NATIONAL ME/FM ACTION NETWORK

Quest Newsletter

www.mefmaction.com Quest 118, Spring 2019 mefminfo@mefmaction.com

From the President

Dear Friends

We would like to give special thanks to everyone who followed up on the pre-budget submission included in our last newsletter. Your messages have made a difference. We have found the doors in the federal government to be more open than they were even six months or a year ago.

We would also like to give special thanks to Member of Parliament Anita Vandenbeld who has taken on ME/FM/MCS as a special issue. We have included the one-minute statement she made to the House of Commons in December. Ms Vandenbeld was surprised by the number of the thank you's that she received from the ME/FM community following her statement and the depth of feeling in those messages. This reinforced to her the importance of the issue.

The Public Use Microdata File for the 2015-16 Canadian Community Health Survey is now available. Statistics Canada went to special effort to put it in a format that the public can use. It does take a little time to learn the coding system and to become familiar with the software. If anyone is interested in trying, let us know and we will get you started.

An international team has proposed new diagnostic criteria for FM which we discuss in this newsletter.

Interesting changes seem to be happening in published research. The journal Frontiers in Pediatrics was so impressed by the interest in the ME Pediatric Primer that it decided to publish a whole issue on adult and pediatric ME. Several bioethics articles were published recently, something new in the ME/FM area. Two studies have come out using artificial intelligence / machine learning. It seems that more research is tapping into the experiences and opinions of patients which is a very good sign. An article was published on the experiences of ME patients in hospital emergency departments, another first. These articles open up very important conversations

We have talked a lot about workplace insurance, but not about critical illness insurance. Somebody called us recently who had this insurance and then developed ME/FM. She found that ME/FM was not covered by her policy. We would like to hear from anyone else who has had experience with critical illness policies.

Margaret

Margaret Parlor, President

Statement by Member of Parliament Anita Vandenbeld Canadian House of Commons

December 13th, 2018

Liberal

Anita Vandenbeld
Ottawa West - Nepean, ON

M. Speaker, I rise today to shed light on a medical condition that affects over 800,000 Canadians. Myalgic encephalomyelitis, commonly referred to as "chronic fatigue syndrome" and fibromyalgia, or ME/FM, is a debilitating physical condition that can severely limit a person's ability to carry out ordinary daily activities. Unlike other conditions, those suffering very real physical

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symptoms, including incapacitating pain, are frequently stigmatized, told that it is in their head and denied basic supports that others with disabilities are entitled to. Poverty and social isolation often follow.

Global research on the causes, diagnostics and possible treatment of this condition are nearing potential breakthroughs, and yet there is no funding for research here in Canada.

I want to thank my constituent, Margaret Parlor, and the National ME/FM Action Network for their tireless advocacy in raising awareness of this issue.

[Translation] Monsieur le Président, je prends la parole aujourd'hui pour faire la lumière sur une maladie qui afflige plus de 800 000 Canadiens. L'encéphalomyélite myalgique et la fibromyalgie, communément appelé « syndrome de fatigue chronique », est une maladie débilitante pouvant limiter gravement la capacité d'une personne à mener ses activités quotidiennes habituelles. Même si ce syndrome provoque des symptômes physiques bien réels, y compris de fortes douleurs, les gens qui en sont atteints, contrairement à ceux atteints d'autres maladies, se font fréquemment stigmatiser. On leur dit que leurs symptômes sont imaginaires, et on les prive des services de base que reçoivent d'autres personnes handicapées. Souvent, ces personnes sombrent dans la pauvreté et dans l'isolement social.

On entrevoit de possibles percées dans les recherches menées à l'échelle mondiale sur les causes, le diagnostic et les traitements possibles de cette maladie. Pourtant, aucuns fonds ne sont prévus pour la recherche ici, au Canada.

Je veux remercier Margaret Parlor, qui habite dans ma circonscription, ainsi que le Réseau national d'action EM/FM de leurs efforts infatigables pour sensibiliser la population à cette maladie.

You can still write and thank Ms Vandenbeld. If you do not have internet, send a letter to:

Anita Vandenbeld MP, House of Commons, Ottawa, Ontario K1A 0A6. No postage required.

United Kingdom House of Commons

There was a ninety minute discussion of Myalgic Encephalomyelitis in the UK House of Commons on Thursday January 24th, 2019.

During the first eighty minutes, two dozen Members of Parliament made powerful statements about ME. Then the Member of Parliament representing the Minister of Health responded to the comments. Finally, the following resolution was put forward and passed unanimously.

That this House

- *calls on the Government to provide increased funding for biomedical research into the diagnosis and treatment of ME,*
- *supports the suspension of Graded Exercise Therapy and Cognitive Behaviour Therapy as means of treatment,*
- *supports updated training of GPs and medical professionals to ensure they are equipped with clear guidance on diagnosis of ME and appropriate management advice to reflect international consensus on best practice, and*
- *is concerned about the current trends of subjecting ME families to unjustified child protection procedures.*

The instructive part of the debate was the government representative's response. He acknowledged the difficulties that patients and family are facing. He then went on to describe ME as being challenging for physicians, suggesting that they were getting a "bad rap". He tried to strike a hopeful tone, referring to ME being included in the medical school curriculum, to an on-line course for physician (though noting that government is not responsible for ensuring that physicians to keep up-to-date), to the updating of the NICE guidelines scheduled for release in October 2020, and to an offer by the Chair of the Royal College of Family Physician to meet with MP's. When it came to research, he said that the funders were waiting for quality proposals. This is the kind of reaction that we are currently encountering – sympathetic but non-committal.

You can view the debate here:
https://www.meaction.net/2019/01/25/historic-parliamentary-debate-shaped-by-people-with-me/

Canada's Data Deficit

The Globe and Mail did a series recently on "Canada's data deficit". It argued that there a gaps in public information needed to support public policy decisions.

The ME/FM community has certainly suffered from the lack of data in several areas, especially

- *the lack of comprehensive, comparable data on research funding*
- *the lack of comprehensive, comparable data on illness burden*
- *the lack of data around non-traditional disabilities.*

We received word recently that Canada is looking to implement a new classification system for research funding. The proposed structure is at a very high level, but we have been advised that more detailed categories will be introduced under this framework. This initiative shows promise.

The Globe and Mail also published an article about a recent study that showed that female researchers have a harder time securing funding from CIHR than male researchers. This provoked me to write a letter to the newspaper which was published on February 11, 2019

DISEASE-GENDER LINK, TOO

Re Gender Bias Hurts Female Scientists' Chances Of Landing Grants, Study Finds (Feb. 8): Now that a study has shown that the Canadian Institutes of Health Research funding system is biased against female researchers, it is time to look at whether CIHR's funding system is biased against female-dominated health issues.

Is less research funding going to female-dominated health conditions than male-dominated health conditions, even after taking into account factors such as prevalence and impact?

A comprehensive study would be challenging because of Canada's data deficit. There is a lack of good quality, comparable figures on the prevalence and impact of health conditions, their gender distribution, and CIHR funding by health condition. Having said that, existing data strongly suggest that female-dominant conditions do indeed receive less generous research funding from CIHR, making such a study extremely important.

Margaret Parlor, Ottawa

Recent Publications

Misdiagnosing Fibromyalgia

In this study, 497 patients at a rheumatology clinic were asked to complete a FM questionnaire based on the 2010/2011 definition. They were then examined by clinicians. Based on the questionnaires, 121 people should have been diagnosed with FM. What the study found is that 60 of those people did not receive a FM diagnosis, while 43 people received a FM diagnosis who should not have received one. The researchers concluded unsurprisingly that there is a disconnect between what should be diagnosed as FM and what is actually diagnosed.

Srinivasan S, Schmukler J, Jamal S, Castrejón I, Gibson KA, Häuser W, Pincus T, Wolfe F. Diagnosis of Fibromyalgia: Disagreement between Fibromyalgia Criteria and Clinician-Based Fibromyalgia Diagnosis in a University Clinic [abstract]. Arthritis Rheumatol. 2018; 70 (suppl 10). *https://acrabstracts.org/abstract/diagnosis-of-fibromyalgia-disagreement-between-fibromyalgia-criteria-and-clinician-based-fibromyalgia-diagnosis-in-a-university-clinic/*

Proposed New Diagnostic Criteria for Fibromyalgia

A number of diagnostic criteria for FM have been developed over the years.

The 1990 criteria, adopted by the American College of Rheumatology, was based on chronic widespread pain and tenderpoints.

In 2003, the Canadian expert panel on FM adopted those criteria but noted that FM often brought with it other symptoms like reduced activity levels, cognitive difficulties, sleep problems and stiffness.

In 2010, a group proposed a new definition based on a combination of multi-site pain, activity reductions, sleep problems, cognitive problems and other symptoms. Modifications to these criteria were published in 2011 and 2016.

Most recently, the US Food and Drug Administration and the American Pain Society have put together groups to look at various pain conditions (chronic cancer pain, chronic sickle cell disease pain, central neuropathic pain. etc). Each team was asked to look at five "dimensions" that paint a picture of the condition and its consequences: core criteria, common accompanying symptoms, common comorbidities, social and economic impact, and aetiology / risk factors

The fibromyalgia team's report was published in January 2019.

The team recommended the following core criteria:

Core Diagnostic Criteria

1. **MSP defined as 6 or more pain sites from a total of 9 possible sites**
2. **Moderate to severe sleep problems OR fatigue**
3. **MSP plus fatigue or sleep problems must have been present for at least 3 months**

NOTE. The presence of another pain disorder or related symptoms does not rule out a diagnosis of FM. However, a clinical assessment is recommended to evaluate for any condition that could fully account for the patient's symptoms or contribute to the severity of the symptoms.
MSP - multi-site pain

Among the common features which support the diagnosis (dimension 2), the group noted tenderness, dyscognition, musculoskeletal stiffness and environmental sensitivities or hypervigilance. They noted that FM is more common in females, that FM occurs in children, and that onset is usually occurs between the ages of 30 and 50.

For comorbidities, the group listed irritable bowel syndrome, chronic pelvic pain and interstitial cystitis (bladder pain), chronic head and orofacial (face and mouth) conditions, otologic (ear related) conditions, chronic headaches and migraines, psychiatric conditions, sleep disorders, rheumatological conditions, rhinitis (colds), urticaria (hives), and obesity. They note that chronic fatigue syndrome has considerable overlap with FM, with the predominance of pain being an identifier of FM.

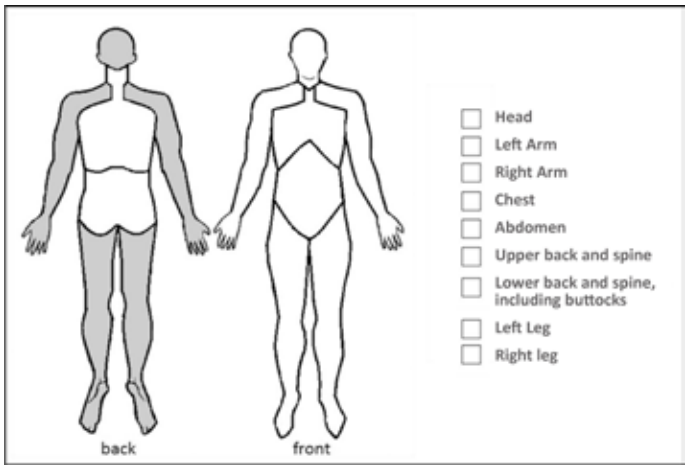


Figure 1
Number of painful body sites.
Patients are asked to check the areas in which they experience pain on the 2-view manikins (ignoring the pre-shaded areas). Alternatively, patients may use the checklist of body sites. The number of separate sites are summed from a maximum of 9 body sites.

The authors went on to review literature on the impact and potential causes of FM (dimensions 4 and 5).

This article is interesting and well written. Considering that the FDA and the APS are behind these criteria and that international FM leaders were on the panel, they are likely to become the international standard.

There are, however, two limitations worthy of note.

The purpose of the criteria is not completely clear. Clinical diagnostic criteria lead to treatment paths while research criteria lead to selecting study participants. The criteria appear to be too general to be useful for treatment purposes and too vague to be useful for research purposes.

The authors gloss over the relationship between ME and FM. People who have multi-site pain along with sleep problems and/or fatigue could also meet the requirements for ME. The authors never use the term ME, relying on the term chronic fatigue syndrome and suggesting that FM can be distinguished based on the level of pain. There is no mention of ME symptoms like post-exertional malaise or orthostatic intolerance. This leaves people with combined ME/FM at risk for inappropriate treatments (graduated exercise therapy and cognitive behaviour therapy are recommended in the 2012 Canadian fibromyalgia guidelines) and deprives them of the benefits of an ME diagnosis.

It is our view whenever anyone is being considered for a diagnosis of Fibromyalgia, the possibility of Myalgic Encephalomyelitis must be considered as well since there are features of ME that greatly affect treatment.

Lesley M. Arnold, Robert M. Bennett, Leslie J. Crofford, Linda E. Dean, Daniel J. Clauw, Don L. Goldenberg, Mary-Ann Fitzcharles, Eduardo S. Paiva, Roland Staud, Piercarlo Sarzi-Puttini, Dan Buskila, and Gary J. Macfarlane, AAPT Diagnostic Criteria for Fibromyalgia

Bioethics

Diane O'Leary, currently working at the University of Western Ontario, has published several recent articles on bioethics. One looks at the proposed addition of "bodily distress function" to the World Health Organization's proposed new International Classification of Diseases. She argues that it would be unethical to include this category and goes further casting doubt on the scientific standards in psychosomatic medicine. The other looks at the UK's project to update its guidance on treating ME and argues that it would be unethical to classify ME as a mental health condition. One reason is because there is enough evidence to consider ME to be a biomedical disease, while a mental illness classification would in practice cut off access to biomedical care.

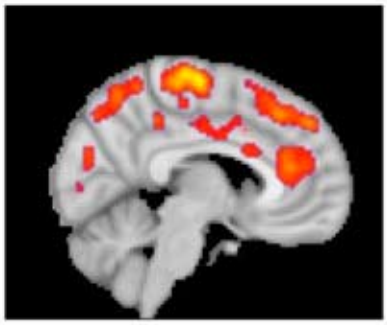
These articles

- put UK and WHO authorities on notice that they are facing bioethical issues
- draw the attention of the bioethics community to issues around contested illnesses, and
- let the affected patient community know that these issues have been identified by the bioethics community

O'Leary, D, Ethical classification of ME/CFS in the United Kingdom, Bioethics, 2019: 1-7

O'Leary, D, Bodily distress syndrome: Concerns about scientific credibility in research and implementation, JBPC vol.18 (2018)

Neuro Inflamation in FM



The results from both a US and a Swedish research center found that glial activation in several regions of the brains of fibromyalgia patients was significantly greater than it was in control participants. “The activation of glial cells we observed in our studies releases inflammatory mediators that are thought to sensitize pain pathways and contribute to symptoms such as fatigue,” stated one of the authors.

https://www.sciencedaily.com/releases/2018/09/180927122946.htm

Patterns in FM

In Michigan, there is a network of pain clinics that have been seeing FM cases for years. The clinic pulled FM files, then used artificial intelligence / machine learning techniques to find patterns in the written records. What they found were four groups of FM patients, listed in increasing complexity.

- The largest group was people with pain in some locations and relatively few other symptoms
- The next largest group was people with more widespread pain and some additional symptoms
- The next group had people with increased widespread pain, additional symptoms, sleep disturbance, and chemical sensitivities
- The last group (very small) were people with complicated medical issues combined with FM.

The study found that over time an individual could change categories both upwards and downwards.

As can be expected, more pain treatments were attempted for the third group than the second or first group. There seems to be some hesitation in attempting pain treatments in the medically complex group.

Diagnosing ME in Young People Correctly

In a British commentary, the writers talk about the importance of diagnosing pediatric ME correctly. They point to a range of prevalence estimates based on different case definitions. They identify two problems with this. At the macro level, the health system cannot plan and monitor properly. At the individual level “Misdiagnosis in this vulnerable group has profound implications, since a false positive diagnosis may lead to inappropriate labeling of a child with ME/CFS and improper intervention with treatment, while under-diagnosis might mean a child or teen not receiving the care they require.”

Geraghty J and Adeniji C (2019) The importance of Accurate Diagnosis of ME/CFS in Children and Adolescents: A Commentary, Front.Pediatr. 6:435

New US statistics on ME/CFS

We got a brand new statistical perspective of ME/CFS in January 2019.

The main sources of statistics on ME/CFS have been surveys of the general population. In one example, the Canadian Community Health Survey asked randomly selected Canadians if they had a diagnosis of Chronic Fatigue Syndrome. In a well known example from the 1990’s, the team led by Dr Jason randomly contacted people, asked about their symptoms, then tested some of them for CFS (Fukuda).

In this study, the researchers went to an administrative database operated by the UnitedHealth Group. There are companies in the US that administer payments to doctors, hospitals and laboratories for services rendered. Doctors, hospitals and laboratories submit forms identifying the individuals served, describing the services provided, and providing information on why the service was provided (symptoms, diagnoses, etc). The UnitedHealth Group has over 100 million individuals on its files though many of the individual records were not used in the study for various reasons.

Some of the researchers were from the analytical section of UnitedHealth Group. There were also some well known ME clinicians involved (Drs Bateman, Lapp and Rowe). The work was coordinated by the Massachusetts ME/CFS & FM Association.

Doctors and hospitals were asked for primary and additional diagnoses. They could code either to ME or to CFS. The researchers tried to answer several questions about ME or CFS using this database. Here are some highlights.

What is the prevalence of diagnosed ME/CFS? Depending on how the data was analysed, the results ranged from half a percent to one percent of the total population. This was higher than the authors expected, leading them to state that "it is not a rare disease, but in fact a relatively common one." (For the record, the Canadian Community Health Survey suggests a prevalence just over 1%. Recall that the prevalence rate for the CCHS applies to Canadians age 12+, not the total population.)

What is the male/female ratio? Depending on how the data was analysed, the results ranged from about 60-65% female. There was a higher proportion of men than the authors expected (but is in line with the results from the CCHS).

How much is being spent on ME/CFS cases for doctor/hospital/laboratory care? The study found that the average annual doctor/hospital/laboratory cost per individual with ME/CFS was around $30k per year. The average annual cost for MS or Lupus was found to be around $20k per year, and the average annual cost for the overall population was around $7k per year.

Can we tell from the data whether the people who have an ME or CFS diagnosis really do have ME/CFS? The researchers assumed that people with a diagnosis of ME or CFS would display similar patterns of symptoms or other characteristics (eg sent for similar tests). They used machine learning (artificial intelligence) techniques to explore the database searching for such patterns. They did not come up with strong patterns on the CFS side, suggesting that the cohort diagnosed with CFS was relatively heterogeneous. They did find stronger patterns on the ME side suggesting that this is a more homogeneous group.

Can we estimate how many people really have ME/CFS? The researchers made the assumption that ME diagnoses (prevalence 0.12%) were relatively good, then looked for other people on the file fitting a similar pattern. Their work suggested a prevalence rate of 0.86%.

It is time to do similar studies on the equivalent Canadian databases. The data bases are maintained by the provinces - OHIP is the database in Ontario. It would likely be found that there are serious gaps in the data due to issues like lack of billing codes in many provinces. It would be an opportunity to get the data quality issues resolved!

Valdez AR, Hancock EE, Adebayo S, Kiernicki DJ, Proskauer D, Attewell JR, Bateman L, DeMaria A Jr, Lapp CW, Rowe PC and Proskauer C (2019) Estimating Prevalence, Demographics, and Costs of ME/CFS Using Large Scale Medical Claims Data and Machine Learning. Front. Pediatr. 6:412.

Listening to Study Participants

The UK Biobank has collected samples from people with ME/CFS and Multiple Sclerosis and from health controls. There are some research results already from biomedical studies using these samples.

In this study, some of the people who provided biosamples were invited to participate in focus groups to talk about the research findings so far, about dissemination of research results and generally about what future research they want their biosamples to support. ME and MS participants were in separate groups. With more understanding of the mechanisms behind MS, it was thought that the experiences and needs of ME and MS participants would be different.

The study found that all the participants wanted to reconcile the findings with their individual experiences. ME patients hoped that research would lead to demonstrable proof of disease. The MS patients noted that even though MS is better known and more demonstrable, it is not always correctly diagnosed and the diagnosis may not always be a positive experience. ME patients wanted research to lead to understanding and acceptance. The MS patients noted that they still encounter situations where they are not socially accepted. When it came to type of research, ME patients leaned more toward finding a cause while MS patients leaned more toward finding treatment. When it came to dissemination, the focus groups recognized the wide range of people who needed to be informed and the need for easy-to-understand material. The participants talked about the material being realistic and about the need to see individual research results as part of a bigger wave moving forward.

Kudos to the CureME group for presenting results so far to study participants and for listening to their feedback. Kudos also to tho patients who took part. They showed that patients have a nuanced understanding of why research is important and valuable ideas on how research results can be shared.

Lacerda EM, McDermott C, Kingdon CC, Butterworth J, Cliff JM, Nacul L. Hope, disappointment and perseverance: Reflections of people with Myalgic encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Multiple Sclerosis participating in biomedical research. A qualitative focus group study. Health Expect. 2018: 1-12

Listening to Patient Experiences with CFS in the Emergency Department

This study was based on a survey of "physician-diagnosed CFS" patients about their experiences with emergency departments. 59% of respondents said that they had gone to an emergency department for CFS symptoms. Many were told that their complaints were psychosomatic. The other 41% of respondents said they did not go to emergency departments, anticipating that nothing could be done or they would not be taken seriously.

The most common reason for going to an emergency department (a third of cases) was related to orthostatic intolerance (lightheadedness, dizziness, general weakness, fainting).

While it is not mentioned in the publication abstract, part of the article discusses how emergency departments could handle ME cases.

Christian Timbol, James Baraniuk. Chronic fatigue syndrome in the emergency department. Open Access Emergency Medicine, 2019; Volume 11: 15 DOI: 10.2147/OAEM.S176843

Other News

The US NIH is holding a conference in Bethesda Maryland April 4-5 . The theme is "Accelerating ME/CFS research"

A conference on Chiari, Syringomelia and Ehlers-Danlos Syndrome will be held in Niagara Falls, June 26-28, 2019.

The Ontario Task Force on Environmental Health was set up by the Minister of Health in 2016 and given a mandate ending in January 2019. It submitted a first report in summer 2017 which was subsequently published. That report formed the basis for our half-day workshop at the research conference in Montreal in May 2018. Shortly thereafter, the Ontario election was called and the work of the Task Force was suspended. This fall, the new Minister of Health of Ontario reactivated the Task Force. A final report was submitted to the Minister at the end of January 2019. We are awaiting its release. Stay tuned.

The Complex Chronic Diseases Program (CCDP) which is located at the BC Women's Hospital, which is run by the BC Provincial Health Services Authority (PHSA) has received two awards.

- Award of Excellence for Interprofessional collaboration: This award honours exemplary interprofessional collaborative practices, leadership and excellence from individuals and teams throughout BC Women's Hospital, BC Women's Hospital & Health Centre, and Sunny Hill Health Centre for Children. 2018 was the first year for the award and the CCDP was excited to be one of the recipients.
- PHSA+ Awards: This award celebrates the people and projects who exemplify PHSA's value of leadership in providing excellent care for vulnerable populations. The CCDEP shared this award with BC Cancer and the Office of Virtual Health.

For an uplifting video about the CCDP, go to:
https://www.youtube.com/watch?v=WW1RNJ_v-0U

Sensory-friendly Shopping Experience

We found two articles on CTVnews.ca on sensory-friendly shopping - one from the maritimes and one from Ontario. We thought this was a great idea!

Sobeys introduces sensory-friendly shopping
Feb 26, 2019 by: Meghan Groff

For one hour every other Sunday, Sobeys customers will notice something a little different when they go shopping

The grocery store chain has partnered with Autism Nova Scotia to introduce a sensory-friendly hour from 6 p.m. to 7 p.m. at their Nova Scotia stores.

"We have our lighting in the store reduced about 50 per cent ... we have all the sounds turned down on our PA systems, music, telephones, scanners at the register, anything we can possibly turn down, we turn down," explained Lori Rhyno, director of operations for Sobeys.

Cart collection takes place before the hour starts so there's no loud clashing metal as the carts crash together, and a manager or Autism Nova Scotia representative is stationed at the front of the store to explain what's going on.

The first province-wide sensory-friendly hour was last Sunday and Rhyno said they got a lot of positive feedback.

"It was pretty powerful when a customer came into the store and said, 'This is the first time that my child has been able to come in and pick out a treat for themselves,'" said Rhyno. "They've never really been able to go into the grocery store because of the noise, the lighting and how confusing that can be for their child."

Prince Edward Island stores implemented the idea just before Christmas and after their successful launch, it expanded to Nova Scotia.

She added store managers in New Brunswick have also shown interest

'Sensory Friendly' shopping experience in Arnprior
February 11, 2019 by: Ryan Flanagan

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One Ontario grocery store owner is being lauded for finding a way to make his store more welcoming forpeople with sensory sensitivities.

Mark Harrison held his first sensory-friendly shopping experience last week, following a suggestion from an employee at his No Frills store in Arnprior, Ont.

"We turned off some of the lights. We turned off the music, eliminated pages over the PA system and asked customers and employees to refrain from wearing strong scents," Harrison told CTV's Your Morning Monday.

...

Harrison says he heard plenty of positive comments about the experience from shoppers and employees. The general impression he received was that shoppers liked the relative peace and quiet, and felt less rushed than they normally do.

"I think they just really enjoyed the calmer experience," he said.

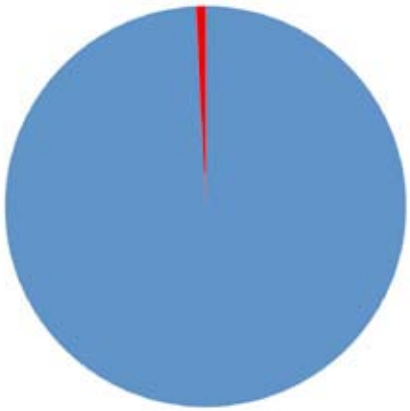
There was also a significant positive reaction on Facebook, where Harrison had publicized his sensory friendly supermarket.

"Thank you so much for making this opportunity for my daughter and I to have a better shopping experience," wrote Heather Adkins.

The sensory-friendly shopping experience was enough of a hit that Harrison has decided to hold it twice this week – adding an evening session for people who are unable to make it to his store in the morning. Other No Frills franchisees have expressed interest in picking up the program themselves, Harrison said.

CIHR Funding

The Canadian Institutes of Health Research maintains a database containing descriptions of the studies they have funded or are funding. They provide a search function so anyone can search the database by keyword, by researcher, by year, etc.



We have been monitoring the database, watching for studies into ME, CFS, FM, and MCS. We have not found any approved studies this fiscal year that refer to ME, CFS or MCS. We have found five studies that refer to FM. Total spending on studies mentioning FM - $189,000. Total spending overall $989,148,771 (as of March 06/19). In other words, for every $1,000 that CIHR has allocated this fiscal year, less than 20 cents has gone to studies mentioning ME, CFS, FM or MCS.

The following are the FM studies funded for 2018-19. Note, the second and third studies are multi-year but only the 2018-19 funding is shown.

$75,000, Jeffrey S Mogil, McGill U Psychology, Catalyst Grant, **Sex as a Variable in Biomedical Research**.

Telomeres are the DNA "caps" that protect the ends of chromosomes. When cells divide, the length of the telomeres decrease, and this telomere shortening has been associated with diseases of aging and mortality. Chronic pain is the most prevalent human health problem, affecting up to 25% of the Canadian population. Available treatments for pain are often ineffective and associated with side effects including addiction, and thus new pain treatments are sorely needed. One potential new avenue of pain research concerns the role of telomeres, as three published studies have associated telomere length with clinical and experimental pain sensitivity. No systematic analysis of the interaction between telomeres and pain has ever been undertaken, however. Our laboratory has amassed preliminary evidence of a bidirectional relationship between telomeres and pain in mice, one that appears to be true only in males. We have observed that injuries associated with chronic pain can shorten blood cell telomeres, that mutant mice unable to synthesize telomeres have altered pain sensitivity, and that telomere length correlates with pain sensitivity. In addition to telomeres in blood cells, we have observed one of the well-known effects of telomere changes-called cellular senescence-in cells known to mediate pain signals in the nervous system. We are proposing a set of studies to evaluate: 1) the mechanism underlying the relationship between telomeres, cellular senescence, and pain in mice; and, 2) the relationship between telomeres and pain in tissues from human pain patients (including those with fibromyalgia and low back pain). These studies will reveal the nature of the sex difference, and serve as another powerful reminder why biomedical research needs to include both sexes.

$60,000, R Nicholas Carleton (new researcher), U Regina Psychology, **Identifying and modifying transdiagnostic risk and resiliency variables for anxiety and pain**

Anxiety and pain are common human experiences that cause significant distress or impairment for almost 1 in 5 Canadians with annual costs exceeding $60 billion. Successful treatments are available, but such treatments are costly, there is limited access to qualified providers, and even with the best available care many people still receive only limited symptom relief; moreover, the overwhelming tendency is to provide treatment rather than prevention. My overarching goal for the next 5 years is to develop inexpensive and broadly deliverable assessment, treatment, and prevention methods for anxiety and pain. I believe this can best be accomplished by identifying the underlying mechanisms and constructs (i.e., vulnerabilities) that are common to different anxiety disorders (e.g., social anxiety disorder, posttraumatic stress disorder) and to different pain experiences. Once identified, methods can be developed for reducing vulnerabilities and, therein, treating and

even preventing anxiety and pain. My research suggests differences in attention are an important vulnerability that can be modified using simple computer tasks that can be administered inexpensively online. My current CIHR-funded research is testing the effectiveness these tasks for patients with chronic pain. Similarly, how well people cope with uncertainty appears to be a critical factor in developing and maintaining clinically-significant anxiety; as such, I am researching methods to increase our ability to tolerate uncertainty. I will apply for CIHR funding to test the effectiveness of delivering those methods online. Finally, I believe prevention is the best treatment, which is why I am leading an international team of experts in testing a method for preventing posttraumatic stress disorder in RCMP. Overall, my research results will support Canadian mental heath care by producing timely, inexpensive, and broadly deliverable methods for assessing, treating, and preventing anxiety and pain.

$35,000, Lyndsay Crump (doctoral award), UNB Psychology, **Are there benefits to participating in Facebook electronic support groups for persons with fibromyalgia?**

Fibromyalgia (FM) is a disorder characterized by chronic pain, fatigue, memory difficulties, and depressive/anxious symptoms. Because FM is an invisible illness of unknown origins, patients often face skepticism from loved ones, employers, and health-care professionals. A widely available means of accessing peer support are Facebook electronic support groups (FESGs), which have become widespread within the FM community. Building on my master's research findings that low self-worth and threats to people's sense of identity interferes with support-seeking, this study will examine three FM FESGs (20,000 members) to assess how group participation can validate patients' suffering and help patients engage in self-affirmation (recognizing and focusing on cherished values, relationships, and personal qualities linked to a positive sense of self and higher self-worth). Patients with high self-worth and a positive sense of self report better relationships with physicians and greater willingness to change health behaviours. I propose that patients reporting self-affirming activities to the group will be less likely to criticize health recommendations that challenge their patient identity and will be more likely to describe engaging in positive behavioural changes (e.g., following physician's recommendations) than patients who do not engage in self-affirmation. Comments posted over 90-days in 2015 will be collected and analyzed using well-established text-based research methodologies. Results indicating FM FESGs help patients validate their suffering and engage in self-affirming activities would suggest FESGs are an accessible, cost-effective resource for reducing patient distress and unhelpful health behaviours. This study will provide a scientific basis for making recommendations to patients and physicians regarding the costs and benefits of FM FESGs, and will provide insight into FM FESGs' impact on patient illness experiences and engagement with health professionals.

$17,500, Martina Agostino (master's award), Lakehead U Biology, Novel Methods for the Treatment and Diagnosis of Fibromyalgia

The diagnosis and treatment of chronic pain disorders is an expanding area of research. Fibromyalgia (FM) is a chronic pain disorder that causes an individual to have a widespread heightened sensitivity to pain and it has no clear diagnosis or treatment. The current research study focuses on evaluating the effectiveness of radial shockwave therapy (RSWT) to treat FM associated pain and symptoms by quantifying cytokine protein concentrations in the blood. Concentrations of the interleukin 6 (IL-6) cytokine secreted by immune system cells, known as peripheral blood mononuclear cells (PBMCs), are specifically analyzed as levels are known to be lower in FM patients compared to healthy individuals. Blood samples are taken before and after FM patients completed a total of five once weekly RSWT treatments. PBMCs are isolated from the blood and half are stimulated with a protein mitogen to release cytokines. IL-6 concentrations are measured in stimulated and unstimulated samples using western blot analysis, and are compared between FM and healthy individuals. It is hypothesized that cytokine deregulations causing reduced IL-6 levels in FM patients will be due to PBMC dysfunction, and RSWT treatments will improve FM associated pain and symptoms as indicated by IL-6 levels before and after treatment. By evaluating cytokine concentration differences between FM and healthy individuals, more studies can be conducted and lead to new and effective treatments for FM and other chronic pain disorders.

$1,500 Simon Deslauriers (travel award), Laval, **Determinants of waiting time to access multidisciplinary pain treatment facilities for persons with rheumatic conditions in Quebec, Canada** ,

Pain is the main symptom reported by persons with arthritis, with a quarter of them reporting frequent and severe joint pain. Persons with arthritis suffering from chronic pain often benefit from a pain management program delivered in pain clinics, as it helps reduce pain, depressive symptoms and opioid use, while improving function and quality of life. Previous research suggests that access to pain clinics in Canada is limited by long waiting lists, but this has not been studied specifically in patients with arthritis. The aims of this project were 1) to determine the waiting time to receive services in pain clinics for persons with arthritis in the province of Quebec and 2) to identify factors associated with longer waiting time. By analyzing the Quebec Pain Registry, a large database of patients who received services within pain clinics, this study found extensive waiting time for patients suffering from arthritis, with more than a third of them waiting over 6 months. Several factors were associated with a longer waiting time: longer pain duration, lower family income, having fibromyalgia, pain onset following a motor vehicle accident and being referred by a family physician (versus specialists). The results of this study will serve as a building block for future work aiming to ensure equitable access to pain clinics for persons with arthritis.

Income Tax Clinics

A free tax clinic is a place where eligible people can go to get their tax returns done for free. You may be eligible for help at a free tax clinic if you have a modest income (eg less than $35,000 for someone living alone) and a simple tax situation.

If you have internet, you can look for locations here:

https://www.canada.ca/en/revenue-agency/campaigns/free-tax-help.html

If not, call Revenue Canada at 1-800-959-8281

Meetings with Government

Lydia and I have had a number of discussions with government officials recently. This includes officials from Statistics Canada regarding the Public Use Micro-data File, the Public Health Agency of Canada, the Canadian Institutes of Health Research, Canada School of Public Service, the Office of Disability Issues, the office of the Minister of Health and the office of the Minister responsible for Accessibility. Here are notes from the meeting with an official from the office of the Minister responsible for accessibility...

Thank you for the very positive meeting yesterday, Thursday Jan 10, 2019. It gave Lydia and me the opportunity to raise disability issues that the National ME/FM Action Network has encountered in our years working on behalf of Canadians with Myalgic Encephalomyelitis (ME, often referred to as Chronic Fatigue Syndrome) and Fibromyalgia (FM). ME and FM are associated with reduced activity levels. People compare their experiences to cell phones with poor batteries such that the phone can function, but not reliably or for the whole day. The Canadian Community Health Survey tells us that there were over 800,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, FM or both in 2014 and confirms that this community was dealing with high degrees of disability and disadvantage. See *http://mefmaction.com/docs/CCHS_Stats_2014.pdf* Nevertheless, this segment of the disability community receives little recognition.

Our goal was to find ways of helping our community. We suspect that our observations could help other communities dealing with disability issues as well. I am documenting the main issues for your convenience

and also for my Member of Parliament who was unable to attend but is extremely concerned. See her statement in the House of Commons, Dec 13, 2018. *https://www.youtube.com/watch?v=kyhA5qyu54M.*

Lydia and I work on the front lines, talking directly to Canadians with ME, FM or both. The major issues we hear about from them are:

- the lack of health care services,the lack of health research, and the lack of attention to what is known about ME and FM
- the difficulty qualifying for income support programs
- social isolation that comes from not being able to participate in society combined with lack of awareness and understanding

The National ME/FM Action Network has been taking issues to the federal government for many years. While we have noted some changes, we do not consider the response to be anywhere near adequate considering the seriousness of the situation.

Our experience is that most public servants have low levels of disability literacy. It is a true joy to have a good conversation such as the one yesterday. We suggest that disability training be emphasized in the public service. Treasury Board was identified as the responsible department.

As part of disability literacy, we note a failure to appreciate the scope of disability. It is commonly recognized that vision, hearing and mobility are important resources for functioning in society, and conversely that impaired vision, hearing or mobility are disabling. It is not commonly recognized that reliable adequate energy is a key resource for functioning in society and conversely that reduced or unreliable energy is disabling.

Current disability policy emphasizes the traditional disabilities. We suggest a test to see if disability policy is well balanced. For working age people, ability to participate in the workplace is key. We suggest looking at who cannot participate in the workplace because of health impairment and then identifying the causal factors. The CPPD database could be the data source. We hypothesize that nontraditional disabilities, including chronic and episodic health conditions, will be found to be more important than currently assumed. (The CCHS tells us that about 20% of Canadians who reported that they were permanently unable to work said that they had a diagnosis of CFS, FM or both.) The findings of this study would have implications for program decisions, organizational funding and consultation processes.

We pointed out a particular gap in disability literacy. Research has found that over-exertion leads to increased symptoms in people with ME. We have talked to many people struggling to stay employed at considerable risk to their health. Nevertheless, we have found no academic studies anywhere on dealing with ME in the workplace. This is a serious knowledge gap affecting employment policy in Canada and should be addressed immediately.

We have found the International Classification of Functioning to be a very useful tool for analyzing social programs. The purpose of social programs is generally to support people who have participation restrictions. Criteria based on impairment or activity limitation regularly fail to identify everyone with participation restrictions. This is why we are concerned about the DTC criteria (which use activity limitations), the new CPP-D application form (which uses activity limitations in part) and the Canadian Survey on Disability (which is based on activity limitations and impairments).

Yes, the disability sector needs a lot of attention. We know that change is difficult. Having watched committee hearings, we know that the government is concerned about budget implications. We know that CPPD changes can require F/P/T agreement. We are mindful of implications like these. But fairness is a concern too, and we find the culture in the public service is quick to defend the status quo and dismiss our concerns. Conversations need to be pushed further than they currently are being pushed.

We would like to comment on Bill C-81. Our submission to the HUMA committee concluded that “the new legislation addresses issues that are important to well-established disabilities, but it does not go as far as we hoped in addressing the needs of the not well-established community that we represent.” As noted above, our primary concerns are around health care, income support and social isolation. Having said that, we also point out that we bring special perspectives to the discussions that flow from Bill C-81 and we hope to be included.

Thank you again for the conversation yesterday. We look forward to working through the issues we have raised and the ideas we have put forward.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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 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

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