-recognized disability groups are broader. We hope that action will be taken to address the needs of under-recognized groups as well.

We want the ME/FM voice to be heard so we are submitting our comments in text form using the topic headings of the survey. Please feel free to contact us at any time to explore the issues we raise. And do not hesitate to share or publicize this email.

**Financial Security**

Financial security is a very important issue for the ME/FM community. As we wrote in our statistical report:

“These findings show high rates of poverty among people with ME/CFS or Fibromyalgia. People with these conditions may be unable to work full-time or may be out of the work force entirely. The situation can continue for extended periods of time. People who cannot work often encounter difficulty qualifying for income support. For the people who do qualify, the payments can be very low. Poverty among people with these conditions hinders their ability to recover from illness.”

Hopefully, the Disability Inclusion Action Plan will consider all these issues.

**Employment**

Canadians with ME, FM or both experience a high degree of unemployment.

The preamble to the employment section of the survey says that employment is central to economic and social well-being. This suggests that everyone with disabilities is better off in the workplace. As much as people with ME and/or FM might want to be employed, employment is not realistic for many of them. The statistics show that over 20% of the working-age ME/FM community reported that they were permanently unable to work.

Canada needs a more nuanced discussion. Employment may be appropriate in many circumstances, but should not be considered universally desirable and should not be a prerequisite to economic and social well-being.

### Disability-Inclusive Spaces

Canadians with ME, FM or both experience a high degree of social isolation.

ME and FM reduce the amount of physical and mental functioning a person can do.  Some people with ME, FM or both are partially or completely home bound. Some are even bed bound. In addition to the reduced physical and mental activity levels, people with ME, FM or both are often hypersensitive to stimuli (sound, lights, smells, etc.).

While it is important to make common spaces more accessible, it is also important to reach out to people who cannot come to the common spaces.

### Modern Approach to Disability

A modern approach to disability is found in the UN Convention on the Rights of Persons with Disabilities. The CRPD bases disability on participation difficulties, not on the old models which list types of impairments or activity limitations.

Two important federal government programs, the Disability Tax Credit and the Canadian Survey of Disability, base disability on the old approach of listing impairments or activity limitations. When disability is defined this way, people with ME and/or FM often get left out. The DTC and CSD programs need to be modernized through moving to a participation based model.

Q12 of the survey asks about tools for disability assessment. The ME/FM community uses the functional capacity scale. This is found in many places, including in the International Association for ME/CFS Primer for Clinicians and in Appendix B of the Guide we wrote to help people applying for CPP-Disability *http://mefmaction.com/images/stories/CPP/CPPGuide-2020.pdf*. Another related concept that can also be used to assess disability, especially where dysautonomia is involved, is Hours of Upright Activity (HUA) *https://content.iospress.com/download/work/wor203169?id=work%2Fwor203169*

### Overarching Questions

The overarching questions around disability are

- who is having difficulty participating in society for health reasons and
- what can be done to help.

These two questions should guide the Disability Inclusion Action Plan.

When it comes to who is having difficult participating in society for health reasons, people with ME and FM are often forgotten. We do not believe that these are the only people left out. A key element of the plan should be identifying the full disability community.

For what can be done to help, the CRPD provides a list of topics that "states parties" (governments) need to consider. For the ME and FM community at its current stage of development, key topics to encourage inclusion are articles 8 – awareness-raising, 19 – being included in the community, 24 – education, 25 – health, and 28 - adequate standard of living. The Disability Inclusion Action Plan survey focuses on articles 9 – accessibility, 27 – work and employment and 28 – adequate standard of living. The disability inclusion plan seems to assume that governments have moved disabilities past the awareness stage and have resolved issues around access to healthcare, education and social programs. That is not the case for ME, FM and some other disabling chronic conditions. We hope that the disability inclusion plan is expanded to recognize emerging areas like ME/FM or that a parallel process is instigated.

### Demographic Questions

Q24 asks individuals to describe their disability. The list provided reflects the old approach of listing impairments and activity limitations. The list doesn't capture the essence of ME or FM and it sends the message that ME and FM are not really considered disabling.

The National ME/FM Action Network is a registered Canadian charity that has been working on behalf of Canadians with ME, FM or both since 1993.

**

*To Quest readers: If you wish to complete the survey yourself, go to the link shown on page 4. The deadline for submissions is August 31, 2021.*

## Moving Forward from the DAC Report

To: Disability Advisory Committee (DAC)
DACCCPHG@cra-arc.gc.ca

The National ME/FM Action Network would like to thank you for your 2nd report prepared for the Minister of National Revenue. It provides a valuable inventory of issues within the existing Disability Tax Credit framework.

We work on behalf of Canadians with Myalgic Encephalomyelitis (aka Chronic Fatigue Syndrome) and/or Fibromyalgia. These are acquired, chronic, disabling diseases. At last count, there were nearly a million Canadians diagnosed with one or both. This number is expected to surge since many COVID "long-haulers" have ME/FM-type symptoms. The existing ME/FM community is predominantly female and predominantly of working age. The health and social systems do not appreciate how disabling ME and FM can be. This has left the ME/FM community poorly served and in distress. You can find statistics demonstrating this at *http://mefmaction.com/docs/CCHS_Stats_2014.pdf*

We know from our community that the DTC eligibility criteria are biased against people with ME and/or FM. People have to be extremely disabled to qualify, documenting the disability is difficult and finding a health professional to support the application can be a challenge.

We would like to see the DAC dig deeper into the purposes of the DTC program. Two purposes of the program are commonly listed – tax reductions and gateway to some existing programs. Recently, the government attempted to use the DTC list as the entry point for the special Covid payment and found serious gaps. The reasons for these gaps should be explored.

There is another purpose of the DTC program which has received little examination. The DTC program is one of the primary ways the Canadian government signals to Canadians what disability means and who deserves to be considered as disabled The fact that it is hard for members of the ME/FM community to qualify for the DTC sends the message that ME and FM are not deserving. Government should be de-stigmatizing disabilities, not entrenching stigmas.

We would encourage you to question the statistics provided in Appendix H. Firstly, the statistics should be broken down between children, adults and seniors because these groups are dealing with different situations. Secondly, the statistics focus around administrative activity rather than examining whether the program is achieving its desired outcomes.

If you have any questions or comments for us, please do not hesitate to be in touch. Meanwhile we wish you the best in your valuable work.

## Disability Inclusion for Everyone

To: Minister for Disability Inclusion,
*Carla.Qualtrough@parl.gc.ca*

The ME/FM community is not receiving the attention it deserves in the disability activities of the federal government. We ask for your help in correcting the situation.

The ME/FM Action Network represents Canadians with Myalgic Encephalomyelitis (aka Chronic Fatigue Syndrome) and Fibromyalgia. These are acquired, chronic, disabling diseases. At last count, there were nearly a million Canadians diagnosed with one or both. This number is expected to surge since many COVID "long-haulers" have ME/FM-type symptoms. The existing ME/FM community is predominantly female and predominantly of working age.

Both the health system and the social system have underestimated how disabling ME and FM can be. This has left the ME/FM community poorly served and in distress. Statistics on poverty, unemployment, food insecurity, social isolation and unmet needs are available at *http://mefmaction.com/docs/CCHS_Stats_2014.pdf*

We have identified several areas that need attention.

- We were recently asked to complete a survey around the Disability Inclusion Action Plan. The initiatives being proposed do not address many of the foundational issues our community encounters like access to healthcare, access to education, and awareness. The Disability Action Plan seemed designed for disabilities that have already resolved these issues. We have written to the officials responsible asking that the Action Plan be expanded or that a new initiative be started so that under-recognized disabilities can catch up. We hope that you will support our request.
- We were recently provided with a report from the Disability Advisory Committee to the Minister of National Revenue. The report did a very good job of identifying issues for groups already included, but did not challenge the eligibility requirements and procedures that are barriers for our community. This program sends out the message that only people with selected impairments or activity limitations are worthy of disability status. We have written to the Disability Advisory Committee asking them to look at the program more broadly. We hope that you will support this work.

- We are concerned about the Canadian Survey of Disability. It focuses on selected impairments and activity limitations rather than participation restrictions. We find the survey exclusionary and virtually useless. While it may be too late to fix the 2022 cycle, we would like to see the whole disability statistics program reviewed to align with the CRPD and hope you will encourage this work.
- We are concerned about the proposed new "Canada disability benefit" (Bill C-35). Firstly, without eligibility criteria being spelled out, we don't know if the ME/FM community will have fair access to the program. Secondly, we don't like the term "benefit". It suggest that people are receiving something special. We would suggest "program" or "payment" or "support" instead. Since this program is being modelled on the Guaranteed Income Supplement for seniors, "supplement" would be another choice. We ask you to consider these issues.
- There were people who were homebound before the pandemic lockdowns and there will be people homebound even after the lockdowns are lifted. Please help us ensure that they are not forgotten.

We appreciate your understanding and support.

http://mefmaction.com

http://www.facebook.com/MEFMActionNetwork

NATIONAL
ME/FM
ACTION NETWORK
SINCE 1993

## 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:

____________________________

# MEMBERSHIP APPLICATION or RENEWAL FORM

*For online application and renewals go 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*
*Our phone number is 613-829-6667*