NATIONAL ME/FM ACTION NETWORK
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Quest Newsletter

www.mefmaction.com Quest 96, Fall 2013 mefminfo@mefmaction.com

We hope that the summer of 2013 went well for you. For some of us, the summer did not go smoothly. The Network sent out a bulletin to people on our email distribution list saying that Quest would be delayed and we asked for ideas and submissions for this issue. Somehow, only about half the people on our list received the bulletin. From those who received it, we got some good suggestions – people asked for articles about probiotics, sleep, and exercise. We also got an article on acceptance by Dolores Griffin – thank you Dolores for tackling this important topic. It turns out that there has been a lot of news this summer, so the newsletter is full, but we are keeping all the suggestions in mind for the future.

We are very aware that a number of our members do not have access to internet or email. We want to reach all our members, so we continue to offer paper copies of Quest to all our members. Sometimes Quest refers to an article that is available in electronic form. If you want a paper copy of a document, just let us know and we will mail it to you.

For our members who are online and have been voting for us in on-line funding contests, we say a big thank you. The Network has now received donations from three contests, from **Nature's Bounty,** from **FedEx** and, most recently, from **Bogs Footwear**. The Network has just been entered in an on-line contest by **Aviva.** Funding would go toward May 12 Awareness activities. The first round of voting closes on Oct 14 and the second round of voting takes place December 2-11.

We hope you enjoy this newsletter.

Margaret

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Dr. Alison Bested, Executive Director of the Chronic Complex Disease Clinic

BC Clinic Holds Official Opening

From the Global News website: September 12, 2013.

The Complex Chronic Disease Clinic is now open at BC Women's Hospital. It is designed specifically for patients suffering from diseases such as chronic fatigue syndrome, fibromyalgia, and Lyme disease.

Patients will require a physician's referral to be considered for admission into the program. Referral forms may be accessed by calling the program (telephone: 604.875.2061 fax: 604.875.3738).

After a patient has been referred, their needs will be further assessed by program staff through the use of a triage process. The triage criteria have been created with input from patient advocacy groups and a medical ethicist to ensure a fair process that prioritizes patients appropriately.

Once a date and time has been determined for a qualifying patient, the CCDP will then contact the referring physician with the information.

A letter from Director Sherri Todd to Clinic officials

I'd like to extend my very sincere thanks and appreciation to each of you, for the part you've played in the success of the Chronic Complex Disease's Open House yesterday! What a wonderful event it was!

As I'd mentioned to some people yesterday, it was the culmination of my personal dream coming to fruition, exactly twenty-five years to the month! I started back then with a meeting between myself, a Nurse and a Government employee I'd connected with in my home. The only thing we all had in common was the same strange collection of symptoms. From that first meeting we continued to grow, and within a couple of months we made a presentation to United Way during a contest they were running where they would present a cheque to a worthy group in need of promoting awareness and research. We were definitely that group, and we won! We used that money to incorporate, and our patient membership has grown continually every month since then.

From my own research in those earliest years of the mid 1980's, the terms our symptoms were discussed in were from "Twenty-First Century Disease to Raggedy-Ann Syndrome; and Firbositis to Epstein-Barr Virus to Chronic Fatigue Syndrome; before coming to the current Myalgic-Encephalomyelitis and Fibromyalgia terms. We've come a long way since then; and have an even greater opportunity to go further!

I've been fielding numerous calls and emails since yesterday from very grateful people who are excited to know we now have supportive medical professionals and a Clinic to care for us. Each of you deserve such high praise for your interest, individual efforts and commitment to work with ME/FM/Lyme and other chronically ill patients. Health and healing can only come from such a positive environment!

I'd like to specifically thank Dr. David Patrick; for his original interest, wisdom, encouragement and courage to seek funding for our Clinic. I thank Dr. Alison Bested, for her never ending commitment, devotion, respect and care she continues to give her patients, and for her continued efforts to fight for education, recognition and awareness within the medical community. And a special thank you to BC Women's President Dr. Jan Christilaw, and the Board of Directors; for their understanding and appreciation of the urgent needs of those in the community of ME/FM/Lyme, and having the new Chronic Complex Disease Clinic be based out of the world respected BC Women's Hospital site.

This indeed, is a new era in British Columbia, and in Canada. I for one, ~ am thrilled!

Sincerely yours,
Sherri Todd
BC Director - The National ME/FM Action Network

Working With the Provinces

After years of being ignored, ME/CFS and FM are now being discussed in British Columbia and Ontario.

BC is leading the way. Its new Complex Chronic Diseases Program for residents with ME/CFS, FM and/or Lyme Disease is up and running. The official opening ceremony was held in September.

Ontario is at the design stage. MEAO received a grant from the Ontario Trillium Foundation to examine the quality of care and support for people living with ME/CFS, ES/MCS and FM. Around the same time, the Association of Ontario Health Centres (AOHC) received a grant from the Ontario ministry of health to develop a business case for new services for Ontarians with ME/FM/MCS. Recognizing that the two projects were overlapping, MEAO and AOHC combined their efforts. Reports will be submitted to the ministry this autumn in the hope that new services will be part of the provincial budget next spring.

When a government shows interest, as BC and Ontario have done, the conversation changes from "please pay attention to our needs" to "how can the government respond to our needs". To have a healthy conversation, people on both sides must understand the needs of the community and understand what the government can and cannot do.

Community Needs

The US Food and Drug Administration (FDA) provides a model for learning about community needs. The FDA is responsible for approving drugs and treatments in the US. They decided to become more patient-focused and identified 15 conditions for special review. ME/CFS was early in the process. Fibromyalgia is slated for review in December 2013.

On April 26 2013, the FDA held a public meeting to hear from patients and caregivers. Further input was invited by email or letter. In late September, the FDA released a summary of what they heard.

The report is 23 pages total with two main sections. One of the sections reviews the symptoms and impacts of ME/CFS. The other main section looks at the drugs and treatments that are currently being used and at the patient experience with them. Knowing the symptoms, impact and treatment status of the illness gives the FDA important background information for making approval decisions in the future. An excerpt from the report is reproduced on the following pages.

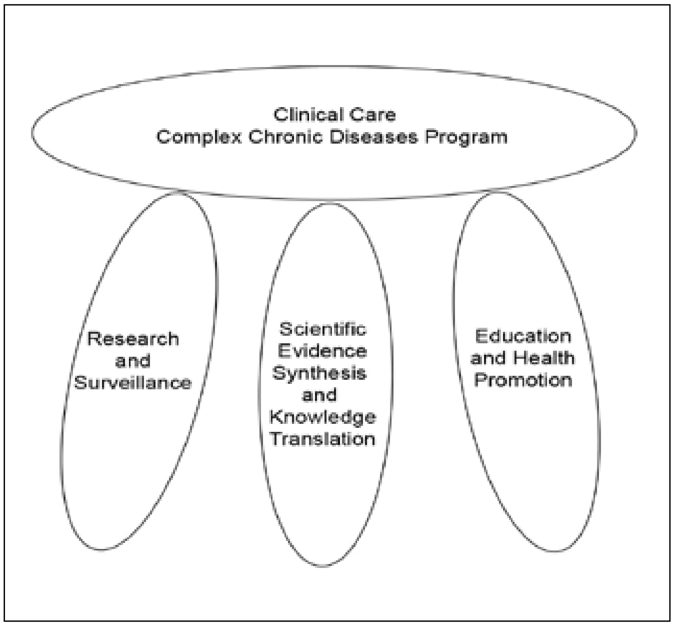
What Governments Can and Cannot Do

Very importantly, governments do not have magic wands. They cannot instantly create knowledgeable doctors, find a cure for ME/CFS or FM, or overcome misinformation and prejudice. They can, however, put the wheels in motion to address these kinds of issues.

Also very importantly, governments are part of a constitutional framework so there are limits on the scope of their activities. Here in Canada for instance, the federal government has primary responsibility for health research while the provinces have primary responsibility for healthcare delivery. The lines of responsibility are of course more nuanced, with provinces having some role in research and the federal government having some role in healthcare delivery. There are a number of other players such as regional officials, universities, and medical associations. It can be challenging, but it is necessary to figure out approaches that respect the scopes of the different organizations.

One thing that has become clear is that the scope of issues that need to be addressed is very broad. Having more clinics in place is important, but not enough. The Ontario project refers to the need for health and social services, research, education and policy development. The BC Program has a basic model saying that clinical care has to be supported by research and surveillance, scientific evidence synthesis and knowledge translation, and education and health promotion. With this broad scope of activities, a number of government and non-government players will be involved.

ME/FM/BC Director Janis Cackette, Dr. Bruce Carruthers, The National ME/FM Action Network's BC Director Sherri Todd



Complex Chronic Diseases Program in B.C

The conversations with the provinces will not be easy, but with commitment from all sides to finding solutions and with respect from all sides about what patients need and about what authorities can and cannot do, the conversations will become more and more nuanced and mature over time.

Excerpt from: The Voice of the Patient

A report from the FDA's Patient-Focused Drug Development Initiative for ME/CFS

http://www.fda.gov/downloads/ForIndustry/UserFees/PrescriptionDrugUserFee/UCM368806.pdf

Range and effectiveness of treatments

In the large-group facilitated discussion that followed the panel presentations, treatments were discussed in two broad categories. The first category was the set of therapies intended to treat the underlying cause of the disease, including immunomodulators, antivirals, and antibiotics. The second category was the wide range of therapies targeting specific symptoms of the condition. Symptomatic treatments most frequently mentioned included those for sleeplessness, enhanced alertness, unrefreshing sleep, pain, orthostatic intolerance, gastrointestinal problems, heart rate, and blood pressure. Participants reported widely varying levels of efficacy for the same treatments.

- The treatment most commented upon was the experimental drug therapy **Ampligen** (rintatolimod). Some participants described dramatic improvements in their physical and cognitive symptoms with their use of Ampligen, calling it "a miracle drug. "One described using Ampligen for three periods in her life; each time she started, she experienced dramatic improvement, and each time she stopped, she eventually reversed to the full devastating impact of the disease. Participants also acknowledged that Ampligen does not work for all patients.
- Participants provided varying accounts of the effectiveness of **antiviral or antibiotic medications or medications targeting their immune system**. A few participants described how specific treatments, often taken in combination, were very effective and "led to an amazing increase in [the] ability to get around. "Others, however, described how specific treatments were not effective for them.
- Participants commented on various medications and other therapies targeting their specific symptoms relating to pain, fatigue, and sleep dysfunction, all with varying degrees of success. Participants described a complex process of trial and error to find an effective regimen to fit their specific needs, particularly with respect to pain management. They described giving a drug enough time to see if it works, for a period of months, unless the side effects are not tolerable.
- **Non-drug therapies** were also raised, including yoga, stretching and relaxation techniques, and mental exercises. One participant who had not responded well to drug treatment noted that pacing (a structured method of moderating activity to avoid overexertion) is "the number one most effective strategy, without which I would never have been able to go back to work." Participants cautioned that therapies involving physical activity were not right for everyone and must be carefully monitored by knowledgeable professionals.
- A few participants commented on the benefit of **intravenous (I.V.) saline**. One participant related a story in which upon experiencing a sudden onset of a crash and fainting while traveling, a doctor "gave me the saline drip, and I got up and went shopping."
- Participants described how they have **adapted in other ways**, including continually monitoring their anaerobic threshold with a heart rate monitor or using

activity monitors to track their activity levels. Others commented on how they "reserve energy" by using mobility aids, handicap stickers, shower chairs, and making changes to their schedules.

- In addition to treatments mentioned, participants discussed a **wide range of diagnostic tools and biomarkers** that clinicians have used to help treat their condition. These include natural killer cells, inflammatory cytokines, viral titers, and VO2 Max.
- Some participants who experienced even marginal effects from treatment noted that **even small improvements could be significant in terms of quality of life**. As one caretaker described: "[My son can now] engage in an hour of activity every other day instead of every fourth day…healthy people in this room would barely notice or think it was important at all…to him, it's like a miracle." Another commented, "Although I am not as well as I would like to be, these treatments have restored a great deal of purpose and meaning to my life."

Treatment Downsides

- Many participants described the **significant impact of the side effects or drug interactions** of their medications, especially when taken concomitantly and over a long term. For example, participants described how opioids used to treat pain exacerbate their fatigue, create "brain fog," and gastrointestinal issues, and risk of addiction. Others mentioned stomach and esophageal problems with anti-inflammatories, sleepwalking-type issues with Ambien, jitters and high pulse rates from Adderall, as examples.
- Some participants commented that their therapies had good initial success, sometimes for long periods of time, but then **became less effective over time** or as the disease progressed or flared. As one commented, "I've probably tried at least 25 drugs [for pain], maybe more, and over time they lose effectiveness. I have to switch it up."
- Some participants expressed frustration with their **access to treatment options**. A few described moving across the country to obtain treatment. One participant stressed that a lot of specialized treatments "are limited to a very small population of CFS patients" who have enough insurance, money, knowledge, and family support to obtain them. A few described experiences with health care professionals who did not take their disease seriously or refused to treat it.
- A few expressed concern that their treatments **focus on the symptoms, not the root cause**.
- A few participants commented that if not handled carefully, symptomatic treatments can **mask symptoms** and make it difficult for patients to monitor or control their activity levels and avoid the overexertion that leads to a crash.
- A few participants commented on the **financial cost of treatment**, particularly the out-of-pocket cost for experimental or other unapproved treatments not covered by their insurance. As one participant noted, "My medical expenses can be as much as $2,500 per month."

Other Issues Raised in the Discussion:

- A few participants stated their belief that there is a variety of subsets or subtypes of people affected with CFS and ME. They pointed to the variability in how treatments work for some, but not others. One web participant urged identification of subtypes "so that we don't hurt ourselves by trying [drugs that don't work for us]."
- A few participants stressed that they or their loved ones would be willing to accept significant risk for the opportunity to try new treatments to potentially alleviate or cure their condition. One web participant, however, commented that "I am quite wary of [taking risks]. I'm very unwell, but I know how to manage at this level. Trying a new medication has typically caused side-effects that take me weeks or months to recover from."

Note: Appendix 4 lists ME/CFS symptoms and the drugs and therapies that are used for these symptoms.

The FDA has scheduled a workshop on Fibromyalgia for December 10, 2013. Patients and caregivers are invited to attend, to watch on-line, or to submit comments. The topics are 1) disease symptoms and their daily impact, and 2) current approaches to treatment. More information is available at *http://www.fda.gov/ForIndustry/UserFees/PrescriptionDrugUserFee/ucm363203.htm*

Article on Healthcare-Patient Relations

We are pleased to share with you the abstract of an article that explores the relationship between health care practitioners and individuals with ME/CFS. The full article is available at the website *eleanorsteinmd.ca* .

How to improve therapeutic encounters between patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Health Care Practitioners

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Abstract

Background: Clinical practice and the medical literature abound with reports of mutual dissatisfaction between individuals with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) and health care practitioners.

Purpose: In this paper we: 1) formulate and describe the common therapeutic challenges in the care of patients with ME/CFS and 2) present a patient-centered, collaborative practice model that may mitigate these challenges.

Method: We have combined clinical experience with hundreds of patients, a thorough review of the medical and psychotherapy literature and comments from patients and colleagues to arrive at our proposed practice model.

Findings and Discussion: We have identified six common therapeutic challenges listed below. From our experience and the psychotherapy literature we have identified a relatively simple patient-centered intervention for each therapeutic challenge. These interventions are recommended for health care practitioners who find themselves in difficulty while working with patients with ME/CFS.

1. Disagreement about the validity and severity of ME/CFS - Validate the patient's experience and openly discuss differences of opinion.
2. Disagreement about the etiology and best management of ME/CFS - Find and validate the truth in the patient's position.
3. Frustration due to lack of improvement - Collaboratively search for hope.
4. Altered power balance between practitioner and patient - Clarify and increase practitioner expertise.
5. Working with patients who feel unheard - Listen to the whole story.
6. Gap between needed and available services - Build a coalition to access needed services.

Conclusions: Therapeutic relationships with patients with ME/CFS can be rewarding and enjoyable. The interventions highlighted in this paper may assist practitioners who feel otherwise.

This summer, the National ME/FM Action Network was pleased to receive a cheque for $2500 from Bogs Footwear. This was a result of voting in an on-line contest.

This is in addition to the $5000 the Network received from the Nature's Bounty Contest and the $4040 received in a FedEx contest. The National ME/FM Action Network has recently been entered in a contest by Aviva. Voting in the first round takes place from Sept 30 - Oct 14. Voting in the second round is Dec 2-11. Go to *https://www.avivacommunityfund.org/search/grid.*

The Network is delighted with the strong community support it has received in these contests.

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The Road to Acceptance

by Dolores Griffin Sept. 5/13

E. Tolle (from his book, The Power of Now) defines acceptance as a "this is it" response to anything occurring in any moment of life. There, strength, peace and serenity are available when one stops struggling to resist, or hang on tightly to what is so in any given moment. What do I have right now? Now what I am I experiencing?

I found an interesting article on a site called Big Girl Bombshell written by jules@biggirlbombshell.com where she talks about her experience on the road to acceptance with a weight issue. She cites Melodie Beattie, author of Codependent No More, who writes extensively on the subject of acceptance. As she reminds us, Acceptance DOES NOT mean Adaptation. It doesn't mean we resign ourselves to that particular way of life with attitudes that stem from "what's the use" or "giving up" which then leads to the vast container of negative self- talk. It simply means – in this present moment, I acknowledge and accept the circumstances of what and who I am. ALL of it.

For me the journey to acceptance has been a long and painful one - one which I am still trying to find my way. I was officially diagnosed with Chronic Fatigue Syndrome (CFS) in 2008. I was at the peak of my career and was completely devastated with the news. Perhaps the worst part is the fact there is no known cause, no treatments per se, and no cure, and what's worse is the fact that many in the medical community and especially the general public, are not knowledgeable or accepting of it. It is difficult for families and friends to understand the effects of the illness, when one day you may be out and about and appear fine and then the next day you are confined to bed.

With the news, my inquisitive and stubborn nature kicked into overdrive as I sought out information from every available source. I researched various websites, read many books, talked to others with the illness. At the same time I was navigating my disability insurance and facing what it meant for my career which got abruptly interrupted. I had planned to work at least another five years and the effect of forced early retirement hit me hard - what was I to do with the rest of my life? I had always been an active person who believed in multitasking. I love to exercise, garden, kayak, travel, etc. I loved to learn new things and to try new hobbies. When CFS hit me, I was losing days of my life each week confined to bed.

Now, physical and even cognitive activities over a certain limit result in a crash which means I lose more days.

At first, I focused more on learning about the physical aspects of my illness and what I could do. Pacing became my way of life and it is a skill I am still struggling to perfect. I have had to accept the fact that I have a limited amount of energy to spend each day and if I go over my quota, I crash. Trying to maintain an even keel and good balance of rest and activity is difficult. Sometimes life gets in the way and you have no choice but to overspend on your energy envelope. Things like family events (weddings, funerals, etc) or just the sheer pleasure of doing something that means a lot is worth the price I must pay.

It's been nearly 4 years and only now am I starting to "accept" my new reality. Part of my success in doing so, has been the spiritual journey I am on. Various things like reading, meditation, and gaining perspective have been helpful. Books like "Tuesdays with Morrie" by Mitch Albom were great to read as it helped me gain perspective and realize the power of "grace" in one's life.

I also realized for the first time what it means to live with a chronic illness. I see others with acute illness like cancer and heart issues and see them come out the other side healed and move on with their lives. While I am thankful I do not have to suffer through horrible procedures or treatments or surgeries, there is a part of me that wished that I could be mended and not face a life sentence with CFS.

It is taking me time to mourn the "old me" and my past lifestyle but I am so thankful for all the blessings in my life and although I may have bad days and limited capacity, I am happy. I practice gratitude each day for all the blessing in my life, especially the gift that is my husband and family and friends.

I try to find purpose each day by setting obtainable goals and helping others when I can.

Most of all, I realize that CFS does not define me - it is something that I must incorporate into my life just as I must deal with my curly unruly hair.

I am many things and blessed in so many ways, that I do what I can, go when I can, and rest and recoup when I must. I listen to my body, respect it limitations and celebrate its strengths.

Melodie Beattie writes:

Self-acceptance is a more humble term than self-esteem or self-love. Self-love has tones of narcissism - me first and to heck with you. Self-esteem rings of pride - holding ourselves up higher than everybody else. Self-acceptance is that gentle place we get to when we make peace with who we are.

NEW Fibromyalgia Research

By Eleanor Stein, MD

The race is on to find a diagnostic test for Fibromyalgia. Whoever discovers the first reliable diagnostic test will help millions of people have their health complaints validated, may become very famous and will likely make a lot of money if the test can be patented. As a result authors and journals are putting early research results such as the papers discussed below into the media and generating interest on FM websites and blogs. While any one of these recent findings may be valid, it is a bit early to get too excited. Ideas come and go. Usually this is because researchers make an observation in a small group of participants which doesn't turn out to be generally true for all patients with a condition. However the papers summarized here hint at a possible sea change occurring in the field of FM. Three of the studies below are challenging the now widely accepted belief that Fibromyalgia is a "central" pain disorder. They are reporting abnormalities in the periphery particularly the skin! Science is a constantly changing landscape which keeps me endlessly curious and interested to learn more.

1. Behm,F.G., Gavin,I.M., Karpenko,O., Lindgren,V., Gaitonde,S., Gashkoff,P.A., & Gillis,B.S. (2012) Unique immunologic patterns in fibromyalgia. BMC. Clin Pathol., 12, 25.

The take home message of this study is that patients with FM have less reactive immune cells than healthy people. Read on for the details...

In this study, conducted at the University of Illinois at Chicago, the researchers compared blood samples of 110 patients with FM and 91 healthy controls. The Fibromyalgia patients had an average age of 53 years and had been ill on average for 16 years. The blood of each participant was drawn and the peripheral blood mononucleocytes (PBMCs), which includes most of the immune cells, were separated and grown in a petri dish. The level of immune chemicals (cytokines) they produced was measured before and after the cells were exposed to molecules that they interpret as an immune threat. In healthy immune cells the level of immune chemicals increases significantly after such an exposure. The PBMC stimulation test is commonly used in research and some advanced clinical labs. It measures the functional capacity of immune cells – whether they respond to threats appropriately?

Before the immune stimulation, the levels of cytokines in the cell cultures were very low in both groups. This is what one would expect. In the healthy group the cytokine levels increased as expected after stimulation. In the Fibromyalgia group the cytokine levels increased far less. Although mixed, the body of research seems to be growing that patients with FM and other chronic pain conditions show decreased production of the cytokines IL-6, IL-8, IL-10 and IFN-gamma under stimulation conditions. Regular blood cytokine tests don't reliably show a FM profile. The reaction to the stress of antigenic stimulation seems necessary to see a difference in immune function between FM and other groups. As I have noted in previous newsletters, most of these cytokines are both elevated and easily stimulated in patients with ME/CFS.

The authors conclude that FM is not a rheumatologic, neurologic or psychiatric condition but an immune condition. Only 9 of the FM group suffered from depression at the time of the study and their results were not different from the rest of the group "proving that depression by itself had an extremely limited impact on the cytokine profiles in FM patients".

2. Hackshaw,K.V., Rodriguez-Saona,L., Plans,M., Bell,L.N., & Buffington,C.A. (2013) A bloodspot-based diagnostic test for fibromyalgia syndrome and related disorders. Analyst, 138, 4453-4462.

This study found a unique FM fingerprint by analyzing the proteins in the blood of FM patients. Read on for the details ...

This study recently published by researchers at the Ohio State University compared the substances present in the blood of small groups of patients with Fibromyalgia (14), Osteoarthritis (12) and Rheumatoid Arthritis (14). They used two strategies to identify the molecules present in blood.

Infrared spectroscopy measures the vibration of molecules after they are exposed to infrared light. Using this method each molecule has its own fingerprint. Using this test no single molecule differentiated the blood of the FM group from the blood of the two arthritis groups. Therefore the researchers used complicated statistics to identify variation in the profiles of the two groups. Using a strategy called SIMCA they were able to identify the blood from FM patients with 100% accuracy. This high level of accuracy is rare in medicine. However, one must remember the sample sizes are very small and replication will be critical to see if the test is as accurate in larger samples.

The group also compared blood samples using matabolomics analysis. This strategy uses mass spectrometry to identify molecules present in human blood. Each molecule present has a unique fingerprint. For this part of the study there were 10 participants in each of the three groups. About 30 molecules had different profiles in the FM, OA and RA groups. The diagnostic accuracy using this approach was only 75% (in other words they would predict the wrong disorder in 25% of cases). For a test to be useful in clinical practice the accuracy should be 99% or higher. Otherwise too many people will be harmed by receiving inaccurate results. The molecules that differentiated between the groups included several amino acids, molecules involved in tryptophan metabolism, molecules associated with oxidative stress, with glucose utilization and with hemoglobin synthesis.

3. Albrecht,P.J., Hou,Q., Argoff,C.E., Storey,J.R., Wymer,J.P., & Rice,F.L. (2013) Excessive Peptidergic Sensory Innervation of Cutaneous Arteriole-Venule Shunts (AVS) in the Palmar Glabrous Skin of Fibromyalgia Patients: Implications for Widespread Deep Tissue Pain and Fatigue. Pain Med., 14, 895-915.

These authors report physical changes to the area where blood moves from arterioles to venules in the hands of patients with FM. Read on for the details ....

The group from upstate New York took tissue biopsies from the thumb side of the palm of the hand of women with FM and compared these biopsies with those from age, gender matched healthy individuals. The tissues were stained and examined under a microscope to identify the types and prevalence of nerve fibres in the biospy samples. In the samples from the participants with FM, they found abnormal types and numbers of nerves at the place where the arterioles become venules ... the place where blood flow to the tissues occurs.

The authors found more small sensory nerve fibres in the palms of the FM group than the healthy group. They hypothesize that this may account for increased hand tenderness in FM. As well, since this area is important for control of blood flow, the nerve changes could lead to decreased circulation and insufficient oxygen in the deep tissues ... maybe explaining the sensation often expressed by patients with FM of “poor circulation”. They also noted that women have twice the sensory innervation to this arteriole-venule region than men. Thus women may be more prone to pain or circulation changes from increased nerve growth than men. The research group is now extending their study to men to see if it is the same or different. The media reporting from this study that “Fibromyalgia has finally been explained” seems premature. Many aspects of the findings need to be replicated and the interpretations are complex and far from clear (at least to me).

4. Uceyler,N., Zeller,D., Kahn,A.K., Kewenig,S., Kittel-Schneider,S., Schmid,A., Casanova-Molla,J., Reiners,K., & Sommer,C. (2013) Small fibre pathology in patients with fibromyalgia syndrome. Brain, 136, 1857-1867.

This study found abnormalities to the small pain sensing nerves in the foot of patients with FM but not in people with depression or healthy participants. Read on for more details ...

This research team from Wurzburg Germany used several strategies to assess the function of small temperature and pain sensing nerve fibres in the feet. They compared 25 patients with FM, 10 individuals with depression and 25 healthy controls. They chose the feet because these are usually the first place affected in small fibre neuropathy, a condition also very common in diabetes. The thresholds for detection of temperature were higher in the FM group than the other two groups meaning participants with FM were a bit “numb” to temperature. As found in many previous studies the FM group had increased pain sensitivity to mechanical stimuli like pressure or pinching.

They then challenged the feet, hands and face with electrical stimulation and measured the nerve response. The FM group had delayed and reduced responses again suggesting neuropathy. Finally they did skin biopsies of the lower leg and upper thigh and found a decrease in unmyelinated small nerve fibers. Note that the study above by Albrecht and colleagues noted increased number of small nerves and this group decreased numbers ... Clearly more research is needed.

The conclusions of this German study are that there is evidence of damage and lack of regeneration of the small, pain sensing nerves in the periphery. The authors speculate that nerves in deeper tissues such as muscles and joints (where patients with FM report the most pain) may also be affected.

Canada News

Professional Misconduct by Psychologist

People with ME/CFS or FM might encounter Odyssey Health Services, perhaps referred there by their disability insurer. Here are quotes from the Odyssey website *http://www.odysseyhealthservices.com/index.php?lang=1 :*

"Odyssey Health Services specializes in treating a variety of mental and physical health conditions that result in: unnecessary or protracted work accommodation or modification, higher than normal levels of absenteeism or prolonged time off work on either sick or disability benefits.

"Odyssey assesses and treats mental health conditions such as mood and anxiety disorders, and physical complaints such as back pain, headache, chronic fatigue, fibromyalgia, and other complex or difficult to manage conditions. Odyssey uses proven, evidence-based approaches that combine medical and behavioural sciences.

"Since 1982, Dr. Richard Marlin, Director of Odyssey Health Services, and his team of practitioners have provided highly effective, interdisciplinary services to treat complex mental and physical health conditions that impair function in the workplace.

"Odyssey Health Services has clinical teams in Nova Scotia, Ontario, Alberta and British Columbia.

"For insurers ...The goal is for the claimant to return to an optimal level of function, including a return to employment, in a timely manner. Return to work is viewed by all as not only possible but probable - and certainly preferable."

The website includes an article entitled "*Treating Chronic Fatigue Syndrome: What Works? What Doesn't?*" The article very clearly supports Cognitive Behaviour Therapy and Graded Exercise Therapy.

On September, 4, 2013, Dr. Marlin appeared before a panel of the College of Psychologists of Ontario. Here are quotes from Dr. Marlin's listing on the Ontario College's website: *https://members.cpo.on.ca/members_search/new*

"On November 14, 2011, the College of Alberta Psychologists ("CAP"), of which Dr. Marlin is also a member, made findings of professional misconduct against him...In particular, the CAP found that Dr. Marlin had:

Failed to obtain informed consent by:

- *Conducting a psychometric test with a client when the client was adverse to doing so;*
- *Limiting access to the client's family physician and other specialists, contrary to the client's choice; and*

Failed to create and maintain an appropriate therapeutic relationship with the client by:

- *Failing to create a relationship in which the respect and dignity of the client was maintained;*
- *Performing a psychometric test when the client was under duress/emotional stress; and*
- *Failing to ensure that there were sufficient professional attendances directly with the client when the pre-existing history and conditions of the client mandated a higher level of interaction than once per month.*

"The [Alberta] Tribunal imposed the following rehabilitative penalty: a reprimand; an ethics course at Dr. Marlin's own expense; a condition that subjected him to monitoring by the Complaints Director for 12 months, subject to peer review at 6 and 12 months at his own expense. He was also ordered to pay costs of the investigation and hearing up to $60,000 in 12 monthly installments....Dr. Marlin has complied with the rehabilitative penalty order...

"[T]he nature of [the Alberta findings] would also constitute misconduct in Ontario...

"The [Ontario] panel found that Dr. Marlin had committed Professional Misconduct and both ordered and administered a reprimand."

If you would like more information about the hearings, you can contact the College of Alberta Psychologists and the College of Psychologists of Ontario to request the full documentation.

Social Security Tribunal

An interesting and up-to-date perspective on the new Social Security Tribunal can be found in the blog by Allison Schmidt of Disability Claims Advocacy Clinic Inc at *www.dcac.ca/blog*. Ms Schmidt has represented CPP-D claimants for 15 years.

Before April 1, 2013, the application/appeal process for CPP-Disability applications went as follows:

Step 1: Application reviewed by staff.

Step 2: Applicant could ask for "reconsideration" and different staff would review the file.

Step 3: Applicant could ask for a hearing before a 3 person Review Tribunal

Step 4: Applicant could ask for a review by the Pension Appeal Board.

On April 1, 2013, the Review Tribunal and Pension Appeal Board were replaced by the Social Security Tribunal (SST), General and Appeal Divisions. There are significant changes at step 3 and step 4.

For Step 3, a member of the General Division - Income Security Section will deal with the appeals. Twelve people have been appointed members (one of whom is a Vice-chair of the SST). There were 5 vacant positions as of Oct 1. No hearings have yet been scheduled by the Section – meaning that there have been no CPP-D appeal hearings since March. There has, it should be noted, been administrative movement on some files. Ms Schmidt estimates that there are almost 9,000 files before the Section, which is more than 700 per appointed board member.

When it comes to Step 4, it is important to know that the rules for appeal have been tightened, meaning that it will be harder to qualify for a step 4 appeal than previously.

The conclusions I draw from this scenario are the following:

- For those starting an application for CPP-D, you should try your hardest to qualify in step 1 or step 2 in order to avoid the problems of step 3 and step 4. You will find the Network's CPP-Disability Guide helpful. You could also consider hiring professional help at an early stage. Let your Member of Parliament know if you do hire help because the new system was supposed to be user-friendly and was not supposed to cost people extra.
- For those turned down at step 2 (reconsideration), file an appeal. Don't let the wait time discourage you. You can't qualify for benefits if you withdraw from the process. You must recognize that it will take time, but you don't have to be happy about that. Let your Member of Parliament know that you are waiting. If you are receiving benefits from a province or from a private insurer, let them know as well. They want you to succeed – it lowers their payments to you. The system is clogged. If enough people speak up, something will have to be done.

Justice delayed is justice denied.

Submission for 2014-15 federal budget

The House of Commons Finance Committee asked the public for suggestions of what might be included in next year's federal budget. The National ME/FM Action Network made two suggestions; 1. A new institute at the Canadian Institutes for Health Research with designated funding to research ME/CFS and FM issues, and 2. An interdepartmental task force to review government information about ME/CFS and FM and to look at programs and services to ensure that the ME/FM community has equitable access. The submission is available on the News section of our website.

2012 Statistics Canada Data

You will remember that FM, CFS and MCS were included on the first three cycles of the Canadian Community Health Survey (CCHS) in 2001, 2003 and 2005. The sample size of these surveys was over 130k Canadians. When the CCHS moved to an annual basis in 2007, the sample size was reduced to about 60k per year and the questions on FM, CFS and MCS were dropped. After pressure from the community, survey officials agreed to include the questions on the CCHS in the years 2010 and 2014.

It turns out that, in addition to the regular CCHS for 2012, a special CCHS was run that year. The survey was restricted to the provinces (not territories) and to Canadians aged 15 and up (rather than 12 and up in the regular CCHS). The sample size was a much smaller 25k. The theme was mental health, but the survey included many of the chronic conditions on the regular CCHS, including diabetes, heart disease, high blood pressure, CFS and MCS. Two of the questions were "arthritis excluding fibromyalgia" and "back problems excluding fibromyalgia and arthritis", but shockingly fibromyalgia itself wasn't asked.

This survey was officially released on September 18, 2013. To protect the confidentiality of the respondents, the detailed data was not released. Instead, two articles and several tables were released to the public, and a "share file" was made available to government agencies and academic institutions but not the Network. The Network won't have direct access to details until the "public use microdata file" is released until next spring. That puts us at a big disadvantage in talking to government officials who have access to the share file.

Through some begging, we were able to get the Canada totals for CFS (373k) and MCS (753k). The numbers were lower than in 2010, more than would be explained by removing the territories and the 12-14 year olds. The drops might be due to sampling variability – 25k is a small sample - or it might be because people with MCS and CFS disproportionately opted out of the survey. It could also be a signal that the 2010 estimates were slight overestimates. For the time being, we don't know why the figures dropped a little, but we are sticking with the 2010 figures which are based on a larger sample size, include fibromyalgia, and are more accessible.

Bike Ride for Fibromyalgia

Leo Begin has big dreams. He wants to ride across Canada in Spring 2015 to raise awareness and collect money for Fibromyalgia. He has FM himself. It developed 24 years ago when he was an active, athletic young adult. He now has a daughter and two grandchildren, and he wants to help with education and research so that their generations don't have to go through the same challenges that he has had to face.

Let's be honest. Leo won't be self-propelling his way all across the country. He is looking at a three-wheeled electricity-powered bicycle and he will have an escort vehicle. He will go for 3 days and rest on the fourth. Even so, he is not expecting it to be easy. But he loves biking, he wants to see the country, and he wants to raise the profile (and bank balances) of FM.

Keep posted as his project evolves. You can read more at *https://www.facebook.com/FibromyalgiaCrossCanadaRide2015*

International News

Founder of May 12 Awareness day passes away

(based on Boca News Now)

Patients around the world suffering from neuro-endocrine-immune diseases such as Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS), Gulf War Illness (GWI) and Lyme Disease are lamenting the passing of devoted activist Thomas Michael Hennessy, Jr. The Boca Raton, Fla. resident battled ME/CFS and Lyme disease for 25 years and was noted for establishing the May 12 International Chronic Fatigue Syndrome Awareness Day, spearheading several aggressive national advocacy campaigns, and being an outspoken champion for patient's rights.

"Tom brought his marketing and public relations talents to the advocacy of neuro-endocrine-immune diseases," said Lori Chapo-Kroger, RN, PANDORA Org President. "His concept of a lobby and awareness day for these illnesses is now commonly observed by patient advocacy organizations around the world, including our organization. Tom was one of the firsts, before most scientists, to recognize that Gulf War Illness is similar to ME/CFS. Because of the similarities among the diseases, the necessity to reduce misconceptions, and the call for a stronger activism voice, Tom conceived of advocating for all of these illnesses together, along with fibromyalgia, environmental illness and chronic tick-borne infections. He suffered from quite a few of these ailments for many years."

Although he was severely ill, Hennessy founded the advocacy organization RESCIND and testified at numerous national and international ME/CFS conferences and meetings with energetic and direct messages confronting the overwhelming stigma attached to ME/CFS.

A funeral mass for Hennessy was held September 19. An phone-in memorial service was held on September 29.

New guidelines for UK schools

In January 2013, the UK Department of Education issued new statutory guidance to school boards on educating children with health needs. Entitled "Ensuring a good education for children who cannot attend school because of health needs," the guidance clarifies what must be done by school authorities for children who cannot attend mainstream or special schools due to illness. This provides a model of what could be done in Canada.

Two US Controversies

The US Department of Health and Human Services (HHS) has hired the Institute of Medicine (IOM) to develop a new definition for ME/CFS. There is a sense that the HHS is bypassing the ME/CFS community and the HHS's own CFS Advisory Committee in awarding this contract. A group of leading ME/CFS doctors and researchers has written the Secretary of HHS endorsing the Canadian definition. We in Canada need to be concerned about this development because a US decision could have strong influence on Canadian practice.

In another controversy, a study being undertaken by the CDC does not include second-day exercise testing in its protocol, downplaying the seriousness of post-exertional malaise.

Timelines for ICD-11 slipping

The World Health Organization publishes the International Classification of Diseases. Most countries are using the ICD-10 which was published in 1990. Work is underway on the ICD-11. The original intention was to approve the new version in 2011, then 2014, then 2015. It is not clear even if that date is achievable.

Karina Hansen still being held

http://www.prohealth.com/library/showarticle.cfm?libid=18201

Karina Hansen is a 24-year-old Danish woman who has had M.E. (myalgic encephalomyeltitis) since she was 16. On February 12, 2013, five policemen, two doctors, two social workers, and a locksmith came to her home and forcibly removed Karina Hansen from her bed and transported her to Hammel Neurocenter.

Karina was able to make a call the next day to her mother saying, ""How can I get out of here? I can't take this." Since that time her parents have been prohibited from seeing her even though preventing relatives from visiting their family members in the hospital is a violation of basic human rights.

There is an international group pressing for her release. For more information about how you can participate, check the facebook page "Justice For Karina Hansen"

https://www.facebook.com/JusticeForKarinaHansen

Association québécoise de l'encéphalomyélite myalgique (AQEM)

L'Association québécoise de l'encéphalomyélite myalgique (AQEM) s'est bâti une solide réputation depuis plus de 20 ans. Elle est devenue au Québec une incontournable source d'informations et de services pour les personnes atteintes d'encéphalomyélite myalgique (PAEM*), maladie aussi connue sous le nom de Syndrome de fatigue chronique, ainsi que pour leurs proches et des intervenants dans le milieu de la santé.

Plusieurs organismes gouvernementaux, privés et communautaires ont reconnu son apport au mieux-être direct envers les personnes atteintes de cette maladie si invalidante qu'est l'EM/SFC. Des liens avec le milieu médical se sont tissés au fil des ans pour contribuer à l'avancement et à la diffusion des connaissances tout comme au développement de méthodes d'interventions chez les personnes atteintes.

L'AQEM est présente dans le milieu : kiosques, entrevues radiophoniques et télévisées, groupes de soutien dans quatre régions du Québec, réseaux de contacts pour les PAEM, les proches et les jeunes (142 membres font partie de l'un ou l'autre de ces réseaux), accompagnement et info-références. L'AQEM compte présentement près de 350 membres.

La recherche progressant, l'AQEM sera d'autant plus sollicitée par la population en général et le milieu médical. Elle doit se préparer… Pour ce faire l'AQEM désire passer à une autre étape de croissance et de développement stratégique tout en conservant son rôle et son identité communautaire d'aidant. En conséquence, la croissance du soutien financier devient également essentielle. Les membres, malgré leurs grandes limitations, participent beaucoup et de différentes manières, à la réalisation des projets. En plus du bénévolat des membres, on a pu aussi compter sur la participation de bénévoles de l'extérieur. L'AQEM a ainsi pu bénéficier de 4 200 heures de bénévolat en 2012-2013.

Les membres contribuent également de façon importante au financement. Près de **30%** du budget provient des cotisations des membres, des dons ainsi que des événements organisés qui génèrent d'autres dons de la part du public en général. Le gouvernement du Québec, pour sa part, par l'intermédiaire **du Programme de soutien aux organismes communautaires du Ministère de la**

Santé et des Services Sociaux, contribue à la hauteur de 70% du budget total de l'organisme.

L'AQEM produit deux publications : **L'Info AQEM** vise à informer les membres des dernières nouvelles et est un lien très important avec l'administration. **Le Ruban bleu** est une revue qui met en valeur les recherches récentes, les percées médicales et gouvernementales, tout sujet en lien avec la maladie.

L'AQEM prend un virage stratégique

Pour ce faire l'association s'est adjoint des personnes pour aider à développer une vision plus large, plus globale. Plus précisément, en 2013-2014, l'AQEM a pour objectifs entre autres, de

- Renforcer les liens avec les régions et développer les groupes de soutien,
- Assurer une permanence forte (une coordonnatrice vient d'être embauchée à raison de 30 heures/semaine pour deux ans renouvelable),
- Recruter de nouveaux membres,
- Améliorer l'accès à l'information, entre autres, par un nouveau site web début 2014 et par la création de guides pratiques pour les PAEM et les proches. Une fondation a généreusement contribué un montant substantiel qui facilitera la réalisation de ces projets.
- Développer les principes de gouvernance
- Accroitre le positionnement comme ressource-clé en information sur la maladie

Pour en arriver à atteindre ces objectifs sans trop exiger des PAEM, les membres du conseil d'administration visent à jumeler une PAEM avec une non-PAEM. Un objectif qui est déjà atteint au sein du C.A. et en développement pour la composition des comités.

Au Québec comme ailleurs, les défis sont toujours aussi grands, les ressources humaines et financières toujours aussi minimes, l'énergie souhaitée rarement au rendez-vous. Cependant, la persévérance et la ténacité des personnes qui se succèdent selon leur capacité font et feront la différence pour que les choses avancent.

Source : Rapport annuel de l'AQEM 2012-2013

www.aqem.org **1-855-369-0386**

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Thank You

THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter - Free with annual membership of $30.00

When you become a member of the National ME/FM Action Network, you receive our quarterly newsletter QUEST. We keep you informed about medical research, disability and legal issues, as well as keeping you up-to-date about our many projects. "Quest" includes original articles by doctors, researchers, and lawyers and also covers support matters such as treatment and happenings in other groups.

ME/CFS and FM Brochures - FREE

If you would like to receive our free informative pamphlets on ME/CFS and/or FM, please contact us or you can print copies off our website at www.mefmaction.net.

Consensus Documents for ME/CFS and FM

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols [Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004 ISBN:0-7890-2207 9] and The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4]] can be viewed on our website at www.mefmaction.net and is also available at Amazon.com or at Chapters.ca

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

ME/CFS and FM Overviews - $7.00 each

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

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

ABREGE DU CONSENSUS CANADIEN SUR LE SFC: DEFINITION CLINIQUE ET LIGNES DIRECTRICES A L'INTENTION DES MEDICINES

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

TEACH-ME (Second Edition) - $22.00 - Discount on bulk orders

TEACH-ME (TRADUCTION FRANCAISE): 22 $

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

QUEST COLLECTION: 1993 TO 2003 - $38.00

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

CANADA PENSION PLAN DISABILITY GUIDE - $10.00

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

NATIONAL LAWYERS' ROSTER

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

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

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