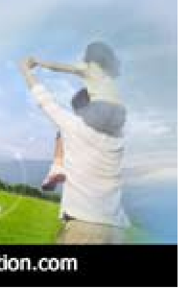
NATIONAL
ME/FM
ACTION NETWORK

Quest
Newsletter



www.mefmaction.com Quest 111, Summer 2017 mefminfo@mefmaction.com

This spring has seen many special events. This newsletter carries reports from AQEM, MEAO, MEFM-BC and the London Ontario Fibromyalgia group. The documentary 'Unrest' was shown in Toronto, Vancouver and Edmonton. The film-maker, Jen Brea, was interviewed on the CBC national radio program, The Current. Among other events, the Victoria BC association showed a different documentary, Opera Mariposa put on their annual fund-raising performance in Vancouver, and Action CIND organized a health fair in Toronto.

The Network continues to draw the federal government's attention to ME/FM issues. Lydia wrote the Prime Minister. He has bounced the letter over to the Minister of Health.

A symposium on health technology assessment was held in Ottawa in April. Attending were academics, representatives of drug and technology companies, health system administrators, and patients. Travel grants were given to ME/FM community members from BC, Manitoba, Toronto and New Brunswick. Anne Marie and I attended as well.

CIHR announced the awarding of an ME/CFS catalyst grant to Dr Ussher at the University of Edmonton. We would like to welcome Dr Ussher to this field of research. Our work with CIHR is quieter than usual at the moment as a major turnover of CIHR senior management is underway.

In international news, the US NIH offered to fund several ME/CFS research centers. Ten applications have been received, indicating major interest. The UK group Invest in ME held its annual conference with a strong field of researchers attending. Duke University held a conference on personalized medicine and ME/CFS was featured.

MAY 12, 2017, International ME/FM Awareness Day

May 12th is the birth date of Florence Nightingale who, although bedridden, saw patients.

Today we commemorate the people who passed and did not live to see the developments that are happening in research and the acknowledgment that ME is a debilitating illness.

It is also the day we need to thank those who are actively involved and contributing to gain acceptance for ME and FM on behalf of those who are not able to.

To all those who are too ill to participate, we pledge our support and our firm promise that no matter what obstacles are placed in our path, we are not and never will stop our fight for recognition, diagnostic criteria and effective treatments.

We thank the powerful research organizations who are working diligently to find answers to a complex illness and have devoted their time and energy to solve once and for all what others have failed to do. We have no doubt they will be successful.

To one and all, you are stronger than you thought you were and although there are many daily challenges and roadblocks in your way, know that we have reasons now to be optimistic.

Stay strong and believe better days are coming. The signs are there.

Sincerely,
NATIONAL ME/FM ACTION NETWORK
Lydia E. Neilson, MSM
Chief Executive Officer & Founder.

Contents

Just released: ME/CFS Pediatric Primer

http://journal.frontiersin.org/article/10.3389/fped.2017.00121/full

Network Writes Prime Minister

Thursday, April 6, 2017
Fax #613-947-0310
Email: Justin.trudeau@parl.gc.ca

The Right Honourable Justin Trudeau
House of Commons
Ottawa, Ontario Canada K1A 0A6

Dear Mr. Trudeau:

Imagine coming to work one day and catching a nasty virus that goes on for days, then weeks and then months. You see your physician who orders many tests, all of which come back negative. You may or may not get a diagnosis of chronic fatigue syndrome or fibromyalgia, but either way, your physician sends you to a psychiatrist because your doctor somehow thinks that you can will your way out of your illnesses. Your family doesn't know what to do. Your applications for disability benefits are questioned or turned down. You continue to feel sick, perhaps unable to go out of the house or even to get out of bed. You feel abandoned by the health system, by the social system, and even by family and friends.

That is the fate of many Canadians with Myalgic Encephalomyelits, often called Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM). Many have been ill for over 30 years. Many were ill as children or teenagers and never had a normal childhood. Imagine how you would feel if this happened to your child.

If you were to be ill with ME/CFS and/or FM today, your prognosis for recovery would be slim if not hopeless. You would be much better off if the illnesses were diagnosed promptly and treatment started early.

The sad part of this story is that information has been available for physicians to diagnose and treat ME/CFS and FM since 2003. Our organization, the National ME/FM Action Network, a Canadian registered charity, worked with Health Canada and 24 experienced and renowned ME/CFS and FM experts chosen by their peers, from Canada and around the world to develop diagnostic and treatment protocols. The protocols have sparked international interest. Overviews have been translated into English, French, Spanish and Italian, with the ME/CFS overview available in German and Dutch as well. I received the Meritorious Service Award from the Canadian Governor General for my role in their development.

The problem is that the protocols have not been endorsed or publicized here in Canada. The only dissemination is what our Network could afford to send out. The Canadian government has made no effort to educate government departments dealing with health issues and has shown no leadership in encouraging their use or their inclusion in medical education. In fact, the Canadian government has been ambiguous whether it even thinks that ME/CFS and FM are real and serious.

Statistics show that over 800,000 Canadians have a diagnosis of CFS, FM or both. The statistics go on to show that Canadians with CFS and FM have very high levels of health system usage coupled with very high levels of unmet health care needs, demonstrating ineffective use of our health resources. Canadians with CFS and FM show very high levels of disability, poverty, food insecurity and social exclusion. And this is not a small problem. Fully 20% of working aged Canadians who said that they were "permanently unable to work" reported a diagnosis of CFS, FM or both.

Research funding is desperately needed. While we have an open dialogue with CIHR, funding is still abysmal. Canada is way behind other countries in the race to understand ME/CFS and FM, to find biomarkers, and to find effective treatments. Canada is not even in a position to follow developments in other countries and bring that knowledge to patients. We need dialogue with the Minister of Health on research and other issues but that dialogue is not happening. We are also encountering difficulties opening dialogue around disability issues.

Canadians with ME/CFS and FM are getting a raw deal that needs to be corrected. Mr. Trudeau, I know you are a busy man but I think you need to meet with our Network's President, Margaret Parlor, and me to discuss how we can correct this miscarriage of justice for those ill with these debilitating illnesses.

We need your leadership, Mr. Trudeau, and your help. This is an opportunity to improve the lives of many Canadians.

Sincerely,

NATIONAL ME/FM ACTION NETWORK
Lydia E. Neilson, MSM
CEO, Founder

Prime Minister Responds

Dear Ms. Neilson:

On behalf of the Right Honourable Justin Trudeau, Prime Minister of Canada, I would like to acknowledge receipt of your correspondence.

Please be assured that your comments have been carefully reviewed. In your correspondence, you raise an issue that falls within the portfolio of the Honourable Jane Philpott, Minister of Health. I have therefore taken the liberty of forwarding your email to Minister Philpott for her information and consideration.

In your correspondence, you express an interest in meeting with the Prime Minister. I regret that the Prime Minister will not be able to meet with you to discuss this situation.

Thank you for taking the time to write.

P. Monteith
Executive Correspondence Officer
for the Prime Minister's Office
Agent de correspondance
de la haute direction
pour le Cabinet du premier minister

[Although this may seem like a minimal response, there is the indication that the Hon. Jane Philpott must take heed. We will therefore pursue that angle further. Lydia]

UNREST

Viewings
Toronto: April 29, May 1, May 5
Edmonton: May 7
Vancouver: May 12, 13

The documentary Unrest premiered in the documentary competition at the 2017 Sundance Film Festival, where it won a Special Jury Prize for editing. In the US, it will be broadcast on PBS's Independent Lens in early 2018.

This fall, the Unrest team will be launching a global campaign to bring Unrest to medical schools, leading research institutions, and advocacy communities around the world. They want to bring new scientists into the field, inspire a generation of doctors, and grow a vibrant community of patients, caregivers and allies to end the stigma and the misconceptions and accelerate the search for a cure.

Jennifer Brea gave the highest-rated talk at the 2016 TED Summit in Banff, Canada, the first ever TED Talk about ME. It launched in January 2017 and has been viewed more that 1 million times and translated into more than 25 languages.

Jennifer Brea was interviewed on the CBC program The Current on April 26, 2017. You can listen here:

http://www.cbc.ca/radio/thecurrent/the-current-for-april-26-2017-1.4084904/unrest-director-documents-debilitating-life-with-chronic-fatigue-syndrome-1.4084978 .

Lydia was interviewed for the same segment and there is a link to her letter to the Prime Minister on the CBC website. The website notes that the Prime Minister had not responded to her letter. We did receive a response very shortly afterwards.

May 12th Events

From AQEM

This year, l'Association Québécoise de l'Encéphalomyélite Myalgique (AQEM) is celebrating its 25th anniversary. We took advantage of the International Day of ME/CFS to celebrate this event. We organized a celebration cocktail where several important guests were present, including Dr. Alain Moreau, as well as guests from medical and political fields which all gave their full support to the cause of ME/CFS during the evening. Montreal City Hall and the Tower of the Montreal Olympic Park were also illuminated in the colors of ME/CFS for the occasion.

In addition to this evening, we organized the transmission of a package containing documents about the illness and our association to nearly 200 federal and provincial MPs. The packages were sent in advance of May 12th and contained a blue ribbon. We invited all elected officials to wear it on May 12th as a sign of their support to those affected by the illness.

On May 11th, Carole Poirier, the Member of Parliament for our riding, made a statement at the National Assembly in Quebec. Following this statement, we met ten elected officials and their representatives during information meetings, in order to make them aware of the difficulties experienced by those affected. We also have other meetings planned in the next couple of weeks with other members of the four political parties in Quebec.

Finally, in parallel to these activities, we were very active on social networks and we actively worked on traditional media to give visibility to ME/CFS. We had a radio interview on Thursday, May 11th that went very well.

Annie Tourville
Coordonnatrice générale
Association québécoise de l'encéphalomyélite myalgique (AQEM)

Montreal City Hall lit in blue on May 12th for ME/CFS awareness

From MEAO

The work of the Minister's Task Force on Environmental Health is proceeding, focusing on the topics of research, care and education. This is year one of a three year endeavor. An interim report is being prepared for submission to Ontario's Minister of Health.

MEAO's Awareness Day Event at Queen's Park was held on May 9th. Members of the Provincial Parliament from the three parties attended.

Mayor John Tory proclaimed May 12th as International Awareness Day for Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, Fibromyalgia and Environmental Sensitivities/Multiple Chemical Sensitivity in the City of Toronto. Thanks to the City of Toronto for their long standing support!

Best wishes from the MEAO Board of Directors,
Denise Magi
Vice-President MEAO

From MEFM BC

The movie Unrest was held at the Doxa film festival on May 12 and 13th.

Opera Mariposa held a fundraising concert at Marpole United Church on May 13th.

MEFM BC worked with the Complex Chronic Diseases Program to hold a 'world cafe' event on May 27th

World Cafe Announcement: For May Awareness month the Society usually brings in a speaker to address patients and health care professionals. This year we are doing something a little different. BC Women's has been looking for ways to increase collaboration with patients from the Complex Chronic Diseases Program (CCDP), and have suggested holding a World cafe in partnership with the Society. A World Cafe is a method for creating dialogue around questions that matter. Tables are set up with a moderator who poses a question to a group and notes are taken. People circulate among the tables to contribute their thoughts on any question of interest. At our event we will have 4 tables, each with an open ended question. Three of the tables will have questions relating to the CCDP, and will be facilitated by their staff, with the goal of creating actions that can be implemented in 2017-2018. One table will present a question in relation to the Society, facilitated by a Society member. Everyone participating in the planning and running of the event, both from the CCDP and the Society, is volunteering. There will be an online component to this event, so that patients who are homebound or not in Vancouver, can participate in some way.

Results: Very interesting dialogue took place. Key messages were reinforced like the shortage of services for people with ME/CFS and FM and the importance of of information and education. Many helpful suggestions were put forward for the CCDP to consider.

Valerie Free attended the Opera Mariposa fundraising concert and had the opportunity to present her book "Lighting Up a Hidden World: CFS and ME"

From the Fibromyalgia London Group

Including key learnings from presentations

In spite of how challenging the weather [or more specifically the barometric pressure] has been on all of us with FM, it was great to have 71 out of the 84 people who registered to attend, show up for our 3rd annual FM Awareness & Information Day event on Saturday, May 6th at Beacock Branch Library.

WOOHOO!!! The Group has entered the 3-digit number zone in our membership - as of Saturday, May 6, 2017,we registered 7 new members, bringing our new membership registration total to 107. Growing in size only means that all of us should continue to be active and engage with each other and with others in the community to help achieve greater recognition, seriousness, and acceptance about FM and CFS.

Learnings From London,On Presentations:

Recommendations for Use of Opiods for Chronic Non-Cancer Pain

Dr. Patricia Morley-Forster – Retired Director, Pain Management Program, St. Joseph's Healthcare, & Professor, Dept. of Anesthesia & Perioperative Medicine, Western University

In her presentation, Dr. Morley-Forster:

- reviewed the 2010 National Opioid Use Guidelines and the Recommendations for monitoring patients and opioids;
- discussed what has changed and the outcomes since the guidelines were released
- explained the new policy measures the Ontario Government has adopted to control the use and dispensation of prescription narcotics, increase in ministry funded addiction treatment centres
- outlined the implications of the 2017 guidelines including how it impacts FM sufferers and those using opioids other than morphine
- reviewed the recommendation and need for patients who have been on opioids a long time to consider the benefits of tapering

10 Key Learnings/Takeaways:

1. There is currently an epidemic of deaths involving prescription opioid overdoses which have quadrupled in 10 years
2. 2,000 Canadians died in 2015 from opioid-related poisoning
3. New research shows opioids are less effective for treating chronic pain than early trials indicated – in fact patients often had more pain as their opioid dose increased
4. There is no proof that opioids are effective for Fibromyalgia pain; in fact the opposite in that FM pain is resistant to opioids
5. Only 1 in 20 people in Japan and Germany receive opioids versus 1 in 5 in Canada
6. It is now known that patients who stay on opioids long-term face the increased risks of osteoporosis, sleep apnea, chronic nausea, mood disturbance and accidental overdoses
7. Opioids taken regularly may cause "opioid hyperalgesia (increased pain sensitivity)
8. 2010 National Opioid Use Guidelines being replaced by new National recommendations in 2017 which include first-line therapy and recommend prescribed doses when starting opioid treatments for patients with
    - chronic non-cancer related pain;
    - chronic pain plus active substance use disorder; or
    - chronic pain plus Serious Psychiatric Disorder
9. FM sufferers on daily doses greater than 90mg of morphine/day, or its equivalent, will have dosage reduced using the 10% rule
10. The Institute of Musculoskeletal Health & Arthritis, part of the Canadian Institute for Health Research, formed a large stakeholder group in 2015 to establish research priorities for FM. *[note: this was discussed in Quest 110]*

Advocacy, Medical Advances & Current Research on FM

Dr. Manfred Harth, Retired Rheumatologist & FM Specialist

In his presentation, Dr. Harth candidly shared some of the frustrations he has with medical practitioners and professionals who refuse to accept the research/medical-based evidence proving that FM is real, and is connected to a disorder in both our brain and spine. Through clinical trials and research, functional MRIs [fMRI] have shown how the brain of a person living with FM responds differently to pain compared to a normal person.

10 Key Learnings/Takeaways:

1. Method of Diagnosing FM has changed from classification criteria [presence of 11 out of 18 tender points of FM] to new “revised in 2016” Diagnostic Criteria using Widespread Pain Index (WPI) of 19 regions; Symptom Severity Scale (SSS) related to cognitive, sleep, fatigue (0-3)+headache, abdominal pain, depression (0-1).
2. A diagnosis of FM is confirmed if symptoms are present for:
    a. > 3 months;
    b. WPI ≥ 7 in ≥ 4 regions + SSS ≥ 5; or
    c. WPI=4-6 in ≥4 regions + SSS ≥ 9
3. Research has proven that:
    a. The Insula, Thalamus and Cortices in a FM sufferer all produce heightened and abnormal responses to pain, compared to that of a normal person.
    b. There is a marked increase in connectivity between the insula and a part of the brain known as the default mode network. This increase in connectivity occurs in other painful conditions.
    c. Grey matter volume in FM sufferers is severely reduced
    d. There is a decrease in the pain inhibitory signal intensity in FM patients
4. The peripheral nervous system is also involved in FM patients - Small fiber sensory neuropathy (SFSN) has been demonstrated in 33-50% of patients with FM
5. The European League Against Rheumatism (EULAR) is the organization which represents the people with arthritis/rheumatism, health professional and scientific societies of rheumatology of all the European nations.
6. 2017 EULAR Recommendations treating FM include:
    a. Exercise
    b. Cognitive Behaviour Therapy (CBT)
    c. Multicomponent
    d. Acupuncture
    e. Hydrotherapy
    f. Yoga
    g. Tai Chi
    h. Mindful Stress Reduction
    i. Prescription Medications – Amitriptyline, Duloxetine (Cymbalta), Tramadol, Pregabalin (Lyrica) and Cyclobenzaprine (Flexaril)
7. According to recent evidence-based research and recommendations on complementary and alternative therapies, participants reported that there has not been much ongoing relief or significant improvement in FM symptoms using MAOI, NSAids, SSRIs, Sodium Oxybate, biofeedback, chiropractic, massage therapy and homeopathy
8. Based on his own research and assessments, Dr. Harth did not see or had poor evidence that trigger/tender point injections, lidocaine infusions, narcotics and naltrexone help persons with FM symptoms in an ongoing/permanent way
9. We, the FM community of persons living with FM symptoms, need to be our own advocates with focused objectives to:
    Better access to treatment
    Better and wider recognition of FM as an important health issue
    Better recognition of FM as an important social issue
    Better recognition and fairer assessments by private and public insurers
10. All of us need to seriously engage in meaningful dialogue with our health professionals particularly physicians, physiotherapists, psychologists, lawyers in medical litigations, unions and politicians about CPP and WSIB.

--
Respectfully yours,
Jacqueline Fraser
Founder & Group Co-Coordinator
The Fibromyalgia London Group

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Find us on Facebook & Twitter @fmlondongroup

Reflections on the 2017 CADTH Symposium

By Kathryn Larouche Imler and Bart Imler

Kathryn Larouche Imler is a former registered nurse and has suffered from ME/CFS & FM for approximately 17 years. Bart Imler is Kathryn's primary caregiver, and has a technical background in computers, telecommunications and electronics.

The Canadian Association for Drugs and Technology in Health (CADTH) is an independent non-profit organization (created by federal, provincial and territorial governments) that works to provide a coordinated approach to assessing health care technologies (including drugs), and to provide information on health care technologies to health care decision makers.

CADTH recently held its annual symposium in Ottawa. The theme of the symposium was "Measuring Value in Theory and the Real World". Thanks to CADTH's generous sponsorship of Patient Group Representatives, and with the facilitation and assistance of National ME/FM Action Network President Margaret Parlor, we were able to attend this symposium and participate in several sessions and events.

Initially we were a little unclear on exactly what role we might play at the symposium. CADTH, Health Technology Assessment (HTA), and the theme of "Measuring Value" were all new to us, and as we investigated we weren't sure how our personal objectives as patient representatives would align with the goals and objectives of CADTH and the symposium theme. We questioned amongst ourselves whether we could make a positive difference. As the symposium progressed, we found that our fears were unfounded.

One of the most exciting and gratifying ways that we were able to make a positive difference was through direct contact with other symposium participants and speakers. We had very satisfying discussions with a diverse range of people, and were able to provide information (pamphlets, fact sheets and personal experiences) on ME/CFS & FM to several people.

One of the most rewarding moments during the symposium came during a discussion with a patient representative/caregiver who is involved with Alzheimer patients. He related the story of a close friend who has been diagnosed with Bipolar Disorder. He described several of her symptoms (fatigue after exertion, chronic pain, etc.) that were unexplained by the diagnosis. We provided some literature on ME/CFS and FM that he felt may explain many of his friend's symptoms, and he was excited to forward the information to her.

During the three days of the symposium we attended two workshops, two plenary discussions, five presentations and oral discussions. The various sessions covered a wide range of topics, including rare diseases, health technology assessments, patient engagement, and the ongoing opioid crisis.

We were able to participate directly in several of the scheduled presentations. Kathryn contributed personal experiences with over-prescription of opioid medications during a presentation on CADTH's response to the opioid crisis, and Bart provided a question on increasing the level and quality of patient participation to the plenary panel discussing meaningful stakeholder engagement. We also had an opportunity to talk directly with several presenters during and after the presentations.

In summary, we found the symposium to be very interesting, and it was an excellent opportunity to interact directly with a wide spectrum people from the health industry. We were able to provide information about ME/CFS & FM to several individuals, and to contribute to several discussions in a meaningful way. Once again we would like to thank CADTH and the National ME/FM Action Network for their sponsorship and for allowing us to participate.

Network members attending the CADTH symposium - Maria Moores, Margaret Parlor, Kathryn Larouche Imler, Anne Marie MacIsaac

2016 Diagnostic Criteria for Fibromyalgia

In his presentation in London, Ontario, Dr Harth referred to the 2016 criteria for diagnosing Fibromyalgia. What are these criteria and what is their status?

In 1990, the American College of Rheumatology (ACR) endorsed diagnostic criteria for Fibromyalgia based on widespread pain and the existence of tender points.

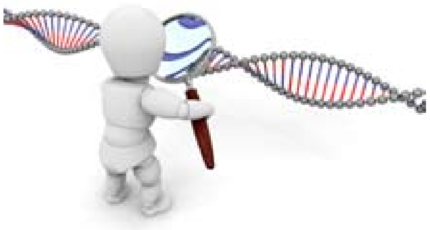
In 2003, the Canadian expert panel essentially adopted this criteria, but noted that "additional clinical symptoms and signs can contribute importantly to the patients' burden of illness." The panel identified six categories, neurological manifestations, neurocognitive manifestations, fatigue, sleep disturbance, autonomic and/or neuroendocrine manifestations, and stiffness.

In 2010, the ACR released what it referred to as "Preliminary Diagnostic Criteria for Fibromyalgia and Measurement of Symptom Severity". Two measurements were proposed, a widespread pain index (WPI) and a symptom severity scale (SSS). The WPI asks in how many of 19 areas of the body did the patient experience pain in the past week. The areas are left and right jaw, shoulder, upper arm, lower arm, hip, upper leg and lower leg, plus the chest, abdomen, upper back, lower back and neck. The Symptom Severity Scale, which partially incorporates the additional symptoms and signs of the Canadian criteria, gives a score of zero to three for each of: fatigue, waking unrefreshed, cognitive symptoms, and somatic symptoms. A diagnosis of Fibromyalgia is made based on certain combinations of WPI and SSS scores, combined with continuity of symptoms over time and the lack of another explanation.

A modification to the 2010 criteria was proposed in 2011 whereby the results could be based on patient self-reports rather than physician assessment.

In 2016, there was a review of the criteria and several adjustments were made. Most importantly, the pain in the WPI score can't be concentrated in one or two regions of the body and a diagnosis of Fibromyalgia can be made even if there are other diagnoses. Discrepencies between the 2010 and 2011 versions were also resolved.

A few years ago, the American College of Rheumatology decided on principle not to endorse any new diagnostic criteria for Fibromyalgia. This means that the 2016 guidelines do not have official status with the ACR, but it also means that no new guidelines will have official status. Interestingly, the US Social Security Administration recognizes both the 1990 and 2012 criteria.



Now step back and look at the diagnostic criteria for Fibromyalgia. To qualify, a person has some combination of pain, fatigue, sleep problems, cognitive problems and other symptoms (headaches, abdominal pain/cramps and depression). These are components of the diagnostic criteria for ME/CFS. The main component that is in the ME/CFS diagnostic criteria but not in the Fibromyalgia diagnostic criteria is post-exertional malaise, the inability to tolerate exertion. It is extremely important to know whether an individual is intolerant of exertion because too much activity or exercise could have serious consequences. The National ME/FM Action Network is extremely concerned that the guidelines for diagnosis and treatment of Fibromyalgia, which were developed for Canadian doctors in 2012, do not recommend that doctors check Fibromyalgia patients for post-exertional malaise. We fear that many patient are given a diagnosis of Fibromyalgia and are put on a treatment plan that does not take into account possible energy impairment. The National ME/FM calls for changes to the Fibromyalgia guidelines to include discussion of post-exertional malaise. The Network also calls for urgent research into the relationship between ME/CFS and Fibromyalgia.

Quote from an article on the Duke University conference on Personalized Medicine: "Another question was on the overlap of fibromyalgia and ME/CFS. Dr. Komaroff said there is no doubt that the diseases share similarities, and early on, he and others thought they might be the same disease. He noted that there may be some underlying biological differences, but that the diseases are 'awfully similar.' He said that three drugs have been approved by the FDA for the treatment of fibromyalgia, but there have been no trials of these drugs in ME/CFS." This emphasizes the need to look at the relationship between ME/CFS and Fibromyalgia and brings out the advantages of learning from each other.

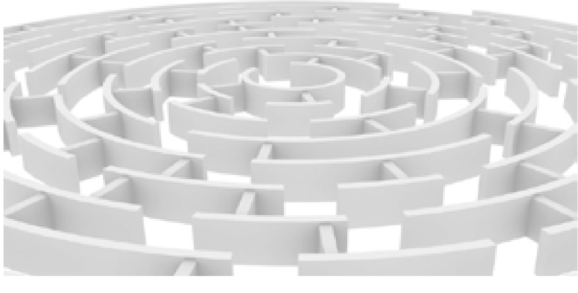
CIHR Catalyst Grant for ME Rresearch

2017-2018 - $99,300

Impaired Skeletal Muscle Pyruvate Dehydrogenase Activity & Chronic Fatigue Syndrome

John Edward Reyes Ussher
University of Alberta, Pharmaceutical Sciences Division

Chronic fatigue syndrome is a disorder characterized by severe fatigue and weakness of unknown origin, affecting anywhere from 2 to 25 of every 1000 individuals in the world today. The disorder affects severely impacts an individual's quality of life and productivity in the work force, and unfortunately has no specific treatments that target the root cause of the disorder, with current treatments aimed at improving its associated symptoms. Recent studies in humans have suggested that a reduced ability to burn carbohydrates/sugars for energy in skeletal muscle leads to muscle weakness and may be a key factor responsible for the severe fatigue in patients with chronic fatigue syndrome. Of interest, we have a developed in our laboratory a genetically modified mouse model that has a reduced ability to burn carbohydrates/sugars for energy, and we have observed that these animals have reduced voluntary activity, which may be the result of early fatigue. Therefore, we would like to carry out detailed studies in our genetically modified mouse model to determine whether an impaired ability to burn carbohydrates/sugars in skeletal muscle for energy is indeed a root cause for chronic fatigue syndrome. We will address this by measuring exercise capacity in our animals (both forced and voluntary exercise). If our results prove true it will suggest that increasing carbohydrate/sugar metabolism in skeletal muscle might be an exciting new strategy to treat chronic fatigue syndrome by actually attacking a mechanism causing this disorder, versus our current treatments that simply deal with improving patient symptoms.



Medical Organizations in Canada

Margaret Parlor

'*Nobody knew health care could be so complicated'*
Donald Trump

In this article I describe some of the medical organizations in Canada we expect to be in contact with as medical education and clinical care move forward. For simplicity, I refer to Ontario organizations when describing provincial organizations. We are not sure what medical specialty will adopt ME/CFS and FM. For this article, I used rheumatology associations as examples.

The **College of Family Physicians of Canada** (CFPC; French: Le Collège des médecins de famille du Canada, CFPC), which is based in Mississauga, Ontario, is a professional association and the legal certifying body for the practice of family medicine in Canada. This national organization of family physicians was founded in 1954, incorporated in 1968, and currently numbers over 35,000 members. The CFPC establishes the standards for the training, certification, and lifelong education of family physicians. It accredits postgraduate family medicine training in Canada's medical schools, conducts the certification examination in family medicine, and grants the certification (CCFP) and fellowship (FCFP) designations. [Note that family doctors who began practicing years ago do not have to join the CFPC. They are referred to as general practitioners rather than family physicians.]

The **Royal College of Physicians and Surgeons of Canada** (French: Collège royal des médecins et chirurgiens du Canada) is regulatory college which acts as a national, nonprofit organization established in 1929 by a special Act of Parliament to oversee the medical education of specialists in Canada. The Royal College is an association of physicians concerned with setting national standards for medical education and continuing professional development in Canada for 80 medical specialties. As such, the Royal College is neither a licensing nor a disciplinary body. Instead, it is a regulatory authority that helps ensure that the training and evaluation of medical and surgical specialists and three special programs maintain certain standards of quality. All specialists in Canada except family physicians must be certified by the Royal College before they obtain a provincial or territorial licence to practice. The only exception is in the Province of Quebec, where the Royal

College shares the responsibility for certifying physicians with the Collège des médecins du Québec.

The **College of Physicians and Surgeons of Ontario** (CPSO) is the regulatory college for medical doctors in Ontario. The college issues certificates of registration for all doctors to allow them to practise medicine as well as: monitors and maintains standards of practice via assessment and remediation, investigates complaints against doctors, and disciplines those found guilty of professional misconduct and/or incompetence. The CPSO's power is derived from Regulated Health Professions Act (RHPA), Health Professions Procedural Code under RHPA and the Medicine Act. The college is based in Toronto.

The **Ontario Medical Association** (OMA) is a membership organization that represents the political, clinical and economic interests of Ontario physicians. The Ontario Medical Association (OMA) represents more than 34,000 physicians and medical students across the province. While membership is voluntary, as of 1991, all practicing physicians in Ontario are mandated by law to pay dues to the organization, regardless of whether or not they choose to be members. While the Ontario Medical Association is not a union, the Ministry of Health recognizes the organization as the sole negotiator on behalf of physicians in Ontario.

The **Canadian Medical Association** (CMA), is a national, voluntary association of physicians that advocates on behalf of its members and the public for access to high-quality health care, and provides leadership and guidance to physicians. The CMA also takes the lead on public health issues. The CMA aims to ensure the survival and robust health of Canada's medicare system in the face of numerous challenges. The CMA is a Canadian civilian organization with the Royal Patronage of Queen Elizabeth II. The Canadian Medical Association Journal (often abbreviated as CMAJ) the CMA's official publication, is a peer-reviewed general medical journal that publishes original clinical research, commentaries, analyses, and reviews of clinical topics, health news, clinical-practice updates, and editorials.

Founded in 1943, the **Association of Faculties of Medicine of Canada** (AFMC) represents Canada's 17 faculties of medicine and is the voice of academic medicine in this country. Member faculties graduate over 2,700 MDs per year; teach over 11,500 undergraduate medical students; train over 15,000 postgraduate trainees; employ nearly 48,000 full and part-time faculty members and undertake over 3 billion dollars of biomedical and health care research annually. Representatives from the AFMC and CMA, along with students and public representatives are members of the Committee on Accreditation of Canadian Medical Schools (CACMS) which accredit the MD program in all 17 faculties of medicine in Canada. Additionally, AFMC, through the Committee on Accreditation of Continuing Medical Education, also participates in the accreditation of the offices of Continuing Medical Education at all Canadian faculties of medicine.

The College of Family Physicians of Canada has provincial chapters such as the **Ontario College of Family Physicians** which describes its role as follows: The OCFP provides high-quality, evidence-based education, promotes family doctor leadership and advocates for the vital role of family doctors in Ontario's health-care system. With 10,500 members, we are the provincial Chapter of the College of Family Physicians of Canada and are an essential voice for family medicine in Ontario.

Likewise, there are many organizations based around the specialties of the Royal College of Physicians and Surgeons of Canada – associations for psychiatrists, pediatricians, oncologists, etc. For example, the mission of the **Ontario Rheumatology Association** is to represent Ontario Rheumatologists and promote their pursuit of excellence in Arthritis care in Ontario through Leadership, Advocacy Research & Education and Communications. The Mission of the **Canadian Rheumatology Association** is to represent Canadian Rheumatologists and promote the pursuit of excellence in arthritis and rheumatic disease care, education and research. The CRA facilitates meetings, and supports education and research via a number of initiatives, including publication of the Journal of the Canadian Rheumatology Association (CRAJ) and The Journal of Rheumatology (Jrheum).

These have been organizations of physicians. There are also organizations for other health professionals such as nurses, psychologists, physiotherapists and occupational therapists. There are health charities and research foundations. Health care is delivered through provincial and regional organizations. Indeed, the health care system is very complicated.

Stress Testing for Research Project

Question: I am a long-term sufferer of ME/CFS, and I have read about your exciting new "stress test" that involves wearing an arm-cuff for 90 minutes, while blood samples are taken before and after to measure changes in a 'stress related' miRNA. Could you possibly send me more information on this 'stress test' and how it works please? I understand it creates a 'stress' but no physical exercise is required - clever! But how is the 'stress' then created that causes the change to the target miRNA?

Answer: As you know, one of the major challenges in effective treatment of various disorders lies in the timing of diagnosis and timing of evolution of the disorder per se. Despite the frequent use of biomarkers in clinical practice, there is relatively little information about validated biomarkers for ME/CFS. Given the clinical heterogeneity of the disease and gender differences (higher prevalence in women), its etiology is not well understood and the timing of progression from an acute to chronic state varies between individuals from months or years or never occurs. Thus, we search for novel biomarkers that reflect the systemic pathophysiological state associated with ME/CFS with a focus on circulating microRNAs that have gained increased attention in molecular medicine. MicroRNAs are small ribonucleic acid non-coding molecules that could interfere with the synthesis/production of specific proteins. Indeed, the importance of the miRNAs and their regulatory pathways are underscored by the impressive list of diseases that have recently been found to be associated with abnormal miRNA expression. ME/CFS will be no exception. MiRNAs, as regulators of gene expression, are crucial to a variety of biological processes and can even serve as biomarkers to predict the clinical phenotype, the activity of the disease and its severity, remission and relapse phases, response to treatment and disease staging over time. Moreover, circulating miRNAs are robust analytes: once collected they exhibit remarkable unexpected stability in body fluids (e.g. blood plasma) even after exposure to room temperature. This gives them utility in routine clinical and outpatient settings.

Given that circulating miRNAs levels can vary as a consequence of lifestyle habits or rhythms, such as medication, circadian-rhythm, physical activity, smoking, aging as well as comorbidities, we developed with the help of ME/CFS patients, a unique method to measure miRNA expression levels at baseline and after a standardised stimulation to reveal stress-activated circulating miRNAs. The rationale for this is that case definitions will remain uncertain and can clearly not serve as the gold standard against which to evaluate potential biomarkers. It is very likely that current selected ME/CFS cohorts for preclinical studies have grouped together people with several different pathologies but under a common label. ME/CFS patients are known to be particularly susceptible to any form of stress. By applying a reproducible experimental stress stimulus to each patient, it has allowed us to identify a unique stress-responsive ME/CFS molecular signature. Each individual provides its own control signature derived before the application of the stress stimulus. We designed an intervention producing a measurable change in symptoms. As a controlled stimulus, it can be used not only for measuring physiological parameters but also as a reproducible means to safely simulate post-exertion malaise, one of the cardinal symptoms of ME/CFS. In this context, we have developed a method to assess the participants by using the ABR™ (Advanced Biomechanical Rehabilitation) apparatus (Panacis Medical Ltd. Ottawa, Ontario, Canada). Each participant wears an inflatable cuff on the arm where the inflation device produces a pulsatile compression ranging from 0 to 4 psi at a frequency of approximately 0.006 Hz. Blood samples are taken before stimulation (baseline values) and after each 30-minute during the stimulation up to 90 minutes.

Alain Moreau PhD, Full Professor, Department of Stomatology, Faculty of Dentistry, Department of Biochemistry and Molecular Medicine, Faculty of Medicine, Université de Montréal

Scientific Director, Viscogliosi Laboratory in Molecular Genetics of Musculoskeletal Diseases, Sainte-Justine University Hospital Research Center

JOHN TORY
MAYOR

Proclamation

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities Awareness Day

May 12, 2017

WHEREAS Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities are chronic illnesses that have the potential to substantially limit function and impact the quality of life.

The City of Toronto supports organizations and individuals committed to raising awareness about diseases, conditions and illnesses that affect all Canadians. Through education, fundraising and support, the health and well-being of our communities are improved.

NOW THEREFORE, I, Mayor John Tory, on behalf of Toronto City Council, do hereby proclaim **May 12, 2017** as **"International Awareness Day for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and Environmental Sensitivities/Multiple Chemical Sensitivity"** in the City of Toronto.

John Tory
Mayor of Toronto

Accessibility Report Released

In their election platform, the Liberals talked about a new Canada Disability Act but did not describe what would be included. Responsibility for developing the act was passed to the Minister responsible for Persons with Disabilities, Carla Qualtrough, and the Minister of Families, Children and Social Development, Jean-Yves Duclos. Minister Qualtrough has taken the lead.

Public consultations were held over the winter. A report summarizing the discussions has just been released.

Traditional federal government actions include encouraging employment of disabled Canadians, regulating transportation services, setting building standards and setting telecommunications standards. This report focuses on these traditional activities. This suggests that the new legislation will focus on traditional issues. These issues are important, but it is also important to break new ground.

The legislation is some months away. Perhaps between now and then there will develop a more aggressive vision of what federal legislation can do to help Canadians with disabilities.

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

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Resources

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

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

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