NATIONAL ME/FM ACTION NETWORK

Quest
Newsletter

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CIHR Supports ME/FM Research

The Canadian Institutes of Health Research (CIHR) / les Instituts de recherche en santé du Canada (IRSC) is the government agency responsible for funding health research. CIHR includes a number of institutes. Issues around ME/CFS and FM have been assigned to the Institute of Musculoskeletal Health and Arthritis (IMHA) / l'Institut de l'appareil locomoteur et de l'arthrite (IALA). In the Nov/Dec 2016 IMHA/IALA newsletter, IMHA issued a statment of support for research into ME/CFS and Fibromyalgia. We have reproduced the announcement on page 2 of this newsletter. The full newsletter is on the CIHR website at: *http://cihr-irsc.gc.ca/e/50100.html*

We would like to express great appreciation to Dr El-Gabalawy, Scientific Director of IMHA/IALA, and others at CIHR/IRSC for speaking so strongly in support of ME/FM research.

CIHR Announces New ME/CFS Catalyst Grant Competition

In November, CIHR announced a new funding opportunity for ME/CFS. They offered two 1-year grants of up to $100,000 each to support the development of new research projects in the area of ME/CFS. This recognizes that researchers often need seed funding to develop proposals. The closing date for applications is January 10, 2017. The anticipated announcement date is February 28, 2017.

Please remember that when the applications are received, they are sent to a committee which reviews and scores the proposals. In order to receive funding, proposals must receive a passing grade. If no proposal receives a passing grade, no proposal will be funded.

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With regards to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), CIHR – IMHA is committed to supporting high-calibre research that will contribute to the evidence base and develop capacity in this field. ME/CFS is a chronic, complex, multisystem illness. Preliminary research has linked it with disturbances in energy metabolism, immunology, brain and nervous system functioning, cardiovascular functioning, epigenetics, and the microbiome. More research is needed to determine the underlying pathology of ME/CFS, advance understandings of its relationship with overlapping conditions such as Fibromyalgia, and establish effective treatments. An estimated 800,000 Canadians are affected by ME/CFS, Fibromyalgia, or both. The National Institutes of Health(NIH) in the United States and the Stafford Fox Medical Research Foundation in Australia are ramping up investment in biomarker discovery, diagnostic testing, and patient subgrouping for ME/CFS. You will see in this newsletter that CIHR-IMHA recently launched a series of Catalyst Grants, with two dedicated to ME/CFS. These grants are intended to serve as seed money to support research activities that represent a first step towards the pursuit of more comprehensive funding opportunities. We are also seeking to engage in partnerships with other funding agencies to advance the ME/CFS research agenda. This is a fascinating area of research in which investigators from many disciplines have the potential to make groundbreaking contributions.

L’IALA des IRSC est soucieux de soutenir la recherche de haut calibre sur l’EM/SFC, qui contribuera à l’acquisition de données probantes et au développement des capacités dans ce secteur. L’EM/SFC est une maladie multisystémique complexe et chronique. La recherche préliminaire a permis d’établir un lien entre cette maladie et une perturbation du métabolisme énergétique, l’immunologie, le fonctionnement du cerveau et du système nerveux, le fonctionnement cardiovasculaire, l’épigénétique et le microbiome. Il est nécessaire de pousser plus loin la recherche afin de déterminer la pathologie sous-jacente à l’EM/SFC, de mieux comprendre son lien avec des affections concomitantes comme la fibromyalgie, et d’instaurer des traitements efficaces. On estime qu’environ 800 000 Canadiens souffrent de l’EM/SFC, de fibromyalgie, ou des deux affections. Les National Institutes of Health(NIH) des États-Unis et la Stafford Fox Medical Research Foundation de l’Australie ont l’intention d’accroître leurs investissements dans la recherche de biomarqueurs, les tests diagnostiques et le sous-groupement de patients en ce qui touche l’EM/SFC. Comme en fait foi le présent bulletin, l’IALA des IRSC a récemment lancé une série de subventions Catalyseur, dont deux réservés à l’EM/SFC. Ces subventions se veulent des fonds de démarrage pouvant soutenir des activités de recherche qui constituent une première étape vers des possibilités de financement plus élaborées. Nous souhaitons établir des partenariats avec d’autres organismes de financement dans le but de faire progresser la recherche sur l’EM/SFC. Il s’agit d’un domaine fascinant donnant à des chercheurs de diverses disciplines la possibilité d’apporter leur audacieuse contribution.

CIHR Looks for Review Committee Members

A major lesson that everybody learned from the previous CIHR catalyst grant competition is the importance of having good people on the committee that reviews ME/CFS and FM applications - people that are familiar with ME/FM theory, the state of ME/FM research, and the needs of the ME/FM community.

CIHR asked the National ME/FM Action Network: “If you know of anyone who would be interested in reviewing for this particular competition, feel free to send me their names. The competition team will be in touch with the ones they feel have the required matching expertize to review the applications that come in to provide them with more information about the timing of the reviews and when they anticipate the committee meeting to happen etc.”

There are people we would obviously suggest as reviewers – people on the previous grant application, people at the IACFS/ME conference in October, etc. We were especially looking for people that were not so obvious. We sent around a bulletin and, to our delight, several very qualified community members stepped forward. We have passed names onto CIHR.

At the IACFS/ME conference, Dr Lenny Jason gave a very interesting talk about how his application for a grant to conduct a survey of the Chicago population to estimate the prevalence of CFS was turned down several times before it was finally accepted. He talked about how the team learned from the comments of the various review committees. The grant was eventually approved and the study was an important success. This illustrates that review committees have an important role not only in allocating funds but in guiding the development of research.

Let us be fair to the reviewers who will be reviewing the applications for these catalyst grants. Their job is not to approve all the applications, as much as we want funding. What we ask is that they review the merits of the proposals put before them in a fair and knowledgeable way and provide constructive comments. This will help good research to evolve.

IACFS/ME Conference

Participant feedback from the IACFS/ME Conference

The IACFS/ME Conference was extremely interesting and inspirational. Groundbreaking science is happening on ME/CFS and a special dynamic is evident in the field – borne out by researchers, clinicians, and patients and their families pulling together to build momentum despite the stigma that has long surrounded the illness. I was particularly impressed by the presentations on mitochondrial dysfunction, immunology, Rituximab, and the microbiome. I was also moved to see how many patients and families participated, and what it took for them to be there. As a Project Officer at CIHR Institute of Musculoskeletal Health and Arthritis, I paid close attention to the challenges raised with respect to securing funding, building research and clinical capacity, and advancing the field. I thank everyone who shared their perspectives with me. I have since been working with staff at CIHR in Ottawa and the National ME/FM Action Network to advance strategic research planning and capacity building around ME/CFS. We will also be discussing these issues in the context of Fibromyalgia.

Nicole Mardis

I attended my first conference this year and it was a very demanding and difficult experience. The conference organizers definitely did not consider patients needs or disabilities and I returned home exhausted and unable to function for many weeks, yet no experience has provided me with more hope or inspiration since the day I was diagnosed. Three days of non-stop reports on research taking place around the world was an amazing sight to behold and be a part of. Hundreds of people trying to figure out what is wrong with us and how to help us was emotionally moving to the core.

I have learned during my 20 year battle with ME that some very good and wondrous things can come from our suffering. And this conference is one of them. Researchers sharing information world wide, learning from each others mistakes and accomplishments. I am so inspired to do what I can to help them. Whether it be donating a few dollars or singing a song, participating as a Board Member on a local ME Society Board, or helping promote awareness on ME Awareness Day. Sometimes even a few minutes can make a difference and most days that's all I have.

Judy-Anne
Treasurer, ME Society of Edmonton

I'm new to the ME/CFS community. I didn't know it existed! My efforts to find you all on the web turned up a couple of defunct websites so I stopped looking. I've been assured by doctors in the family that if there was credible research that turned up biological causes and treatment of CFS, Canada would have implemented it into the medical protocol. I was assured I was wasting my time at the conference but it was nice I'd go to Florida to rest.

Imagine my surprise when I discovered the calibre of clinicians and scientists at the conference, all conducting highly credible research. I learned from a presentation by Dr. Rowe of John Hopkins University that neuralmuscular strain can cause ME/CFS symptoms to flare up to 24 hours after the strain. Hmm. Maybe that's why my foot injury hasn't healed for 3 years - overstretching. I learned about upper spinal cord inflamation from Dr. Perrin's presentation. Maybe that's why my upper back is sore after I breathe in chemical cleaners. I also learned about acidosis and histamines, which explained the science behind anti-histamines and made me think of taking an anti-histamine when I got a migraine at home after the conference. The anti-histamine worked. And yet we are supposed to get all this information from psychiatrists, according to the US and Canadian governments. Please, someone tell the psychiatrists so they can tell us and earn their funding. What other disease has a rehabilitation program run by psychiatrists? Certainly not heart disease, and not even Alzheimers. A 2015 Globe and Mail article said that psychiatrists are so hard to get that suicidal teens are being sent home from hospital with no follow-up. The Globe called for a national mental health care strategy to help fill a $50 billion need. Maybe mental health patients should claim they have ME/CFS. We seem to have psychiatrists to spare indeed.

Best,
Laura

Margaret Parlor, Laura, and Eve from Norway

I was so thankful for the opportunity to attend this conference, as I have been dealing with this ME/CFS for the past 1.5 years, guided only by books and the Health Rising website!

It was a wonderful opportunity to understand a little better the various organizations and how they assist patients, learn of the newest research as well as the response to it, and most importantly, to meet and discuss with others how they are coping. Seeing our ME/CFS community united and supporting one another, whether patient, doctor, researcher, or advocate, was nourishing to my soul!

Although much exciting research was reviewed, I'd love to see a greater number of patient-oriented sessions, coping strategies, nutritional support, caregiver health strategies, etc, which would be of great benefit to those of us who have little support with this disease. I think this would be a greater draw to those who just want to know how to live with ME/CFS.

It would be wonderful if we could have this conference more frequently and have more people attend - it was wonderful to have the freedom to leave for rest breaks and the quiet room provided was very thoughtful!

All in all, I believe everyone impacted by this disease would benefit from attending as there is always something new to learn whether in a session, or simply from talking with other attendees! It isn't often that one is surrounded by a group who "speaks your language" and truly understands what this disease is like. Everyone looked out for one another asking "how are you doing?" and "did you rest?" to people they just met!

Hope to see you at the next one!

Erin

Talking to your doctor

Dr. Lily Chu, a clinician with ME/CFS, gave a presentation at the IACFS/ME conference on ways to ensure effective and efficient medical appointments. The advice was in three categories – before, during and after the appointment. The following article is based on her notes.

Before the appointment, take time to think about

What is the purpose of the visit For example:

- regular on-going visit;
- special visit to make the doctor aware of a new problem;
- visit to fill out a form (if so, take 3 copies of the form, one with suggested answers, one for drafting answers, and one for the final copy);
- specialist visit to deal with a specific symptom.

What do you hope to achieve – what are your questions and concerns

How familiar is the doctor with ME/CFS and how familiar the doctor is with you.

Do you have new symptoms, how are the chronic ongoing symptoms doing, and how are the symptoms affecting your life

Would it be helpful to take documentation to the appointment such as

- medication you are talking and how it is working
- tests you have taken
- any special material you would like to draw to the doctor's attention

Consider letting the office know about your questions and priorities before the appointment.

At the appointment,

Make sure you know how long the appointment is scheduled.

Let the doctor know what you would like to accomplish. Perhaps the doctor has different priorities so make sure the two of you are on the same page.

To ensure you will remember what was said, take notes, bring a friend, or ask the doctor if you can record the meeting.

At the conclusion, make sure you know what was agreed to and what are the next step. Make sure you know how to contact the doctor if questions or problems arise.

After the appointment

Write a summary of the visit and keep a record

Follow up on any tests or treatments.

Get back to the doctor if you have any questions or issues.

Further resources recommended by Dr Chu:

https://newsinhealth.nih.gov/issue/Jun2015/Feature2

https://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/index.html

Here are 10 questions you can ask your doctor (taken from the second website):

1. What is the test for?
2. How many times have you done this procedure?
3. When will I get the results?
4. Why do I need this treatment?
5. Are there any alternatives?
6. What are the possible complications?
7. Which hospital is best for my needs?
8. How do you spell the name of that drug?
9. Are there any side effects?
10. Will this medicine interact with medicines that I'm already taking?

Opioids

Dr Jared Younger gave a presentation at the IACFS/ME conference on opioid use. Here some hightlights based on my hand written notes.

Pain can be very debilitating and doctors have an obligation to address pain.

Opioids (examples Percocet, OxyContin, morphine) work by docking on opioid receptors

Side effects of opioids can include constipation, dizziness, nausea, sedation, memory problems, sexual dysfunction, and dry mouth

Withdrawal symptoms can include shaking and anxiety

Chronic use can lead to respiratory depression, overdose death, abuse, addicion and hyperalgesia.

In 1999, the US called pain the "fifth vital sign"; doctors then felt obliged to ask about and treat it.

US deaths from prescription opioids jumped from about 6k in 2001 to about 20k in 2014

In 2016, the FDA added warnings to packaging

In 2016, the CDC published recommendations for doctors, recommending opioids as a last resort; doctors should try other therapies first and if using opioids - set a plan, start low go slow, and follow up frequently.

The problem is that people become tolerant to pain relief, but not to side effects.

7-8% become addicted – affecting family and work

The body has a dopamine neuron firing system. 30 fires per second and you feel great. 1 fire per second and you feel low. Opioids make the system fire faster than it should. But over time the system slows down to compensate, so you need more and more opioids to get the same effect.

There are a few people who can handle opioids long term

But generally it is best to come off opioids, using a tapering protocol

Unfortunately, doctors have few tools to manage pain

There is a rush to create new treatments – possibly a Nobel prize for solving pain.

In the meantime, some drugs can help, try to identify triggers, etc.

Not a good situation!

My Parking Spot Was Far Away

by Gail McIndoe

Last spring I moved to a large apartment building in Brampton. A few months before I moved in, I met with the leasing agent and told her that I needed a handicapped parking spot close to the door of the underground garage because I have mobility and chronic pain issues and usually use a walker. She assured me that she tried to keep a few spots "open" for tenants like me. I was thankful that I would have parking close by.

But it didn't happen when I moved into the building on June 1st.

The office manager stated that she had no spots close to the door and I was given a spot 147 paces away. Back and forth I went each day with my walker. The extensive walking made me extremely tired for a lot of the day and evening. I also sprained my left ankle. My right knee became extremely swollen and painful. The increased pain kept me up at night despite taking my regular pain medications.

I kept going back to the office politely requesting a closer parking spot to the door in the underground. Repeatedly I was told by the office manager that "I have nothing". I was asked to wait until the next month to see if a closer spot would come up with "someone moving out".

Luckily, I found out about the Centre for Equality Rights in Accommodation (CERA). Their website (*www.equalityrights.org)* states: "The Centre for Equality Rights in Accommodation (CERA) is a not-for-profit charitable organization dedicated to preventing evictions and ending housing discrimination across Ontario. CERA was founded in 1987 as the only organization in Canada with a primary focus on promoting human rights in housing."

I worked with their 3rd year summer law student, Madison. She told me that it was the law that my landlord provide me with a parking spot closer to the door. Madison also stated that it was not up to me to solve their problem.

I was eventually told by the head office of this landlord that I needed to contact the Property Manager of this building. I then emailed the Property Manager and stated that my health had suffered quite a bit with all of the walking each day to the parking spot that I had been assigned.

A few days later, I received an email from the office manager stating that she had a tandem spot here for me much closer to the door. A tandem spot is a long spot where two cars from one apartment in the building can park one behind the other. She emphatically stated that "It was $120" because it was a tandem spot for two cars. The charge for single spots was $75 per month. I told her that I was not paying $120.

I again contacted Madison at CERA and she stated that the parking spot should still be $75 as this was an accommodation by the landlord for my disability. Madison also mentioned that it is up to the landlord to pay for the accommodation of my disability (in this situation), not the tenant's responsibility to pay the extra cost of the tandem spot. I emailed the Property Manager once again and she agreed to honour the $75 parking charge.

All of the help that I received from the excellent staff at CERA was absolutely free.

If you or anyone else you know in Ontario that has trouble with their landlord accommodating their disabilities, please consider contacting CERA for help. I called and emailed the staff at CERA countless times and each time I was treated in a courteous manner. My many questions were answered politely and accurately by all of the staff there.

I highly recommend this organization and feel extremely fortunate and thankful that they helped me out getting a parking spot here closer to the door in the underground garage.

CERA can be reached at 416 944-0087 or toll free outside of Toronto at 1 800 263-1139.

Adjudicating Disability Cases

In the 1760's, the English jurist William Blackstone wrote that "It is better that ten guilty persons escape than that one innocent suffer".

When it comes to qualifying for disability benefits, applicants might argue that it is better to let ten undeserving applicants qualify than to let one deserving applicant be turned down. In contrast, disability providers might argue that it is better to let ten deserving applicants be turned down than to let one undeserving applicant qualify.

The CPP-Disability program was reviewed in 2011. The reviewers did not exactly say that too many people were being turned down, but they came as close as possible, stating that "Evaluation evidence, such as the high number of denied applicants who never work after denial, and the substantial efforts that go into the reconsideration and appeals process, suggests that the determination of CPPD eligibility is an area that warrants further analysis."

http://www.esdc.gc.ca/eng/publications/evaluations/income/2011/january.shtml

This fall, the Auditor-General of Alberta released a report on Alberta's disability program "AISH". The audit found that "The AISH application process favours people who are good at completing forms and are persistent. Assessing eligibility takes too long, and the department cannot be sure its staff's decisions are consistent." The Auditor-General noted that the audit was important because "When someone has a disability that limits their ability to work, they need income to meet their basic needs. If the department does not have systems to ensure AISH workers consider applications in a consistently and timely manner, there is a risk that the people who need support do not receive it, or receive it too late."

John Wodak ties a number of issues together in the following article. An edited version of this article was published in the Edmonton Journal on November 19, 2016. John is a long-time advocate for people applying for disability supports, a co-author of our CPP-Disability Guide, and an advisor to the National ME/FM Action Network.

WHAT IS WRONG WITH THE AISH INTAKE?

by John Wodak

The latest report from the Alberta Auditor General includes a brief statistical summary of the Assured Income for the Severely Handicapped (AISH) program: fifty percent of all applicants are denied; and more than half (53%) of denied applicants either appeal or submit additional medical evidence, of whom 42% are subsequently approved for AISH benefits. Auditor General Merwan Saher concluded, rightly, that these numbers are not acceptable; the proportions of appeals and successful appeals are too high. However, these numbers will not surprise anyone who is familiar with disability benefits – these programs are extraordinarily difficult to access. Last year the federal Auditor General had similar criticisms of the disability component of the Canada Pension Plan. The A G's report makes several good recommendations but does not address the fundamental question: why are the numbers of denials and appeals so high? We need to answer this question before we can correct the program's problems.

Typically, "being disabled" is equated to "being unable to hold a full-time job". Determining whether someone is (or is not) disabled is not an exact science. It always requires the decision-maker to make a judgement call. Therefore, the best we can hope for is that the judgement call minimizes the numbers of ineligible applicants who are approved (false positives) and the eligible applicants who are denied (false negatives). In practice, it seems that the AISH decision-makers (and, federally, the CPP decision-makers) are far more concerned with minimizing the false positives (although these numbers are – as far as I know – never reported) than with the possibility that an eligible applicant will be denied. We need to understand how this happens.

As the Auditor General notes, almost all the AISH denials occur at the medical eligibility stage of the intake process. Applicants are assessed against three key criteria: do you have a medical condition; does this condition cause a "substantial limitation in [your] ability to earn a livelihood"; and is there "[probably] no remedial therapy that would materially improve [your] ability to earn a livelihood"? A typical reason for denying an application is failure to meet one or both of the second and third criteria.

What information do the AISH staff use in making their determinations? In theory, they should use all the information in the application, otherwise there would be no reason to ask for it. In practice, based on reviews of the denial letters, the AISH staff rely almost exclusively on the medical report. More precisely, it appears that they rely most heavily on only two sections of the medical report.

In the first of the two sections, the physician is asked to estimate the degree to which the applicant's activities of daily living are affected, by checking one of five boxes ("none", "mild" "moderate", "severe" or "unknown"). For approval, the only acceptable answer is "severe". There are two problems with this: first, the physician has (most probably) not observed the relevant activities (or lack thereof), so the opinion is based on hearsay; and second, the correlation between activities of daily living and ability to work is not exact. The CNIB is currently running a campaign highlighting the employability of blind people, and no one is likely to forget Steven Fletcher, the quadriplegic M.P. Curiously, the form does not ask the physician for an opinion on employability, although a statement that the applicant **can** work is invariably accepted.

The other important section of the medical report deals with the duration and treatment of the medical condition(s). The physician is presented with a set of four boxes for prognosis ("permanent", "temporary", "indefinite" or "episodic"), of which "permanent" is most likely to secure approval. And any suggested treatment is liable to be taken as a remedial therapy which will enable the applicant to go back to work. The Auditor General's report referred to inconsistencies in the review of applications. An example of this is that applicants with the same diagnosis can be approved or told there is a remedial therapy for their condition, apparently at random.

Finally, some suggestions for improving AISH, in addition to the Auditor General's recommendations:

- Conduct a follow-up survey of a statistically significant sample of denied applicants. This will help to define the size of the problem (if one exists), and whether it is related to the "substantial limitation" requirement, the "remedial therapy" criterion, or both.
- Develop a list of the most common diagnoses of current AISH beneficiaries. It should be a given that applicants with these conditions already satisfy the "no remedial therapy" criterion and can be approved if they satisfy the "substantial limitation" requirement.
- Reinstate the intake interview (this step was discontinued in 2012, presumably as a cost-saving measure). Human resources specialists tell us they can learn more in five minutes of face-to-face time than from any quantity of paperwork.
- Create incentives for employers to provide accommodations for AISH beneficiaries.

Alberta can, and should, do better to meet the needs of its residents who are severely handicapped.

#MillionsMissing Canada - Toronto Event, October 6, 2016

Staying in the Workforce With Fibromyalgia

by Dr. Margaret Oldfield

Remaining employed with fibromyalgia can be difficult in the increasingly precarious world of work, where jobs are being cut, people laid off and those left behind have bigger workloads. On top of that, employees are often expected to be healthy and able to consistently meet their job demands.

Fibromyalgia also lacks medical legitimacy, an attitude that seeps into social relationships at work. Telling people at work that you have FM can bring a risk of damaged relationships and workplace discrimination, ranging from not being believed to potentially losing one's job. For women, the majority of people with FM, family responsibilities at home may also affect their ability to remain employed. Yet, despite varying degrees of pain, fatigue, and other health issues, 44% of Canadians with fibromyalgia remain in the workforce.

In her PhD thesis research, Dr. Oldfield aimed to understand how, given the challenges of remaining employed, women with FM stay at work. The thesis research had two parts. In the first study, Dr. Oldfield looked at information materials about FM and found that they generally portray employment as not compatible with fibromyalgia. When they very rarely mention work, employees are seen as responsible for managing their own symptoms so they can stay on the job. The dearth of information about staying at work in FM information materials led to another study.

The second study looked at the perspectives of women with fibromyalgia, their family members and workmates on how the women remained employed. In that study all three groups of participants talked about the stigma against FM. To deal with it, employed women with fibromyalgia improvised 'disclosure dances' that responded to everyday disclosure risks in workplace relationships. Some only told people they trusted, often workmates who understood what it is like to have a chronic illness. Other women with FM gave what they felt were more legitimate causes for their impairments, such as "a bad back". The women with FM, their family members, and workmates portrayed the women as normal, valuable employees who had not 'given in' to their fibromyalgia. These portrayals may have helped the women stay at work by boosting their motivation and confidence in meeting the challenges their impairments posed.

In summary, the study found that participants managed the identities of the women with FM to avoid stigma and reduce the risk of workplace discrimination. They managed the women's identities through two strategies, improvised disclosure dances and positive portrayals. It is clear from the research that social relationships at work play an important role in the ability of women with FM to remain employed.

Want to read more?

Besides the thesis itself (available at: *https://tspace.library.utoronto.ca/bitstream/1807/71587/1/Oldfield_Margaret_A_201511_PhD_thesis.pdf*) several publications and conference presentations came out of the research. If you would like to watch a webinar that Dr. Oldfield gave about the main conclusions of the research on December 1, 2015, go to https://www.iwh.on.ca/plenaries/2015. You can also download the article

"It's not all in my head, the pain I feel is real: How moral judgment marginalizes women with fibromyalgia in Canadian health care" from *https://tspace.library.utoronto.ca/bitstream/1807/35223/1/12.1.Oldfield.pdf*

If you have questions about the research or want more information about it, you can reach Dr. Oldfield at margaret.oldfield@alum.utoronto.ca

Note: Dr Oldfield wrote this article before data were available from the 2014 Canadian Community Health Survey. Here are updated figures.

Canadians aged 18-64 by reported work status, Canadian Community Health Survey 2014

	Total Population	CFS	FM
Had a job – at work last week	71%	32%	39%
Had a job – absent from work last week	6%	11%	8%
Did not have a job last week	20%	35%	31%
Permanently unable to work	3%	23%	23%

The Road to Acceptance

by Dolores Griffin

E. Tolle , author of “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, and I love 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 a 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 several years and only now am I starting to “accept” my new reality. Part of my success in doing so, has been in part due to my spiritual journey. 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 come out the other side healed and able to 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 blessings in my life, especially the gifts that are my husband, 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, 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.

Letter to the Lancet

In 2011, the British medical journal "The Lancet" published results from the PACE trial. The results purportedly showed benefits from Cognitive Behaviour Therapy and Graded Exercise Therapy in the treatment of ME/CFS. The publication came under immediate criticism from the patient community. The story festered, and then gained new life as it was picked up by journalists. In parallel, an access to information request forced the release of raw data in summer 2016. Recalculation shows that CBT and GET did not benefit patients in statistically significant ways. These recalculations have been published, but not in a peer review journal as of yet.

Journalist David Tuller was given an award at the IACFS/ME gala dinner for shining light on this topic. In his acceptance speech, he tore a copy of the PACE publication to shreds while commenting on the worth of the document.

But the publication is still officially on the books and doing harm. This led Lydia to write the following letter to the editor of the journal on behalf of the National ME/FM Action Network.

Sunday, December 18, 2016

Mr.Richard Horton, Editor
The Lancet
125 London Wall
London, EC2Y 5AS UK

Via: Email at Richard.horton@lancet.com

Dear Mr. Horton:

Re: Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. Volume 377, No. 9768 p823-836, 5 March 2011

In Volume 385, No. 9966 p394, 31 January 2015 The Lancet Retracted and Republished the China Peace study as the authors pointed out substantive errors in its findings which needed corrections.

In Volume 351, No. 9103, p637-648, 28 February 1998 entitled Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children authored by Dr AJ Wakefield, FRCS, etal was retracted as the theory was proven wrong regarding what caused autism.

In its Retraction and Republication, The Lancet pointed out that The Committee on Publication Ethics in its guidelines and The Lancet quoted "journal editors should consider issuing a correction if a small portion of an otherwise reliable publication proves to be misleading (especially because of an honest error)".

The Lancet then goes on to say "So what should happen if a large portion is misleading? We believe that if many of the numerical findings in the results section change or the interpretation of the work is altered following a miscalculation or misclassification due to an honest error, republication should be considered. The corrected paper should pass peer review and editorial scrutiny once again and when republished the changes should be made transparent. Retraction and republication is a further example of correcting the scientific literature. In our opinion, it should be considered by journal editors in the interests of readers, research users, and the scientific community."

The Lancet goes on to say "It is important to reiterate that the purpose of retractions is the correction of the scientific literature, if the findings as presented are invalid or unreliable."

This brings us to the subject that we captioned in our reference. A U.K. tribunal through an Access To Information request rejected an appeal by the authors of the subject study not to release the data of their PACE study published in 2011. Not only had the authors failed to release the raw date until forced to, the raw data does not support the evidence published. It leaves the erroneous impression that Chronic Fatigue Syndrome is a mental condition rather than a physical disorder which scientific data clearly indicates.

This is further bolstered by the re-analysis of the evidence by the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services. In its Publication No. 15-E001-EF December 2014 Addendum July 2016 AHRQ states that " Our sensitivity analysis would result in a downgrading of our strength of evidence on several outcomes which can be attributed to the decrease in power, dominance of one large trial, or lack of trials using criteria other than the Oxford (Sharpe, 1991) case definition for inclusion."

Mr. Horton, the National ME/FM Action Network and the ME/CFS community believe that in order to protect those ill as well as the credibility of the scientific and research communities that this PACE study needs to be either retracted or amended and republished so that the misleading information of CBT/GET being a treatment for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome is eliminated. The AHRQ study so aptly pointed out that "Blatantly missing from this body of literature are trials evaluating effectiveness of interventions in the treatment of individuals meeting case definitions for ME or ME/CFS."

We await your reply.
Sincerely,
Lydia E. Neilson, MSM
Founder, Chief Executive Officer
NATIONAL ME/FM ACTION NETWORK

The Movie Unrest will Premiere at Sundance!

Jennifer Brea

(Note: This movie was previously called Canary in a Coal Mine).

I am thrilled and humbled to announce that our documentary film about M.E. will premiere this January at the Sundance Film Festival. This has been a long, incredible, hard fought, life-destroying, friendship-making, world-changing, horrible, wondrous journey. When I began, I had never made a film. I could barely make it down the stairs most days, let alone leave my house. I didn't know how I was going to get here, but I had the belief and conviction that this story deserved and needed to be told. And that in telling it, we could change our lives. It took three years, 2,593 Kickstarter backers, a dozen amazing partners, an incredible, gifted team of filmmakers, but we've done that part. Now, the second part begins.

There are so, so many people to thank. You know who you are and I hold you in my heart every single day. I dedicate this moment and everything extraordinary to the love of my life, Omar.

Read more: *http://www.unrest.film/blog/2016/11/30/feature-documentary-unrest-formerly-known-as-canary-in-a-coalmine-to-receive-its-world-premiere-at-sundance-film-festival-january-2017*

Sundance announcement of premiere lineup: *http://www.sundance.org/blogs/news/competition-and-next-films-announced-for-2017-festival*

Care by First Responders

We know that Canadians with ME/CFS and FM encounter difficulties finding ongoing medical support. We know that people encounter difficulty when they go to hospital emergency departments. Then we talked to Kevin who was poorly treated by paramedics. Lydia went to Facebook and asked readers about their experiences with paramedics. If you have information to share, we would like to hear from you.

A local or Nation-Wide Dilemma?

On Monday night, November 22nd, 2016 Kevin who was diagnosed with Fibromyalgia (FM) was in extreme pain. As he put it "over his maximum pain tolerance level" of 7. He was unable to walk and called his father for help.

The Emergency Services in Ottawa (EMS) had to be called as Kevin's father was unable to assist him to get to his car and hospital.

The paramedics arrived but rather than putting him on a stretcher they advised him that Fibromyalgia is a psychological condition and therefore had no protocol for FM. They kept telling him to push through the pain and forced him to walk the hallway of the apartment complex where he collapsed.

Kevin's pain by then had increased to a 10 and the forcing of activity was now at a stage he collapsed. Through his dad's insistence, they were finally had no choice but to put him on a stretcher.

The National ME/FM Action Network is contacting the City of Otttawa who are responsible for emergency services as well as the EMS and the local politician of Kevin's riding.

We Need YOUR Help

Those who are capable, please contact your local EMS and enquire whether they have a protocol for FM as well as asking if they have one for ME/CFS and what it is.

Please email me the details of the one you contact and helpful information that will assist in our Network following up.

CPP Retirement Benefits to Expand

but less for people on CPP-D or taking time out for childrearing

The federal government and the provinces have agreed to expand CPP retirement benefits in the future. Legislation has already passed the House of Commons.

Amazingly, legislation does not include "the drop-out" provisions that are in the existing CPP retirement program. Drop-out provisions means that the years people spend on CPP-D or on childrearing are not included in the calculation of income. Let's say you spent 10 years working at $40k/year and 10 years on CPP-D with no income. With drop out provisions, your average salary would be $40k (because the CPP-D years are dropped out). With no dropout provisions, your average salary would be $20k (because all 20 years are considered). As the legislation is written now, future CPP retirement benefits would be based on $40k for the base portion and on $20k for the expanded portion, meaning that people on CPP-D or taking time out for child rearing will not get the full benefit of the increase in retirement payments. The House of Commons Committee was told about the problem. They felt they could not recommend changes to the legislation because this is what came out of the federal-provincial discussions. Hopefully, this problem will be fixed before the program is implemented.

Postal Service in Canada

by Council of Canadians with Disabilities

If you don't have home delivery and it is causing you problems, please let us or the Council of Canadians with Disabilities know.

The Standing Committee on Government Operations and Estimates released its report The Way Forward for Canada Post, which contains 45 recommendations for maintaining a universal public service – but not an accessible service. Disappointingly, the Committee only recommended the reinstatement of door-to-door mail delivery in communities that were converted to community mailboxes after August 3, 2015. The Committee's recommendation is unfair to Canadians with disabilities living in communities converted before August 3, 2015, who will continue to face barriers and inconveniences when accessing their mail. Mail is an essential service. Some people with disabilities receive medical supplies and other critical items, such as cheques, through the mail. We are left wondering why a Government that is proposing to create accessibility legislation left the inaccessible community mailbox model in place, for some neighborhoods. The good news is that the report recommends no new neighborhoods will be getting inaccessible community mailboxes.

ENQUÊTE SUR LA SANTÉ DANS LES COLLECTIVITÉS CANADIENNES 2014

OBSERVATIONS RELATIVES À

L'ENCÉPHALOMYÉLITE MYALGIQUE/SYNDROME DE FATIGUE CHRONIQUE
ET À LA
FIBROMYALGIE

The statistics report from the 2014 Canadian Community Health Survey is now available in French on our website: *http://mefmaction.com/docs/CCHS_Stats_2014_Fr.pdf*

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

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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

NATIONAL ME/FM ACTION NETWORK

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