NATIONAL ME/FM ACTION NETWORK

Quest Newsletter

www.mefmaction.com
Quest 99, Summer 2014
mefminfo@mefmaction.com

A very successful May 12th

May 12 Awareness was very successful this year. Old activities were repeated and new activities were added. A big thank you to everyone who participated.

Some very important events from last year were repeated this year.

- Dr. Eleanor Stein (Calgary) help a special information event which was broadcast on the web
- Valerie Free (Calgary) and Judi Day (Fredericton) held their information displays
- Jacqueline Ko (Vancouver) held her second benefit concert
- In Mississauga, Susan Monaco handed out flyers and spread awareness in her community about a new doctor treating FM.
- Lisa Schneiderman, Gordon Broderick and Margaret Parlor gave a presentation to health public servants this year, similar to the presentation they gave to parliamentarians last year.
- Niagara Falls was lighted blue, purple and green.

MEAO (Ontario) had planned an event at the Legislature in Queen's Park, but that had to be cancelled when the Ontario Provincial election was called.

A special mention goes to the May 12th committee, led by Alison Rae, who took us in new directions:

- the international Light up the Night contest was introduced (Northern Ireland lit up the most public buildings, while Canada lit up the most private homes!)
- information letters were sent to all federal and provincial elected officials across Canada
- individuals were provided with a letter that they could send to their elected officials and a number of individuals did so.
- a media release was issued

Thanks to an anonymous member who donated copies of the following documents to the Okanagan Regional Library System.

- Dr. Ellie Stein's manual "Let your Light Shine Through";
- Dr. Bruce Carruthers and Marjorie van de Sande's Overviews of the Canadian Consensus Documents for ME/CFS and FMS,
- the "Teach-ME Source Book for Teachers of Young People With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and/or Fibromyalgia", and
- the "International Association for Chronic Fatigue Syndrome Primer for Physicians".

These documents can be borrowed by Okanagan library users but, because the ORL is part of an inter-library system, they can be borrowed by any library user in BC.

Ottawa City Hall Heritage Building, May 12th 2014

Contents

Share the Bounty Contest

NATURE'S BOUNTY®
Be Your Healthy Best™

The National ME/FM Action Network was very delighted to be awarded $10,000 in the on-line contest sponsored by Nature's Bounty, a company that produces vitamins. Their products can be purchased at many retail stores across Canada.

We are often asked what we do with our money.

A large part goes to producing and providing information. The Network maintains a website and Facebook page. We publish important products like brochures, Quest newsletters, the CPP-Disability Guide and the Teach-ME Sourcebook. We have had material translated into French which is very important in having ME/CFS and FM officially accepted at the national level. We also respond to phone and email enquires.

We use some resources to attend conferences and meetings such as the International Association meeting in March and an Ontario conference for public health and community health centre officials in June. We select conferences strategically, work to increase our profile and to bring back useful information and connections. We find ways to keep our expenses low.

Recently, we have been funding medical students through the Dr. Alison Bested Scholarship Fund. This fund provides financial support to students who are in medical schools as they learn about ME/CFS, FM and MCS. We believe that this is a tremendous investment in the future – the students go back to their schools and then on into the medical profession with good information and attitudes.

People ask if the Network funds research. At the present time, we do not have the spare funds, but if people would like to provide funding, we could build a research program. In the meantime, we are encouraging the Canadian Institutes of Health Research, the federal government's funding agency, to take a greater interest in ME/CFS and FM.

Our May 12, 2014 Summary from Calgary

My daughter, Jenna, and I had our third annual May 12th International Awareness Event in Calgary at Planet Organic south. It is interesting every year but this year, I could see more curiosity growing in the people who came by our table. Thankfully, I had many left-over packets and brochures from last year to offer, because I was not feeling as strong as some of the other years to prepare, due to the brutal weather fluctuations here in Calgary and illness severity. Thanks to Jenna, we did make it happen.

Every year, it is becoming easier for me to present what is relevant because I realize how most people want small amounts of new information and yet it still seems effective at building awareness for ME, FM and MCS. May is Lyme Awareness month as well so I was ready with info should anyone ask.

Luckily for me, I also have celiac disease and it is Celiac Awareness month in May. That is the main attraction at our presentation table because so many people are struggling with this autoimmune disease or at least sensitivity or allergy to gluten and/or many other foods.

Planet Organic kindly offered some gluten-free treats for people to try at our display...and hopefully it also helped their sales of those items. This definitely was the drawing card for our table.

My friend and fellow patient, Lisa, and her daughter came by to sit with us for a while. We all had T-shirts on as well as ribbons from MEAO and wristbands from Invest in ME, and buttons that said “It’s not ME, it’s M.E.” . We were all decked out....go big or go home I say. (I am sorry we didn’t get a picture of the four of us together but we got busy and forgot)

Although the afternoon started a bit slow with one lady relating ME/CFS to the fatigue of anemia, things got better. By the end of the three hours, many people stopped by: some very interested people who were looking for answers to their own health problems, or looking to help others with theirs, as well as professionals in the health care industry. Some great conversations ensued between the four of us and them.

One of the most powerful bits of conversation I remember is when we were speaking about the ability to work: In a chat with one lady who was curious, I asked my friend Lisa about her ability to work (or not) since she became ill with CFS and FM. She said it had been 19 years; and for me, personally, I have been unable to work for nearly 20 years at a job of any sort. The look on the lady’s face who was listening was astonishment.

The visiting professionals were eager to take the packets on both celiac disease and neuro-immune illness, and said they deal with these every day in their alternative practices and in their personal lives. One young chiropracter was happy to get more information as she was giving a public talk at Planet Organic in the next week and might incorporate some of the new knowledge she picked up.

People are interested, and perplexed, by the amount of information available on diseases they were not aware of - or had misperceptions about - and that is why it is important to make our presence known each year for at least one day.

Everyone, no matter their primary interest, was wowed by the Light up the Night Challenge and we shared pictures with them from the Press Release of the National ME/FM Action Network.

Thank you to Planet Organic and all those who could participate in International Awareness Day May 12, 2014, and also to those who live with these illnesses, whether you can participate or not. Progress is being made and we have felt it even over the last three years.

Chins up, everyone. We are getting there! Next year I hope to have my book published about the ME/CFS and neuro-immune illness community, and that will be another eye opener: a new tool to build awareness which will help us to create the changes we need for care, cure and prevention.

Best, Valerie Free

Dr Alison Bested leaves BC Program

Here is the announcement that we sent around announcing that Dr Bested departure from the BC Complex Chronic Diseases Program. Let's compare it to the Edmonton Oilers losing Wayne Gretzky. Dr Bested is a superstar in the ME/FM world.

The British Columbia Women's Hospital and Health Centre has announced that Dr. Alison Bested is leaving the Complex Chronic Diseases Program (CCDP).

Dr Bested was hired by the Program as its first medical director. She brought with her many years of experience in this difficult and underdeveloped area of medicine. She was a member of the expert panel that developed the Canadian Consensus Criteria for ME/CFS. She was also a member of the expert panel that developed the IACFS/ME Primer. She has been a medical adviser to the National ME/FM Action Network for many years. Prior to joining the CCDP she ran a very busy clinical practice in Toronto Ontario specializing in ME/CFS and FM. Her Ontario patients were sorely disappointed when she left for BC and established a medical student scholarship fund to recognize her work.

The National ME/FM Action Network has heard from a number of patients who are upset by the changes. We consider the departure of Dr Bested to be a serious setback for the Program. We contacted both the Minister of Health and the President of the Hospital urging them to consider the consequences of Dr Bested's departure.

Nothing ever seems to come easily in the ME/FM world. This is another challenge we will have to work through.

Margaret Parlor
President

CPP-D Guide – to be updated

The Network plans to update the CPP-Disability Guide. This will reflect the introduction of the Social Security Tribunal in April 2013 and what we can learn from the US guidelines for ME/CFS which were updated in April 2014. If you have suggestions or comments on the existing Guide, please phone, write or email us.

Unheard Voices: My Story

Update

Dear Friends:

You may recall that after speaking to many people over the years, I thought it would be great if I put everybody's story together and hence the title "Unheard Voices: My Story" was born. Many of us have never spoken about their experiences and how they are who they are today. Some of you have already drafted your story and have entrusted me with it.

I now have the opportunity to devote some time on working on our stories and are therefore contacting those who have already sent their stories to me and as I want to be able to contact them for follow-up, please let me know if you have changed your email address so that I can be in touch with you.

I am looking for more stories from those who would like to share their experiences with others or for no other reason but that they can be heard. For many of us, years have gone by since our lives first changed and a new beginning had to be made. This is the opportunity to let your voices be heard and your thoughts shared.

Let me hear from you and let me know if you wish to participate. This is a story about your lives, your thoughts and feelings. There is no need for full identification, and a first name for publishing on our website is all that is needed. Nothing will be on our website without first being approved by you.

Let me hear from you. You can contact me at: Lydia@mefmaction.com

Sincerely,

Lydia

Lydia E. Neilson, MSM
Founder, Chief Executive Officer

Staying in the Workforce with Invisible, Stigmatized Chronic Illness:

Preliminary Findings of a Study on Fibromyalgia

Margaret A. Oldfield, PhD Candidate
Graduate Dept. of Rehabilitation Science, University of Toronto

For more information on the study, please contact: margaret.oldfield@mail.utoronto.ca

Staying at work with chronic illness can be difficult, particularly when it is invisible and supervisors and co-workers do not believe it is real. Many people with such stigmatized, invisible illnesses are women.[1] To access workplace accommodations, employees with chronic illness must disclose that they have a problem doing their jobs and so, understandably in today's competitive work environments, may be unwilling to reveal their impairments[2] and request accommodations. Even those who do disclose face stigma, and stereotyped labels, once attached, can be extraordinarily sticky.[3]

Disability policy presents these employees with a devil's choice. Because their illnesses produce fluctuating impairments,[4] they may not be totally work disabled and, therefore, may not qualify for disability payments.[5] So they struggle either to work full-time or to convince government and private disability insurers that they are totally disabled, when they often can and want to work. Leaving the workforce often leads to poverty and poorer health.[6]

This ongoing study tackles these problems by examining how people with invisible, stigmatized chronic illnesses stay at work despite obstacles. Literature on work disability generally covers stable, visible disabilities and gives minimal attention to invisible, episodic disabilities. It focuses on barriers to remaining at work, rather than strategies for doing so. Literature on work disability tends not to consider the perspectives of family members. These are particularly relevant for women, because women's home responsibilities often impinge on their time and energy available for work. This impact is magnified when they also contend with a chronic illness.[7-8]

Methods

The methodology, critical discourse analysis, is combined with an approach designed to elicit multiple perspectives: interview triads comprising women with fibromyalgia, their family members, and their work supervisors or co-workers. Supplementary interviews with employer or union representatives not related to the women round out the data set. A total of 26 participants were interviewed: nine women with fibromyalgia, seven family members, six supervisors or co-workers, three employer representatives, and one union representative.

After transcription and coding, data are currently being analyzed through (1) narrative summaries of each triad,[10] comparing three perspectives and (2) summaries of dimensions in the data for each code, comparing four perspectives. Relational diagrams explore relationships between the dimensions in the codes.[11] This data-analysis process generates concepts with which to build an explanatory framework for understanding how women with FM stay at work.

Some preliminary findings

The women with fibromyalgia (FM) had multiple chronic illnesses, and they reported substantial pain, fatigue, and poor sleep. Some of the women described carefully conserving their energy for work by resting and sleeping a lot at home. This did not seem possible, however, for the women with young children. In some families, couples shared housework and/or hired housework help. In other families, the women were primarily responsible for housework, even when they were sole-support mothers with adult children living at home. Women who were primarily responsible for housework and did not have hired housework help struggled to perform these tasks and paid the price: pain flares that led to work absences and lost income.

The analysis shows that the women's impairments affected their work, and their work affected their impairments. The women situated work as integral to their self-esteem and expressed pride in their talents. They described seeking jobs that fit their illnesses and pushing through pain and fatigue to earn an income and get housework done. All said they would rather do their jobs part time, but only two felt they could afford to. They expressed concern that going on permanent disability meant living in poverty; therefore, for them, it did not seem an option.

The women managed their identities by taking pride in the fact that they were still working despite the challenges of fibromyalgia. Some used human rights legislation which calls on employers to accommodate disabilities and not to discriminate. Some women (and their family members) felt it was important not to complain about pain and fatigue. The women described finding empathetic understanding at work from co-workers (and in some cases, supervisors) who had chronic illnesses themselves, knew someone who did, or had supervised others with chronic illness. The women and their family members emphasized the importance of others at work and at home believing they were really ill.

The women described making a myriad of strategic decisions about disclosure, on a continuing basis, to selected people, at selected times, and for selected situations.

The women's strategic-disclosure decisions contrasted with what managers stated as their preference. They generally wanted employees to disclose their needs for formal accommodations (through not their illnesses) as early as possible, and to seek accommodations. Some managers described a concern with the unreliability of some employees with chronic illness and a consequence for work teams: co-workers having to cover for these employees' frequent absences. At other workplaces, co-workers knew some of each other's duties and were used to covering for each other. The managers and the women reported that some co-workers resented accommodations, particularly starting work later than others and, in unionized workplaces, job reassignments.

Women who did not disclose or did not seek formal accommodations described finding other ways to stay at work when their impairments flared. They used benefits available to all employees: sick leave, vacation leave, personal leave, time in lieu of overtime pay, unpaid leave, and flexible work options (work at home and flexible hours), where they were available.

References

1. Doyal, Lesley. (1995). *What makes women sick: Gender and the political economy of health*. London: MacMillan.
2. Gignac, Monique, & Cao, Xingshan. (2009). "Should I tell my employer and coworkers I have arthritis?" A longitudinal examination of self-disclosure in the workplace. *Arthritis & Rheumatism (Arthritis Care & Research), 61*(12), 1753-1761.
3. Vickers, Margaret H. (2012). "For the crime of being different…": Multiple sclerosis, teams, and stigmatisation at work—Lessons from a case study. *Employ Respons Rights Journal, 24*, 177-195.
4. Vick, A. & Lightman, E. (2010). Barriers to employment among women with complex episodic disabilities. *Journal of Disability Policy Studies, 21*(2), 70-80.
5. Lightman, E., Vick, A., Herd, D., & Mitchell, A. (2009). 'Not disabled enough': Episodic disabilities and the Ontario Disability Support Program. *Disability Studies Quarterly, 29*(3). Retrieved June 21, 2011 from www.dsq-sds.org/article/view/932/1108.
6. Wigers, S. H. (1996). Fibromyalgia outcome: The predictive value of symptom duration, physical activity, disability pension, and critical life events – A 4.5 year prospective study. *Journal of Psychsomatic Research, 41*, 235-243.
7. Côté, Daniel, & Coutu, Marie-France. (2010). A critical review of gender issues in understanding prolonged disability related to musculoskeletal pain: How are they relevant to rehabilitation? *Disability and Rehabilitation, 32*(2), 87-102.
8. Crooks, Valorie, Stone, Sharon Dale, & Owen, Michelle. (2009). Multiple sclerosis and academic work: Socio-spatial strategies adopted to maintain employment. *Journal of Occupational Science, 16*(1), 25-31.
9. Statistics Canada. (2010). *Canadian Community Health Survey* [data file, University of Toronto Data Library]. Retrieved November 13, 2011, from University of Toronto Libraries.
10. Mauthner, N., & Doucet, A. (1998). Reflections on a voice-centred relational method: Analysing maternal and domestic voices. In J. Ribbens & K. Edwards, *Feminist dilemmas in qualitative research* (pp. 119-145). Thousand Oaks, CA: Sage.
11. Clarke, A. (2005). Doing situational maps and analysis. In A. Clarke, *Situation analysis: Grounded theory after the postmodern turn* (pp. 63-144). Sage.

Acknowledgments

The author wishes to thank all the participants, without whom there would be no study. This research was funded by a Graduate Award from the Centre for Research on Work Disability and Rehabilitation Science Fellowships from the Faculty of Medicine, University of Toronto.

Is ME/CFS fatal?

Lily Chu M.D.

Dr. Chu is a member of the IACFS/ME Board of Directors. She gave the following statement at the IACFS/ME conference in San Francisco in March 2014.

First, I would like to thank the Primer Authoring Committee for volunteering their time, energy ,and expertise in revising the 2012 Primer. There are many valuable and useful parts to the Primer that I agree with and would like disseminated. However, there is one section that I disagree with strongly and that I cared about enough to withdraw my approval of the Primer when it came before the Board in January. I asked the Board for permission to express my disagreement publicly and they have graciously allowed me this time.

The 2012 Primer does not contain any statements about death but the 2014 Primer states that **"Even if patients get progressively worse, ME itself is not known to be fatal."** I disagree with this statement for four reasons:

1) We do not have evidence to say that ME is not fatal. As far as I know, and please correct me if I am wrong, there are no longitudinal studies involving large ME/CFS populations that address this question. The one study cited in the Primer, by Dedra Buchwald in 2001, had a sample size of only 600 subjects and was not intended to address whether this medical condition could cause deaths.

2) On the other hand, there have been cases, although rare, where death was attributed to ME. For example, in 2005, Sophie Mirza became the first person in the UK to have CFS listed as the cause on her death certificate. During his severely ill talk, Dr. Lapp mentioned Emily Collinridge, who wrote a book on severe ME. What you may not know is she too died of ME at age 31 in 2012. Here in the US, Casey Fero, whose mother has ME/CFS and who became sick with it also at age 9, died at age 23 in 2003. Casey would be 32 in 3 days had he lived.

3) This statement may not have been intended to discount deaths from ME related to co-morbidities and suicides but the way it is written not only dishonors these people's lives but may discourage further scientific investigation. For example, Dr. Knox mentioned the SEER study which found a significantly higher risk of Non-Hodgkin's lymphoma in elderly ME/CFS patients. Given Dr. Jason's 2006 study suggesting ME/CFS subjects may die at an earlier age from cancer than the general population, it would be interesting for those study methods to be replicated in a younger cohort. And you heard yesterday from CFI [Chronic Fatigue Initiative] about the 4-fold increased cancer rates in their subjects.

   Suicides should not be regarded as "second-rate" deaths. Some people may not count them as "ME-related" because of the method of dying or the existence of depression. But in my experience, people with ME who commit suicide, are not necessarily depressed. Many times, like my geriatric medicine patients, they are driven to suicide by unbearable symptoms or exhaustion from the daily struggle to exist.

4) The statement dismisses and downplays the seriousness of ME/CFS. When patients hear about deaths and bring it up to their healthcare providers, those who have read our Primer may be confused about the discrepancy in information. Some providers may conclude that their patients are exaggerating the severity of this illness and may doubt other things they say or bring up.

The IACFS/ME is the only international scientific organization dedicated to ME/CFS. Anything we state should be evidence-based as much as possible. Statements surrounding mortality should be qualified to acknowledge the lack of and the need for more investigation.

Along that vein, I want to suggest to US clinicians that you consider listing ME/CFS, if not as an immediate, than as a possible underlying cause of death on certificates if that is warranted in individual cases. There is also space to list significant co-morbidities. It is also appropriate to use words like "possible" or "probable" when the situation is not clear. Documenting mortality influences issues like research funding and access to health services. The CDC website has multiple resources on how to fill out death certificates.

Finally, I want to mention a survey of deaths in ME/CFS that Dr. Leonard Jason and Billie Moore have recently launched. Please contact either of them if you are interested in participating.

In conclusion, please remove or modify the statement about mortality. Once information gets out, it is hard to correct misconceptions. Thank you for your attention.

[If you know someone with ME/CFS who has died, please go to http://www.njcfsa.org/wp-content/uploads/2014/03/AB081913PSY_Recruitment_flyer.pdf or call Abby Brown at 773-325-1164]

A Cautious View of Naturopaths

Submitted by a Canadian with ME/CFS and FM. The Canadian Association of Naturopathic Doctors was invited to respond to this article and did not reply.

Over my 25 year experience with Myalgic Encephalomyelitis (ME) and my 30 year experience with treatments from naturopathic doctors (ND's) I have come to some understandings regarding the practice of naturopathic medicine and its contrasts with allopathic (mainstream) medicine.

Over the years, I have seen 8 ND's for ME. I never doctor hopped. I saw most of the ND's for a minimum of a year and I saw one for 11 years. I have tried many dozens of therapies, and have spent approximately $200,000 to $300,000 with very little to show for all the effort and cost, except a much, much, much larger mortgage.

The potential for spending huge sums of money on ND treatments with little effect is the reason why I think that dialogue with the ND community about ME and Fibromyalgia (FM) is needed at this time. Perhaps with more knowledge about ME and FM, ND's will be able to be more precise, realistic and sensitive in their treatment approach. If so, treatment length and costs may decrease and patient outcomes may improve.

It is my understanding that ND's receive standardized training for 4 years at accredited ND colleges following an undergraduate degree. I find that ND's are well intentioned and generally knowledgeable about health issues and that they employ an array of what appear to be reasonable approaches to many diseases.

It seems to me that ND's and mainstream medicine ME/FM experts speak very different languages when it comes to understanding and treating ME and FM. To be fair, I find that regular MD's and ME/FM experts speak different languages as well.

It is my understanding that naturopathic doctors do not use the allopathic disease labels. Without a common label, information doesn't flow between the allopathic and naturopathic communities. I find that ND's are not up on the latest research re ME and FM. I have never heard ND's talk about ME as a neurological disease, nor have they told me they think it is a neuro/endocrine/immune system disorder. Instead, ND's have relied on the old standbys of low adrenal function, a sluggish liver, food allergies, heavy metal toxicity, candidiasis etc.

Since ND's appear to eschew a significant amount of mainstream medical teaching regarding treatment of disease, they end up re-inventing the wheel when it comes to treating ME and FM. For example, ND's continually want to treat me for low adrenal function when mainstream medicine studies have already shown that this does not work for ME. In addition, during my personal experience over several years, I have tried many varied, and extensive ND recommended treatments for low adrenal function without success.

It seems to me that ND's do not label diseases at all. If that is the case, then ND's do not view ME and FM as distinct diseases with characteristic symptoms and specific diagnostic criteria. It appears that ND's often oversimplify these complex illnesses, and view overcoming them as a simple task. This serves to trivialize and denigrate what has been, and continues to be a devastating and life changing illness which I have worked exceedingly hard to overcome without success.

One of ND's main approaches is lifestyle modification; diet, exercise etc. Some ND's seem to view much disease as a character failing of the patient, and if the patient would just live a cleaner more holistic life, they would recover. Some MD's view ME and FM as character failings as well, but from the standpoint the patient is lazy, or has psychological problems.

I have been assured by most of the ND's I have seen, that they have a good to excellent cure rate with their ME patients. I don't know if individual ND's or their associations have done any actual follow-up studies on their cure rates for true ME and FM. I would love to meet these ME/FM patients my ND's have said they have cured. Did they really have ME/CFS? Were they diagnosed by a ME/FM expert or did they just self diagnose themselves as having ME/FM? Did they actually have some treatable disease such as hypothyroidism that their mainstream doctor missed but the ND picked up on and, because this hypothyroid person had fatigue, the ND's cure for this person was chalked up as another win against ME/FM?

When, after lengthy time and money have been spent with a naturopath and the patient does not recover, ND's may resort to viewing this failure as the patient's fault and not one of their own. This results in the patient wondering what is wrong with themselves. If the ND has said they have a near perfect cure rate for ME/CFS, and many other illnesses, that patient ends up asking what's wrong with me that I can't recover too? This scenario has been a long standing source of frustration and disappointment for me, and I would imagine others with ME as well.

As a final few words, to be fair, ND's appear to help many people whom mainstream medicine has apparently failed. Indeed they have helped me with some minor improvement. Naturopathic doctors are intelligent people with many years of training, and many means of treatment at their disposal. It would be very helpful for those of us looking for hope and help outside the mainstream medical community if ND's were more knowledgeable about ME and FM, incorporated expert knowledge about these illnesses into their own work with patients, were more realistic about what can be accomplished, and were more sensitive to the challenges that ME and FM patients face.

BC Place lit up Blue and Purple on May 12th, 2014.

To view all of the photos submitted for the international Light up the Night contest, go to the Facebook page for May 12th - International ME/CFS & FM Awareness Day and look for the photo album "Light Up the Night Challenge 2014" https://www.facebook.com/may12th.awareness/photos_albums

Nicole Landry

Dr Alison Bested Scholarship Fund Recipient

Nicole Landry, a medical student from Nova Scotia is the latest recipient of funding from the Dr Alison Bested Scholarship fund.

Nicole had chosen a family medicine elective at the University of Toronto and was placed at the Environmental Health Clinic. “Before this time I knew very little about environmental medicine.”

“I was at the EHC for 4 weeks. I worked Monday - Friday from 9am - 5pm with one of the four physicians. Their schedules vary so I ended up spending one day a week with each and then one day a week in Richmond Hill with Dr. Bray. I would see patients for initial and follow up appointments, and help with the dictations afterward. At the onset of the rotation I was given a ton of material to read to familiarize myself with the conditions (as there is little exposure in medical school). During the rotation I tried to make a package for future students to receive before their start date to enable them to have some understanding of the content before they started.”

“Environmental health issues are not currently addressed in most medical school curriculums. After having spent four weeks at the Environmental Health Clinic at the Women’s College Hospital in Toronto, I feel as if I have been exposed to a totally new way of thinking about health and wellness. The holistic approach to health that I was exposed to by Dr. Riina Bray, Dr. Katherine Kerr, Dr. John Molot, and Dr. Lynn Marshall has changed the way that I view complex medical conditions and the challenges of those that are faced with these illnesses. Being a native of Nova Scotia and a foreign student at the Medical University of the Americas, I am incredibly thankful for this opportunity at the Environmental Health Clinic and would like to extend a heartfelt thank you to all of those that made this possible through their generous donations.”

Ontario Ministry of Health announces 2 new fellowships

The Ontario Ministry of Health has announced that it will fund 2 new fellowships in Environmental Health at the University of Toronto.

The funding will support education on environmentally linked illness like environmental sensitivities, myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia and other chronic, complex disorders.

The province is providing nearly $560,000 to support two new annual fellowships over three years for a total of six new fellowships. They will allow family medicine graduates to complete an extra year of focused training in environmental health, and will help primary care providers like family doctors offer the right care to assess, diagnose and treat environmentally-linked health issues.

The new fellowships will be offered by the University of Toronto’s Department of Family and Community Medicine and the Dalla Lana School of Public Health, in collaboration with physicians at the Environmental Health Clinic at Women’s College Hospital.

Human Rights Settlement Creates Blueprint for Housing Providers.

A woman with Myalgic Encephalomyelitis suffered severe asthma attacks and other health problems as a result of cigarette and drug smoke in her apartment building. Despite repeated complaints to the building manager, little was done and her health deteriorated markedly.

As a result of a very significant settlement negotiated by the Human Rights Legal Support Centre, her former landlord has promised to protect the future rights of thousands of other tenant households in buildings operated by the landlord across the Greater Toronto Area.

In a signed statement, the landlord [Mr. Aykler of Villa Otthon and Aykler Real Estate Inc.] expressed "deep and sincere regret for the significant distress and exacerbation of [Ms. VandenBroek's] medical conditions" and acknowledged that they should have done things very differently, including meeting with her in person and "giving more serious consideration to transferring you to another available unit."

The Centre negotiated an agreement to have the landlord do the following within six months:

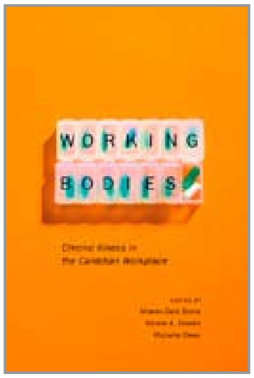
- Develop and implement a disability accommodation policy at all their subsidized buildings, including specific requirements that:
  - the policy provide a procedure to make and to respond to accommodation requests;
  - all communications be timely and respectful;
  - the landlord is required to pursue additional information if necessary to clarify an accommodation request;
  - the decisions of management be communicated in writing, with reasons, if the request is denied in whole or in part.
- Notify all tenants of the new disability accommodation policy;
- Require all managers to take human rights training.
- Make a donation to the Myalgic Encephalomyelitis Association of Ontario.

"This was a serious struggle, and I'm left quite damaged and traumatized by the whole experience.

From my heart though, I'm so thankful that persevering with the truth has caused these significant changes to the way the landlords will respond in the future to tenants with disabilities, be they living in subsidized housing or not. I pray no one will ever have to lose so much of precious life and health, or go through this much affliction to just become safe in their apartment homes again."

Mary-Lou VandenBroeK

Two New Books

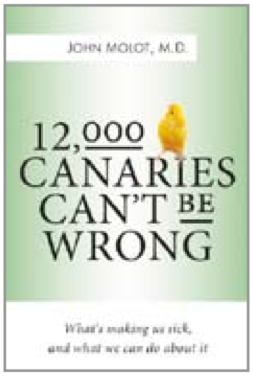


Working Bodies: Chronic Illness in the Canadian Workplace

Edited by Sharon-Dale Stone, Valorie A.
Crooks, Michelle Owen

McGill-Queen's University Press

"This book is dedicated to all Canadians living with chronic illnesses who want to have meaningful employment and engagement in the workplace."



12,000 Canaries Can't be Wrong; What's making us sick, and what we can do about it

by John Molot, M.D.
ECW Press

"This book is a culmination of Dr. Molot's 30 years of experience assessing, treating, and advocating for more than 12,000 patients with environmentally linked illnesses. He explains how the environment contributes to the development and progression of chronic fatigue syndrome, fibromyalgia and other pain disorders, and chemical sensitivity. He also shows how these disorders are just the tip of a giant iceberg, linking environmental conditions to the increasing numbers of cases of common chronic illnesses in adults and even in children."

Private Members Bill

OTTAWA – Elizabeth May's Private Members Bill, C-442, An Act respecting a Federal Framework on Lyme Disease, has passed through 3rd reading with the unanimous consent of the House of Commons. Bill C-442 will now be referred to the Senate, where it will be sponsored by Senator Janis Johnson and taken up in the fall.

3. The Minister must, no later than 12 months after the day on which this Act comes into force, convene a conference with the provincial and territorial ministers and stakeholders, including representatives of the medical community and patients' groups, for the purpose of developing a comprehensive federal framework that includes

(*a*) the establishment of a national medical surveillance program to use data collected by the Agency to properly track incidence rates and the associated economic costs of Lyme disease;

(*b*) the establishment of guidelines regarding the prevention, identification, treatment and management of Lyme disease, and the sharing of best practices throughout Canada; and

(c) the creation and distribution of standardized educational materials related to Lyme disease, for use by any public health care provider within Canada, designed to increase national awareness about the disease and enhance its prevention, identification, treatment and management.

4. The Minister must prepare a report that sets out the federal framework and publish the report on the Agency's website within one year after the federal framework referred to in section 3 is developed.

Project de loi - Lyme

OTTAWA – Le projet de loi d'Elizabeth May sur une Stratégie nationale relative à la maladie de Lyme a été adopté à l'unanimité par la Chambre des communes et est maintenant devant le Sénat.

3. Au plus tard douze mois après la date d'entrée en vigueur de la présente loi, le ministre convoque une conférence avec les ministres provinciaux et territoriaux et des intervenants, notamment des représentants de la communauté médicale et des groupes de patients, dans le but d'élaborer un cadre fédéral global qui prévoit notamment :

a) l'établissement d'un programme national de surveillance médicale qui utilise les données recueillies par l'Agence pour qu'il soit possible de suivre adéquatement l'évolution des taux d'incidence et des coûts économiques liés à la maladie de Lyme;

b) l'établissement de lignes directrices concernant la prévention, l'identification, le traitement et la gestion de la maladie de Lyme, et la mise en commun des meilleures pratiques à l'échelle nationale;

c) la création et la distribution de matériel didactique normalisé portant sur la maladie de Lyme, à l'intention des fournisseurs de soins de santé au Canada, en vue de mieux faire connaître cette maladie à l'échelle nationale et d'en améliorer la prévention, l'identification, le traitement et la gestion.

4. Le ministre établit un rapport énonçant le cadre fédéral et le publie sur le site Web de l'Agence dans l'année suivant l'élaboration du cadre fédéral visé à l'article 3.

Hope

At a recent support group meeting held by the M. E. Society of Edmonton, the theme was "HOPE". Lynn, the moderator, gave attendees a handout with some inspirational messages. We have duplicated some of her messages here.

Definition of Hope:

- Just like ME/CFS, people cannot agree on one definition.
  - *"Hope is the ability to envision a future in which we wish to participate."*

    ~ Denise Larsen, University of Alberta
  - *"Hope is a process of anticipation that involves the interaction of thinking, acting, feeling and relating, and is directed toward a future fulfillment that is personally meaningful."*

    ~ Charlotte Stephenson, 1991

May 12. 2014, Toronto, Ontario

Why is Hope Important?

- It is essential to the quality of our life.
- It has a beneficial effect on your health.
- It is a valuable tool in dealing with life's difficulties.
- Life is difficult without hope.
- Hopelessness sets in without hope and depression with it.

∗ *"Hope is the YES to life"*

~ Ronna Jevne, Professor Emeritus, University of Alberta

Characteristics of Hope

- It is one of those things that you may not pay attention to until it is no longer visible.
- It strength fluctuates with life.
- Hope is unique to each person.
- Each person has specific and non-specific hopes.
- You can have big hopes, medium hopes, small hopes and very teeny, tiny hopes.
- There is no such thing as false hope. There is only false despair.

∗ *"We've been warned against offering the people of this nation false hope. But in the unlikely story that is America, there has never been anything false about hope."*

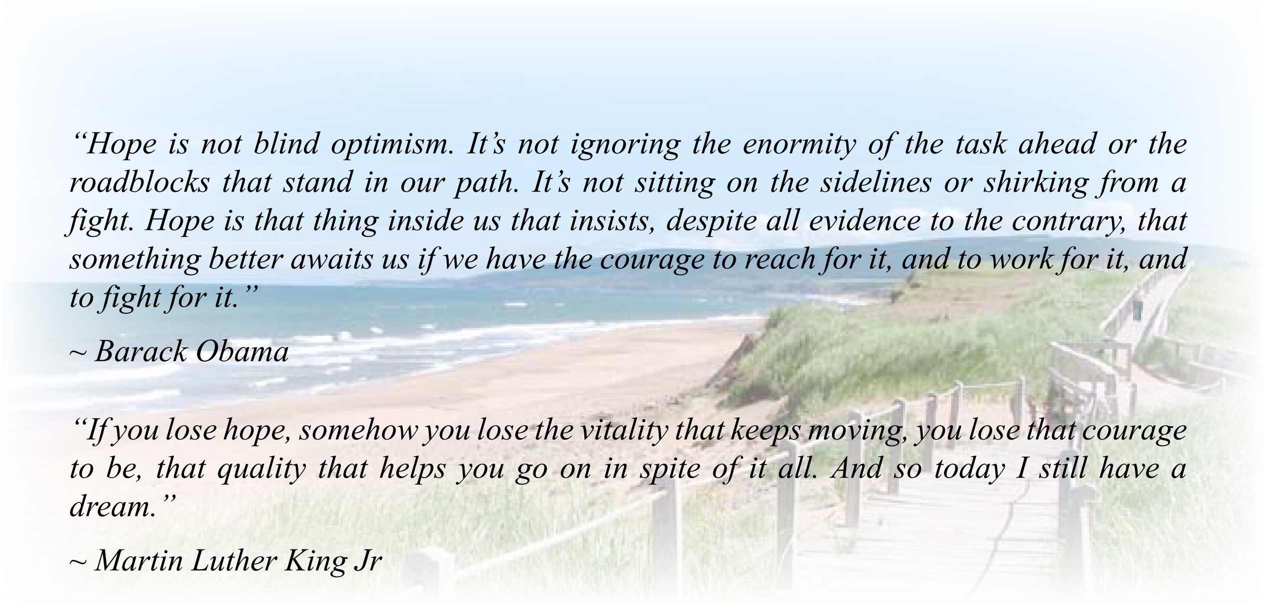
~ Barack Obama

∗ *"Where some see despair, others see hope. Hope then, like beauty, is in the eye of the beholder."*

~ Wendy Edey, Hope Foundation

∗ *"Fear can hold you prisoner. Hope can set you free."*

~ Stephen King (the Shawshank Redemption)



"Hope is not blind optimism. It's not ignoring the enormity of the task ahead or the roadblocks that stand in our path. It's not sitting on the sidelines or shirking from a fight. Hope is that thing inside us that insists, despite all evidence to the contrary, that something better awaits us if we have the courage to reach for it, and to work for it, and to fight for it."

~ Barack Obama

"If you lose hope, somehow you lose the vitality that keeps moving, you lose that courage to be, that quality that helps you go on in spite of it all. And so today I still have a dream."

~ Martin Luther King Jr

http://twitter.com/mefmaction

http://www.facebook.com/MEFMActionNetwork

NATIONAL ME/FM ACTION NETWORK

512-33 Banner Road, Nepean, ON K2H 8V7 Canada
Phone: 613-829-6667 • Fax: 613-829-8518
Email: mefminfo@mefmaction.com • www.mefmaction.com
(BN) 89183 3642 RR0001

Resources

Item	Qty	Total
Membership Fee $30		
ME/CFS Brochure *free*		
FM Brochure *free*		
ME/CFS Overview $7.00		
FM (Eng) Overview $7.00		
FM (Fr) Overview $7.00		
TEACH-ME (Eng) $22		
TEACH-ME (Fr) $22		
QUEST $38 Collection II		
QUEST $38 Collection III		
CPP Guide $10		
SUB TOTAL		

Please transfer the above "sub total" onto the front, to tally in to the total payment being made.

Thank You

THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter – Free with annual membership of $30.00

When you become a member of the National ME/FM Action Network, you receive our quarterly newsletter QUEST. We keep you informed about medical research, disability and legal issues, 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

Coloured pamphlets on ME/CFS and FM are available in English or French. Please specify if you would like copies in French.

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.com

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.com

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
QUEST COLLECTION: 2004 TO 2008 - $38.00

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

NATIONAL
ME/FM
ACTION NETWORK

MEMBERSHIP APPLICATION or RENEWAL FORM

Please see reverse for available network resources.

NEW MEMBERSHIP or RENEWAL fees

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

IN ADDITION, I would like to donate *$ ______________ to help with the many projects of the National ME/FM Action Network.

**Tax Receipt issued for all donations.*

Resources $ ____________

Please see reverse.

TOTAL PAYMENT:

$ ____________________

PAYMENT OPTIONS

☐ Cheque

Please make Cheque Payable to the:

NATIONAL ME/FM ACTION NETWORK

☐ VISA

☐ MasterCard

☐ Other ______________

Card Number:

____

Expiry Date:

month _____ year _______

Name on card:

____

Signature:

____

Date:

____

Name / Organization

____

Contact Name

____

Address

____

City • Province/State • Postal Code/ZIP

____

Phone

____

Facsimile

____

Email

____

Website:

____

MAIL FORM & PAYMENT TO:

NATIONAL ME/FM ACTION NETWORK
512-33 Banner Road
Nepean, ON K2H 8V7

THANK YOU FOR YOUR SUPPORT!

*CREDIT CARD TRANSACTIONS CAN BE FAXED TO: **613-829-8518***