www.mefmaction.com Quest 102, Spring 2015 mefminfo@mefmaction.com

ME/CFS seems to be turning a corner toward credibility with two major US government reports saying that this is a real and serious disease. It is generally felt that the P2P draft report went a long way but should have gone even further. At least 72 public submissions have suggested additions or improvements to the draft. It is generally felt that the IOM report made some very important points but went too far in recommending that a new untested case definition be implemented immediately in the US. We spend some time in this newsletter talking about case definitions. Along the way, we review the development and growth of the Canadian Consensus Criteria.

On February 28th, a research study was released by Columbia University documenting immune dysfunction in ME/CFS. To quote the author: "It appears that ME/CFS patients are flush with cytokines until around the three-year mark, at which point the immune system shows evidence of exhaustion and cytokine levels drop." This study will certainly add to credibility.

Meanwhile, FM also seems to be turning a corner, but going in the wrong direction. FM is getting muddled with chronic pain and with rheumatic conditions. Step 1 in dealing with this problem is to identify the issue and talk about it.

Two syndromes that share many characteristics with ME/CFS and FM are Ehlers-Danlos Syndrome (EDS) and Post-Polio Syndrome. We have articles on both.

The Quebec and Ontario organizations have news to share. We are pleased to announce the availability of two new documents – the updated CPP-Disability Guide and the bilingual Primer.

Planning is well underway for May 12th Awareness Day and for the next IACFS/ME conference which is tentatively scheduled for March 10-13, 2016 in Hollywood, Florida.

Contents

Fibromyalgia Developments in Canada:

Fibromyalgia – Losing its Identity

Lydia E. Neilson M.S.M.
Founder and CEO, National ME/FM Action Network
(circulated by email, Jan 19, 2015)

There are developments at the Canadian Institutes of Health Research (CIHR) which cause the National ME/FM Action Network great concern. CIHR is confusing Fibromyalgia with chronic pain and with symptoms of rheumatic diseases.

Let's start in March 2014 when CIHR promised to hold a research workshop for the ME/FM community. The Network then received an invitation to a September research workshop with the theme of "Chronic pain and fatigue." The invitation list included people from the ME/FM, chronic pain and arthritis communities. The Network was not clear whether this was the promised workshop or not. Knowing that chronic pain and fatigue is a misleading theme for ME/CFS and FM, we considered not attending but decided to go to try to build communication.

The workshop included presentations on Fibromyalgia, opiate use and ME/CFS. Another presentation was on a generic process that brings together patients, carers and clinicians dealing with a particular medical issue. The patients, carers and clinicians are asked to identify their top 10 unanswered questions about the effects of treatments. The agreed-upon list is then publicized with the hope that researchers would take on the topics and that funders would fund them. The person giving the presentation had participated in a priority-identifying process for kidney dialysis which had taken a year to complete.

A positive outcome of the September workshop was the designation of a research fellowship for ME/FM. Having received no other news, we contacted CIHR in early December 2014 asking what the next steps would be. In the reply we were told that a priority-identifying process was going ahead for Adult-Fibromyalgia and that a steering committee had already been established.

We asked for a list of steering committee members, figuring that the composition of the committee would say a lot about CIHR's understanding of Fibromyalgia and about whom they think should be in charge of identifying the priorities of Fibromyalgia patient, carers and clinicians. We were advised that the committee is chaired by a rheumatologist from McGill University. The other members of the steering committee are:

- the Scientific Director of CIHR's Institute of Musculoskeletal Health and Arthritis who has been assigned responsibility for ME/CFS and FM;
- a Kingston family doctor who focuses on chronic pain, chronic pain self management programs and mindfulness based chronic pain programs and who is the chair of the chronic pain program committee of the College of Family Physicians of Canada ;
- an assistant professor in the rheumatology section of the department of pediatrics and child health of the University of Manitoba;
- an associate professor of psychology from UBC who studies cannabis issues;
- the University of Toronto professor who gave the presentation about the priority-identification process at the September 2014 workshop;
- the president (a patient) of Chronic Pain Coalition of Canada which describes itself as "a Partnership of patient pain groups, health professionals who care for people in pain, and scientists studying better ways of treating pain,";
- three individuals – no affiliations listed.

The chair of the steering committee was the lead author of the 2012 Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome (see Quest 92). Here are some points around those Guidelines that raise red flags:

- The 2012 Guidelines do not mention the 2003 Clinical Case Definition for Practitioners for Fibromyalgia Syndrome, spearheaded by the National ME/FM Action Network, even though the 2003 case definition was approved unanimously by the international panel of experts who were selected by their peers and appointed by Health Canada and even though the case definition was published in a peer reviewed journal.
- Despite the fact that the 2012 Guidelines have major impact on the Fibromyalgia community, there was only one "patient representative" on the guidelines committee and there was no indication that she represented an organization. The National ME/FM Action Network was never consulted in developing the Guidelines.

- The 2012 Guidelines showed no role for rheumatologists in diagnosing or treating Fibromyalgia (which leads us to ask why there are three rheumatologists on the steering committee , the chair, the CIHR representative and the assistant professor from Manitoba.)

The steering committee chair is also the person who gave the presentation on Fibromyalgia at the September workshop. The presentation is available on our website. The presentation mentions several case definitions but again omits the 2003 Clinical Case Definition for Fibromyalgia Syndrome spearheaded by the National ME/FM Action Network. Omitting this Fibromyalgia definition makes the presentation appear lacking in objectivity.

The workshop presentation says that Fibromyalgia would ideally be called "chronic widespread pain". Chronic pain is a broad topic. We know from the statistics in Quest 101 that only about 10% of Canadians whose lives are moderately or severely affected by pain have a diagnosis of Fibromyalgia. Back in 1988, ME was labeled "chronic fatigue syndrome" with disastrous results. Highlighting one of the symptoms and ignoring the other symptoms of Fibromyalgia would cause a major setback. The workshop presentation also seems to equate Fibromyalgia with symptoms of rheumatic diseases which would be a radical shift in definition. The presentation goes further by calling Fibromyalgia a "clinical construct" and a "grab bag diagnosis" and by warning against over-medicalizing. In a completely baffling statement, the presentation says "Do not apply criteria to diagnose individuals".

Even after viewing this presentation, CIHR wrote that it considers Fibromyalgia to be a "well-defined clinical question" and put the workshop presenter in charge of the steering committee for the priority-identification project. With the confusing set of definitions and the confusing composition of the steering committee, the Network questions whose priorities will be identified and where CIHR is going with Fibromyalgia research.

The National ME/FM Action Network understands the importance of identifying research priorities for Fibromyalgia, chronic pain and rheumatic diseases, but these are separate topics and cannot be combined. We are not supportive of research into other conditions pretending to be research into Fibromyalgia. The National ME/FM Action Network understands the fundamental importance of developing good case definitions and sticking with them. We have seen the terrible problems that resulted from confusing ME/CFS with chronic fatigue or psychiatric conditions. We are not going to allow Fibromyalgia to be confused with chronic pain or symptoms of rheumatic diseases. We will be asking both the ME/CFS and the Fibromyalgia communities to support us in the battle to ensure that Fibromyalgia keeps its identity.

People with Fibromyalgia have enough challenges to conquer without being swallowed up and disappearing into the world of chronic pain and rheumatic diseases.

Our aim as always is :
DO NOT REACT TO UNFAIRNESS BUT ACT FOR CHANGE.

CIHR Announces Priority Setting Exercise

Editor's note: Subsequent to the circulation of Lydia's statement above, the Institute of Musculoskeletal Health (IMHA) of the Canadian Institutes of Health Research (CIHR) released this public announcement on the priority-setting exercise. As you can see, the topic has been changed from "Adult fibromyalgia" to "fibromyalgia and widespread chronic pain". To reiterate Lydia's words, these are separate topics and cannot be combined.

Members of the IMHA community will be interested to hear that the Institute has begun work on a new initiative, the James Lind Alliance Priority Setting Partnerships (PSP). Priority Setting Partnerships bring patients, care givers and clinicians together to identify and prioritize treatment uncertainties in a particular area of focus. IMHA is engaging in this process to address the top 10 uncertainties or 'unanswered questions' with regards to the management of **fibromyalgia and widespread chronic pain**. Updates on this initiative will appear regularly in this newsletter.

As always, I encourage you to continue to submit any questions or comments to IMHA@cihr-irsc.gc.ca. Please also follow me on Twitter @HaniElgabalawy.

Sincerely,

Hani El-Gabalawy MD FRCPC
Scientific Director CIHR
Institute of Musculoskeletal Health and Arthritis

see http://cihr-irsc.gc.ca/e/49007.html

Diagnosing an Illness

Diagnostic Criteria

Having good quality diagnostic criteria is fundamental to any illness. Diagnostic criteria affect people's lives.

What are diagnostic criteria? Criteria are simply rules to decide whether or not someone qualifies to belong to a group or "cohort". Diagnostic criteria provide guidance to clinicians on how to diagnose medical conditions, i.e. to decide whether or not someone qualifies as having diabetes, ME/CFS, FM etc.

Different diagnostic criteria define different cohorts. For example, the cohorts delineated by the Canadian and Fukuda diagnostic criteria are different. How does one decide which criteria to use?

One of the qualities to look for is conceptual - whether the criteria select the group you want to select. Clinicians want to distinguish groups of people whose illnesses share the same causes or determinants of outcome, particularly their response to treatment.

Another quality is operational. How easily and accurately can the criteria be applied? Practical considerations come into play. For example, one argument for dropping the tender point test in Fibromyalgia is that doctors don't know how to do it or don't like doing it.

Spearheading Diagnostic and Treatment Protocols for ME and FM

The National ME/FM Action Network has always looked for ways to better serve the ME/FM community. In the late 1990's, we sent a questionnaire to 200 medical doctors who were knowledgeable about ME, CFS and/or FM. We asked them what they felt was needed to increase recognition of these illnesses. About 150 doctors responded and they were all of the opinion that having clinical definitions and treatment protocols was of primary importance.

We recruited Dr Anil Jain of Ontario and Dr. Bruce Carruthers of British Columbia, two Canadian experts who were diagnosing and treating ME and FM patients. Between them they came up with draft diagnostic and treatment protocols. These draft documents were very evidence-based. The drafts were presented to the Minister of Health, the Honourable Allan Rock. He replied that "The development of draft clinical definitions for ME/FM is a milestone in the fight against this complex and tragic condition." We interpreted this as agreement to work together to take the draft documents to the next stage.

The National ME/FM Action Network worked in partnership with Health Canada to develop a review process for the draft documents. Health Canada established the "Terms of Reference" for two expert panels. One of the stipulations was that at least one member of each panel must be nominated by each of five stake holder groups of government, universities, clinicians, advocacy and industry. Over 80 nominations were received. Selecting from this group, Health Canada created two Expert Medical Consensus Panels, one for ME and one for FM. Four members of each panel came from outside Canada. Even though the resulting protocols are called the Canadian Consensus Criteria, this was an international initiative!

The Network found funding to allow the panels to do their work. Consensus meetings were held in Toronto from March 30 to April 1, 2001. Both expert panels arrived at unanimous consensus on their documents, a truly remarkable achievement.

The ME expert panel chose to use the term ME/CFS to bridge the international divide. ME was the term used in most countries while CFS was the term used the United States.

The resulting documents were published in peer reviewed journals in 2003. And they have grown from there.

Canadian Consensus Criteria for ME/CFS

The diagnostic and treatment protocols for ME/CFS have become know as the "Canadian Consensus Criteria." The CCC has received a lot of attention since it was published. For example:

- An Overview of the document was written and is now available in at least 6 languages.
- The CCC forms the basis for the IACFS/ME Primer for Clinical Practitioners and the IACFS/ME Pediatric Case Definition.
- Other documents have been developed based on the CCC including the Network's Sourcebook for teachers and CPP-Disability Guide, Dr Eleanor Stein's Psychiatrist's Guide and her "Let Your Light Shine Through" manual for patients, and Dr. Alison Bested's book for the general public "Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia".

Lydia Neilson received awards from Canada's Governor-General and the IACFSME for her work on behalf of the ME/FM community. Here is the announcement from the Governor-General.

Lydia Neilson, M.S.M., Ottawa, Ontario
Meritorious Service Medal (civil division)
May 30, 2005

In March 1993, Lydia Neilson founded the National ME/FM Action Network, an advocacy organization dedicated to advancing the recognition and understanding of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and fibromyalgia syndrome (FMS) through education, advocacy, support and research. Actively involved in issues that affect individuals with ME/CFS and FMS, Ms. Neilson also spearheaded the publication of internationally acclaimed diagnostic and treatment protocols for these conditions, bringing much-needed information and standardization to these areas of research.

- The CCC is being used as a research definition worldwide, one example being the Columbia University study referred to on page 1 of this newsletter.
- The US government's CFS Advisory Committee has recommended that the US government use the CCC.
- Fifty experts (38 from the US and the remainder from 8 other countries) wrote the Secretary of Health and Human Services recommending that the US use the CCC.
- Patient groups and advocates around the world have based their work on the CCC.

Why has the CCC been so well received? The answer, we would suggest, is that it has the qualities of defining a meaningful group and being operationally practical. Patients find they relate very well to the illness description and find the advice pertinent. Clinicians find that the criteria do a very good job of delineating a group of people whose illness is handled in similar fashion. Researcher find that the cohort delineated by the CCC can be used to study etiology.

Contrast this with the definition used by the US government for the last 25 years (Holmes 1988 replaced by Fukuda 1994). The US definition delineates a vague, heterogeneous group of people, tied together primarily by chronic fatigue. Patients don't find that it really describes them. The use of this definition has not led to major advances in research or treatment since the cohort is too broad to provide a well-defined research or treatment focus.

The IOM Report in a Nutshell

Six key agencies within the US government's department of Health and Human Services hired the US Institute of Medicine (IOM) to look at diagnostic issues around ME/CFS. The IOM was not asked to look at treatment issues. The IOM is part of the National Academy of Sciences, a society of distinguished scholars.

The IOM report was released February 10, 2015. It focuses on operational rather than conceptual issues. The report sets the stage in the second paragraph of page 1.

Diagnosing ME/CFS in the clinical setting remains a challenge. Patients often struggle with their illness for years before receiving a diagnosis, and an estimated 84 to 91 percent of patients affected by ME/CFS are not yet diagnosed [citation]. In multiple surveys, 67 to 77% of patients reported that it took longer than a year to get a diagnosis, and about 29 percent have reported that it took longer than 5 years. [citations]...

The committee then asks why seeking a diagnosis can be so frustrating and put forward three reasons:

- *skepticism of health care providers about the serious nature of ME/CFS and the misconception that it is a psychogenic illness or even a figment of the patients imagination.*
- *Less than one-third of medical schools include ME/CFS-specific information in the curriculum information of the disorder [citation].*
- *ME/CFS often is seen as a diagnosis of exclusion, which also can lead to delays in diagnosis or to misdiagnosis of a psychological problem [citations]...*

Clinical Working Case Definition of ME/CFS (CCC)

A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations; and adhere to item 7.

1. *Fatigue:* The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.

2. *Post-Exertional Malaise and/or Fatigue:* There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period–usually 24 hours or longer.

3. *Sleep Dysfunction:** There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.

4. *Pain:** There is a significant degree of myalgia. Pain can be experienced in the muscles and/or joints, and is often widespread and migratory in nature. Often there are significant *headaches* of new type, pattern or severity.

5. *Neurological/Cognitive Manifestations:* <u>Two or more</u> of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances–e.g., spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory–e.g., photophobia and hypersensitivity to noise–and/or emotional overload, which may lead to "crash" periods and/or anxiety.

6. *At Least <u>One</u> Symptom from <u>Two</u> of the Following Categories:*

a. *Autonomic Manifestations:* orthostatic intolerance–neurally mediated hypotenstion (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.

b. *Neuroendocrine Manifestations:* loss of thermostatic stability–subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change–anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress.

c. *Immune Manifestations:* tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.

7. *The illness persists for at least six months. It usually has a distinct onset,** although it may be gradual*. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

*To be included, the symptoms must have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in criteria 5 and 6. The disturbances tend to form symptom clusters that may fluctuate and change over time. Children often have numerous prominent symptoms but their order of severity tends to vary from day to day. *There is a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME/CFS. A diagnosis of ME/CFS can be entertained when this group has an infectious illness type onset. **Some patients have been unhealthy for other reasons prior to the onset of ME/CFS and lack detectable triggers at onset and/or have more gradual or insidious onset.*

Exclusions: Exclude *active* disease processes that explain most of the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction. It is essential to exclude certain diseases, which would be tragic to miss: Addison's disease, Cushing's Syndrome, hypothyroidism, hyperthyroidism, iron deficiency, other treatable forms of anemia, iron overload syndrome, diabetes mellitus, and cancer. It is also essential to exclude treatable sleep disorders such as upper airway resistance syndrome and obstructive or central sleep apnea; rheumatological disorders such as rheumatoid arthritis, lupus, polymyositis and polymyalgia rheumatica; immune disorders such as AIDS; neurological disorders such as multiple sclerosis (MS), Parkinsonism, myasthenia gravis and B12 deficiency; infectious diseases such as tuberculosis, chronic hepatitis, Lyme disease, etc.; primary psychiatric disorders and substance abuse. *Exclusion of other diagnoses, which cannot be reasonably excluded by the patient's history and physical examination, is achieved by laboratory testing and imaging. If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if patients meet the criteria otherwise.*

Co-Morbid Entities: Fibromyalgia Syndrome (FMS), Myofascial Pain Syndrome (MPS), Temporomandibular Joint Syndrome (TMJ), Irritable Bowel Syndrome (IBS), Interstitial Cystitis, Irritable Bladder Syndrome, Raynaud's Phenomenon, Prolapsed Mitral Valve, Depression, Migraine, Allergies, Multiple Chemical Sensitivities (MCS), Hashimoto's thyroiditis, Sicca Syndrome, etc. *Such co-morbid entities may occur in the setting of ME/CFS. Others such as IBS may precede the development of ME/CFS by many years, but then become associated with it. The same holds true for migraines and depression. Their association is thus looser than between the symptoms within the syndrome. ME/CFS and FMS often closely connect and should be considered to be "overlap syndromes."*

Idiopathic Chronic Fatigue: If the patient has unexplained prolonged fatigue (6 months or more) but has insufficient symptoms to meet the criteria for ME/CFS, it should be classified as idiopathic chronic fatigue.

Proposed Diagnostic Criteria for ME/CFS (SEID)

Diagnosis requires that the patient have the following three symptoms:

1. A substantial reduction or impairment in the ability to engage in preillness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, and
2. Post-exertional malaise,* and
3. Unrefreshing sleep*

At least one of the two following manifestations is also required:

1. Cognitive impairment* or
2. Orthostatic intolerance

* Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS (SEID) should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.

To overcome these barriers, the committee declares that ME/CFS is a real illness, recommends new diagnostic criteria that are short and simple, recommends removal of the exclusionary criteria, recommends giving the illness a new name "systemic exertion intolerance disease" or SEID, and proposes a strategy for disseminating the new criteria.

If organizations have been slow to respond to the report, it is because they have been struggling to figure out what the report really means.

The report uses the term ME/CFS to refer to the CCC, Fukuda and SEID concepts. It is like having all the characters in a book named "John" and trying to figure out which John is intended. The report does not clarify the relationship between the CCC, Fukuda and SEID cohorts. The report seems to move away from the Fukuda definition which has been criticized as vague, heterogeneous and overly fatigue-focused. However, simplification may lead to vagueness, the removal of exclusion criteria might allow many patients with active treatable conditions to be diagnosed with SEID, and putting fatigue in the top line of the "diagnostic algorithm" puts fatigue back as the primary focus.

The IOM seems to be continuing the 25 year struggle to find meaning in the broad heterogeneous cohort of people with chronic fatigue. The CCC comes from a different direction, focusing on people with the particular set of symptoms. SEID and CCC are talking about different research and clinical problems.

International Impact

The IOM was instructed that "[t]he recommendations will have a domestic focus; however, major international issues may be identified." No international issues were identified in the report. We see that as a serious oversight. ME/CFS is an illness that crosses international borders. It affects people in the US, in Canada, and all around the world. What happens in the US has spill-over effects into Canada and other countries. The international impact should have been considered.

The IOM report is proving to be very divisive in the ME/FM community.

There is a positive side to the report. A powerful US committee has recognized ME/CFS as a disease that is real, complex and serious, that affects young people as well as adults, that needs much more research and that needs greater awareness among health professionals and the public.

There is also a negative side to the report. The open letter from 50 experts warned that failing to adopt the CCC "will significantly impede research and harm patient care". They warned that the IOM process "threatens to move ME/CFS science backward". They said that using the CCC "will jump start progress and lead to much more rapid advancement in research and care for ME/CFS patients". The IOM had the opportunity to recommend that the US adopt the CCC. Instead, the IOM recommended a new, untested, unsupported diagnostic criteria with a new name, no history and no place within the International Classification of Diseases. The IOM recommendation for SEID will be costly and time consuming to implement. Meanwhile, studies suggest it takes on average 17 years for clinical acceptance. The CCC is already 12 years old and is coming into its own. The IOM'S failure to recommend the CCC, without giving a reason, casts a shadow over the CCC. This is a major setback for the ME/FM community worldwide.

Having the IOM recognize ME/CFS is helpful, but having the US take a new and separate approach to ME/CFS would not be in the interests of researchers, clinicians or patients. If the US has issues with the CCC, then they need to be articulated. The National ME/FM Action Network spearheaded the development of the CCC in the first place. We would be pleased to spearhead an international discussion process to reconcile the differences in order to arrive at an single worldwide approach to ME/CFS. Patients deserve as much!

Related Conditions

Post-polio Syndrome

Here is information on Post-Polio Syndrome taken from a March of Dimes Canada brochure. The March of Dimes started in Canada around 65 years ago in response to outbreaks of Polio. After a vaccine was developed, the organization's emphasis shifted to rehabilitation and job training for people who had polio. Subsequently, the emphasis shifted to include all adults with physical disabilities. But the organization still has special programs for survivors of polio.

History of Polio:

Poliomyelitis, also known as polio, is a highly contagious virus that attacks the nervous system. It can be disabling and sometimes fatal. During the polio epidemics in the 1920s -1950s, many people died and tens of thousands more were left paralyzed. The March of Dimes "Marching Mothers" helped collect money to fund the research for a discovery of the polio vaccine in 1955.

Post-polio Syndrome

Some survivors of polio may find they experience new symptoms in the form of post-polio syndrome. The symptoms may include:

- unaccustomed fatigue
- reduced endurance
- new joint and muscle pain
- muscle weaknesses
- trouble sleeping
- respiratory problems
- difficulty swallowing food and frequent choking
- emotional stress

Consult your doctor if you experience these symptoms.

Join Post-Polio Canada

Post-Polio Canada provides a range of services to survivors of polio, family members and caregivers, and to new Canadians who may not know of polio in their past.

Education and Information

Education and information are key components of Post-Polio Canada membership, and we are committed to reporting on new research about the long-term needs of survivors of polio and their family members. All members of Post-Polio Canada receive a "Welcome Kit" and continue to receive timely information through newsletters, seminars, conferences and publications.

Peer Support Groups

It is important to know that you are not alone. Post-Polio Canada peer support groups give survivors, families, friends and caregivers the opportunity to share personal experiences, exchange valuable information and offer a network of mutual support. Peer support groups are located across Canada.Call today, or visit us online, to find a group near you.

Toll-free Warmline 1 800 380-5903

Connect with March of Dimes staff and fellow survivors for support and to access leading edge information and resources.

Note: There are support groups in Calgary, Edmonton, Lethbridge, Saskatoon, Regina, Winnipeg, Charlottetown, Montreal, Bathurst, and St. John's, as well as 15 groups throughout Ontario.

Ehlers-Danlos Syndrome (EDS)

The ILC Foundation (Improving the Lives of Children and Families Living with Chronic Pain) held their 2nd Annual Canadian Medical Conference *on November 1-2, 2014 in Toronto. The topic was* Difficult to Diagnose Diseases: Ehlers-Danlos Syndrome. *Around 150 physicians, patients and families members attended the conference. This summary was prepared by a ME/CFS patient who was there. You will see that the discussions are very similar to the discussions around ME/CFS and FM. Videos of the presentations are available at* http://www.theilcfoundation.org/ *. Look for "conference videos" in the left column.*

There is considerable discussion in this report about postural orthostatic tachycardis syndrome (POTS), orthostatic intolerance (OI) and dysautonomia. Dysautonomia is an umbrella term for dysfunction of the Autonomic Nervous System. The ANS controls the "automatic" functions of the body that we do not consciously think about, such as heart rate, blood pressure, digestion, dilation and constriction of the pupils of the eye, kidney function, and temperature control. OI iand POTS are forms of dysautonomia. OI refers to the inability to sustain upright activity, while POTS is diagnosed based on rapid heartbeat while standing. The IACFS/ME Primer for Clinical Practitioners lists both EDS, OI and POTS as non-exclusionary overlapping conditions with EDS under the Rheumatological heading and POTS and OI under autonomic dysfunction which is under the Cardiovascular heading.

***

According to The Ehlers-Danlos National Foundation, "EDS is a heterogeneous group of **heritable connective tissue disorders**, characterized by articular (joint) hypermobility, skin extensibility and tissue fragility." EDS is being thought of more and more as "a multi-system connective tissue disorder." There are several subtypes of EDS including hypermobility, classical and vascular. There are varying degrees of severity, with **pain, fatigue, dizziness and headaches** common features. **There is no cure for EDS and treatment is symptomatic**.

As an ME/CFS patient with comorbid POTS but not EDS, I found the doctor and patient presentations described symptoms and debilitating effects that are very similarly to those described at any ME/CFS conference. **EDS research is, however, more advanced in the key areas of genetic testing and disease definition compared with ME/CFS**.

A Genetic Test for one EDS Subtype

EDS has a genetic test for one subtype, vascular EDS, though finding a doctor who will order the test can be a challenge. The other subtypes are based on clinical diagnosis. In ME/CFS, there are gene studies underway but no genetic test have been developed so diagnosis is clinical.

This EDS subtype genetic test, though, does not appear to give the patients credibility. Many of the experiences of EDS patients are identical to those of ME/CFS patients – their complaints are often dismissed or misunderstood. They have the same issues bringing test results and reports back from the U.S. and having them dismissed by their Canadian physicians. And for those with EDS-literate physicians, **treatment for EDS remains just as tricky as it is for ME/CFS**.

Disease Subtypes Are Defined (Albeit in Flux)

EDS patients are diagnosed according to their disease subtype. The subtype definitions are in flux as research advances and there remains **symptom overlap between EDS subtypes**;. ME/CFS patients are still waiting for this important advance.

Geneticist Dr. Roberto Mendoza, who completed a residency in paediatrics at the State University of New York in Brooklyn and a fellowship in clinical and metabolic genetics at Baylor College of Medicine in Houston, Texas, gave a presentation on Molecular Genetics. He posed the question: **why diagnose if there is no treatment?** He answered by saying that the diagnosis means they can begin to ***target the treatments*** that address the specific molecular defect. He discussed Next Generation Sequencing (a term that has been used by ME/CFS researchers, including famed "virus-hunter" Dr. Ian Lipkin). Instead of doing one genetic test at a time, these gene panels can at once sequence 5 to 100 genes, or even all of the genes in the sample. He announced that there will soon be an EDS Panel of 17 genes that will be available at Toronto Sick Kids Hospital.

Dr. Mendoza responded to an audience member's question: **"Why are doctors so dismissive?"** He said that medicine has been taught as evidence-based for so many years … that without unifying diagnoses and with the non-specific symptoms … we need to build evidence … (that) can't be anecdotal … must be systematic … that's why they're here (attending the conference).

For the hypermobility subtype of EDS, there are is a 9-part test that can be performed to measure the number of degrees beyond 90° that joints (elbow, pinky finger, thumb, foot, both feet on floor without knee bending) are hypermobile in order to obtain a Beighton score. However, presenter and geneticist Dr. Clair Francomano, Associate Professor of Medicine at Johns Hopkins University School of Medicine, cautioned that a **specific instrument should be used to measure the degree of hypermobility properly**. Studies have shown the Beighton score varies with age, so it does not give fixed result over time.

Dr Francomano presented: "Clinical Genetics" and stated that **the fatigue in patients was more disabling than pain.** She described the **autonomic nervous system dysfunction as having manifold consequences**. She showed a graphic of the human body, saying that they see **problems in virtually every area of human functioning**.

Interestingly, Dr. Mendoza commented **that hypermobility may not even be a critical part of EDS**.

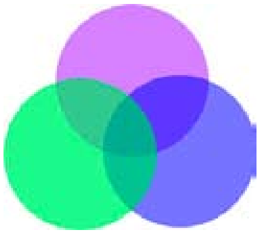
POTS: A Common and Debilitating Comorbidity in Both EDS and ME/CFS

The conference featured two speakers who addressed the topic of POTS: Dr. Peter Rowe, Professor of Pediatrics at the Johns Hopkins Children's Center in Baltimore, Maryland; and cardiologist Dr. Juan Guzman, Assistant Professor of Medicine at McMaster University, Internal Medicine Specialist at Hamilton Health Sciences and member of the ILC's Medical Advisory Board.

Dr. Peter Rowe is credited with the **first description of the relationship between CFS and treatable orthostatic intolerance (OI) syndromes**. Also, he was the **first to report the association between EDS and CFS**. Dr. Rowe presented: "Chronic fatigue in EDS and its impact on quality of life." He described post-exertional malaise (PEM) as the ability of patients to push through activity, but the next day, are much more impaired. He stated that it extends past fatigue and that patients use terms like collapse, relapse and payback. He thinks that PEM is probably not unique to CFS.

He discussed one particular case where an OI patient was prescribed methylphenidate (Ritalin), who at 1-year follow-up was walking 3-4 miles/day. When they were taken off the drug for one week, the symptoms returned. He described these results as obviously showing that their OI was NOT due to deconditioning.

In the classical type of EDS, **"fatigue is a foremost complaint".** Dr. Rowe discussed some studies done in the Netherlands that focused on Cognitive Behaviour Therapy (CBT) as the *only* technique and said that here are a couple of problems with this: first, they ignored OI; second, they are sticking with their own biases. He emphasized that he is **not an opponent of CBT but thinks that its effect on CFS is "not that great"**. He stated, "*I'd* probably be better if I did CBT! As an example, he said he'd learn not to stay up late to watch basketball games! He expressed concern about those who don't acknowledge the circulatory dysfunction and said that it's *nonsense* to think of CFS as women who want to escape life. He said the **severity is comparable to Multiple Sclerosis (MS).** He showed a Venn diagram of 3 overlapping circles to portray the **overlap between EDS/Joint Hypermobility, CFS and OI**.



Interestingly, Dr. Rowe commented that he no longer used the Tilt Table Test except in research. When asked why, he frankly stated that insurance stopped the practice, the 10 minute "bedside test" was just as good, and that it was **useful for parents of children with OI see the ill effects of only 10 minutes of standing**. He also mentioned that the removal of the tilt table test meant avoiding having to give saline infusions afterward.

An audience member asked how a patient with CFS and POTS could exercise if they also have joint hypermobility. Dr. Rowe replied that he has seen CFS patients sent to physiotherapists, who would then call him in a couple of weeks to complain that the patient was not trying. The patient would tell him the physiotherapist was trying to kill them! Dr. Rowe said there is **a need to work manually first in order to strengthen the**

muscles around the joints and make sure that the nerves are not being stretched. He said there is a need for a skilled therapist and close collaboration between the physiotherapist and the doctor.

Dr. Juan Guzman described cardiovascular disease as a well-known complication in EDS, but said that **the risk of developing heart disease is low**. He stated there was a **30% incidence of diastolic dysfunction**. The filling of the ventricle could be affected, and this could be related to connective tissue disease.

He went on to describe autonomic dysfunction in EDS/JHS (EDS/Joint Hypermobility Syndrome). He sees the disabling nature of POTS in his patients. He stated that **one of the most debilitating consequences of dysautonomia in daily life is OI**. He stated that autonomic dysfunction leads to poor outcomes in other chronic disease models – including mortality and morbidity – but the outcomes have not been examined for EDS. He described several studies and their **hypotheses for the cause of OI, including peripheral neuropathy (PN)**.

He stated that **if you diagnose a patient with POTS, you must consider a diagnosis of EDS**, and vice versa. He described a study with 23 patients with *both* POTS and EDS, and 23 patients with *only* POTS. They performed a number of tests on both patient groups, including the tilt table test, and found *no difference*. He stated that POTS is a final pathway – and the treatments, both prescription and non-prescription, are similar.

Disease Severity

One of the studies discussed described the Karnofsky Performance Status Scale average score for EDS study participants as 67 and 71 for classical type and hypermobile type, respectively. A Karnofsky score of 70 means: I am able to care for myself but unable to carry on normal activities. It is described as **"unable to work; able to live at home and care for most personal needs; varying amount of assistance needed."**

The Question of Misdiagnoses

Dr. Howard Meng, medical resident at the University of Toronto, presented: "EDS Heterogeneity – a Foray into the Diagnostic Dilemma". Nineteen of 48 patients had a Fibromyalgia (FM) diagnosis and an additional three were suspected of having FM, so **he *wondered if there is a tendency to diagnose FM instead of EDS***.

Mast Cell Activation Syndrome (MCAS): Same Symptoms as POTS

Dr. Peter Vadas, a specialist in Allergy and Clinical Immunology at St. Michael's Hospital Toronto, presented: "Mast Cell in EDS and its impact on quality of life". Mast cells are frequently mentioned in the context of ME/CFS. Dr. Vadas said there is not a lot in the current literature about functionally abnormal mast cells. He said the manifestations of MCAS depend on where the mast cells are – the lungs, or the gastrointestinal (GI) tract, etc. Following a common theme, the patients represent a very diverse clinical presentation and the illness waxes and wanes. **The symptoms are the same as POTS**.

Tests can include a gut biopsy during colonoscopy and treatment can involve putting a patient on a mast cell stabilizer and seeing if the GI symptoms resolve. There are also blood and urine test panels. He listed some possible prescription medications, including mast cell stabilizers and receptor antagonists, but detailed some medications' side effects including poor efficacy. Some medications are very expensive. In a study he found 67% of patients with both POTS and EDS had validated symptoms of MCAS. He stated that **if a patient has both EDS and POTS, it is appropriate to look for MCAS.** Dr. Mendoza asked Dr. Vadas what the minimum criteria was for an MCAS diagnosis. Dr. Vadas replied that **only St. Michael's does the screening tests and sends them to the U.S.**

Neurosurgery and Neuroradiology in EDS

There were three presentations on neurosurgery. In one, Dr. Fraser Henderson, Director of Neurosurgery at Doctors Hospital and Director of the Chiari Center of Excellence in Maryland, presented: "Neurosurgical management of EDS". He stated there was a long list of causes of headaches in EDS. He referred to other connective tissue disorders such as Rheumatoid Arthritis (RA). He also discussed **mitochondrial dysfunction**, another common topic in ME/CFS research. He discussed surgery in some cases where compression of the brainstem had led to sleep apnea. He also discussed surgery in about 10 to 20% of cases of patients presenting with neurological problems and severe headaches, with pain levels decreasing from 8/10 to 4/10 post surgery. The Karnofsky scale ratings improved from 45 to 71 after surgery, so **there still remain a number of patients unable to return to work**.. Dr. Henderson commented that it was an interesting thing that cardiologists are now thinking of brainstem problems. This was a great example of the benefits of conferences like this bringing the medical specialties together.

Translating Research to Clinical Practice

An audience member asked Dr. Koby (Neuroradiologist from Maryland) why upright MRI's done in the U.S., which are diagnosed as abnormal, are received by Canadian radiologists as "nothing wrong". He stated that radiologists find lack of knowledge and lack of an open mind, saying, **"It will take a generation to change peoples' thoughts".**

Dr. Norm Buckley, Chair and Associate Professor in the Department of Anesthesia of the Michael G. DeGroote School of Medicine at McMaster University, and Chair of the ILC Medical Advisory Board, said that **when something is established in research, it still takes 10 years until it becomes common practice, not even universal practice.** Dr. Mendoza added that what is needed is primary care that integrates all the care … that unifies the information and ensures all the specialists are involved.

On this theme of collaboration, the ILC awarded Dr. Juan Guzman with the "2014 Award of Recognition for Exemplary Care" in recognition of efforts to reach out of his own specialty to other, related specialties.

Private Support in the EDS Community

There are several families who have been instrumental to the ILC, including the Mills family, who first started the ILC. The Hawkins family also contributed to the conference with their fundraising efforts. Susan Hawkins is a direction of ILC and her daughter Erin Somers is the ILC's EDS Community Ambassador. In her presentation, Erin Somers described how ill she had been from birth. She received an EDS diagnosis from Dr. Allan Gordon ("on the spot") and had two surgeries performed by Dr. Fraser Henderson. She then achieved a **90% improvement in symptoms** and now leads a full life, having walked out of the hospital a day after surgery feeling much better.

My Take: Federal Funding Needed Commensurate with Debility and Prevalence

As with ME/CFS conferences I have attended, it is gratifying as a patient to see these knowledgeable and dedicated physicians and researchers together in one room, sharing their expertise with each other and with patients. It is also frustrating because, if appropriate federal funding were available to them, they could advance the research so much faster and further.

There were two giant paintings of zebras at the front of the room, though one presenter noted that **EDS may well be a horse (more common than recognized) and not a zebra (uncommon)**. It all sounded very familiar to an ME/CFS patient. EDS and ME/CFS have much in common, so perhaps our organizations can learn from each other. Strength in numbers.

P2P Report on ME/CFS Research in US

The goal of the Pathways to Prevention (P2P) program of the US National Institutes of Health is "to host workshops that identify research gaps in a selected scientific area, identify methodological and scientific weaknesses in that scientific area, suggest research needs, and move the field forward through an unbiased, evidence-based assessment of a complex public health issue."

ME/CFS was selected as a scientific area for review.

The process included:

- appointing an independent panel to review the research situation
- preparing a literature review
- holding a workshop to discuss research issues
- releasing a draft report by the panel
- receiving comments from the public on the draft report
- releasing a final report.

The draft report was released in December 2014. The panel made a number of points including: ME/CFS is real, patients are badly served, there is a need for more research, patients need to be involved, and it is time to retire the Oxford definition. However,the draft gets somewhat vague and confused about the details.

The NIH did not create a website for comments from the public, but a blogger did. There are 64 submissions from individuals and 8 submissions from organizations on that site. The submissions are all of good quality, thoughtful and sincere, and the messages are similar. This shows how knowledgeable, articulate and unified the ME/CFS community has become.

May 12th Awareness Day Activities

Planning for May 12th activities is well underway.

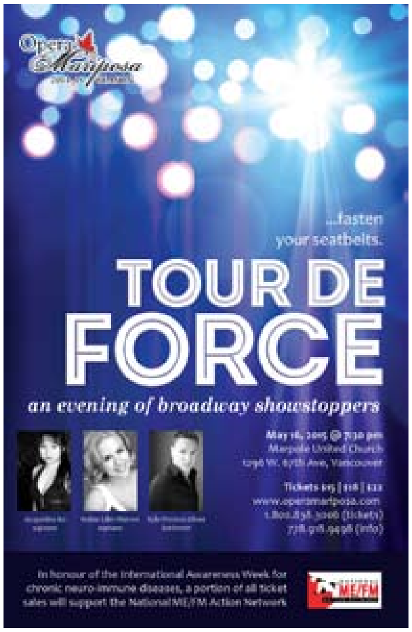
Light Up the Night, where homes and buildings are lit blue (ME/CFS), purple (FM) and green (MCS), will be happening again. There will be proclamations, write your MP and MPP, wear a coloured scarf, dye your hair, tie a ribbon around your tree or mailbox and a Thunderclap.

As we hear about other events, they will be posted at *www.facebook.com/may12th.awareness*.

MEAO's May 12th event at Queen's Park:

Save the date ..... MEAO will be holding an event on May 12th to mark International Awareness Day for ME/CFS, FM and MCS/ES. Full details will follow from MEAO in the very near future.

Opera Mariposa



Soprano Jacqueline Ko has lived with ME/CFS since the age of six. Despite her struggle with illness, she has managed to realize her dream of becoming an award-winning singer and founding a critically acclaimed opera and musical theatre company. She is committed to using her passion for music to help others, and since 2009, her benefit performances have raised over $26,000 for those with chronic neuro-immune diseases.

Tour de Force brings you an evening of hit songs, featuring musical theatre highlights from *Wicked*, *Gypsy*, *Sweeney Todd* and many more. Presented by Opera Mariposa, the Vancouver company whose performances have been hailed as "an evening of delight" (Review Vancouver), "an extraordinary feat" (North Shore News) and "a stroke of genius" (The Voice), you won't want to miss this unforgettable Broadway extravaganza for a wonderful cause.

In honour of the International Awareness Week for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and other chronic neuro-immune diseases, a portion of the proceeds will go to the National ME/FM Action Network.

http://operamariposa.com

Provincial Associations Reports

MEAO working toward a Centre of Excellence

MEAO's held a Community Engagement event on November 5th, at Queen's Park. The purpose of the meeting was to hear from the Ontario government about the status of the Business Case proposal for the Ontario Centre of Excellence in Environmental Health (OCEEH), which was submitted to the Ontario Ministry of Health and Long Term Care one year before.

John Fraser, Parliamentary Assistant to the Minister of Health, spoke on behalf of the Health Minister, Eric Hoskins. Mr Fraser reminded the audience that last April the government announced funding for clinical fellowships in environmental health through the University of Toronto. (Funding was $560k to support 2 fellowships per year for each of 3 years). Mr Fraser also announced that the Minister would be establishing an inter-ministerial Task Force to raise the profile on environmental health conditions.

Several other politicians were present at the event including MPP Joe Dickson and Bill Walker and Minister for children Tracy Fitzcharles. Also in attendance were the policy advisor to the Minister of Health and two ministry officials who are now working on this file.

Earlier in the day, statements had been made in the provincial parliament by Joe Dickson on behalf of the Liberal Party, Bill Walker on behalf of the Conservative Party, and Taras Natyshak on behalf of the NDP. All expressed support for the Centre of Excellence proposal.

A lot is happening with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) in Quebec!

Last year was eventful for ME/CFS in the province of Quebec. The efforts of the people at the Quebec Association for Myalgic Encephalomyelitis (AQEM) in recent years have certainly contributed to increased understanding and recognition of the illness. Much remains to be done, but we see every advance as a great victory. For patients, obtaining a diagnosis and finding follow up care is difficult. Establishing a care program is even rarer. Professionals in our health care system should receive more education about the illness in order to provide adequate care to people with ME. As an association, our goal is to help people live better with their condition. We want to increase understanding and recognition of the disease throughout society! Here is an overview of our achievements in the past year:

Translating the International Consensus Primer for Medical Practitioners

The International Consensus Primer (ICP) has now been translated from English to French, and we would like to thank the Sibylla Hesse Foundation, which assumed the entire cost of translation, publication and distribution. With the participation of an experienced translator, Hélène Dion, who also did the translation of the Overview of the ME/CFS Canadian Consensus document; Dr Philippe Tournesac of Paris France, a dedicated doctor who reviewed this translation as well as the translation of the Overview; volunteers from our board of directors, and the very supportive foundation, we have made this project happen. The translation into French of recent literature on ME/CFS makes important tools available to doctors in our province. In addition to this document, there are now other publications available in French including the Overview of the 2003 Canadian Consensus document (translated by AQEM), the 2014 IACFS/ME Primer (translated by the National ME/FM Action Network), and the Teach-ME Sourcebook for Teachers of Young People with ME/CFS and/or FM (also translated by the Network).

It is obvious that the French version of the ICP is an important tool in the understanding and recognition of ME/CFS.

Une année importante pour l'encéphalomyélite myalgique/Syndrome de fatigue chronique (EM/SFC) au Québec

L'année qui vient de s'écouler a été riche en événements pour l'EM/SFC au Québec. Les efforts déployés par l'équipe de l'Association québécoise de l'encéphalomyélite myalgique (AQEM) depuis les dernières années ont certainement contribué à l'avancement de la connaissance et de la reconnaissance de la maladie. Il reste toutefois beaucoup à faire mais chaque avancement est pour l'association une grande victoire. Pour une personne, recevoir le diagnostic d'EM/SFC et avoir un suivi médical ne sont pas choses faciles. Bénéficier d'une bonne prise en charge est encore plus difficile. Les professionnels de notre système de santé doivent être mieux renseignés sur la maladie afin d'offrir des soins adéquats et adaptés aux personnes atteintes d'encéphalomyélite myalgique (PAEM). Offrir support et aide aux PAEM dans le cheminement de leur maladie est la raison d'être de l'AQEM. Le développement de la connaissance et la reconnaissance de la maladie motivent nombreuses de nos actions. Voici un aperçu des réalisations de l'association au cours de la dernière année :

La traduction du Manuel du consensus international à l'usage des médecins

Le projet de traduction de la version anglaise *International consensus primer(ICP)* s'est enfin réalisé et ce, grâce à la Fondation Sibylla Hesse qui a assumé l'entièreté des coûts de traduction, de publication et de distribution. C'est avec la participation de Mme Hélène Dion, traductrice chevronnée qui a également traduit dans le passé l'*Abrégé du Consensus canadien*, d'un médecin réviseur passionné, Dr Philippe Tournesac, de Paris en France, qui a aussi contribué dans le passé à la révision de *l'Abrégé du Consensus canadien*, combinées à l'action bénévole des membres de notre conseil d'administration et enfin, l'implication d'une fondation consciencieuse, que ce projet a pu voir le jour. Avoir accès à de la documentation récente et française sur l'EM/SFC est un élément important pour les médecins de notre province. Ce document traduit en français vient s'ajouter à d'autres publications françaises *comme l'Abrégé du consensus canadien* de 2003, *le Petit guide pour la médecine clinique*, Édition 2014 de l'IACFS/ME et *Teach-ME : Guide de référence pour l'enseignement aux élèves souffrant de l'EM/SFC et/ou du SFM* du National ME/FM Action Network, etc.

Nous pouvons facilement conclure que ce nouveau document de référence pour les médecins est un outil important pour la connaissance et la reconnaissance de l'EM/SFC.

Distributing the manual to health care professionals

Following the release of the ICP in French, AQEM took the opportunity to participate in a major symposium of francophone general practitioners in Montreal. We were able to distribute the manual to more than 900 physicians by having it included in the complimentary package handed out to attendees. AQEM was on site during the whole conference with an information table. This raised awareness and allowed us to distribute other documents and to share information with doctors. In addition to the distribution at the symposium, we have provided all our members with a copy of the manual to share with their physicians. We plan to distribute the document to hospitals across the province, to community clinics, to private doctors' offices, as well as to physiotherapists, occupational therapists, social workers and other health professionals in Quebec.

Establishing a major research project on the possible causes of ME / CFS

A person with ME/CFS, who wishes to remain anonymous and is very concerned about the lack of significant advances in research around ME/CFS, contacted the board of directors of AQEM. Work got underway to identify doctors and researchers in Quebec who have an interest in ME/CFS and then to secure funding that would permit the completion of the project. Thanks to the efforts of the initiator of the project and to other contacts, a project was carefully put together.

For now, here is a summary of the project which will be headed by Dr. Alain Moreau, PhD, Director of Research at the CHU (University Hospital Centre) Sainte-Justine; Professor in the Department of Stomatology, Faculty of Dentistry and in the Department of Biochemistry and Molecular Medicine, Faculty of Medicine, University of Montreal; and Scientific Director at the Viscogliosi Molecular Genetics Laboratory of Musculoskeletal Disorders at CHU Sainte-Justine Research Center. Dr. Moreau holds 36 patents to date and received the first medal given by the Yves Cotrel Foundation of France.

Dr. Alain Moreau and his research team at Ste-Justine will examine the molecular and genetic mechanisms

Le projet de distribution de l'ICP aux professionnels de la santé

Suite à la sortie de ce manuel, l'AQEM a profité de l'occasion qui lui était offerte pour participer à un important symposium des médecins omnipraticiens francophones à Montréal. Il a ainsi été possible de glisser ce document dans des sacs qui ont été remis gratuitement à plus de 900 médecins participants. L'AQEM était également sur place durant toute la durée du congrès afin de présenter un kiosque d'information. Cela a permis de faire connaître l'association, de distribuer d'autres documents et donner de l'information aux médecins. En plus de cette distribution massive, un exemplaire a été donné à chaque membre de l'association afin qu'ils puissent le remettre à leur médecin traitant. Nous prévoyons également faire la distribution du manuel dans les centres hospitaliers de la province, les Centres locaux de services sociaux (CLSC), les cabinets privés de médecine, de même que les physiothérapeutes, ergothérapeutes, travailleurs sociaux et autres professionnels de médecine alternative du Québec.

La mise sur pied d'un projet de recherche de grande envergure sur les causes possibles de l'EM/SFC

Une personne atteinte de la maladie, désirant garder l'anonymat et très soucieuse du peu d'avancées significatives de la recherche sur l'EM/SFC, a contacté des membres du conseil d'administration de l'AQEM. Des échanges ont alors débuté afin, dans un premier temps, de trouver des médecins et des chercheurs au Québec qui ont un intérêt pour l'EM/SFC et d'autre part, afin d'obtenir un support financier qui pourrait permettre de mener à terme ce projet. Grâce aux efforts de l'initiateur du projet de même qu'à ses contacts, c'est ainsi que, de fil en aiguille, un projet de recherche fort intéressant a été proposé.

Pour le moment, voici un résumé de l'essentiel du projet que pilotera le responsable de l'équipe de recherche, Dr Alain Moreau, PhD, Directeur de la recherche au CHU Sainte-Justine, Professeur titulaire au Département de stomatologie, Faculté de médecine dentaire, Département de biochimie et médecine moléculaire, Faculté de médecine, Université de Montréal et Directeur scientifique au Laboratoire Viscogliosi en génétique moléculaire des maladies musculo-squelettiques du Centre de recherche du CHU Sainte-Justine. Le Dr Moreau détient 36 brevets à ce jour et a reçu la première médaille de la Fondation Cotrel - Institut de France.

Dr Alain Moreau et son équipe de recherche au CHU Ste-Justine examineront les mécanismes moléculaires et associated with Myalgic Encephalomyelitis (ME). As part of a research project funded by the Foundation Sibylla Hesse, new concepts and experimental approaches will be studied in order to identify the causes of ME, most notably exploring the contribution of a pro-inflammatory cytokine called osteopontin and the contribution of circulating microRNAs to its pathogenesis. MicroRNAs are small fragments of non-coding RNA that can block the production of certain proteins in various organs or tissues. The identification of circulating microRNAs associated with ME will identify a specific molecular signature for this condition, but also will identify the genes targeted by these fragments. Moreover, their levels in the blood, as well as those of osteopontin, may fluctuate in response to physical activity, to stress, to viral or bacterial infections, as well as to certain medications. Therefore, it is anticipated that the results will be key to deciphering the biological mechanisms involved in the onset of ME and/or its aggravation. In addition, this research may lead to the development of an innovative non-invasive diagnostic test through the development of molecular tools that could help doctors provide better care for patients by having more objective measures.

Piloting a self-management program at the Rehabilitation Centre Constance-Lethbridge

The Rehabilitation Centre Constance-Lethbridge completed a pilot project on self-management of ME/CFS on October 31. It began on May 5, 2014 as a 6-month project. A review of the program will be undertaken by the Quebec Ministry of Health and Social Services and the Agency for Health and Social Services of Montreal. The evaluation report is eagerly awaited and we hope it will have a major impact on the visibility and the recognition of the illness.

This program offered one-on-one meetings with people with ME/CFS, which were held once a week for 6 weeks. Some meetings were held by phone or Skype to accommodate participants. The goal of the program was to allow patients to optimize functional abilities in order to achieve greater autonomy and increased participation in daily living activities. An individualized approach was selected in order to meet the specific needs of each participant. The meetings involved the following disciplines: occupational therapy, physiotherapy,

génétiques associés à l’EM. Dans le cadre d’un projet de recherche subventionné par la Fondation Sibylla Hesse, de nouveaux concepts et approches expérimentales seront étudiés dans le but d’identifier les causes de l’EM, notamment en étudiant la contribution d’une cytokine pro-inflammatoire, appelée ostéopontine, ainsi que la contribution des microARN circulants dans sa pathogenèse. Les microARN représentent de petits fragments d’ARN non-codants qui peuvent bloquer la production de certaines protéines dans plusieurs organes ou tissus. L’identification de microARN circulants associés avec l’EM permettra d’identifier une signature moléculaire spécifique pour cette condition, mais aussi d’identifier les gènes ciblés par ceux-ci. De plus, leurs niveaux dans le sang, tout comme ceux de l’ostéopontine, peuvent fluctuer en réponse à l’activité physique, au stress, aux infections virales ou bactériennes, de même qu’en réponse à certaines médications. Par conséquent, il est anticipé que les résultats obtenus seront essentiels pour décrypter les mécanismes biologiques impliqués dans l’apparition de l’EM et/ou de son aggravation. En outre, ce projet de recherche pourrait conduire à la mise au point d’un test diagnostique non invasif innovant, à travers le développement d’outils moléculaires qui pourraient aider les médecins à mieux prendre en charge les patients, notamment par l’utilisation de méthodes plus objectives.

Projet pilote sur l’autogestion de l’EM/SFC par le Centre de réadaptation Constance-Lethbridge (CRCL)

Le CRCL a complété le 31 octobre dernier, son projet pilote portant sur l’autogestion de l’EM/SFC. Débuté le 5 mai dernier, la durée du projet avait été fixée à six mois. Celui-ci sera analysé par le Ministère de la Santé et des Services sociaux ainsi que par l’Agence de la santé et des services sociaux de Montréal afin d’en tirer des conclusions. Il s’agit d’un rapport qui est fort attendu et qui nous le souhaitons, aura des impacts sur la visibilité et la reconnaissance de la maladie.

Le programme visait à offrir une rencontre individuelle hebdomadaire sur une durée de 6 semaines. Afin d’accommoder des participants, certaines rencontres se sont déroulées par téléphones ou via *Skype.* Le but du programme était de permettre aux PAEM d’optimiser leurs capacités fonctionnelles afin d’atteindre une plus grande autonomie, ainsi qu’une participation plus optimale au niveau des activités de la vie quotidienne. Une approche individuelle a été privilégiée afin de répondre aux besoins spécifiques de chacun. Les interventions ont mis psychology and if necessary, social service. At the end of this program a survey was given to the participants to obtain their feedback. A majority of participants expressed that they were satisfied with the support received.

According to a briefing note from the Centre at the end of the project, participants concluded that the combined bio-psycho-social approach was essential in helping them manage their illness. Patients may have different needs at different times in terms of knowledge, home care, medical monitoring and rehabilitation. The integration of services is therefore essential to properly serve the ME/CFS population. The development of research would, among other things, facilitate and support the implementation of the clinical approach best suited to the needs of patients.

Final Note

With these many activities and projects, we are increasing the visibility of the disease in our province. Our goal is to improve the understanding and recognition of ME/CFS and improve access to diagnosis, treatment and support for people with ME/CFS. We are very motivated to work with stakeholders in other provinces to achieve significant breakthroughs for ME/CFS in Canada as well as throughout the world.

For updates about developments and future projects from our association, you can become a member of AQEM and receive our newsletter and publications or you can visit our website at the following address: **www.aqem.org.**

We wish everyone a positive sense of well-being.

à contribution les disciplines suivantes : ergothérapie, physiothérapie, psychologie et, au besoin, une consultation en service social. À la fin de ce projet, un questionnaire a été remis aux participants dans le but de connaître leur avis sur celui-ci. La majorité des participants se sont dits satisfaits des interventions reçues.

Selon une note de fin de parcours du CRCL, les intervenants ont conclu que l'approche bio-psycho-sociale est un incontournable pour la gestion de l'EM. Les PAEM peuvent présenter différents types de besoins simultanément ou en alternance en terme de connaissances, de soutien à domicile, de suivi médical et de réadaptation. L'intégration des services reste donc primordiale afin de bien desservir les PAEM. Le développement de la recherche permettrait, entre autres, de faciliter/soutenir l'application de l'approche clinique la plus adaptée aux besoins de ceux-ci.

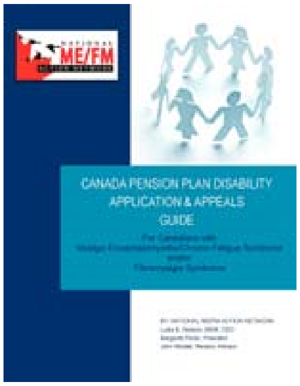
Mot de la fin

C'est grâce à ces nombreuses avancées et les projets réalisés que nous augmentons la visibilité de la maladie dans notre province. La connaissance et la reconnaissance de l'EM/SFC, rendre les soins ainsi que le suivi plus accessibles sont des buts visés que nous souhaitons atteindre. Travailler en collaboration avec tous les intervenants ainsi que les autres provinces afin de réaliser des percées significatives pour l'EM/SFC, non seulement au Canada, mais aussi à travers le monde, l'AQEM veut faire partie de l'équipe!

Enfin, nous vous invitons à rester à l'affût des avancées et des projets de notre association en vous inscrivant à notre infolettre, en recevant nos publications comme membre ou simplement, en allant visiter régulièrement notre site internet à l'adresse suivante : **www.aqem.org.**

Nous souhaitons à tous, l'atteinte du mieux-être.

Two New Documents

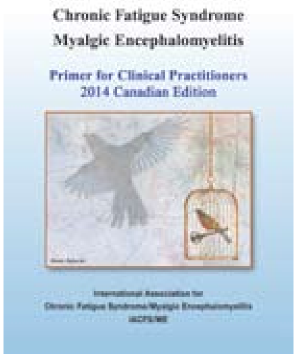

CANADA PENSION PLAN DISABILITY
APPLICATION & APPEALS
GUIDE

CPP-Disability Guide 2015

The Network has now revised its Canada Pension Plan - Disability Applications and Appeals Guide to reflect the changes in the appeal process. You will remember that the federal government replaced the Review Tribunal and Pension Appeal Board with the Social Security Tribunal in April 2013. You can find the new edition under Patient Resources on our website or you can ask that a printed copy be mailed to you ($10). Thanks to John Wodak, our pension adviser, for revising the document.

IACFS/ME Primer

The IACFS/ME Primer is now available in print format, with English on one side and French on the other. It is also available under resources on our website.


Chronic Fatigue Syndrome
Myalgic Encephalomyelitis
Primer for Clinical Practitioners
2014 Canadian Edition

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TEACH-ME (Eng) $25		
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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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