NATIONAL ME/FM ACTION NETWORK
Charitable tax no. (BN) 89183 3642 RR0001 ISSN 1205-786X

Quest
Newsletter

www.mefmaction.com Quest 97, Winter 2014 mefminfo@mefmaction.com

In This Issue

2014 is just underway. The National ME/FM Action Network looks back at 2013 and sees many signs of progress. Among other things, the clinic in BC started seeing patients, a team in Ontario documented the need for improved services there (see page 2) and the Network identified some ways that services could be improved at the national level (see page 9).

We look forward to continued progress in 2014. The Network is planning for the IACFS/ME conference in San Francisco in March. I have been invited to appear on the Public Health panel chaired by Dr. Elizabeth Unger of the CDC. My presentation will be based on the statistical report prepared for the Ontario project. Special credit goes to Erika Halapy who was the primary author of that report.

We are also planning for May 12, Awareness Day. We tried for funding through the Aviva Community fund on-line contest. Funding would have allowed us to take on some important projects, but it was not to be. We are looking at what we can do with the resources we have available to us. The Network is very good at doing a lot with very little. Some ideas appear on page 7.

We were truly delighted to have the opportunity to publish a remarkable poem by Kitty Ibele which looks at the impact of ME on her relationship with her Dad (see page 16). Kitty presented her poem at the School of Pharmacy at the University of Waterloo. You can watch her presentation on the WWMEA (Waterloo-Wellington ME Association) facebook page: *https://www.facebook.com/photo.php?v=418107628316189.*

Contents

Big Step forward in Ontario

Glossary of Abbreviations used:

Conditions:

ME/CFS - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

FM - Fibromyalgia

ES/MCS - Environmental Sensitivities/Multiple Chemical Sensitivity

CELCs - Chronic Environmentally-linked Conditions, an umbrella term used in some of the Ontario reports for ME/CFS, FM and ES/MCS

Organizations:

MEAO - The Myalgic Encephalomyelitis Association of Ontario

AOHC - Association of Ontario Health Centres (There are 120 community-governed health centres in Ontario)

MOHLTC - Ministry of Health and Long Term Care (Ontario)

OCEEH - Ontario Centre of Excellence in Environment Health, the proposed new organization to serve the ME/FM/MCS community

OTF - Ontario Trillium Foundation (the grant-giving agency of the Ontario government)

Other:

BCP - Business Case Proposal

PCP - Primary Care provider

The Ontario government now has the evidence they need to justify new services for the ME/FM/MCS community in Ontario. MEAO and AOHC have taken a hard look at what is needed at the provincial level. They approached the issues from four directions:

By looking at data

- Δ *The Quantitative Data* is a 47 page document using statistics to show the situation facing Ontarians with ES/MCS, FM and ME/CFS

By interviewing patients and caregivers and drawing on experiences of people working in the field

- Δ *Recognition, Inclusion and Equity – The Time is Now - Perspectives of Ontarians Living with ES/MCS, ME/CFS and FM* – is a 264 page report is based around focus groups of patients and caregivers which were held in summer 2012. There is a 35 page document with highlights of this report.

By examining the state of academic and clinical knowledge about ME/FM/MCS.

- Δ *Academic and Clinical Perspectives – Ontario Centre of Excellence in Environmental Health – Chronic Complex Conditions* is a 202 page report documenting the current medical situation and proposing how the medical needs of Ontarians with these conditions could be met.

By looking at the architectural needs of a clinic.

- Δ *Architectural Considerations for the Ontario Centre of Excellence in Environmental Health* is a 14 page, technical document looking at construction guidelines for clinics serving people with ES/MCS

Check the MEAO site for the full reports:
http://meao.ca/events-dec5.html

The documents are now being considered by the Ontario government as part of the budget process for the 2014-15 fiscal year.

Some Quotes:

By far, the most important finding for future state planning was this: where study participants did find expert health professionals who were familiar with their conditions, they had exceptional, life-changing, often life-saving positive support which raised their quality of life, and in significant cases, restored productivity and ability to function in many social spheres.

[Since a committee of inquiry into environmental hypersensitivity 30 years ago] Ontario lost a significant number of physicians who used to care for people living with these conditions, even as the numbers of those afflicted increased at an alarming rates. As a result, individuals living with the CELCs and their families have experienced invisibility, exclusion and discrimination in our health and social services systems, resulting in great suffering and hardship.

As far as our current state is concerned, our community consultation and our environmental scanning processes over several years revealed what we have called a “void in services with a few tiny islands of assistance.” It also revealed a body of knowledge and practice that, when Ontarians are able to access, makes an extraordinary, life-changing difference for the better in their lives. So we feel confident in saying that now truly is the time to take the steps needed to bring about the implementation of our goals and aspirations.

Small and piece-meal initiatives alone are unlikely to solve this “void in service”. Instead, a whole-system strategy for the “normalization” of these conditions is urgent and imperative. Two types of recommendations are involved.

1) Direct services – through a new and dedicated network of service delivery, based in primary care, comprising the OCEEH hub, its regional spokes, and, eventually the whole primary care system in the province.
2) Policy shifts in the MOHLTC, broader health care system and in relevant and related government ministries – to accelerate change and remove systemic barriers.

Facilities**:**

1 Tertiary care main hub in the Greater Toronto Area

Provincial resource

Referral centre for the whole province (the spokes and other health care professionals)

10 Primary and secondary care “spokes” in selected regions – 6 to begin

Providing on-site and linked health and social supports to clients with the 3 conditions and their families

To act as regional resource centres for all primary care providers in their area

Primary Care Providers

All PCPs have referral access to the whole OCEEH, ie to spokes or to the hub

PCPs a priority for physician education initiatives

Eventually (5-7 years) it is hoped that most PCPs will have sufficient knowledge to be able to identify, diagnose and treat; or to be able to identify and refer for more specialized support.

Statistics Canada Canadian Community Health Survey 2014

Statistics Canada will be asking about Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities on the Canadian Community Health Survey questionnaire throughout the year 2014. The questionnaire goes to about 1 in every 500 Canadians. Some readers of this newsletter could be asked to complete the survey.

If you are asked, we do encourage you to participate. The information provided in past surveys have been very useful to us.

One particular issue is Statistics Canada’s use of the term “chronic fatigue syndrome”. Many people prefer the term “myalgic encephalomyelitis”. This has been drawn to Statistics Canada’s attention, but it was too late to make a change to the 2014 survey. If you are surveyed and asked about “chronic fatigue syndrome”, you can ask the interviewer to note that you prefer the term “ME” but please accept “chronic fatigue syndrome” for now. Otherwise, your experiences with ME won’t be recorded.

Fibromyalgia Health, Diet Guide & Cookbook

This book, written by leading experts in fibromyalgia, gives common sense tools that will help fibromyalgia patients help themselves on to a road to improvement and perhaps recovery. There are few books on fibromyalgia that provide a program for recovery and a cache of antifibromyalgia foods and recipes as successfully as this book. It uses The SEEDS of health approach (Support, Environment, Exercise/Pacing, Diet/Drugs, Sleep) and has shown significant success rates in patients.

The goal of this book is to help patients improve their ability to function and their quality of life. The treatment approach is centered around rebuilding: helping to decrease pain, control inflammation, improve sleep, improve cognitive function (reduce brain fog) and improve energy levels. The book is also a source of support for family and friends.

Part 1: Understanding Fibromyalgia Causes, patient profile, symptoms, assessment tools, diagnosis

Part 2: Managing Fibromyalgia
SEEDS of health program, medications, complementary and alternative medicines, dietary therapy and strategies

Part 3: Fibromyalgia Diet Program
Step-by-step plan including shopping lists, shortcuts for meal preparation & meal schedules

Part 4: 125 Recipes for Breakfast, Lunch, Dinner & Snacks.

About the Authors:

Dr. Louise S. McCrindle B.Sc. (Hons), ND is a naturopathic doctor and currently in charge of the Fibromyalgia and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinic at the Robert Schad Clinic, affiliated with the Canadian College of Naturopathic Medicine in Toronto.

Dr. Alison Bested MD, FRCPC has devoted the last 20 years of her practice to treating fibromyalgia patients, myalgic encephalomyelitis/chronic fatigue syndrome, and multiple chemical sensitivities. Recently she has been appointed the Medical Director of the Complex Chronic Diseases Program at BC Women's Hospital in Vancouver, British Columbia

Decisions on Disability – The UK experience

In 2008, the United Kingdom government introduced the "Employment and Support Allowance" (ESA) program. The ESA is aimed at people of working age who are found to have limited capability for work. The ESA encompasses aspects of Canada's Employment Insurance sickness benefits, provincial disability benefits and Canada Pension Plan disability benefits.

In 2010, the UK announced that everyone already receiving benefits under the previous disability support program would have to re-qualify under the ESA program. At the same time, the government introduced the "Work Capability Assessment" (WCA). The WCA is a scoring sheet with 17 areas of impairment (manual dexterity, understanding communications, etc.) The French company Atos Healthcare was given a contract in the range of 100M British pounds per year to conduct the assessments. Applicants with very obvious disabilities could qualify for ESA without a WCA. All others would be interviewed by a health professional working for Atos. The interviewer would review written documentation and ask the applicant questions in order to complete the WCA scoring sheet. The findings would be passed to employees of the Department of Work and Pension (DWP). Generally a score of 15 or higher on the WCA would qualify someone for the ESA. The decision can be appealed but appeals involve time, effort and stress.

In 2011, as a result of a program evaluation, the DWP set up two advisory groups from disability organizations to comment on the WCA. The government then developed an "Alternative Assessment" (AA) scoring sheet and designed a study to see if the AA would be an improvement over the WCA. The report on the study was released in December 2013.

The study can be summarized in simple terms. A number of people applying or reapplying for disability benefits were selected, not entirely at random. Three different methods were used to determine whether the applicant was "fit for work".

Method 1: The "Work Capability Assessment" (WCA) scoring sheet.

Method 2: The "Alternate Assessment" (AA) scoring sheet.

Method 3: Determination by "expert panels" based on a review of each applicant's paper file.

The UK study assumed that the expert panels were correct, looked only at the question of whether the AA should replace the WCA, and decided that "[t]here was no evidence that the AA was a significant improvement on the WCA ...However, the AA did reveal some areas... which have relevance for the ongoing refinement of the WCA."

End of story? Not at all.

In my mind, the most important finding in the study was that the WCA and the expert panels were arriving a quite different results. There were times when the both methods designed a person as not-fit-for-work, but were many more cases where someone was found unfit using one method and fit using the other. The lack of agreement between the scoring tool and the expert panels should set off alarm bells that there is a fundamental problem in the whole system.

So I went back to see if there were criticisms of the ESA system in general and indeed there were. Disability groups have been complaining for a long time. Their complaints have been picked by newspapers. In May 2013, a whistleblower joined the fray. Dr Greg Wood worked for 17 years as a navy doctor and then was hired by Atos in 2010. He resigned in 2013 after having been asked to change an assessment from unfit to fit. He alleged that staff training included elements that were contrary to program policy and detrimental to applicants. The Secretary of State for Work and Pensions since 2010 has asked Atos to conduct retraining and recently stated that "We're not mucking about here, this is really serious stuff" and " We are picking up the mess...the mess we picked up with WCA was astronomical." The Prime Minister is quoted as saying "Everyone...knows that we need to improve the quality of decision-making".

The other aspect of the study that interested me was the content of the WCA and the AA. I went back to one of the advisory group reports to see what their recommendations had been. It turns out that the committee had made some very important recommendations that were not reflected in the AA.

The advisory group had observed that if one is to make decisions about capability of working, one has to have a definition of work, and there is no definition of work in the ESA model. The group endorsed an Australian model that says that *"in order to be 'capable of work', the claimant should be able to:*

- *Work for at least 15/16 hours each week in meaningful work that pays the national minimum wage or above.*
- *Reliably perform their work on a sustainable basis without requiring excessive leave or absences. The Australian system takes this to be at least 26 weeks.*
- *Work in open unsupported employment without requiring excessive support to perform their work.*

In addition, the claimant must be able to prepare themselves for work and safely travel to and from work, without these factors having an adverse effect on their health or disability.

The advisory group report also pointed out that the ESA regulations say that, even if a person does not qualify for disability under the WCA, they can be declared disabled if working could adversely affect their physical or mental health.

The group's observations would suggest a two step process for determining fitness for work. Step one would ask whether a claimant can prepare for work, travel to and from work, and work 15/16 hours per week. If the applicant passes this test, step two would ask whether the applicant would need excessive support, would need excessive time-off, or would be risking their health by going to work.

Dr. Wood, the whistleblower who did assessments for several years, also addressed the question of how the system should have been designed. He concluded that

The first question that the designers would have had to answer is:

Δ *What is meant by 'work'?*

Is it working down the pit, in a foundry, building ships, or putting cars together by hand? Well yes, but we don't do much of that in this country anymore; those activities have either gone overseas or have been mechanised. Nowadays, working in a call centre, typing data into a computer, driving a vehicle, working on reception, security work, food handling, and caring for others are more typical forms of work.

Δ *So what abilities does a person need to do these jobs?*

They require adequate hearing; good manual dexterity, vision and mental concentration and an ability to sit for long periods; good interpersonal skills; physical

> *fitness; an awareness of safety issues; a sense of responsibility; and a high degree of empathy.*

Later he makes the following observation which is relevant to the ME/FM community: *"A snapshot functional test will never adequately gauge conditions like ME, fibromyalgia, migraine, epilepsy, mood disorders and anxiety. In all likelihood, these kinds of conditions are best assessed using medical knowledge and the evidence from the claimants' doctors, as well as the history from the patients themselves."*

The UK government is learning the hard way that determining disability is a difficult proposition that affects people in very fundamental ways. How they are going to get out of the mess they are in is not clear. They have to deal with the assessments awaiting decisions and the decisions under appeal. There is a hint that they will try moving the emphasis from the disabled individuals to making workplaces more welcoming.

For more information, go to:

http://worktestwhistleblower.blogspot.ca/

http://www.meassociation.org.uk/2013/12/report-on-the-evidence-based-review-of-proposals-to-refine-the-work-capability-assessment-summary-and-statement-from-the-mea-17-december-2013/

Planning for Emergencies

An email from Alison Rae to MEAO and the team that put together the Ontario Proposal, written five days after the ice storm hit Toronto and other parts of eastern Canada.

Merry Christmas! I hope you've survived the ice storm.

We had a situation Monday that I think a solution to it should some how be incorporated into the project vision and the services provided by the hub/spokes and patient organizations.

I got home from being in Toronto only to find a message on Facebook and another on Twitter from a Toronto ME patient that is severely disabled - essentially bed bound. She was unable to contact any of the emergency numbers, her power was out and all her assisted devices were about to run out of battery power. She had live wires down behind her apartment building she was trying to report. Also she was worried about her food going bad. She needed help.

To make a long story short, it took over 3 hours, but myself and some fellow facebookers in BC got the police to finally go find her and made sure she was getting adequate care. We're still waiting to see her come back online to know for sure she's alright. We also started a Facebook card and started a fund raiser to help her replace her food.

What has come out of this, is that emergency responses need to do better for disabled individuals in general and specifically ME/FM/MCS sufferers. We need a way to have people registered and a way to contact them to ascertain their status and give them whatever aid is necessary both during the disaster and after. We also need a way for them to contact us for assistance when the standard emergency lines are overloaded with calls.

Exactly how to best accomplish this needs to be studied, but we need a safe place for people to go, safe food to eat, medical care, medicines, transportation to safe sites, assistance with dealing with insurance adjusters and clean up crews just to name a few areas of concern. The solutions need to be in every response plan in Ontario (and Canada) and understood by organizations like Red Cross, hospitals, paramedics, police and fire.

Our patient community needs to articulate our requirements in an emergency situation and to have input to all emergency response plans.

I realize this is easier said than done, but I think it must be a deliverable as we move forward. We may be able to take advantage of this storm to do some of the data gathering now from patients while it is fresh in their minds. I expect there will be a review of the response and we should try to be a part of that review.

A situation like the ice storms in Toronto would be extremely difficult for our patient community to deal with and I think we must find ways to provide assistance. Perhaps MEAO can even do something now to assist people with the aftermath of this storm.

I hope this will be possible.

Regards

Alison

Fundraising and Awareness Raising

The National ME/FM Action Network entered the Aviva on-line voting contest, looking for up to $100k for awareness activities. While we did well in the first round of voting, we were eliminated in the second round. We would like to express our appreciation to everyone who supported us. One day our time will come.

Just as we were dealing with the disappointment of the Aviva contest, we received the following email which buoyed our spirits.

Holiday greetings to the Network,

I sent a donation about a week ago; thank you for canvassing for donations, it is a very good idea, and much needed! I have trimmed back my donations to other causes, as I realize we need to crowd fund our own cause. It does not appear our Federal Government will be stepping up to the plate anytime soon to provide research/treatment money, so we need to do what we can.

I have a few ideas for May 12th awareness day:

I plan to purchase some more Overviews from the Network, and donate them to our regional library system. I hope to donate Overviews to a medical library as well. I plan to do a "press release"/letter to the editor of local newspapers re the addition of Overviews to our regional library. Maybe other members of the Network, who can afford to, would like to do this in their own cities as well?

I have read on the Internet about something called Thunderclap. It appears to be a group email/messaging website, where several people of like mind, sign up to email a specific message to recipients all at once. My understanding is that we could organize with Thunderclap to email: politicians, newspapers etc., all at once on, or just before May 12th with a message from the Network.

This idea is more time consuming, but local cable outlets sometimes have their volunteers do short TV programs/ads for NGO's, or assist the NGO's to do the program themselves. My suggestion would be a TV ad/announcement/program on children with ME. Maybe the Network has already done this? Perhaps media/communications students could get involved in this as a project for the Network.

In the past, I have sent hand painted cards to politicians with a message about ME. I hope to do some of this again. This is a very time consuming endeavour, but if anyone in the Network wants to try it, I have personally found that I do get pretty much a 100 percent positive response. At least to my card/painting.

I donate paintings to a few local fund raisers. This helps the organizations, as well as me, as I receive a tax receipt, and maybe a bit of money too!

These are some ideas I have been mulling over. I hope some of them are of interest to The Network.

Thanks for your time and consideration, and all the best to everyone at the Network this Christmas, and in 2014!

Contacting the Prime Minister

You may have considered writing or phoning the Prime Minister. You may have already done so. Many people have. Here are some statistics taken from a story in the Ottawa Citizen by Jason Fekete, November 15, 2013.

In 2012-13, Prime Minister Stephen Harper received more than

1.4 million pieces of electronic mail,

320,000 pieces of paper mail, and

13,000 telephone calls.

Of the paper mail correspondence,
28,775 pieces were considered general mail;
12,408 were considered priority mail,
232,187 were considered "write-in campaigns, junk mail, copies",
39,049 were considered greetings; and
8,035 were classified as others

The Prime Minister's Office sent 54,581 pieces of correspondence in reply to those messages. The government says the difference between the correspondence received and the number of items sent is because things such as petitions, thank you letters and some other messages don't require a response.

The bottom line is that many of the messages sent to the Prime Minister do NOT receive replies. Your chances of receiving a reply improve if you state that it is a personal letter and not a copy or campaign and if you ask the Prime Minister for specific information. A letter saying that FM is a terrible condition might be ignored. A letter asking the Prime Minister what the government proposes to do to deal with FM is more likely to receive a reply.

BC Government Consults on Disabilities

The BC government has established a consultation process to explore ways to improve services for people with disabilities. They invite people to submit ideas to their website before March 11, 2014, *http://engage.gov.bc.ca/disabilitywhitepaper*, to attend one of the public meetings being held in January and February, or to mail, tweet or phone in comments.

The consultation process has not won unanimous support. Here is what one commentator wrote (*http://beaconnews.ca/blog/2013/12/disabled-needs-secret-bc-government/*):

The BC Government is not ignorant of what disabled people need. It knows how badly it has treated disabled people since the nineteenth century. But the Government's priority is how to dodge having to act on the facts.

Experience has taught the Government that many disabled people and their families are suckers for what Public Relation fraudsters call "stakeholder engagement." Stakeholder engagement is a magic show intended to create an illusion of democracy. And like all magic shows, stakeholder engagement only works if the audience wants to be fooled.

To which someone replied "I'm a bit of a sucker because I will participate in this process if only to tell them that they should already know what to do."

With that background, we suggest that people do take the opportunity to submit their thoughts and ideas. They may be heard!

Federal funding of National Disability Charities

The National ME/FM Action Network was sent a questionnaire about the "Social Development Partnership Program – Disability Component" (SDPP-D), a program of the Office of Disability Issues (ODI) which is part of the federal department Employment and Social Development Canada (ESDC). The SDPP-D gives out money for disability issues.

This federal department is proposing an application-based, project-based, medium-level funding program for national disability charities. The project basis would not provide our organization with stability. The medium financing would be insufficient to deal with the major needs of the ME/FM community. The application-basis would favour groups with fun projects. While we don't want to miss opportunities for funding, it just didn't seem that this proposal aligns with our needs. We responded to the questionnaire by asking for direct discussions.

The Santa Claus Run, held in Montreal, raised funds for AQEM.

La course des pères Noël , qui s'est tenue à Montréal, a levé des fonds pour l`AQEM.

(Association Québécoise de l'Encéphalomyélite Myalgique)

House of Commons Standing Committee on Finance - Pre-budget Consultations 2013

This brief is submitted by: National ME/FM Action Network (see www.mefmaction.com)

Recommendation 1: Topic: Health

- Create a new institute at the Canadian Institutes for Health Research to investigate health research issues around Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia. This research would support the health care system in addressing the needs of ME/FM patients.
- Provide the new institute with designated long term funding to encourage researchers to move into this field of study.

Expected cost or savings: $100 Million to $499.9 Million over 5 or more years

Federal funding: Reallocation within CIHR. CIHR has $1Billion per year for research. Almost none has been allocated to ME/FM research. Designating some of the CIHR funding for ME/FM research would allow a ME/FM research community to develop to the point that it can eventually compete for funding on an equitable basis with established research areas.

Intended beneficiaries:

- people with ME/CFS and/or FM, their families and caregivers
- health professionals who are grappling inefficiently and ineffectively with these illnesses
- taxpayers who are paying for the inefficient and ineffective health system
- the economy which is losing valuable human resources to these illnesses
- Canada's international reputation in health and research

General impacts:

With better understanding of these illnesses, some cases could be prevented or minimized while the quality of life of other people could be substantially improved.

Comité permanent des finances de la Chambre des communes - Consultations pré-budgétaires 2013

Ce mémoire est soumis par : Réseau national d'action EM/FM (www.mefmaction.com)

Recommandation 1 : Sujet : Santé

- Créer un nouvel institut qui ferait partie des Instituts de recherche en santé du Canada et qui aurait pour mandat d'explorer les enjeux qui touchent la recherche médicale sur l'encéphalomyélite myalgique / syndrome de la fatigue chronique et la fibromyalgie. Cette recherche aiderait le système de santé à répondre aux besoins des patients atteints d'EM/FM.
- Mettre à la disposition de ce nouvel institut un financement à long terme qui servirait à amener les chercheurs à s'intéresser à ce champ d'études.

Coût ou économies prévus : $100 Million - $499.9 Million, 5 ans ou plus

Financement fédéral : L'institut serait financé par la réaffectation de fonds à l'intérieur des IRSC. Le budget annuel de recherche des IRSC est de 1 milliard de dollars, mais presque aucune somme n'est affectée à la recherche sur l'EM/FM. L'affectation d'une partie du financement des IRSC à la recherche sur l'EM/FM permettrait au milieu de la recherche sur l'EM/FM d'avoir autant de chances que les autres secteurs de recherche établis d'obtenir du financement.

Bénéficiaires visés :

- Les personnes atteintes d'EM/SFC et/ou de FM, les membres de leur famille et leurs fournisseurs de soins;
- Les professionnels de la santé, qui n'interviennent pas efficacement auprès des personnes atteintes de ces maladies;
- Les contribuables, qui financent un système de santé inefficace;
- L'économie, qui perd des ressources humaines précieuses en raison de ces maladies;
- La réputation internationale du Canada en santé et en recherche.

Répercussions générales: L'amélioration de la compréhension de ces maladies permettrait de prévenir certains cas ou d'en diminuer la gravité tout en améliorant considérablement la qualité de vie des autres personnes.

Recommendation 2: Topic: Disabled Persons

Create an interdepartmental task force to address the discrimination and stigma facing Canadians with ME/FM. 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/FM.

Expected cost or savings: $5Million-$9.9Million over 2 years

Federal funding: Health Canada funds the Mental Health Commission to undertake an anti-stigma anti-discrimination strategy in the area of mental health, a parallel exercise. Other funding could come from participating departments and agencies.

Intended beneficiaries:

- people with ME/FM, their families and caregivers
- officials who want to provide optimal, inclusive programs and services
- members of the public who encounter people with ME/FM such as employers, co-workers, teachers, fellow students, neighbours and friends
- taxpayers who are paying for an inefficient, ineffective and unfair social system
- the economy which is losing valuable human resources to these illnesses
- Canada's international reputation for justice and equity

Recommandation 2 : Sujet : Personnes handicappées

Créer un groupe de travail interministériel qui aurait pour mandat de régler les problèmes de discrimination et de stigmatisation auxquels font face les Canadiens atteints d'EM/FM. Ce groupe de travail aurait les tâches suivantes :

- examiner les publications et les sites Web du gouvernement pour voir à ce que l'information sur la maladie qu'ils contiennent soit complète et exacte;
- examiner les programmes et les services du gouvernement afin de voir à ce qu'ils soient inclusifs et à ce que les candidats qui en ont réellement besoin y aient accès facilement et sans délai;
- mettre en œuvre une campagne de sensibilisation du public pour voir à ce que les Canadiens soient informés au sujet de ces maladies et des incapacités qu'elles entraînent;
- relever les initiatives supplémentaires nécessaires pour assurer un traitement juste et équitable aux Canadiens atteints d'EM/FM.

Coût ou économies prévus : $5 millions - $9.9 millions, 2 ans

Financement fédéral : Santé Canada finance la Commission de la santé mentale du Canada, dont l'un des objectifs consiste à mettre en place une stratégie de lutte contre la stigmatisation et la discrimination dans le domaine de la santé mentale. Une autre partie du financement pourrait provenir des ministères et organismes participants.

Bénéficiaires visés :

- Les personnes atteintes d'EM/SFC et/ou de FM, les membres de leur famille et leurs fournisseurs de soins;
- Les représentants du gouvernement qui souhaitent proposer des programmes et des services optimaux;
- Les membres du public qui rencontrent des personnes atteintes d'EM/FM, qu'il s'agisse d'employeurs, de collègues, d'enseignants, d'étudiants, de voisins ou d'amis;
- Les contribuables, qui financent un système social inefficace et injuste;
- L'économie, qui perd actuellement des ressources humaines précieuses en raison de ces maladies;
- La réputation internationale du Canada, qui est perçu comme un défenseur de la justice et de l'équité.

General impacts: This recommendation will go a long way toward addressing the social disadvantage experienced by the vulnerable ME/FM community. With better public understanding of the illnesses, there will be less sense of isolation. With better programs and services, there will be less economic and social distress.

Please use this page if you wish to provide more explanation about your recommendation(s).

“If you are sick, you want to have an illness that is well understood and respected. You don’t want to have ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) or Fibromalgia.” Lydia Neilson MSM, CEO of the National ME/FM Action Network since 1993.

According to Statistics Canada’s Canadian Community Health Survey 2010

- There were 756,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia or both. This is equivalent to the population of New Brunswick.
- ME/FM patients were predominantly female and predominantly of working age.

People with ME/FM reported high levels of

- unmet health care needs and unmet home care needs. They are poorly served
- needing help with tasks, difficulty in social situations and permanently unable to work. They are disabled even if they are rarely though of as disabled.
- low income, isolation and even food insecurity. They are socially disadvantaged.

The ME/FM community is a vulnerable community in crisis. Canada can do much better. The Federal government has an important role to play. The two recommendations are major steps toward addressing the needs of this vulnerable community.

Répercussions générales : Cette recommandation fera beaucoup pour atténuer le désavantage social que subissent les personnes atteintes d’EM/FM, qui sont vulnérables. Mieux le public comprendra ces maladies, moins les personnes atteintes se sentiront isolées. De plus, l’amélioration des programmes et des services atténuera la détresse économique et sociale des personnes atteintes.

Inscrivez ici toute explication complémentaire sur votre ou vos recommandations.

“Si vous êtes malade, vous souhaitez à tout le moins être atteint d’une maladie qui est bien comprise et respectée, ce qui n’est pas le cas de l’EM/SFC (l’encéphalomyélite myalgique / syndrome de la fatigue chronique) ou la fibromyalgie.” Lydia Neilson, MSc, PDG du Réseau national d’action EM/FM depuis 1993.

Selon l’Enquête sur la santé dans les collectivités canadiennes de Statistique Canada de 2010 :

- 756 000 Canadiens avaient reçu un diagnostic de syndrome de la fatigue chronique, de fibromyalgie ou des deux, soit l’équivalent de la population du Nouveau-Brunswick;
- la majorité des patients atteints d’EM/FM étaient des femmes en âge de travailler.

Une proportion élevée des personnes atteintes d’EM/FM se trouvent dans la situation suivante :

- Leurs besoins en soins de santé et en soins à domicile ne sont pas comblés. Elles sont mal servies.
- Elles ont besoin d’aide pour accomplir leurs tâches, ont de la difficulté en situation sociale et sont incapables de travailler de façon permanente. Elles souffrent d’un handicap, mais sont rarement perçues comme des personnes handicapées.
- Elles ont un faible revenu, souffrent d’isolement et même d’insécurité alimentaire. Elles sont désavantagées sur le plan social.

Les personnes atteintes d’EM/FM forment un groupe vulnérable en situation de crise. Le Canada peut faire beaucoup mieux. Le gouvernement fédéral a un rôle important à jouer. Les deux recommandations constituent des étapes importantes dans la prise en charge des besoins de ce groupe vulnérable.

Recommendation #1

ME/CFS and FM are complex multi-system illnesses with abnormalities in the neurological, immune, endocrine and metabolic systems.

Research is needed to support prevention, diagnosis and treatment of these illnesses

Canada has almost no ME/FM research activity. There has been almost zero funding from CIHR over the past decade.

The mandate of CIHR includes developing research capacity in emerging areas. Current strategies haven't worked for this emerging area. CIHR needs a new strategy

Our recommendation asks for the creation of a new institute at CIHR with long term designated funding to attract research to this neglected area of study and to prove the health system with a solid foundation for diagnosing, treating and preventing ME/CFS and FM.

Recommendation #2

ME/CFS and FM have been plagued by lack of information and misinformation. The seriousness of the illnesses and resulting disability have been grossly underestimated. It is hard enough dealing with the illnesses without having to deal with misinformation and stigma as well. We are asking for an interdepartmental team to fix the problems right away so that people with ME/FM do not have to deal with this additional burden.

These two initiatives are needed for patients and their families. These initiatives will also benefit all Canadians who value an efficient, effective health care system and a fair and inclusive society.

Recommandation 1

L'EM/SFC et la FM sont des maladies multisystémiques complexes qui se caractérisent par des anomalies des systèmes neurologique, immunitaire, endocrinien et métabolique.

Il faut stimuler la recherche pour soutenir la prévention, le diagnostic et le traitement de ces maladies.

La recherche sur l'EM/FM au Canada est presque inexistante. Au cours de la dernière décennie, les IRSC n'ont accordé presque aucun financement à la recherche sur ces maladies.

Le mandat des IRSC comprend le soutien des capacités de recherche dans les nouveaux champs d'études. Les stratégies actuelles ne fonctionnent pas pour ce nouveau champ d'études. Le IRSC ont besoin d'une nouvelle stratégie.

Notre recommandation requiert la création d'un nouvel institut aux IRSC qui obtiendrait un financement désigné à long terme qui servirait à stimuler la recherche dans ce domaine d'études négligé et à doter le système de santé d'une base solide pour le diagnostic, le traitement et la prévention de l'EM/SFC et de la FM.

Recommandation 2

Le manque d'information et la désinformation font partie des principaux problèmes touchant l'EM/SFC et la FM. Nous savons maintenant que nous avons largement sous-estimé la gravité de la maladie et de l'incapacité qui en découle. Les personnes atteintes de la maladie souffrent suffisamment de la maladie elle-même et n'ont pas à être en plus victimes de désinformation et de stigmatisation. Nous demandons à une équipe interministérielle de régler ces problèmes sans tarder afin que les personnes atteintes d'EM/FM n'aient plus à porter ce fardeau supplémentaire.

Ces deux initiatives sont nécessaires pour les patients et leurs familles. Elles bénéficieront également à tous les Canadiens qui tiennent à avoir un système de santé efficace et à vivre dans une société juste et inclusive.

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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, as well as keeping you up-to-date about our many projects. "Quest" includes original articles by doctors, researchers, and lawyers and also covers support matters such as treatment and happenings in other groups.

ME/CFS and FM Brochures - FREE

Coloured pamphlets on ME/CFS and FM are available in English or French. Please specify if you would like copies in French.

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] and The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4}] can be viewed on our website at www.mefmaction.net and is also available at Amazon.com or at Chapters.ca

Or view the Consensus Documents on our website at www.mefmaction.com

ME/CFS and FM Overviews - $7.00 each

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents entitled Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols and The Fibromyalgic Syndrome: A Clinical Case Definition for Practitioners.

Overviews can be ordered from Marjorie Van de Sande via email at mvandesande@shaw.ca or by regular mail at 151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 Canada, or from the NATIONAL ME/FM ACTION NETWORK Or may be viewed on our website at www.mefmaction.com

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To order, please contact AQEM, 7400 Boul. Les Galeries, Box 410, Anjou, QC H1M 3M2 Canada or call 514.369.0386 or via email at aqem@spg.qc.ca

TEACH-ME (Second Edition) - $22.00 - Discount on bulk orders
TEACH-ME (TRADUCTION FRANCAISE): 22 $

Our TEACH-ME Resource Book is for Parents and Teachers of children and youth with ME/CFS and/or FM.

QUEST COLLECTION: 1993 TO 2003 - $38.00
QUEST COLLECTION: 2004 TO 2008 - $38.00

These are a collection of medical and legal articles that appeared in our newsletters for the periods indicated and combined for easy reference.

CANADA PENSION PLAN DISABILITY GUIDE - $10.00

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

NATIONAL LAWYERS' ROSTER

A roster of lawyers and legal advocates who are knowledgeable about ME/CFS and FM. This roster is a guide only and the National ME/FM Action Network plays no role in any decisions made by the individual or in the legal professional selected. Please contact us for more information.

NATIONAL ME/FM ACTION NETWORK WEBSITE http://www.mefmaction.com

Network adds two new Directors

The National ME/FM Action Network is pleased to announce that we have two new Directors.

Anne Mare MacIsaac has been volunteering with the Network here in Ottawa. She helped at the 2011 conference, attended meetings with government officials, worked on the CPP-D Guide, the Newsletter, the website and email bulletins, and maintained our membership list. She hails from Nova Scotia, her background is in IT management and she is the proud mother of four.

Alison Rae is a well known volunteer based in the Toronto area. She manages our Facebook site and Twitter account. She also runs a support group and belongs to a group for support group leaders. Her background is in IT management.

QUEST EDITOR: Margaret Parlor **Quest Layout:** Anne Marie MacIsaac

http://twitter.com/mefmaction

http://www.facebook.com/MEFMActionNetwork

ME, my Dad and I - by Kitty Ibele

You’re probably wondering before I begin / who I am and where do I really fit in?
But it’s not about me? / It’s about M period E.
This distinction’s important throughout my story
Myalgic Encephalomyelitis
It’s almost as if they picked such a BIG name / knowing such a disease would be such a BIG pain!

My empathy flows for those who have got / such a disease, I know you’ve been through a lot
I look at my dad! He’s sure one of a kind / He’s a hero and heroes these days you rare find!
You see… although he is constantly fighting his pain / and feels like his energy’s gone down the drain
His dizzy spells, faintness, ache in his head / make him often so weak, he’s trapped in his bed
Exhaustion, muscle pain, joint pain as well /but to look at him briefly, you never would tell
That he’s in so much pain! That’s the problem, you know…
Chronic pain is an issue cause this pain doesn’t show

Most people who meet my dad always do say, /“he doesn’t look sick, he looks perfectly ok!”
But I live with my dad, witness behind the scenes
I’ve dealt with his struggles, right through to my teens
It’s hard growing up with a dad who’s not there / like a “normal” dad is since he needs constant care
Family trips were a drag when my dad came along
He’d have highs, he’d have lows, but with pain never gone
Our fun would be limited to how he was feeling / so vacations for us kids, never seemed appealing
We mostly stayed home, our home was real quiet / my dad can’t take noise, he’s sensitive by it
So no friends were allowed to come over to play /cause the noise and commotion always got in the way
But with saying all that, please don’t get me wrong / no one else on this planet I feel is as strong
As my dad is to carry on, determined to be / the best he can possibly be with M.E.
I’ve cried many times because I love my dad / and to think he’s in pain 24/7 is sad
But the fact that in spite of the pain, he won’t quit / Inspires me to go out and talk about it
Educating more people is key for success / and so far M.E has been a stalled process
Since not many doctors are researching cures / Hopefully we can change this, so that we ensure
That the future to come will be brighter than now / so that people with similar stories know how
To deal with such pain, such trauma and stress / that comes from the disease M.E., the illness

My dad is the greatest! He’s one of a kind
And no disease could ever change that in my mind!
Maybe his body is full of such pain
But I know our hearts are both healthily the same
I’ll love him forever! I admit, I’m daddy’s girl
And as far as I’m concerned, he’s the BEST dad in the world!