NATIONAL ME/FM ACTION NETWORK

Quest

Newsletter

www.mefmaction.com Quest 107, Summer 2016 mefminfo@mefmaction.com

Catching Up on Events.

So much has happened recently affecting the ME/FM community that it is hard to keep track. This newsletter highlights some important developments in Canada and internationally.

We start with a look at chronic pain. The Unites States announced a National Pain Strategy in March. Two weeks later, Canada's health research funding agency announced major funding for chronic pain research in Canada. What are the implications for FM and ME/CFS patients in Canada? Here are some basic principles.

People with both FM and ME/CFS experience chronic pain. (Pain statistics can be found in Quest 101.) Because chronic pain is a symptom of both FM and ME/CFS, the National ME/FM Action Network recognizes that chronic pain initiatives could benefit people with FM and ME/CFS.

There are many, many people with chronic pain that is not associated with FM or ME/CFS. In fact, the 2010 Canadian Community Health Survey found that 82% of Canadians with severe chronic pain did NOT have a diagnosis of either FM or ME/CFS. See Quest 101. Because chronic pain is a large heterogeneous category, the National ME/FM Action Network is afraid that FM and ME/CFS will be lost in it, just as ME/CFS got lost in the morass of chronic fatigue.

People with FM and ME/CFS experience many additional symptoms. (For additional FM symptoms, see page 2.) Because FM and ME/CFS are about much more than chronic pain, the National ME/FM Action Network takes the position that FM and ME/CFS need to be looked at in their own right as multi-system illnesses and not simply as chronic pain conditions.

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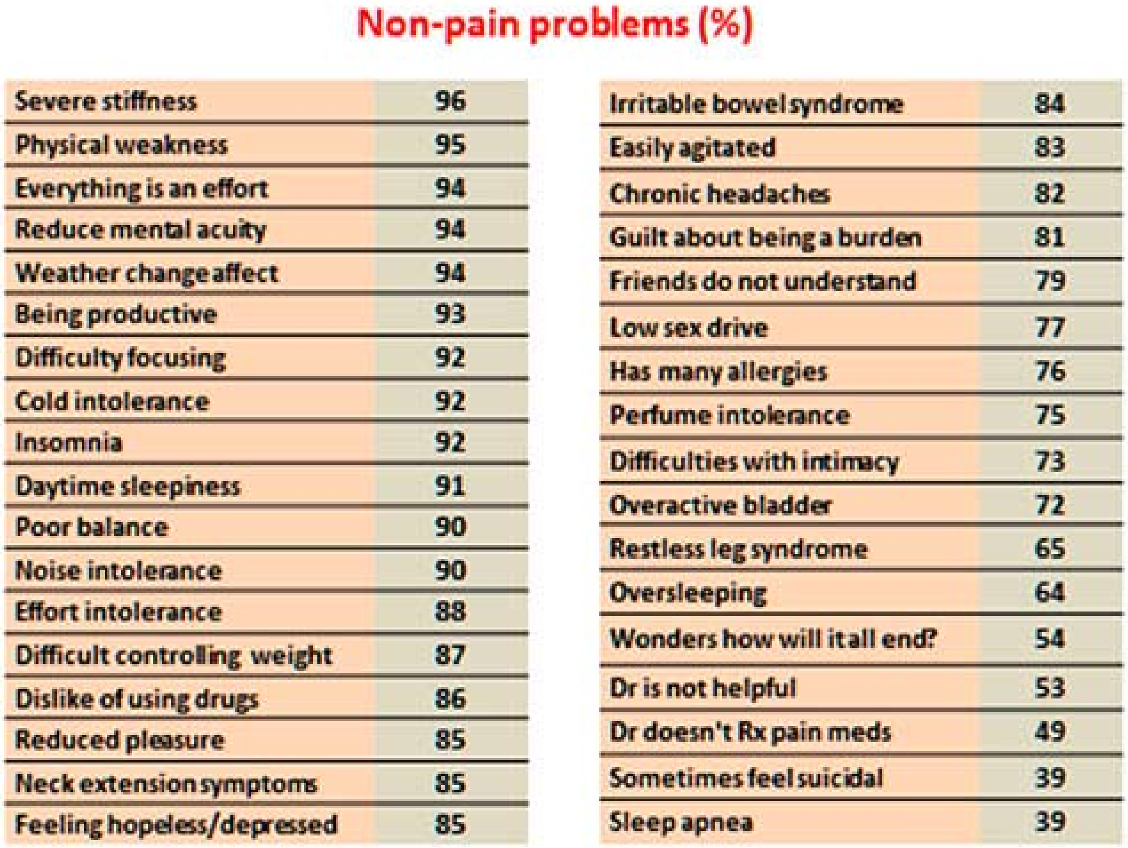
Glossary of Terms:

ME/CFS - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
FM - Fibromyalgia
CIHR - Canadian Institutes of Health Research (Canada's health research funding agency)
SPOR - CIHR's Strategy for Patient-Oriented Research
NPS - U.S. National Pain Strategy
CBT - Cognitive Behaviour Therapy
GET - Graded Exercise Therapy
PACE - a study done in the United Kingdom comparing pacing, CBT, GET and expert care.
HHS - the US department of Health and Human Services, which includes the following four agencies:
*NIH - the US National Institutes of Research (which both fund and carry out research)
*CDC - the US Centers for Disease Control and Prevention
*FDA - the US Food and Drug Administration
*AHRQ - the US Agency for Healthcare Research and Quality

FM - A Multi-System Illness

The National Fibromyalgia & Chronic Pain Association (based in the US) did a survey of their FM members in November 2013. Over 2,000 people responded. Among other questions, respondents were asked what symptoms they experienced other than pain. Here is a table of their answers. The table makes it clear that people with FM experience multiple symptoms such as reduced activity levels, cognitive problems, and sleep dysfunction. These are very similar to ME/CFS symptoms. Research is needed to determine how ME/CFS and FM are related.



Non-pain problems (%)

Severe stiffness	96
Physical weakness	95
Everything is an effort	94
Reduce mental acuity	94
Weather change affect	94
Being productive	93
Difficulty focusing	92
Cold intolerance	92
Insomnia	92
Daytime sleepiness	91
Poor balance	90
Noise intolerance	90
Effort intolerance	88
Difficult controlling weight	87
Dislike of using drugs	86
Reduced pleasure	85
Neck extension symptoms	85
Feeling hopeless/depressed	85
Irritable bowel syndrome	84
Easily agitated	83
Chronic headaches	82
Guilt about being a burden	81
Friends do not understand	79
Low sex drive	77
Has many allergies	76
Perfume intolerance	75
Difficulties with intimacy	73
Overactive bladder	72
Restless leg syndrome	65
Oversleeping	64
Wonders how will it all end?	54
Dr is not helpful	53
Dr doesn't Rx pain meds	49
Sometimes feel suicidal	39
Sleep apnea	39

http://www.fmcpaware.org/ohsu-nfmcpa-survey-of-symptoms-other-than-pain-for-fda-meeting-part-1.html

US Drafts National Pain Strategy

On March 18, 2016, the United States government announced a National Pain Strategy. The strategy was put together by the “Interagency Pain Research Coordinating Committee” representing different parts of the department of Health and Human Services (NIH, CDC, FDA, AHRQ) along with the Department of Defense and the Department of Veterans Affairs. (Soldiers and veterans often deal with chronic pain as a result of injuries.) The interagency team reached out to researcher, clinicians and patients in developing the strategy.

What does NPS cover?

The strategy identifies six areas of focus and for each of the areas it identifies a series of actions that can be taken in the short term (within 1 year), medium term (within 2-4 years) and longer term (within 5 years) :

- Population research - increasing what is known quantitatively and qualitatively about chronic pain in the US
- Prevention and care - increasing the emphasis on prevention strategies throughout the health care system to lessen the occurrence and impact of chronic pain. (Prevention strategies are broadly defined – see box 1.) This includes researching various approaches and improving self management programs.
- Disparities – identifying and addressing biases in vulnerable populations such as youth, older, poor or ethnic populations.
- Service delivery and payment – addressing the frequent disconnect between theory and practice, particularly those caused by funding models. (Example: not paying clinicians to take the time to develop individualized chronic pain plans.)
- Professional education and training: the training would cover competencies and attitudes and would be aimed at physicians, nurses, pharmacists, dentists, psychologists, social workers, physiotherapists, occupational therapists, etc.
- Public education and communication – two campaigns are suggested, a broad campaign to increase public awareness about pain (see box 2), and a targeted campaign to make patients aware of safer medication use (see box 3).

Will the NPS help people with chronic pain?

On the positive side, this is a comprehensive strategy developed by a broad, high-level team. It takes the under-served health issue of chronic pain and suggests a way forward. The messaging is strong and supportive of patients. There is, however, no commitment to move forward. The Office of the Assistant Secretary for Health,

Box 1

Prevention

Primary, secondary and tertiary prevention are terms used in the report.

Prevention includes a wide range of activities — known as “interventions” — aimed at reducing risks or threats to health.

Primary prevention aims to prevent disease or injury before it ever occurs. This is done by preventing exposures to hazards that cause disease or injury, altering unhealthy or unsafe behaviours that can lead to disease or injury, and increasing resistance to disease or injury should exposure occur.

Secondary prevention aims to reduce the impact of a disease or injury that has already occurred. This is done by detecting and treating disease or injury as soon as possible to halt or slow its progress, encouraging personal strategies to prevent reinjury or recurrence, and implementing programs to return people to their original health and function to prevent long-term problems.

Tertiary prevention aims to soften the impact of an ongoing illness or injury that has lasting effects. This is done by helping people manage long-term, often-complex health problems and injuries (e.g. chronic diseases, permanent impairments) in order to improve as much as possible their ability to function, their quality of life and their life expectancy.

Extracted from *https://www.iwh.on.ca/wrmb/primary-secondary-and-tertiary-prevention*

Traditionally, prevention is used only in the primary sense. Interpreting prevention to include secondary and tertiary prevention has huge benefit for the ME/FM community. There is much that can be done to reduce the impact of FM or ME/CFS from getting worse (eg early detection, pacing) and to improve quality of life (eg dealing with financial and social issues).

in conjunction with HHS operating and staff divisions, will consider the recommendations included in the Strategy and develop an implementation and evaluation plan based on this process. Further, the motivation for the strategy can be questioned. This strategy arises out of a desire to control opioid use as much as a desire to help people with chronic pain. Will chronic pain get the attention it deserves?

Box 2

Appendix K. Suggested learning objectives for a public awareness campaign

To increase public awareness about pain and people with pain, the committee recommends developing a campaign that will cover the following learning objectives (listed in order of priority):

1. Chronic pain is a disease.
2. Chronic pain is manageable.
3. Chronic pain is more prevalent than cancer, diabetes, and heart disease combined.
4. Chronic pain is real.
5. Most Americans will experience chronic pain or care for someone with chronic pain.
6. People in chronic pain deserve respect, compassion, and access to timely treatment.
7. Many people in chronic pain nevertheless live productive lives.
8. The goal for chronic pain management is to alleviate pain and restore function. Patients should be aware of realistic treatment expectations.
9. Chronic pain may cause depression and depression increases the severity of pain.
10. Chronic pain may require a spectrum of medical and surgical treatments and/or non-medical interventions, including self-management strategies along with the active participation of people with chronic pain in their own pain care management.
11. Appropriate chronic pain management may involve prescription medications, which require knowledge of risks for adverse effects such as dependency and addiction.
12. Activity level and mood may vary depending on the intensity of chronic pain (good days and bad days).
13. Awareness of conditions and activities that contribute to injury, especially in the workplace, can prevent pain.

<u>Will the NPS help people with FM and ME/CFS?</u>

On the positive side, the NPS mentions FM and ME/CFS. It notes that there is reported bias against women experiencing pain from chronic fatigue syndrome and fibromyalgia, the president of the National Fibromyalgia and Chronic Pain Association was on one of the working groups, and "Fibromyalgia and wide-spread muscle pain" is one of the 11 categories proposed for data collection (see box 4). However, it is worrisome that chronic pain is referred to as "a disease", rather than as a group of diseases.

As the NPS moves forward (assuming it moves forward), it will be interesting to watch how the system balances the general issues that apply to all chronic pain and the specific issues that apply to groups like FM and ME/CFS.

Box 3

Appendix L. Learning objectives for an educational campaign on safer use of pain medications

Increasing the number of people with chronic pain who report that they:

1. Talk with their clinician about their hopes and expectations and share activities of daily living or function that are important to them.
2. Work with their clinician to develop a plan of treatment consistent with their goals.
3. Know that analgesic medications can be an appropriate pain management option in selected and monitored patients and they are not the only option.
4. Know their prescription medication is only for them and do not share it with others.
5. Store their medicine in a safe place where children or pets cannot reach it.
6. Dispose of unused medication properly.
7. Take medicine only if it has been prescribed or approved by their doctor.

8. Do not take more medicine or take it more often than instructed. They call their doctor if their pain worsens.
9. Know how to understand and recognize expected and unexpected adverse effects such as dependency and addiction and to discuss risks with their doctor.
10. They talk to their doctor before taking prescription medications in combination with other drugs, including alcohol, sleeping pills, or anti-anxiety medication.
11. Have discussed with family and friends how to recognize and respond to overdose, including the use of naloxone.
12. Encourage family and friends to utilize Poison Control Centers as a confidential resource and to report possible opioid exposure and/or abuse by calling the Poison Help line

Box 4

Appendix F Diagnostic Clusters for population health research

1. Back pain
2. Neck pain
3. Limb/extremity pain, arthritis disorders (including osteoarthritis and joint pain)
4. **Fibromyalgia** and wide-spread muscle pain
5. Headache
6. Orofacial, ear, and temporomandibular disorder pain
7. Abdominal pain and bowel pain
8. Chest pain
9. Urogenital, pelvic, and menstrual pain
10. Fractures, contusions, sprains and strains
11. Other painful conditions. This includes sickle cell disease, Complex Regional Pain Syndrome, systemic lupus erythematosus, acquired deformities (excluding spinal disorders), spinal cord injury, Lyme disease, Neuropathic pain. Note: Cancer pain is included here, but relevant diagnostic codes need to be identified.

PACE Studies Come Under Fire

This is based on an excellent article by Jennie Spotila, May 12, 2016 at OccupyCFS.com

The PACE Trial was a large clinical trial in the UK that compared Graded Exercise Therapy, adaptive pacing, supportive medical care and Cognitive Behaviour Therapy. Results were first published in The Lancet in 2011. On the surface, they justify GET and CBT for ME/CFS patients.

The study immediately came under criticism from patient advocates.

Dr David Tuller, an academic and journalist, published his own analysis of the study in Ocober 2015. He found very fundamental flaws in the way the study was conducted and the data was analysed.

In November 2015, Dr James Coyne requested access to the data used in another PACE article. The journal in question requires authors to make their data available. Dr Coyne has not received the data.

In December 2015, Dr Tuller and others requested access to data in the Lancet article. They have not received the data.

An individual also requested some PACE data. He was turned down. He appealed to an Information Commissioner who agreed that he should receive it. The PACE officials appealed. A hearing was held in April. No decision has been rendered as of May 29th.

There have been multiple requests to The Lancet, including a request from our organization, for an independent review of the study. Nothing has happened.

With the PACE results under such a dark shadow, the US government has been called upon to remove any conclusions based on the PACE study from US health policy.

At this point in time, the credibility of PACE recommendations have been seriously undermined but they are still officially in peer reviewed literature.

CIHR Announces SPOR Networks in Chronic Disease

SPOR = Strategy on Patient-Oriented Research

The following announcement was made by CIHR on April 1, 2016. Each of the successful applicants will receive $12.5M over 5 years. There are two projects that have major overlap with FM and ME/CFS – the chronic pain network and the digestive system network. The Child-Bright initiative could overlap as well. Our organization was not invited to participate on these networks, suggesting that ME/FM issues are not a priority for them..

The primary objective of these Networks is to translate existing and new knowledge generated by health research into testing of innovations that can improve clinical science and practice and foster policy changes, leading to transformative and measureable improvements in patient health outcomes, and in efficiency and effectiveness healthcare delivery within five years.

The five Networks funded are:

<u>Chronic Pain Network</u>

Dr. Norman Buckley, McMaster University

This network will direct new research, train researchers and clinicians, increase access to care for chronic pain sufferers, and speed up the translation of the most recent research into the reality of care

<u>Listening, Learning, Leading: Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD)</u>

Dr. Adeera Levin, University of British Columbia

This network will improve care for people with kidney disease. It aims to reduce the number of people who require dialysis or organ transplants, or who develop related illnesses that are debilitating or deadly.

<u>SPOR Network in Diabetes and its Related Complications</u>

Dr. Gary Lewis, University of Toronto

This network will transform the health outcomes of people with diabetes and its related complications. It will facilitate important and meaningful connections between patients, their primary healthcare providers, and specialists to achieve improved health care and significant cost savings within the health system.

Réseaux de la SRAP sur les maladies chroniques

SRAP = Stratégie de recherche axée sur le patient

Le principal objectif de ces réseaux est d'appliquer les connaissances existantes et nouvelles issues de la recherche en santé fondamentale (biomédicale, clinique, sur la santé des populations) à la mise à l'essai d'innovations pouvant améliorer la science et la pratique et entraîner des changements aux politiques, pour ainsi créer un impact transformateur mesurable sur les résultats pour les patients, ainsi que sur l'efficacité de la prestation de soins de santé d'ici cinq ans.

Les cinq réseaux financés sont :

<u>Chronic Pain Network [réseau sur la douleur chronique]</u>

Dr Norman Buckley, Université McMaster
Ce réseau dirigera de nouvelles recherches, formera des chercheurs et des cliniciens, accroîtra l'accès aux soins pour les personnes qui ont des douleurs chroniques, et accélérera l'application de la recherche la plus pertinente à la réalité des soins de santé.

<u>Listening, Learning, Leading: Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) [écouter, apprendre, diriger : des Canadiens à la recherche de solutions pour vaincre la maladie rénale chronique]</u>

Dre Adeera Levin, Université de la Colombie-Britannique

Ce réseau améliorera les soins pour les personnes atteintes de maladies rénales. Son but est de réduire le nombre de personnes qui ont besoin de dialyse et de transplantation d'organe, ou qui contractent des maladies connexes débilitantes ou mortelles.

<u>SPOR Network in Diabetes and its Related Complications [réseau de la SRAP sur le diabète et ses complications]</u>

Dr Gary Lewis, Université de Toronto

Ce réseau transformera la santé des personnes aux prises avec le diabète et ses complications. Il facilitera des rapports utiles et significatifs entre les patients, leurs fournisseurs de soins de première ligne et les spécialistes pour améliorer les soins et faire réaliser d'importantes économies au système de santé.

CHILD-BRIGHT: Child Health Initiatives Limiting Disability – Brain Research Improving Growth and Health Trajectories

Dr. Annette Majnemer, Research Institute of the McGill University Health Centre

This network will achieve brighter futures for children with brain-based developmental disabilities and their families by creating novel interventions to optimize development, promote healthy outcomes, and deliver responsive and supportive services across the life-course.

Inflammation, Microbiome, and Alimentation: Gastro-Intestinal and Neuropsychiatric Effects: the IMAGINE-SPOR chronic disease network

Dr. Paul Moayyedi, McMaster University

This network is a national collaboration of patients and scientists that will look at how gut bacteria and diet cause inflammatory bowel disease and irritable bowel syndrome, and at the anxiety and depression associated with these disorders.

US Addresses ME/CFS

Both the Pathway to Prevention panel and the Institute of Medicine panel recommended that the US National Institutes of Health pay more attention to ME/CFS. Subsequently, the NIH reassigned primary responsibility for ME/CFS to the National Institute of Neurological Disorders and Stroke, set up a trans-NIH working group, and announced an intramural study. There is activity within NIH to find and allocate money for ME/CFS research grant competitions which could be announced this summer.

Meanwhile, the Health department's Chronic Fatigue Syndrome Advisory Committee recommended the establishment of twelve Centers of Excellence with minimum funding of $1M per year for five years. ME/CFS Centers of Excellence, while primarily targeted for ME/CFS research and patients, may include the study of related illnesses such as Lyme disease, fibromyalgia, Gulf War Illness, and Multiple Chemical Sensitivity. Such an inclusive strategy recognizes the similarities of pathophysiological mechanisms of illnesses which exhibit similar symptoms, and the efficiency in advancing the understanding of mechanisms contributing to these illnesses by studying more than one of them.

CHILD-BRIGHT: Child Health Initiatives Limiting Disability – Brain Research Improving Growth and Health Trajectories [initiatives sur la santé des enfants pour contrer les handicaps : recherche sur le cerveau en vue d'améliorer la croissance et les perspectives de santé]

Dre Annette Majnemer, Institut de recherche du Centre universitaire de santé McGill

Ce réseau assurera un avenir meilleur pour les enfants qui présentent des troubles du développement cérébral et leurs familles en créant des interventions nouvelles pour optimiser leur développement, promouvoir des résultats favorables, et leur fournir des services de soutien adaptés à toutes les étapes de la vie.

Inflammation, Microbiome, and Alimentation: Gastro-Intestinal and Neuropsychiatric Effects: the IMAGINE-SPOR chronic disease network [effets gastro-intestinaux et neuropsychiatriques de l'inflammation, du microbiome et de l'alimentation : réseau IMAGINE de la SRAP sur les maladies chroniques]

Dr Paul Moayyedi, Université McMaster

Collaboration internationale formée de patients et de chercheurs, ce réseau se penchera sur la façon dont les bactéries intestinales et le régime alimentaire causent la maladie intestinale inflammatoire et le syndrome du côlon irritable, de même que sur l'anxiété et la dépression qui sont associées à ces troubles.

ME/CFS Catalyst Grant Handed Out in Europe

In October 2015, a grant was awarded "to create a sustainable integrated network of researchers in Europe working in the field of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, this way tackling the research challenges arising from unkown aetiology, clinical variability, lack of diagnostic biomarkers and limited treatment options, high associated socio-economic burden." The amount of the award was 32M euros over 4 years which is over $10M Cdn per year.

Go to *http://www.cost.eu/COST_Actions/ca/CA15111* and download the Memorandum of Understanding.

Meeting With Health Minister's Staff

April 14. Dr Philpott was appointed as Minister of Health six months ago. She has been given many challenges such as brining Syrian refugees to Canada, setting policy to legalize marijuana and leading the assisted dying debate. She has not found time to meet with the ME/FM community.

One person in the ME/FM community, Scott Simpson, was able to get a meeting with one of her staff members in Ottawa. He invited Dr Bested and Margaret Parlor to join him. (Dr Bested joined by phone.)

The meeting was very much an initial meeting. Health officials tend to assume that all is well within the health system. It is hard for them to grapple with the idea that there are problems, and especially problems on the scale that ME/FM is encountering. Officials either reject the message outright or leave room for further discussion. Fortunately, the staff member did leave room for more discussions. We hope to continue the dialogue soon.

Meeting with NDP health critic

May 3: Thanks to the hard work of one of our members, we were able to get a meeting with MP Don Davies, the NDP Health Critic. Anne Marie MacIsaac and Margaret Parlor attended. One of the issues we raised is putting ME/FM on the agenda of the House of Commons Health committee. This is an idea put forward by Toronto Liberal MP Robert Oliphant. Mr Davies is a vice-chair of the committee. There are already several issues on the committee's priority list. We asked to be considered for the home care discussions.

MP Don Davies, Anne Marie MacIsaac, Margaret Parlor

Parliamentary Breakfast Held

Margaret Parlor, Dr Gordon Broderick, Senator Art Eggleton, MP Terry Duguid and his wife, Linda

May 19. Our timing was good and bad.
Good: The breakfast took place on the same day as CIHR was holding its scientific council and two institute directors were in town and able to attend (Dr Hani El-Gabalawy, director of the Institute of Muscular Skeletal Health and Dr Brian Rowe, director of the Institute of Circulatory and Repiratory Health. Dr Rowe is the brother of Dr Peter Rowe who does pediatric ME/FM at Johns Hopkins and was a member of the IOM panel.)

Bad: The breakfast took place the morning after "elbow-gate" which had cause quite a stir in the Commons. A number of MP's who indicated that they were coming did not show up. Nevertheless, we had one senator, several MP's and staff of other MP's in attendance.

Margaret Parlor gave a broad overview. Lisa Schneiderman gave a patient perspective, and Dr Gordon Broderick gave an overview of scientific research. The discussion following the presentations was lively, with Dr Alison Bested and Anne Marie MacIsaac contributing as well.

Write your Encounter

Encounters articles in CMAJ Humanities give patients and health care practitioners room to reflect on their experience with illness or medicine. Narratives should be between 750 and 1400 words. All submissions are peer reviewed. Contact Barbara Sibbald, Editor, News and Humanities (barbara.sibbald@cmaj.ca), to discuss ideas.

Ontario Announces Task Force on Environmental Health

The following announcement was posted on the Ontario Ministry of Health website on May26th:

http://www.health.gov.on.ca/en/public/programs/environmentalhealth

Many Ontarians live with conditions triggered by environmental factors that are difficult to diagnose and treat.

These conditions may include:

- Environmental Sensitivities/Multiple Chemical Sensitivity;
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; and
- Fibromyalgia.

People diagnosed with these types of conditions face challenges in their experiences as patients, from diagnosis to treatment to living with the long-term impacts. People also suffer from stigmatization in clinical settings, the workplace and other areas of their lives as a result of a general lack of understanding of these complex conditions.

The Ministry of Health and Long-Term Care (MOHLTC) has announced the establishment of a Task Force on Environmental Health to provide recommendations and advice to:

- inform possible guidelines and policies to support patients with conditions triggered by environmental factors;
- increase public and health care providers' knowledge of health conditions triggered by environmental factors;
- identify gaps in evidence, knowledge transfer and care for those affected by these conditions; and
- identify patient-focused actions to improve health outcomes of affected patients.

The Task Force consists of 15 members appointed by the Minister of Health and Long-Term Care, of which 1/3 are patients or caregivers. The Task Force has a term of up to three years beginning in 2016 and ending in 2019. The Task Force members are:

- Howard Hu (Chair), Dean, Dalla Lana School of Public Health, University of Toronto
- Neil Stuart (Vice-Chair), Health Care Consultant
- Bill Manson, Senior Director, Performance Management, Toronto Central Local Health Integration Network
- Cornelia Baines, Professor Emerita, Dalla Lana Faculty of Public Health, University of Toronto
- Denise Magi, Vice-President, Myalgic Encephalomyelitis Association of Ontario
- Dona Bowers, Physician, Somerset West Community Health Centre
- Izzat Jiwani, person with lived experience
- Joanne Plaxton, Director, Health Equity Branch, Ontario Ministry of Health and Long-Term Care
- John Molot, Staff Physician and Medical/Legal Liaison, Environmental Health Clinic, Women's College Hospital
- Julie Schroeder, Standards Development Branch, Ontario Ministry of the Environment and Climate Change
- Maureen MacQuarrie, person with lived experience
- Mike Ford, person with lived experience
- Nancy Sikich, Director, Health Technology Assessment, Health Quality Ontario
- Sharron Ellis, person with lived experience
- Varda Burstyn, person with lived experience

ME/CFS Catalyst Grant Offered in Canada

In an unexpected move, the Canadian Institutes of Health Research announced that it was making available $200k for each of three years to bring people together around ME/CFS research. The money would not be used to fund research, but rather to help build the ability to put forward research proposals. (A catalyst is something that stimulates action.)

The deadline was short, but a team of people came together very quickly. Dr Alain Moreau of Montreal coordinated the grant application along with his amazing administrative assistant Dominika Kozubska. The team that came together includes people from the following universities and organizations: University of Alberta, University of British Columbia, University of Calgary, Université de Montréal, University of Toronto, Association Québecoise de l'encéphalomyélite myalgique, National

ME/FM Action Network, Nova Scotia Health Authority, Ontario College of Family Physicians, Shepherd's Hill Medical Clinic and Women's College Hospital.

The application has been submitted. CIHR is expected to announce in late August whether the grant will be awarded. Work would begin almost immediately.

May 12th Awareness

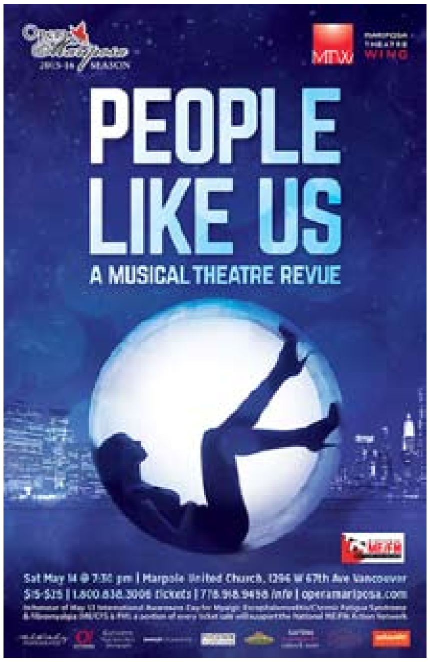
May 12th was celebrated again this year with events across the country Here are a few highlights:

Opera Mariposa held a concert with proceeds going to the National ME/FM Action Network. We are so appreciative of the work that Jacqueline and Stephanie Ko and their team.

MEAO held an event at Queen's Park. MPP's from the three parties all made statements in the legislature supporting the concept of a task force to implement a Centre of Excellence into ME/CFS, FM and MCS. See announcement, page 8.

MEFM BC had an information event with Dr. Mark Van Ness speaking about exertion intolerance.

Niagara Falls was once again lit up in blue, purple and green.



Canadian Lyme Conference held

A national Lyme conference was held in Ottawa on the evening of Sunday May 15, and all day on May 16th and 17. The conference came about because of a private member's bill (MP Elizabeth May). The bill required the government to hold a conference to develop a federal framework on Lyme Disease. Three hundred people registered to attend in person and four hundred registered to participate on-line. Registrants included patients, advocates, clinicians and health officials. Dr Jane Philpott, Minister of Health, welcome participants. The Chief Public Health Officer of Canada, Dr Gregory Taylor, attended the whole conference.

Sunday evening started with some introductory remarks, then people were invited to tell their stories. Over 100 people spoke. Their speeches were recorded and will be made available. Monday was focused on getting facts on the table, with presentations by a number of researchers and clinicians. Tuesday was set aside for discussions and recommendations under three major headings – surveillance, guidelines/best practices and education/awareness.

There is a lot of work to be done sorting out the ideas brought forward during the conference. What is significant is the dynamics. The personal stories impressed on officials the hurt, frustration and anger in the community. The very positive contributions that people were making impressed on officials how much the community wants to work for improvement. This understanding should change the relationship between the Lyme community and officials.

The discussion on surveillance attracted the entomologists (insect specialists). They addressed surveillance primarily from the perspective of tick surveillance – where are they located and are they infected. There was not much discussion of human surveillance – who has Lyme, how did they get it, how sick are they. This is partly because science is not good at distinguishing Lyme from similar conditions like ME/CFS and FM. This is an important issue that needs to be sorted out.

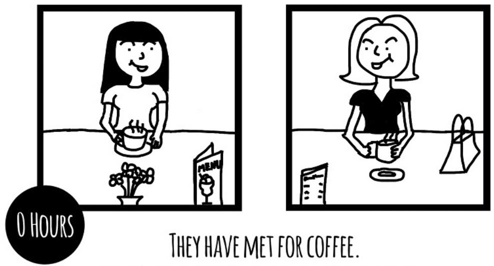
You may find the sheet on the next page helpful in explaining your situation to others.

THE M.E. ADVENTURES

BY LAURA'S PEN
LAURACHAMBERLAIN.CO.UK

ENERGY & EXERTION

THIS IS MADDIE, SHE HAS M.E. — THIS IS "NORMAL" NANCY



THEY HAVE MET FOR COFFEE.
FOR MADDIE THIS IS A HIGH ENERGY ACTIVITY.
FOR NANCY THIS IS LOW ENERGY.

MADDIE GOES HOME — NANCY POPS TO THE SHOPS

MADDIE IS EXHAUSTED.
NANCY GOES AND GETS SOME BITS WHILE SHE'S OUT.

MADDIE RESTS IN BED — NANCY GOES HOME

MADDIE FEELS VERY ILL AND HAS TO GO TO SLEEP.
NANCY FINISHES SHOPPING AND DECIDES TO HEAD HOME.

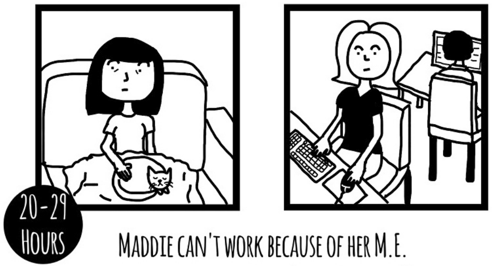
MADDIE & NANCY BOTH WARM UP A READY MEAL AND WATCH TV

MADDIE DOES THIS OUT OF NECESSITY.
SHE HAS NO ENERGY TO COOK AND STRUGGLES TO FOLLOW THE TV.
NANCY DOES THIS OUT OF CHOICE BECAUSE SHE WANTS TO RELAX.

MADDIE WAKES UP — NANCY GETS UP

MADDIE WAKES UP FEELING AS THOUGH SHE HASN'T SLEPT (SHE HAS)
NANCY FEELS A BIT TIRED BUT PERKS UP ONCE SHE GETS UP.

MADDIE STAYS AT HOME — NANCY GOES TO WORK



MADDIE CAN'T WORK BECAUSE OF HER M.E.
BUT ALSO FEELS SLIGHTLY WORSE BECAUSE OF YESTERDAY'S EXERTION.
SHE IS HAPPY, HOWEVER, THAT SHE DOESN'T FEEL AS BAD AS SHE EXPECTED.

MADDIE'S EXHAUSTION HITS — NANCY GETS ON WITH HER LIFE

MADDIE THOUGHT SHE'D GOT AWAY WITH DOING SOMETHING FUN
WITH ONLY MINOR REPERCUSSIONS. BUT THE FULL EFFECT OF HER EXERTION
HITS HER LIKE A TON OF BRICKS 24-48 HOURS AFTER MEETING NANCY.

FACTS TO REMEMBER

- PEOPLE WITH M.E. SUFFER FROM SOMETHING CALLED POST EXERTIONAL MALAISE (PEM)
- PEM IS A WORSENING OF SYMPTOMS THAT KICKS IN 24-48 HOURS AFTER EXERTION
- IT CAN LAST DAYS, WEEKS, OR BE THE TRIGGER FOR A RELAPSE OR DETERIORATION
- IT DOESN'T JUST MAKE YOU FEEL "A BIT WORSE", IT MAKES TASKS YOU CAN NORMALLY DO FEEL LIKE WADING THROUGH TREACLE WITH THE FLU AND A HANGOVER

LAURACHAMBERLAIN.CO.UK

#MillionsMissing

On May 25th, an international protest called #MillionsMissing was held. The name reprepresents the millions of dollars missing in research funding as well as the millions of sufferers missing from careers, schools, social lives and families. Protests were held in 9 US cities, London, Belfast, Ottawa, Melbourne and the Netherlands.Shoes were used to represent the millions who could not participate in person. In Canada supporters sent emails to MPs. The following is a letter that was sent by one of our members to the Prime Minister and key Members of Parliament.

I am writing on behalf of over four hundred thousand fellow Canadian citizens whose lives have been, and will continue to be, devastated by the well-known biomedical condition Myalgic Encephalomyelitis (ME); I write as a member of the additional hundreds of thousands of Canadian citizens who are the significant others of ME patients, and whose lives and careers are also fundamentally altered and disrupted whilst we provide the substantial care and support our loved ones cannot live without.

Attached you will find an overview from the patient network of the current situation for ME in Canada, with particular emphasis on the need for research funding. Let me expand a little here:

My experience, and my overwhelming frustration, has been that our loved ones, and their illness, have been and continue to be dismissed, discounted, demeaned, and effectively disenfranchised. It is evidently not enough, in our “just and equal” society, that a person be living through the daily hell of physical torment and disability that this condition generates; no, these patients must further endure social isolation and ridicule, misdiagnosis and mistreatment by a largely uninformed and/or overtly misguided medical community, refused access to income replacement supports, utterly disregarded by their Government, and a myriad other ongoing personal, social, medical, and financial disasters.

This nightmare has its roots in flawed medical and political process. Had the Canadian government formally sanctioned and promulgated throughout medical practice and research, the Canadian Consensus Criteria for diagnosis and treatment of ME, in accordance with the long-standing recognition by the World Health Organization of ME as a biophysical disorder, then patients would at the very least have had access to properly informed medical diagnosis and treatment. Patients would have the dignity of assurance that their disorder is accorded an equal and just allocation of research funding and effort, properly guided by scientifically proven diagnostic criteria. Media would long ago have been provided appropriate scientific understandings of ME as a biophysical disorder, rather than the dismissive, demeaning, and unbelievably degrading popular concepts of “chronic fatigue”, “yuppie flu”, and so forth. Friends and family would thus have had popular access to informed, intelligent, and supportive commentary similar to the coverage of other comparable disorders such as Multiple Sclerosis. Decades on, we’re still waiting.

Incredibly, our Government has never undertaken steps to fully and properly address this illness. I say incredibly, because the patients involved have Canadian Charter Rights to just address. Equality Rights, 15(1) of the Charter: Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. (2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

We, the supporters of patients with ME, have long since wearied of the ongoing failure of the Canadian Government to adequately and appropriately recognize, fund, direct, and otherwise support medical care/research for ME; we are a frustrated and justly angry body of constituents. We are the very embodiment of the malaise which grips democracy in this nation: when government turns away from, and dismisses the needs of its citizens, then citizens turn away from democratic process.

With this letter, I call on you to rise in the House, rise in Committee, rise up in all your dealings in and with our Government’s offices and officials, to finally redress the inequity which the patients with ME suffer in our great country. Allow us, the patients and their supporters within the ME community, the dignity of once again being proud Canadians, fully included in the national fabric.

Sincerely,

Wm. A. Downey, BA, BSW.

#MillionsMissing

London, UK

The Netherlands

Melbourne, Austrailia

Dr Ron Davis in San Francisco

Washington DC

Ottawa

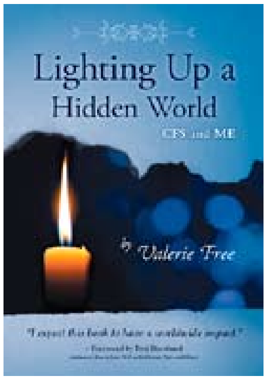
Documents Being Translated

Two very important documents are being translated into French and will be available soon:

Canada Pension Plan Disability: Application & Appeals Guide by Lydia E Neilson, Margaret Parlor and John Wodak

Review of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: an evidence-based approach to diagnosis and management by clinicians by Dr Alison C Bested and Dr Lynn M Marshall (published by Reviews on Environmental Health)

New Book Coming This Summer



Lighting Up A Hidden World: CFS and ME

by Valerie Free

Lighting Up a Hidden World: CFS and ME advocates for those too ill to speak out, abounds with patient resources, and offers realistic hope for the future.

See more at :
http://www.valeriefree.org

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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**

MEMBERSHIP APPLICATION or RENEWAL FORM

Please see reverse for available network resources.

For online application and renewals goto to MEFMaction.com

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.
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