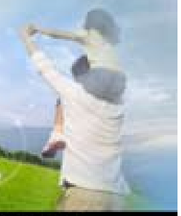
NATIONAL ME/FM ACTION NETWORK

Quest Newsletter



www.mefmaction.com
Quest 104, Fall 2015
mefminfo@mefmaction.com

Network Offering Research Microgrants

The National ME/FM Action Network has wanted to fund research for some time. Now, thanks to the generosity and support of the community, we have some money to get started.

We have decided to try an idea developed by our colleagues at the Rare Disease Foundation. They hand out "microgrants" of up to $3,500 each. This works very well for them. We are going to offer two Micrograrants of up to $3,500 each and hope that we have similar success.

We invite applications from Canadian researchers – we want to spend the money in Canada. The proposed work must lead to greater understanding of biomedical aspects of ME, FM or both – we want this research to be biomedical. The application should be a short letter (two or three pages) describing how the money will be used and how it will benefit the ME/FM community in Canada. The closing date for applications will be Dec 31, 2015. The decision on grants will be made by the Board of Directors on or before Feb 28, 2016. In considering the applications, the Board may consult applicants for more information and may turn to our medical advisers for input. We will publicize the winning proposals. If no suitable applications are received, no grants will be awarded.

We also want some broader dialogue with the research community. If you are a biomedical researcher and have ideas that require funding, let us know. We can advertise the ideas and see if there is up-take in the community.

We would like everyone's help making these micrograrants and our interest in supporting research known to Canadian researchers. Please pass this information on to anyone you think would be interested.

Questions and applications can be directed to *mefminfo@mefmaction.com*.

The Network very much appreciates the community's support in online contests – it has led to funding from Aviva, Karma Wellness Water, Nature's Bounty and FedEx. We also appreciate the donations we have received from organizations and individuals. Through your support and generosity, we hope that we will be able to continue and expand our research program as well as continue and expand our other activities.

Contents

In This Issue

The next Canadian federal election is scheduled for October 19, 2015. The National ME/FM Action Network is a non-partisan organization. We are not going to suggest for whom you should vote in this election. And we promise to work with whomever is elected to office.

We encourage everyone who is eligible to vote to do so. People who are homebound can vote by mail or ask Elections Canada to come to the house. Contact Elections Canada as soon as possible to make arrangements – this cannot be done at the last minute.

We invited the five main political parties to submit a statement to our website and newsletter. You will see the results in this newsletter.

We have put together a handout in English and French that you can give to candidates who knock on your door, or send to candidates if they don't. People with internet can print off the pages. People who receive the newsletter by regular mail can remove the center pages and cut down the fold. Voila, you have two handouts.

Also in this issue

- The Network announces a microgrant competition for biomedical research.
- Chronic Fatigue Syndrome, Fibromylagia and Multiple Chemical Sensitivities were on the 2014 Canada's Canadian Community Health Survey. We feature two tables – prevalence and unmet healthcare needs.
- Once again, CFS and FM had very high rates of unmet healthcare needs, so we propose a new vision for healthcare delivery.
- We look at discussions taking place in the United States related to research funding by the National Institutes of Health.
- We draw your attention to a study that critically reviews Independent Medical Examinations.
- We let you know about a study looking for volunteers with FM.
- We let you know about an event in Kitchener in November, and tell you about Opera Mariposa's event in Vancouver next May.

Casting Your Ballot

Contact information for Elections Canada:

website: electionscanada.ca

toll-free 1-800-463-6868

The 2015 Canadian Federal Election is officially underway. We would encourage everyone to vote. For some of you, regular voting would be a challenge. Elections Canada understands this and has provided a number of ways for you to cast your ballot, including voting at home.

In all cases, you have to be a Canadian citizen, age 18 or older, and provide appropriate identification. A driver's licence or any other government-issued ID card with your name, address and photo is the easiest form of ID. If you don't have that ID, check the Elections Canada website or ask a candidate or official for help.

Candidates have until September 28 to file their nomination papers. Elections Canada needs a little time after that to prepare the official ballots. If you vote early in the election period (at an Elections Canada office, by mail or at home), you will receive a blank ballot and you write in the name of the candidate you want. If you vote later in the election period, you will get an official ballot. Both are accepted.

Voting outside your home

- Vote at your local polling station on election day, October 19. The polls are open for 12 hours.
- Vote at an advance poll. There will be several locations in your riding. Advance poll times are October 9, 10, 11 and 12 (Friday to Monday), noon to 8 pm local time.
- Vote at any Election Canada office anytime between now and 6 pm EST on October 13.

You can find the locations of the Elections Canada offices, the advance polls, and the election day polls by checking the Elections Canada website, by calling Elections Canada, or by asking any of your candidates for this information. Generally, the election-day polling station will be closer to your house than the advance polls or the Elections Canada office, but you may have reasons for voting early even if those polls are farther away.

A few suggestions:

- Check whether you are registered to vote at your current address before you go to vote. You can check online or by contacting Elections Canada. It can be simpler and safer to register in advance (but it can still be possible to register at the poll).
- If you don't drive, ask a family member, neighbour or friend to take you to the poll or office, or ask one of the candidates for a drive – some candidates may offer this service.
- If there is a line-up at the poll, don't hesitate to ask for someplace to sit down.
- Think about bringing earplugs to cut out some of the noise.
- Don't forget to bring ID. Check that you have the right ID material before you leave the house.

Voting at home

- Vote by mail.
- Arrange for an Elections Canada home-visit.

Both options use the "special ballot" system to ensure your ballot is secret. You fill out the ballot and put it in a blank envelope; then you put the blank envelope in a envelope that provides basic information. The outer envelopes are verified and then discarded. The blank inner envelopes are put into a ballot box and opened when the polls close on election night.

If you want to vote by mail, Elections Canada must receive your application form by October 13th. You can find the form on the Elections Canada website or contact them for a copy. After reviewing your application, Elections Canada will mail a voting package to your home. You must get the ballot back to Elections Canada by October 19.

If you want/need Elections Canada to come to your house, contact them (or have someone contact them for you) to set up an appointment. Two people will come – an official and a witness. The official will help you fill out the application form (checking your registration and ID), give you a voting package, and take away your ballot in the double envelope. The appointment must be on or before October 13.

**

The National ME/FM Action Network is interested in hearing from you about your experiences voting. We are especially interested in hearing from people who use the mail or home-visit option.

We want people to know about their voting options. If you know someone who could use this information, please pass it on.

Statements by Political Parties

Early this summer, the House of Commons Finance Committee asked Canadians to submit ideas for the next federal budget. The Network put together a submission, just as we have done for the last two years. This year, the committee asked that the submissions focus on themes like productivity and infrastructure. In our 2015 submission, we noted that ME/CFS and FM cause a remarkable loss of productivity to the Canadian economy and we suggested that the federal government rethink the ME/FM infrastructures for health research, for healthcare delivery and for social services.

By the time we sent in the submission, the election had been called and the committee no longer officially existed, so our submission was returned to us.

What we did instead was send the submission to each of the 5 main political parties on August 13 and invite them to provide us with a statement for our website and newsletter. We set a deadline of August 31. We sent a reminder on August 27.

We received one response by the deadline. The four other parties did not respond.

Recommendations From Network Submission

1. Our recommendation is to create a new institute at CIHR with long term designated funding. A new institute is needed because this is a large and complex area of study but also because a fresh start is needed to dispel faulty information about these illnesses. Designated funding is needed to attract new researchers to this neglected area of study. The research will provide the healthcare system with a new and solid foundation for diagnosing, treating and preventing ME/CFS and FM.
2. Our recommendation is to create a task force to address healthcare delivery to Canadians with ME/CFS and FM. The task force would consult with patients, provinces, territories and other stakeholder and be mandated to:
    - develop a model of healthcare delivery for ME/CFS and FM in Canada
    - estimate the health human resources needed to implement the model
    - develop a strategy to getting the resources in place as quickly a possible
3. Our recommendation is to create an interdepartmental task force to address the discrimination and stigma facing Canadians with ME/CFS and/or FM. Working with the patient community and other stakeholders, the task force would:
    - review government publications and websites to ensure that information is complete and correct
    - review government programs and services to ensure that they are inclusive and that deserving applicants are approved without undue effort or delay
    - implement a public awareness campaign to ensure that Canadians are informed about these illnesses and resulting disabilities
    - identify additional initiatives needed to ensure justice and equality for Canadians with ME/CFS and/or FM.

Reponse From the Green Party of Canada

green PARTY OF CANADA PARTI vert DU CANADA

Dear Ms. Parlor,

Thank you very much for writing to the Green Party of Canada with your recommendations for improving the quality of life for people living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM).

In a prosperous country like ours, no Canadian's disability should ever preclude them from meaningful engagement with their communities. However, the unfortunate reality is that Canadians with disabilities are disproportionately vulnerable to poverty and excluded from full participation in our society. In particular, Canadians living with ME/CFS or FM are stigmatized and left without the social and economic support they need to meet their unique needs.

ME/CFS and FM are frequently misunderstood, as are those living with these illnesses. The contributions of hardworking Canadians with ME/CFS and FM are invaluable. We must make inclusion a priority, and take action to promote better understanding of ME/CFS and FM. Canadians with ME/CFS and FM should be fully supported in their workplaces and in our communities. Indeed, as you mentioned, all Canadians would benefit from a greater awareness of and respect for the realities of ME/CFS and FM.

The Green Party supports your call for stronger research, health, and social infrastructure to support Canadians living with ME/CFS and FM. The fact that ME/CFS is poorly understood contributes to a lack of treatment and care options for those living with the illnesses. Moreover, a general lack of public awareness has contributed to the unfair stigma associated with these conditions, which, in turn, makes it more difficult for people living with ME/CFS to access the accommodation they are entitled to.

For these reasons, we agree that improved funding and research, health care delivery, and public awareness that respects the realities and needs of Canadians living with ME/CFS and FM is needed.

The Green Party strongly believes that every Canadian deserves access to high quality, patient centred care, that extends beyond the clinic. The federal government must work with the provinces and the medical community to ensure that general practitioners are properly equipped, and that there are enough specialists to provide appropriate treatment to Canadians with ME/CFS and FM.

With stronger support for improved research, health, and social outcomes, the federal government can ensure that Canadians living with ME/CFS and FM are treated with understanding, justice and equity.

Sincerely,

Emily McMillan

Executive Director
Green Party of Canada

US Research Developments

The National ME/FM Action Network sent the following letter to the Canadian Institutes of Health Research (CIHR).

Dr. Alain Beaudet
President
Canadian Institutes of Health Research

Dr. Jane Aubin
Chief Scientific Officer and Vice-President,
Research, Knowledge Translation and Ethics
Canadian Institutes of Health Research

Dear Dr. Beaudet and Dr Aubin,

Re: Research into ME/CFS and FM - US Developments

For several years, the National ME/FM Action Network has been asking CIHR to reconsider its approach to ME/CFS and FM research. The Network has

- asked that these diseases be taken much more seriously,
- asked that appropriate funding be made available, and
- suggested that a new institute be established.

While there has been a bit of movement, notably the designation of a fellowship, CIHR's overall response to date tells us that CIHR does not share our perspective on the seriousness of the diseases, the barriers in the funding process, and the novelty and importance of the medical issues.

The ME/CFS patient community in the United States has been asking NIH to reconsider its approach. The US discussions have now moved to a new level. Government appointed committees and serious researchers are joining the discussions and are siding with patients. We would like to ensure that you are aware of these developments.

The US Chronic Fatigue Syndrome Advisory Committee (CFSAC) makes recommendations to the US Secretary of Health and Human Services (HHS). The committee met on August 18-19, 2015. At the meeting, CFSAC considered two recent reports on ME/CFS: the Institute of Medicine (IOM) and the Pathways to Prevention (P2P) reports. The IOM report was commissioned directly by HHS and the P2P report was commissioned through the National Institutes of Health. In the background were two additional, recent reports on ME/CFS done through two other HHS agencies: the Agency for Healthcare Research and Quality (AHRQ) and the Federal Drug Administration (FDA). **The reports consider ME/CFS to be very serious. They identify lack of research as a roadblock to their being able to answer thoroughly the questions they were assigned and they call for more research.** See Appendix 1 for some quotes from those reports

At the CFSAC meeting, a NIH official (Dr. Cheryl Kitt, Deputy Director of the Center for Scientific Review) suggested that the reason for low NH funding was poor submissions. This comment raised the hackles of patients because the community knows that proposals for some very good research has been rejected. This comment also raised hackles in the research community, including among some very prominent US researchers.

Dr. Ron Davis, a member of the National Academy of Sciences and winner of the 2011 Gruber prize in Genetics, is one of the greatest scientists in the US today. He has developed many of the technologies used for modern diagnostic testing. Dr. Davis was a member of the IOM ME/CFS panel and is the parent of a young adult with very severe ME/CFS. Dr. Davis has put together a medical team of prominent researchers and a medical advisory board that includes three Nobel Laureates to study ME/CFS in a project they call "The End ME/CFS Project." They submitted proposals aimed at finding biomarkers for diagnosing ME/CFS using biochemical tests. Both their submissions were rejected at the pre-proposal stage. Following Dr. Kitt's comment, Dr. Davis released a short but powerful statement listing the reasons NIH gave for rejecting the proposals and his rebuttal to the rejections.

One reason for rejection was the lack of a hypothesis; Dr Davis responded that ME/CFS is in the observation stage which comes before the hypothesis stage. Another reason for rejection was that the proposal did not fit within the neurological institute's mandate; Dr. Davis argued that it certainly did.

Dr. Ian Lipkin is a very respected scientist popularly known as 'the Virus hunter'. He has, until very recently, had his ME/CFS proposals rejected. Here is a quote from Dr. Lipkin:

"I have been in competition now twice to get funded, and the people there who reviewed me gave me abysmal scores. And the critiques of my work were unfair, and one of the people who critiqued my work said, in fact, that this is a psychosomatic illness. I was floored."

Just before the CFSAC meeting, a group of researchers released a letter stating that ME/CFS research was massively underfunded and asking for designated funding using a Request for Applications process . A Canadian researcher was one of the signatories.

An issue that came up in this letter, in the statement prepared by Dr. Davis, at the CFSAC meeting and in general discussions is the question of which institute of NIH is or should be responsible for ME/CFS. ME/CFS has been acknowledged as a multi-systemic acquired chronic condition with a hallmark symptom post-exertional malaise (also known as post-exertion collapse, post-exertional neuroimmune exhaustion or systemic exertion intolerance). The NIH grants which have been awarded to study the biological underpinnings of ME/CFS have come from a wide range of Institutes including NINDS, NIAID, Office of the Director and the Institute of Nursing Research. Dr. Davis found his proposals in the middle of a ping-pong match between two institutes.

In a video, Dr. Davis noted that his son scores normal on usual tests, but scored an astonishing 16 standard deviations from the mean on a special test. The implication is that ME/CFS is very different from commonly-considered diseases and that new approaches are needed. Dr. Davis describes ME/CFS as perhaps the last major unexplored area of medicine. He mentions that there are other diseases like it. While he doesn't mention FM, that is an obvious candidate. He suggests the establishment of a new institute at NIH to look into this area.

In summary, the issue of ME/CFS research is being actively discussed in the US, there is increasing recognition of the seriousness of the disease, and the pressure for change is growing.

Many of the issues raised in the discussions apply equally to Fibromyalgia as to ME/CFS. Although the IOM, P2P and AHRQ reports were commissioned to deal with ME/CFS, they did acknowledge the often co-existing condition of Fibromyalgia and its clinical overlaps with ME/CFS. There were several presentations at the P2P Workshop dealing with overlapping conditions and the need for research studies that take these conditions into account. The IOM report (footnote 1 pp. 145-147) discusses some of the issues related to distinguishing ME/CFS and FM while the AHRQ report (footnote 3 page ES-10 and 89) specifically highlights the need for diagnostic instruments that would enable the conditions to be clinically distinguished.

As always, the National ME/FM Action Network is prepared to work with CIHR to more research into ME/CFS and FM forward.

Yours truly,

*Margaret Parlo*r

President

Handout for Candidates →

ME/CFS AND FIBROMYALGIA IN CANADA

ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) and FM (fibromyalgia) are chronic, neuroimmune diseases which can severely impair both physical and cognitive function.

PREVALENT

756 000

Canadians have a diagnosis of ME/CFS and/or FM[1]

More Canadians have ME/CFS or FM than have breast cancer, multiple sclerosis and Parkinson's disease combined[1,2,3]

47%

of ME/CFS

patients need help with tasks such as preparing meals, housework and getting to appointments (FM 38%, cancer 27%)[1]

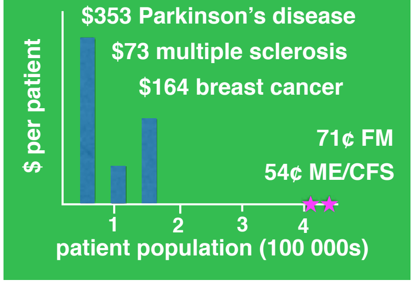
DISABLING

20%

of working age Canadians who are permanently unable to work have ME/CFS and/or FM[1]

CIHR Research Funding

Fiscal Year 2014-2015[1,2,3,4,*]



$15 Billion

per year is the estimated loss of productivity in Canada due to ME/CFS and/or FM[1,5]

UNDERFUNDED

Canada should be funding ME/CFS and FM research at a level commensurate with their impact, severity and prevalence. There are no Health Canada approved treatments for ME/CFS and only a few modestly helpful ones for FM. Investigating the underlying biological mechanisms, and developing diagnostic tests and treatment protocols for ME/CFS and FM should be a priority.

* CIHR - The Canadian Institutes of Health Research. 1. Parlor, M. 2010 Canadian Community Healthy Survey, Quest #88, 2011. 2. Statistics Canada. Table 105-1305 - Neurological Conditions in Institutions in Canada, 2011/2012. 3. Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2015. Toronto, ON: Canadian Cancer Society, 2015. 4. CIHR Funded Research Database. 5. Reynolds KJ, et al. The Economic Impact of Chronic Fatigue Syndrome. Cost Effectiveness and Resource Allocation 2004, 2:4. For more information, please visit www.mefmaction.com.

NATIONAL ME/FM ACTION NETWORK

EM/SFC ET FIBROMYALGIE AU CANADA

L’EM/SFC (encéphalomyélite myalgique/syndrome de fatigue chronique) et la fibromyalgie (FM)
sont des maladies chroniques du système neuro-immunitaire,
qui peuvent avoir des effets graves sur les fonctions tant physiques que cognitives.

DES MALADIES TERRIBLEMENT RÉPANDUES

756 000

Canadiennes et Canadiens ont reçu un diagnostic d’EM/SFC, de FM ou des deux[1].

Au Canada, ces maladies affectent plus de gens que le cancer du sein, la sclérose en plaques et la maladie de Parkinson ENSEMBLE[1,2,3].

47 %

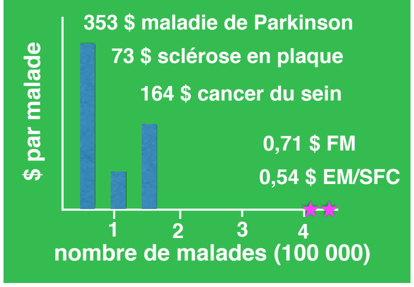
DES PERSONNES SOUFFRANT D’EM/SFC ont besoin d’aide pour préparer les repas, faire le ménage, se rendre à un rendez-vous, etc. (FM 38 %, cancer 27 %)[1]

DES MALADIES TERRIBLEMENT INVALIDANTES

20 %

des gens au Canada en âge de travailler mais en incapacité permanente sont des personnes souffrant d’EM/SFC, de FM ou des deux[1].

Subventions à la recherche de l'IRSC
Exercice fiscal 2014-2015[1,2,3,4*]



15 milliards $

par année : c’est le montant estimé de la perte de productivité au Canada causée par l’EM/SFC, la FM ou les deux[1,5].

DES MALADIES TERRIBLEMENT SOUS-FINANCÉES

Le Canada devrait subventionner la recherche sur l’EM/SFC et la fibromyalgie à un niveau proportionnel à leur impact, leur gravité et leur fréquence. Il n’existe aucun traitement approuvé par Santé Canada pour l’EM/SFC et il n’en existe que quelques-uns aux résultats bien modestes pour la fibromyalgie. Chercher à comprendre les mécanismes biologiques sous-jacents de ces maladies, mettre au point des tests diagnostiques et élaborer des protocoles de traitement devraient être des priorités.

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* IRSC - Instituts de recherche en santé du Canada 1. Parlor, M. (2011) Enquête sur la santé dans les collectivités canadiennes 2010, *Quest,* 88. 2. Statistique Canada. Tableau 105-1305 - Problèmes neurologiques dans les établissements au Canada, 2011-2012. 3. Comité consultatif de la Société canadienne du cancer : *Statistiques canadiennes sur le cancer 2015*. Toronto (Ontario) : Société canadienne du cancer, 2015. 4. Base de données sur la recherche financée par les IRSC. 5. Reynolds, K.J., et al. (2004) The Economic Impact of Chronic Fatigue Syndrome, *Cost Effectiveness and Resource Allocation*, 2:4. Pour en savoir plus, consulter le site www.mefmaction.com.

NATIONAL ME/FM ACTION NETWORK

A New Vision for ME/FM Healthcare

The current healthcare delivery system for ME/CFS and FM does not work. It does not work for patients who have very high levels of unmet healthcare needs. It does not work for taxpayers -- the data shows that patients make numerous visits to doctors looking for help. And it doesn't work for the economy – ME/CFS and FM cause a loss of productivity we estimate to be in the range of $15Billion per year.

$15 Billion/Year in lost productivity

A 2004 US CDC study found a $20,000 per year loss of productivity for each CFS patient. Multiplying $20k by the number of people in Canada with a diagnosis of CFS or FM gives us $15Billion (using prevalence figures from CCHS 2010) or $16Billon (using CCHS 2014).

Certain assumptions are implicit in this calculation including:

1. that the patients in the 2004 CDC study are representative of ME/FM patients in Canada,
2. that the CCHS prevalence estimates are true prevalence numbers,
3. that the productivity impact of CFS has not changed over time,
4. that there was no inflation between then and today, and
5. that the US and Canadian dollars are at par.

We do have information on assumptions 4 and 5; factoring in inflation and the exchange rate would increase the estimate. Under assumption 1, we do know that the CDC study was restricted to people aged 18-69. We included Canadians aged 12-17 and 70+ who would be expected to have lower productivity losses, but this could be offset by caregiver productivity losses. We don't have any more information on assumptions 1, and we don't have information on assumptions 2, or 3. Studies are needed.

So what should ME/CFS and FM healthcare look like?

- ME/CFS is a complex medical condition affecting multiple body systems. It is extremely important that patients with the signs and symptoms of ME/CFS be seen on a timely basis by a medical specialist who has the necessary training and expertise to diagnose the disease. It is extremely important that patients with diagnosed ME/CFS be seen on a regular basis by a specialist in ME/CFS to monitor symptoms and to manage the disease in order to minimize its impact.
- FM is a complex medical condition affecting multiple body systems. It is extremely important that patients with the signs and symptoms of FM be seen on a timely basis by a medical specialist who has the necessary training and expertise to diagnose the disease. It is extremely important that patients with diagnosed FM be seen on a regular basis by a specialist in FM to monitor symptoms and to manage the disease in order to minimize its impact.
- Because ME/CFS and FM are frequent found in the same individual and because it is medically important to determine whether a patient has one, the other or both, the same specialists should handle both ME/CFS and FM.
- It is questionable whether any existing medical specialty is positioned to serve the ME/FM community. Either an existing specialty needs to expand its scope or a new medical specialty needs to be created.

System of specialists:

There are about 80,000 active medical doctors in Canada. About half are in primary care (family medicine) and about half are specialists.

Specialists are divided into clinical specialists (~27k), laboratory specialists (~2k) and surgical specialists (~10k).

Among clinical specialists, the largest category is internal medicine (~9k). Internal medicine has a number of sub-specialties including rheumatology, cardiology, endocrinology and metabolism, gastroenterolgy and immunology (but not neurology). Other major specialties are psychiatry (~5k), pediatrics (~3k) anesthesiology (~3k), diagnostic radiology (~3k), and neurology (~1k). The smallest specialty is medical genetics with about 100 doctors.

Here are a few observations:

- ME/CFS and FM are too complex to be handled exclusively by primary care physicians. Specialists are needed.
- ME/CFS and FM do not fit within any one of the existing specialties and no specialty currently claims responsibility for ME/CFS or FM.

Either ME/CFS and FM have to be assigned to an existing specialty which will have to expand its mandate, or a new specialty is required

- There should be enough ME/FM specialists to meet the medial needs of the ME/FM community.

How many specialists?

In our submission to the Finance Committee, the Network suggested that an extremely conservative estimate would be 300 specialists. We arrived at the estimate as follows: Rheumatologist deal with Inflammatory Arthritis (IA). The model of care for IA is that everyone is referred to a specialist for diagnosis and treatment. There are just over 400 adult and pediatric rheumatologists for one million Canadians with IA. The 2010 prevalence count for ME/FM was three quarters that of IA. Hence 300 ME/FM specialists.

On examination, this estimate seems to be far too low for ME/FM. Assuming all 300 ME/FM specialists see patients 40 hours a week and 50 weeks a year, there are 600k available hours for patient care. This is less that an hour per year per ME/FM patient. ME/CFS and FM are complex illnesses and the procedures for treatment have not been standardized to the same extent as the procedures for IA, meaning that specialists have to take more time with ME/FM patients and that they cannot delegate as much to support staff. The assumption that the specialist sees patients full time leaves the specialists with no time to receive training, provide training, attend conferences, follow research, conduct research, administer their offices, etc.

The Network suggests that planning get underway immediately to develop specialists using 300 as the interim target. Three hundred physicians may seem like a large number, but it is less than half of one percent of the physicians in Canada today. At the same time, a study could be undertaken (perhaps by the health human resources team at Health Canada) to determine how many additional specialists will be needed. The planning target would then be adjusted accordingly.

- There needs to be an associations of ME/FM specialists to promote care, education and research, as there are for other medical conditions.

Role of Specialist Organizations

Examples:

CSIM – Canadian Society of Internal Medicine

Mission : The CSIM is a non-profit professional society that promotes the health and well being of Canadian patients, their communities, and their health care systems. We seek to foster leadership and excellence in the practice of General Internal Medicine (GIM) through research, education, and advocacy for health promotion and disease management.

Canadian Neurological Society (CNS)

Mission: To enhance the care of patients with diseases of the nervous system through education, advocacy, and improved methods of diagnosis, treatment and rehabilitation.

Canadian Rheumatology Association (CRA)

The mission of the Canadian Rheumatology Association (CRA) is to represent Canadian Rheumatologists and promote the pursuit of excellence in Arthritis Care, Education and Research.

Research Notes

Do You Have Fibromyalgia?

A team of researchers at the University of New Brunswick (Department of Psychology) and at Saint-Thomas University (Department of Gerontonlogy), led by Dr. Sandra Byers, are conducting a research study about relationship and sexual well-being in people living with fibromyalgia. In order to develop effective interventions to prevent or ameliorate any negative effects of FM on sexual well-being, we are interested in hearing your first-hand account of how living with fibromyalgia has impacted your relationship and sexual well-being.

If you are a man or woman aged 21 or over, have been diagnosed with fibromyalgia, are in a romantic relationship of at least 12 months, and live in Canada, you can participate in this study. However, we will not be able to include people with certain serious illnesses (e.g., cancer).

By participating, you will complete a background questionnaire and participate in an audiotaped individual interview. The interview will take approximately 1.5 hours. To compensate you for your time, you will be given a $50 gift card.

If you would like to participate or would like more details about the study, please contact the research group at hsrg@unb.ca, (506) 452-6301

This study is on file with the Research Ethics Board of the University of New Brunswick (File number REB 2013-142.)

What psychologists think of IMEs

In a study out of Australia (with a Canadian co-author), psychologists who work with people applying for or receiving Workers' Compensation were asked about their views on Independent Medical Examinations (IMEs). Here are two quotes from the study:

Most psychologists said that session time was taken up by helping injured workers to cope with the anxiety that they felt about impending IME assessments. Further session time was frequently taken up with debriefing, in an effort to address any negative sequelae and offset potential deterioration in the injured worker's psychological function.

Independent medical examinations were viewed by psychologists as an inescapable by-product of being involved with the workers' compensation system that had powerful ramifications for injured worker recovery. Psychologists were frustrated by IME-related issues that intruded into therapy and felt unfairly evaluated by examiners who sometimes had little understanding of psychological therapy. Psychologists described the current IME system as flawed and adversarial which contributed to delayed recovery for injured workers and withdrawal of services by some practitioners. In essence, participants felt the current IME process was unfair to injured workers and to psychologists alike.

The study goes on to suggest ways that the IME system could be made more palatable for psychologists and patients.

For people going to IMEs, recognize that they have the potential to delay recovery, and try not to let that happen to you.

Procedural Justice and the Use of Independent Medical Evaluations in Workers' Compensation, E Kilgour et al.

The Canadian Community Health Survey

The tables on the right present results from the 2014 Canadian Community Health Survey. Table 1 shows the prevalence of ME/CFS, FM and MCS in Canada. Table 2 shows the percentage of Canadians with chronic illnesses that report unmet health care needs. Once again Chronic Fatigue Syndrome and Fibromyalgia are at the top.

Notes:

Master versus Share File:

You may notice slight differences between the prevalence numbers in this newsletter and numbers we sent by email in June. This is because the numbers in this newsletter are based on the "share file" while the previous numbers were based on the "master file".

Participating on future surveys:

CFS, FM and MCS are included on CCHS in 2015 and 2016 (but will not be included in 2017 or 2018). If you are the 1 in about 250 Canadians invited to complete the 2015 or 2016 survey, we encourage you:

- to agree to participate because you have important information to share,
- to answer yes to "Chronic Fatigue Syndrome" if you have a diagnosis, even though we are all uncomfortable with the name. Otherwise, we won't know about you, and
- to agree to share your individual records, minus name and address, with provinces and universities. This allows your record to get on the share file and be used in provincial/academic studies. While nobody can absolutely promise that the information won't be misused, there are many, many protections in place to make this extremely unlikely.

COMMUNITY ART GALLERY

In honour of

NATIONAL PAIN AWARENESS WEEK

Participant body map from the study, *Maps of Marginalization: Exploring the Healthcare Experiences of Men and Women with Fibromyalgia* (Skop, 2015).

FRIDAY NOVEMBER 6TH
1:00-3:00PM

FACULTY OF SOCIAL WORK AUDITORIUM
WILFRID LAURIER UNIVERSITY
120 DUKE STREET WEST
KITCHENER, ONTARIO

Presentation by:

Dr. Michelle Skop, PhD, RSW

An Overview of Findings from a Study about the Healthcare Experiences of People with Fibromyalgia

Please join us for information booths, refreshments, and a display of body map artwork created by people with fibromyalgia.

For additional information please contact:
michellejskop@gmail.com

SCENT-FREE ENVIRONMENT

Parking on side streets
& at Kitchener City Hall

Elevator access via side building
entrance on College Street

Community Partners:

- Canadian Pain Coalition
- Kitchener-Waterloo Fibromyalgia Support Group
- Waterloo Wellington Myalgic Encephalomyelitis Association

Table 1 : Canadians with Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitvities, 2014

Condition	No. with Condition	% with Condition
CFS	412,000	1.4
FM	519,000	1.7
MCS	732,200	2.4
CFS and/or FM	814,700	2.7
One or more	1,445,700	4.8

Source: Statistics Canada, Candian Community Health Survey, 2014, Share File

Table 2: Canadians Self-Reporting Unmet Health Care Needs according to their Chronic Health Condition, 2014

Chronic Condition	% with Unmet Health Care Needs
Chronic Fatigue Syndrome	33.6
Fibromyalgia	28.1
Stomach or Intestinal Ulcers	25.5
Anxiety Disorder	25.0
Mood Disorder	23.9
COPD	22.8
Multiple Chemical Sensitivities	22.5
Effects of a Stroke	22.1
Bowel Disorder	22.0
Migraines	19.1
Cancer	18.9
Back problems	18.4
Asthma	17.4
Urinary Incontinence	17.0
Arthritis	15.7
Total Population	11.2
Heart Disease	11.0
High blood pressure	10.9
Diabetes	10.8

Source: Statistics Canada, Candian Community Health Survey, 2014, Share File

COPD = Chronic Obstructive Pulmonary Disease

Arthritis = ages 14+; COPD = ages 35+; Urinary Incontinence = ages 25+

Opera Maripoza

PEOPLE LIKE US
a new musical theatre revue
May 14, 2016 @ 7:30 pm

Join Mariposa's multi-award-winning performers for our fourth annual charity benefit production! Our new Broadway revue *People Like Us* frames modern musical theatre songs in an innovative new setting, as multiple lives (and Broadway shows) intersect one night in New York City. Enjoy an evening of hit songs performed by talented young artists from across the Lower Mainland. In honour of May 12th International Awareness Day for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM), a portion of every ticket sale will support charities that aid people living with chronic neuro-immune diseases. The evening will include a charity raffle contest, as well as a reception for those who wish to stay.

http://mefmaction.com http://twitter.com/mefmaction http://www.facebook.com/MEFMActionNetwork

NATIONAL ME/FM ACTION NETWORK

512-33 Banner Road, Nepean, ON K2H 8V7 Canada
Phone: 613-829-6667 • Fax: 613-829-8518
Email: mefminfo@mefmaction.com • www.mefmaction.com

(BN) 89183 3642 RR0001

Resources

Item	Qty	Total
Membership Fee $30		
ME/CFS Brochure (Eng)		*free*
ME/CFS Brochure (Fr)		*free*
FM Brochure (Eng)		*free*
FM Brochure (Fr)		*free*
ME/CFS Overview $7		
FM Overview $7		
TEACH-ME (Eng) $25		
TEACH-ME (Fr) $25		
CPP Disability Guide $10		
Primer-Bilingual Edition $25		
SUB TOTAL		

Please transfer the above "sub total" onto the front, to tally in to the total payment being made.
Thank You

THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter—Free with annual membership of $30.00

When you become a member of the National ME/FM Action Network, you receive our quarterly newsletter QUEST. We keep you informed about medical research, disability and legal issues and on developments affecting the ME/FM community in Canada and internationally.

ME/CFS and FM Brochures - FREE

Coloured pamphlets on ME/CFS and FM are available in English and French. You can view them on our website

Consensus Documents for ME/CFS and FM

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols [Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004 ISBN:0-7890-2207 9]
- The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4]

The consensus documents are available at Amazon.ca or at Chapters.ca or view them on our website.

ME/CFS and FM Overviews - $7.00

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents.

- You can view the ME/CFS Overview in English, French, Spanish, German, Italian and Dutch on our website. English versions of the ME/CFS Overviews are available for purchase from the National ME/FM Action Network. French versions of the ME/CFS Overview are available for purchase from Quebce Association for ME, AQEM (aqem.ca)- call (514) 369-0386 or 1-855-369-0386 or email info@aqem.ca.
- You can view the FM Overview in English, French, Spanish and Italian on our website. English versions of the FM Overview are available for purchase from the National ME/FM Action Network.

TEACH-ME (Second Edition) - $25.00

Our TEACH-ME Source Book is for Parents and Teachers of children and youth with ME/CFS and/or FM. This document is available in English and French.

CANADA PENSION PLAN DISABILITY GUIDE 2015 Edition- $10.00

A Guide designed for those who are disabled and wish to apply for Canada Pension Plan Disability Benefits. It outlines the various steps in the process.

Chronic Fatigue Syndrome / Myalgic Encephalomyelitis - Primer for Clinical Practitioners

Syndrome de fatigue chronique Encéphalomyélite myalgique - Petit guide pour la médecine clinique - $25.00

The ME/CFS Primer was produced by the International Association for Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (IACFS/ME). It was translated into French by the National ME/FM Action Network. You can view both the English and the French on our website. Bilingual versions are available for purchase from the National ME/FM Action Network.

All of the above resources can be viewed on the

National ME/FM Action Network website at **http://mefmaction.com**

NATIONAL
ME/FM
ACTION NETWORK

MEMBERSHIP APPLICATION or RENEWAL FORM

Please see reverse for available network resources.

NEW MEMBERSHIP or RENEWAL fees

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

Resources $____________
Please see reverse

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

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month ______ year ________

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Date: ____________________

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Contact Name ____________________________________

Address ____

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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

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☐ 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