NATIONAL ME/FM ACTION NETWORK
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Quest Newsletter

www.mefmaction.com Quest # 95, Summer 2013 mefminfo@mefmaction.com

On the evening of May 12, Niagara Falls was illuminated in blue to recognize ME/CFS, purple to recognize FM and green to recognize MCS.

We had a some very exciting events around Awareness Day from one end of the country to the other. This included a benefit concert in Vancouver that raised funds for the new BC Clinic, the information session held in Calgary but watched right across the web, the lighting of Niagara Falls, the information breakfast on Parliament Hill, and the presentation to Fredericton City Council by our intrepid director Judi Day. Judi wore three thematic T-shirts on top of each other and displayed them one by one. There were other individual and group efforts, and all are appreciated.

Another excitement was receiving not one but two donations as a result of on-line contests. We would like to thank Nature's Bounty and FedEx for the funding. We would like to thank our supporters for entering us and voting for us. We have asked our Facebook users for advice on how to use the money. Education, awareness-raising and research are major themes.

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NATURE'S BOUNTY

Nature's Bounty Donation

Nature's Bounty is a vitamin and nutritional supplement company.

Nature's Bounty held a contest to make $50k available to Canadian charities with prizes based on the number of on-line votes the various charities received. The charity with the most votes would get $20k, second place $10k and third place $5k. In addition, there would be three random $5k prizes. The National ME/FM Action Network was enrolled in the contest.

We were so pleased with the amount of support we received, nearing a thousand votes a day during the contest. However, when the contest closed, we finished in fourth place, just out of the money. Nature's Bounty held its random draw, and the Network was not chosen.

Nature's Bounty then did something that was very generous and very wonderful. They gave the Network a donation of $5k to recognize the work of our organization and the support we had received.

A big thank you to Nature's Bounty! Their gesture was greatly appreciated.

Fedex Donation

Ottawa, ON (L-R) - Greg Carter of FedEx Express Canada presents a cheque for $4,040 to Margaret Parlor and Lydia Neilson of the National ME/FM Action Network, the winning organization in our FedEx 40th Anniversary Canadian Charity Giveaway.

Marginalizing Women with Fibromyalgia

An article has been published in the peer-reviewed journal, Women's Health and Urban Life. The author is Margaret Oldfield and the article is entitled “It’s not all in my head. The pain I feel is real”: How Moral Judgment Marginalizes Women with Fibromyalgia in Canadian Health Care.

According to the author, moral judgment can take the following forms:

- disbelief of women's pain reports,
- blaming women with FM for adding to their pain by catastrophizing,
- dismissing new symptoms by assuming that they are related to FM,
- accusing women of not wanting to get better, and
- seeing them as a frustrating waste of time.

You can read the article here:
http://www.utsc.utoronto.ca/~womenshealth/womenshealth/Blog/Entries/2013/5/1_Vol_12,_Issue_1,_2013__Contents.html

An article has been published in the Canadian Medical Association Journal (CMAJ). The lead author is Dr Mary-Ann Fitzcharles and the article is entitled “Fibromyalgia; evolving concepts over the past 2 decades”. It builds on the 2012 Canadian Fibromyalgia Guidelines. Concerns about these guidelines have been discussed in Quest 92 and Quest 94.

What stands out in the CMAJ article are comments like:

- patient reports of functional impairment...require critical assessment with the concern that this diagnosis may be given too freely
- the current practice of extensive investigations should be curtailed
- treatment failure is associated with passivity, uncontrolled mood disorder, catastrophizing and secondary gain
- In that symptoms of fibromyalgia are entirely subjective, they can be faked for dishonest reasons.

These certainly sound like the types of moral judgments that Ms Oldfield discusses in her article.

The Fibromyalgia Society of Edmonton and Area

The Fibromyalgia Society of Edmonton and Area is a Registered Society in Alberta. It began as a small support group thirty-two years ago and is a totally volunteer-led, not for profit organization. Today we have a membership of approximately 100 women, men and youth with Fibromyalgia, people of all ages and backgrounds, and their "support people", plus medical professionals. We serve many more people and a wide area in Alberta.

We offer:

- Monthly General Meetings (open to everyone) with Guest Speakers on topics of interest to our members, "Share and Care" meetings and "Round Table" discussions of current changes in health care.
- Small, less formal support groups for members – "Circle of Friends" for women and the "Men's Group" and a "Young Adults Group" – which meet monthly at members' homes.
- Monthly Newsletter "TOGETHER" mailed to all our members.
- Educational Workshops "Fibromyalgia: Living Daily With A Chronic Illness", "Transitions: Coping with Losses and Changes in Our Lives", "Grieving for Health and Healing", and other educational and networking sessions and resources.
- A Library, Resource Table, educational pamphlets and booklets are also available.
- A support network through the "Keeping in Touch" Committee and John Wodak, our Volunteer Advocate, our FM Society phone line 780-988-4575, email:fmsocietyedmontonarea@yahoo.ca and website: www.fibrosocietyedmonton.ca and networking with other groups.
- Public Awareness and Fundraising events in Edmonton and Sherwood Park, especially highlighting "International Fibromyalgia Awareness" in May, with Mayors' Proclamations and a major annual Fibromyalgia Fair and Fun(d) Raiser", this year on Saturday, May 4th in Sherwood Park.

Submitted by Chris Swaren, President and Newsletter Coordinator.

Opera Mariposa

For more information, please visit
OPERAMARIPOSA.COM

The Singer
A benefit concert for
the BC Women's Hospital Foundation

May 12th, 2013, 7:30 pm
Marpole United Church
1296 W. 67th Ave, Vancouver

Jacqueline Ko, soprano
Robin Eder-Warren, soprano
Zeus Ghadban, tenor
Angus Kellett, piano

Admission by donation (suggested $20) • 778.918.9498 • operamariposa@gmail.com

Proceeds in support of the BC Women's Hospital Foundation

BC WOMEN'S HOSPITAL + HEALTH CENTRE FOUNDATION

Benefit Concert Vancouver

- by Jaqueline Ko

We had a nearly full house for the concert, and we also received generous contributions from private donors and corporate partners including Allied Shipbuilders, Lumiere Studio, and DragonDiva Operatic Theatre. Thanks to the wonderful outpouring of support, Opera Mariposa was able to donate $10,000 to the BC Women's Hospital Foundation in support of the new Complex Chronic Diseases Program.

I was delighted to be able to use my passion for music to raise awareness for these life-altering diseases and to support sorely needed research and treatment. It was incredible to have such a positive audience response, and to meet with audience members during the reception and hear stories from others whose lives have been affected by ME/CFS and Fibromyalgia.

BCIT Broadcast News also did a TV news story about the show, which you can find here:
http://www.youtube.com/watch?v=fyZUedU_9KE
If you want to learn more about Opera Mariposa or any of the performers, you can visit us at:
http://operamariposa.com
You can also find Opera Mariposa on Facebook, Twitter and YouTube.

United Nations Convention on the Rights of Persons with Disabilities

Canada ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) on March 11, 2010. The CRPD is based on the social model of disability and places obligations on governments to ensure that the human rights of persons with disabilities are respected. There is a reporting and review process to monitor whether governments are meeting their obligations. This article

- describes the social model of disability,
- lists some of the rights enumerated in the CRPD,
- looks at some of the ways government is called upon to support people with disabilities, and
- looks at the reporting and review process.

The story in a nutshell? The CRPD could have been the springboard for the government to tackle a myriad of disability issues in Canada. Instead, the Canadian government has chosen a minimalist approach. (In contrast, Australia and New Zealand have taken proactive approaches.) On the positive side, the CRPD has been ratified by Canada and is another tool that Canadians can use to insist on basic human rights.

The Social Model of Disability

The social model of disability can be contrasted with the medical model of disability. The medical model says that disability is based on an individual's medical impairments. The response to medical impairments would be medical interventions (e.g. eyeglasses or a wheelchair) or creation of a solution designed around the impairment (e.g. sheltered workshops).

The social model of disability looks at the interaction between people and societal systems. The preamble of the CRPD includes this clause:

“recognizing that disability is an evolving concept and that disability results from the interactions between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others...”

The solution to social disability could be accommodation or social change. Importantly, the CRPD assigns responsibility for ensuring that basic rights are met to “States Parties”(i.e. governments), meaning that they are expected to make the necessary changes.

Example 1: A young person with ME/FM can attend school only an hour a day because of his reduced (impaired) activity levels. The school has no provisions for part-time attendance. They expect him to attend school full time or not at all. This all-or-nothing attitude hinders him from participating in any schooling. Under Article 24, governments commit to the principle that people should not be excluded from Education because of their impairments. The attitude that students must attend full time is a barrier that governments can fix by designing programs for part-time students.

Example 2: A working age single parent with ME/FM cannot participate in the workforce because of her reduced (impaired) activity levels. There are income support programs for people who are unable to work so that they can continue to support themselves and their families. People with ME/FM encounter barriers when trying to qualify for income support (finding knowledgeable doctors, knowing how to explain their disability, finding help to complete the application forms, countering wrong information on their medical records, etc). That is a social problem. Under Article 28, governments are expected to ensure that people with disabilities have an adequate standard of living for themselves and their families. This means removing the barriers around qualifying for income support and ensuring that income support is sufficient to maintain an adequate standard of living.

Rights under the CRPD

Here are several of the important provisions under the CRPD:

<u>Article 19 – Living independently and being included in the community:</u> States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community;

Article 24 – Education States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning...

Article 25 – Health States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:...

b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities...

Article 28 – Adequate standard of living and social protection 1) States Parties recognize the rights of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability...

Supporting People with Disabilities

In order to support these kinds of rights, the Convention calls upon governments to involve people with disabilities in decision-making.

Article 4 - General Obligations: 3) In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues related to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Article 8 – Awareness-raising 1) States Parties undertake to adopt immediate, effective and appropriate measures:

a) to raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;

b) to combat stereotypes, prejudices and harmful practices relating to persons with disabilities....

Article 31 Statistics and data collection 1) States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention....

3) States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Enforcement of government obligations

Under Article 33.2, States Parties shall...establish...a framework to promote, protect and monitor implementation of the CRPD. The Minister of Justice was asked about the framework and responded that Canada already had sufficient mechanisms in place to fulfill its obligations. No new organizations were created or resources assigned.

Canada was supposed to submit a comprehensive report on CRPD implementation in April 2012. A report has been drafted and is being discussed at the political level, but has not been submitted to the UN. It will be made public at the same time it is officially submitted.

Canada's human rights record was reviewed by a UN committee in April. The Canadian government organized the international feedback into five significant areas: Relationship with Aboriginal Peoples; Violence against Women and Children; Canada’s Social Protection Framework; Immigration and Refugee Protection; and National Security and Public Safety.

Canada has been called upon to prepare its response to the UN by September. To do so, the Canadian government is working with its provincial and territorial partners. This committee, coordinated by the department of Canadian Heritage, has invited input from non-governmental organzations (NGOs). I attended a forum for NGOs on May 28, 2013. The following email was subsequently submitted by the National ME/FM Action Network.

For more information on the Universal Periodic Review, go to:
http://www.pch.gc.ca/pgm/pdp-hrp/inter/upr-eng.cfm

The convention itself can be found here:
http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx

Extraits de la Convention relative aux droits des personnes handicapées

Préambule

e) Reconnaissant que la notion de handicap évolue et que le handicap résulte de l'interaction entre des personnes présentant des incapacités et les barrières comportementales et environnementales qui font obstacle à leur pleine et effective participation à la société sur la base de l'égalité avec les autres,

Article 4 - Obligations générales

3. Dans l'élaboration et la mise en ouvre des lois et des politiques adoptées aux fins de l'application de la présente Convention, ainsi que dans l'adoption de toute décision sur des questions relatives aux personnes handicapées, les États Parties consultent étroitement et font activement participer ces personnes, y compris les enfants handicapés, par l'intermédiaire des organisations qui les représentent.

Article 8 - Sensibilisation

1. Les États Parties s'engagent à prendre des mesures immédiates, efficaces et appropriées en vue de :

a) Sensibiliser l'ensemble de la société, y compris au niveau de la famille, à la situation des personnes handicapées et promouvoir le respect des droits et de la dignité des personnes handicapées;

b) Combattre les stéréotypes, les préjugés et les pratiques dangereuses concernant les personnes handicapées, y compris ceux liés au sexe et à l'âge, dans tous les domaines;

Article 19 - Autonomie de vie et inclusion dans la société

Les États Parties à la présente Convention reconnaissent à toutes les personnes handicapées le droit de vivre dans la société, avec la même liberté de choix que les autres personnes, et prennent des mesures efficaces et appropriées pour faciliter aux personnes handicapées la pleine jouissance de ce droit ainsi que leur pleine intégration et participation à la société, notamment en veillant à ce que :

b) Les personnes handicapées aient accès à une gamme de services à domicile ou en établissement et autres services sociaux d'accompagnement, y compris l'aide personnelle nécessaire pour leur permettre de vivre dans la société et de s'y insérer et pour empêcher qu'elles ne soient isolées ou victimes de ségrégation;

Article 24 - Éducation

1. Les États Parties reconnaissent le droit des personnes handicapées à l'éducation. En vue d'assurer l'exercice de ce droit sans discrimination et sur la base de l'égalité des chances, les États Parties font en sorte que le système éducatif pourvoie à l'insertion scolaire à tous les niveaux et offre, tout au long de la vie...

Article 25 - Santé

Les États Parties reconnaissent que les personnes handicapées ont le droit de jouir du meilleur état de santé possible sans discrimination fondée sur le handicap. Ils prennent toutes les mesures appropriées pour leur assurer l'accès à des services de santé qui prennent en compte les sexospécificités, y compris des services de réadaptation. En particulier, les États Parties

b) Fournissent aux personnes handicapées les services de santé dont celles-ci ont besoin en raison spécifiquement de leur handicap, y compris des services de dépistage précoce et, s'il y a lieu, d'intervention précoce, et des services destinés à réduire au maximum ou à prévenir les nouveaux handicaps, notamment chez les enfants et les personnes âgées;

Article 28 - Niveau de vie adéquat et protection sociale

1. Les États Parties reconnaissent le droit des personnes handicapées à un niveau de vie adéquat pour elles-mêmes et pour leur famille, notamment une alimentation, un habillement et un logement adéquats, et à une amélioration constante de leurs conditions de vie et prennent des mesures appropriées pour protéger et promouvoir l'exercice de ce droit sans discrimination fondée sur le handicap.

Article 31 - Statistiques et collecte des données

1. Les États Parties s'engagent à recueillir des informations appropriées, y compris des données statistiques et résultats de recherches, qui leur permettent de formuler et d'appliquer des politiques visant à donner effet à la présente Convention...

3. Les États Parties ont la responsabilité de diffuser ces statistiques et veillent à ce qu'elles soient accessibles aux personnes handicapées et autres personnes.

Article 33 - Application et suivi au niveau national

2. Les États Parties, conformément à leurs systèmes administratif et juridique, maintiennent, renforcent, désignent ou créent, au niveau interne, un dispositif, y compris un ou plusieurs mécanismes indépendants, selon qu'il conviendra, de promotion, de protection et de suivi de l'application de la présente Convention.

Network Submission to the Universal Periodic Review

The National ME/FM Action Network would like to thank you for the opportunity to participate in the UPR process, the United Nations review of Canada's human rights situation.

Our organization was founded in 1993 to represent Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and Fibromyalgia. These are two chronic disabling illnesses. People with ME/FM encounter many serious human rights issues. Two of our people have been to the Supreme Court of Canada. The Supreme Court found that Ms Fidler, who had FM, had been unfairly denied insurance benefits and that Mr Keays, who had ME/CFS, had been unfairly dismissed from his job. **These cases are just the tip of a very large iceberg of unfairness experienced by Canadians with ME/FM.**

Here are key messages from our organization, some of which were touched upon at the May 28th forum:

- Disability issues need to be a priority for Canada.
- Recommendation #127 deserves special attention. Poverty, food insecurity, access to health care and access to education are all very real issues for the ME/FM community in Canada. Appropriate housing is also an important issue, and special consideration should be given to the housing needs of Canadians with environmental sensitivities.
- Implementing the CRPD means adopting a broad, inclusive definition of disability. Fifty years ago, autism wasn't recognized as a disability. My autistic sister ended up at a school for the blind because there were no programs for students with autism. That was completely inappropriate. Today, the disabilities that accompany ME/FM are not properly recognized. Young people with ME/FM have ended up at home unsupported because of a lack of educational options. That too is completely inappropriate.
- Socio-economic issues need to be looked at through a disability lens. For instance, food insecurity is rarely discussed as a disability issue. The ME/FM community reports a high rate of food insecurity and accounts for some of the most severe cases. Many ME/FM people are housebound and can't get to a grocery store. Standing in line at a food bank is impossible. Even cooking a simple meal can be a struggle. To make matters worse, many are dealing with meagre incomes and lack of home support.
- Good access to health care is critical not only for the health benefits but because health care is often the gateway to social services like home care, income support and special dietary allowances. A major Statistics Canada survey found that Fibromyalgia and Chronic Fatigue Syndrome had the highest rates of unmet health care needs among the 18 chronic conditions surveyed in 2010.
- The CRPD calls for participation through representative organizations. Thought needs to be given to ensuring that these organizations have the resources to carry out their roles, or even to ensuring that the full range of representative organizations are in place.

Following the forum, I had a private discussion with one official who suggested that government would not involve itself in human rights for the ME/FM community as long as the medical conditions were considered controversial. **This attitude needs to be confronted because it is the equivalent of saying that human rights do not apply to certain groups.**

For decades, autism was attributed to “cold refrigerator mothers”. The sub-text was that society should refuse to help the families with autism because the mothers were unworthy and the situation would be made worse if their behaviour was condoned. Many people suffered because of the misguided attitudes toward autism and the failure to support the families. Human rights interventions would have lessened the suffering.

Mischief-makers have introduced concepts like “distorted illness beliefs” and “faking symptoms” to stigmatize the ME/FM community. These terms suggest that people with ME/FM can control their illness and are not worthy of services. That misguided attitude is causing enormous suffering. States Parties have obligations under Article 5 of the CRPD to prevent discrimination and under Article 8 to raise awareness and to combat stereotypes Instead, this is a time where aggressive government interventions are desperately needed to protect the ME/FM community's human rights.

You can learn more about ME/CFS and FM on our website: www.mefmaction.com.

For an overview of the seriousness of the situation, please take a look at this report: *http://mefmaction.com/images/stories/quest_newsletters/Quest80springsummer2009.pdf*

If you have any questions, please don't hesitate to contact us at mefminfo@mefmaction.com.

We look forward to working with you to reduce the stigma and ensure the rights of Canadians with disabilities in general and Canadians with ME/FM in particular.

Margaret Parlor
President
National ME/FM Action Network

Looking for Study Participants

Ontario Health Study

The Harvard study (see next article) is a "longitudinal" study, meaning that they followed people over time. This gives a perspective that is not possible with studies that reflect a single point in time.

The Ontario Health Study is a major new longitudinal study that is looking for volunteers. Participants must be Ontario residents aged 18 or older. Participants are asked to fill out an on-line questionnaire. Some participants may be selected for an optional follow-up assessment or blood test. Volunteers will be contacted each year to fill out optional questionnaires. For more information, call 1-866-606-0686 or go to: https://ontariohealthstudy.ca/en/about-study?autoplay=true&nid=362

Staying in the Workplace with FM

Margaret Oldfield is working on her PhD at the University of Toronto. Her research is focusing on women with FM who are able to participate in the workforce and is looking at what supports can help. She is looking for working women with FM in or around Toronto to participate in her study. Here is the announcement she sent us:

Would you like to share your experiences, so that others can learn from them - people like government policymakers? health professionals, and other women with FM. Then please join us in the study 'Staying in the Workforce with Fibromyalgia'. The study is being conducted by Margaret Oldfield, a PhD student at the University of Toronto. She is interviewing women who have been medically diagnosed with FM, as well as people who can make a difference in whether they stay at work: an adult family member and someone in her workplace.

If you'd like to join the study, or simply want more information about it, please email the researcher at margaret.oldfield@mail.utoronto.ca or phone her at 416-975-5199. If you don't have FM yourself but know a woman who might want to join the study, please forward this message to her. Thank you.

What's Harder than Quantum Physics?

By the late 1930's, there were theories of child development but the study of adult development was in its infancy. Harvard University decided to start a study. They selected several hundred undergraduates (all male) to follow for 15 years, but ended up following them for 75 years. There have been four directors of the study over the years. George Vaillant became the third director in 1972. He recently published a book entitled "Triumphs of Experience" looking back at the study and the people in the study.

One of his observations was that matters that seemed obvious in the early days did not turn out to be true, while matters that we take for granted today were not obvious in the early days. In particular, he notes that in the first decade of the study there was little attention given to the importance of relationships, attachment and bonding. Participants were not even asked about girlfriends. He goes on to note:

There is an interesting parallel here with infantile autism. This fairly common disorder, which is due to a congenital absence of empathy, was not spotted until 1943, when a child psychiatrist finally noticed it in his own son. Its close relative, Asperger's syndrome, was identified in 1944. But it was fifty years more before those genetic disorders were absorbed into psychiatry's diagnostic framework. ***In other words, in the 1930s, the congenital impairment of attachment reflected in childhood autism was harder for scientists to grasp than quantum physics.*** *The functional reality of relatedness had not been incorporated into the consciousness of the social sciences.*

There are aspects of ME/CFS and FM that seem harder for scientists to grasp than quantum physics. It could be the failure to generate energy on demand that is seen in ME/CFS and the undesirable pain signalling experienced in FM. When science comes to understand the illnesses, the underlying problems will all seem so obvious.

Guidelines

The topic of guidelines may seem like an obscure issue, but how the health and social systems approach illnesses can have a major impact.

In thinking about the topic of guidelines, consider that:

- There are two very different models of Lyme disease, with two very different guidelines.
- There are a number of different guidelines for diagnosing and treating ME/CFS including the Canadian Consensus Guidelines and the UK NICE guidelines.
- There are now two different guidelines for the diagnosis and treatment of Fibromyalgia in Canada, the Canadian Consensus Guidelines and the 2012 Canadian Guidelines
- The American Psychiatric Association has just released its new Diagnostic and Statistics Manual (DSM-5) that includes many contentious diagnoses including the new somatic symptom disorder.

The key message is that guidelines can be questioned. For the new DSM-5, a top official at the US National Institutes of Health has expressed reservations. Several years ago, the Attorney-General of Connecticut challenged the Lyme guidelines developed by the Infectious Diseases Society of America, sending the IDSA back to the drawing board. A recent article in the Canadian Medical Association Journal (CMAJ) points out that most clinical practice guidelines are not tested before they are used and some have caused harm.

How influential are clinical practice guidelines?

For starters, individual health professionals are expected to use their learning, experience and judgment and do not have to follow a cook-book. However guidelines can make their lives easier by guiding them in decision making. If there are disputes over the handling of cases, doctors want to show that they were following recognized guidelines because this is evidence that they were acting appropriately. In the Lyme debate, disciplinary organizations often insist that doctors use the IDSA guidelines. A classic paper entitled “Lyme Disease: Two standards of care” argues that the medical community does not know whether the IDSA or the ILADS model is correct, so patients should have the right to choose which guidelines they want to follow provided their consent is informed. Because of the intensity of the debate, some states have passed legislation protecting doctors who use the ILADS guidelines.

Health and social systems make assumptions. The decision whether or not to fund a medical test makes assumptions about the cost-benefit of the test. The method to qualify for disability benefits makes assumptions about how the condition should be diagnosed, what treatments should be tried, and how effective treatments are likely to be. These assumptions may be closely linked to explicitly written guidelines or may be a sort of unwritten guideline.

Which guidelines should one use? Two tools have been developed to assess guidelines, the AGREE tool and the GLIA (GuideLine Implementability Appraisal) tool. The AGREE tool is described next. The CMAJ commentary notes that the tools “focus on methodological issues related to the gathering of evidence and development of guidelines, but they do not consider whether the guidelines have been tested.” As you go through the tool, consider how the question leads to better outcomes for patients.

The following section looks at selected terminology, in particular the terms “guidelines” and “evidence based”. It shows that these terms are subject to interpretation.

The CMAJ commentary suggests that guidelines should be tested before they are adopted. This is an opportunity for patient voices to be heard.

The AGREE Tool

AGREE stands for the Appraisal of Guidelines for Research and Evaluation. The AGREE tool is available at www.agreetrust.org. The first version of the tool was published in 2003 and the second version in 2009.

The AGREE II consists of 23 key items organized within 6 domains followed by 2 global rating items (“Overall Assessment”). Each domain captures a unique dimension of guideline quality. Each question is scored from 1 (strongly disagree) to 7 (strongly agree). Generally, two to four reviewers should score each guideline and their scores should be averaged.

Domain 1. **Scope and Purpose** is concerned with the overall aim of the guideline, the specific health questions, and the target population.

- The overall objective(s) of the guideline is (are) specifically described.
- The health question(s) covered by the guideline is

(are) specifically described.

- The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described.

Domain 2. **Stakeholder Involvement** focuses on the extent to which the guideline was developed by the appropriate stakeholders and represents the views of its intended users.

- The guideline development group includes individuals from all relevant professional groups.
- The views and preferences of the target population (patients, public, etc.) have been sought.
- The target users of the guideline are clearly defined.

Domain 3. **Rigour of Development** relates to the process used to gather and synthesize the evidence, the methods to formulate the recommendations, and to update them.

- Systematic methods were used to search for evidence.
- The criteria for selecting the evidence are clearly described.
- The strengths and limitations of the body of evidence are clearly described.
- The methods for formulating the recommendations are clearly described.
- The health benefits, side effects, and risks have been considered in formulating the recommendations.
- There is an explicit link between the recommendations and the supporting evidence.
- The guideline has been externally reviewed by experts prior to its publication.
- A procedure for updating the guideline is provided.

Domain 4. **Clarity of Presentation** deals with the language, structure, and format of the guideline.

- The recommendations are specific and unambiguous.
- The different options for management of the condition or health issue are clearly presented.
- Key recommendations are easily identifiable.

Domain 5. **Applicability** pertains to the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the guideline.

- The guideline describes facilitators and barriers to its application.
- The guideline provides advice and/or tools on how the recommendations can be put into practice.
- The potential resource implications of applying the recommendations have been considered.
- The guideline presents monitoring and/or auditing criteria.

Domain 6. **Editorial Independence** is concerned with the formulation of recommendations not being unduly biased with competing interests.

- The views of the funding body have not influenced the content of the guideline.
- Competing interests of guideline development group members have been recorded and addressed.

Overall assessment includes the rating of the overall quality of the guideline and whether the guideline would be recommended for use in practice.

- Rate the overall quality of this guideline. (from 1 lowest possible quality to highest possible quality)
- Rate the overall quality of this guideline (yes, yes with modifications, no)

Selective Terminology

The following correspondence brings out two important questions. What are guidelines? And what is meant by "evidence based?" Here is a quote from a press release that was issued on May 6, 2013.

Physicians from the McGill University Health Centre (MUHC) and the University of Calgary have published a review article in the CMAJ (Canadian Medical Association Journal) to help family doctors diagnose and treat fibromyalgia. The article represents the first time researchers have published Canadian guidelines to help manage the condition.

'Finally there are national guidelines to help diagnose and treat this syndrome,' says Dr. John Pereira, a study co-author from the University of Calgary's Faculty of Medicine and a physician at the Calgary Chronic Pain Centre.

In the review, the authors provide evidence-based tools for primary care physicians to make the diagnosis and manage the condition long-term.

'We are the first ones to develop guidelines that look at

diagnosis, treatment and follow-up of fibromyalgia,' says Dr. Mary-Ann Fitzcharles, corresponding author from the Research Institute of the MUHC and MUHC's rheumatologist. 'Currently, there is no cure for fibromyalgia but the guidelines set out the most appropriate management strategy.'

The Network contacted the media officer responsible for this press release challenging the statement that these were the "first" national guidelines. The Network pointed to the Canadian Consensus Guidelines for Fibromyalgia. The media officer passed the question to the 2012 Guidelines Committee and here is the reply:

We appreciate the interest that your group has shown in the 2012 Canadian Fibromylagia Guidelines. The document to which you referred was in fact a "consensus statement" and not a guideline, and which essentially results from a discussion amongst experts. Over the past decade it has become increasingly clear that a consensus statement is an inadequate method to provide direction. It is for this reason that formally developed evidence based guidelines are now the standard to provide guidance. The 2012 FM guidelines adhered to current accepted evidence based standards.

The 2012 Canadian Fibromyalgia guidelines were developed with input from over 100 health care professionals caring for persons with fibromyalgia with the intention of improving patient care and providing direction for the health care community. It is clearly acknowledged that patient care should be individually tailored.

We hope that this clarification is to your satisfaction

Sincerely,

The Canadian Fibromyalgia Guidelines Committee

So the Committee brushed aside the Canadian consensus guidelines as a "consensus statement" and emphasized the point that the 2012 Guidelines used "evidence based standards."

We took this response to Marjorie van de Sande, the Network's representative on the consensus panel. Here is her reply addressing both the "guidelines" and the "evidence based" issue:

They [the Canadian consensus guidelines] were consensus clinical guidelines. They were based on research and the clinical experience of clinicians who had diagnosed/treated more than 20,000 FM patients. The panel consisted of both clinicians and researchers. The extensive research section of the paper is almost 20 pages long (pgs. 43-61). There are 433 medical references cited upon which the guidelines were based. Not only was it published in a medical journal, The Haworth Medical Press published it as a medical book.

It is interesting to examine how the 2012 guidelines can be qualified as "evidence based". Here is the methodology the committee followed:

A needs assessment by structured consultation with 139 healthcare professionals from relevant disciplines across Canada generated 18 key questions. Questions drove a literature search to identify evidence, which was graded according to the classification system of the Oxford Centre for Evidence Based Medicine, and supporting recommendations were drafted. Recommendations were edited and appraised by an advisory panel to reflect meaningful clinical practice. The whole document was reviewed by an international expert.

There are a number of holes that can be poked in this methodology:

Many of the questions were not framed in an evidence-testable fashion. The first key question was "How should FM be diagnosed?" An evidence-based answer could involve studies of alternative definitions along the lines of Dr. Leonard Jason's studies around the various definitions of CFS. The 2012 committee's answer to the question is found in the first paragraph of the 2012 guidelines: "These evidence-based guidelines...were developed taking into account...the new American College of Rheumatology 2010 diagnostic criteria." In other words, the document is about implementing the diagnostic criteria, not evidence-based analysis of the diagnostic criteria.

Most of the recommendations were based on literature that were classified as "opinion". The committee itself has acknowledged that "As you understand, particularly in the diagnosis of FM, there is a dearth of evidence and, thus, the collection of expert opinion (level D) is the best that can be offered, at this time." This dearth of evidence did not prevent the committee from making "evidence based" recommendations. Compounding the opinion issue, the literature searches were restricted to peer-reviewed journals. These journals have restricted participation, meaning that they do not necessarily represent a full range of perspectives and that issues may have been only partially addressed.

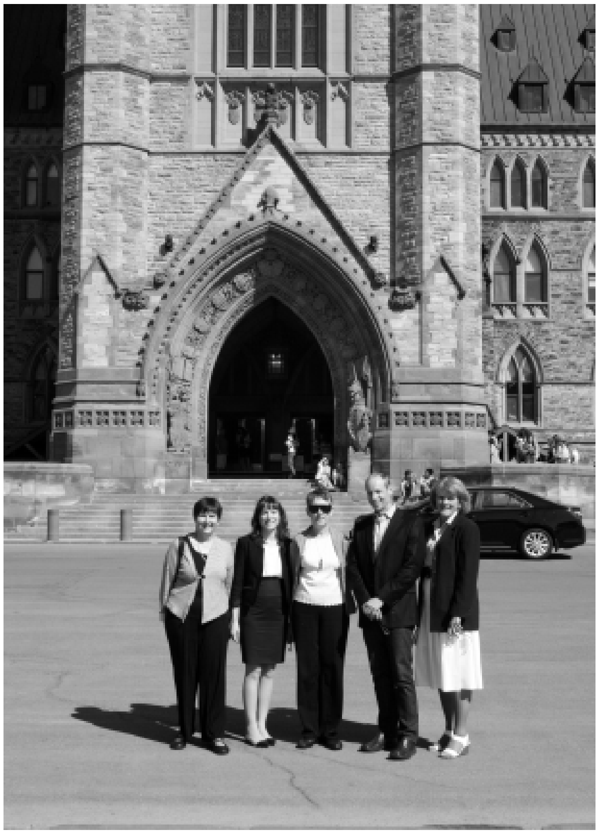
Saying that the Canadian consensus document is not a "guideline" doesn't make that statement true. Saying that the 2012 Guidelines are "evidence based" doesn't make that statement true either.

Support for the Canadian Consensus Criteria

On May 12, a consortium of US patient groups and advocates wrote to the US Secretary of Health and Human Services along with her assistant secretary, the Director of the National Institutes of Health and the Director of the Centers for Disease Control and Prevention. Here are the key requests in the letter. A petition in support is here: *http://www.thepetitionsite.com/255/349/958/fatigue-is-not-a-disease/* People from any country can sign.

The following steps are necessary in order to move forward with improved research and treatment for patients with ME:

1. **Adopt a disease appropriate case definition:** ME, as defined by the Canadian Consensus Criteria (CCC), must be recognized by DHHS and the United States government for the serious and debilitating disease that it is. ME is not a subtype of "CFS". The CCC must be adopted now as the baseline case definition for this disease. It can be evolved as additional knowledge is gained, the definition is operationalized and markers are validated. We do not need more years of study to fix what is so clearly broken today.
2. **Stop using "CFS":** The terms "Chronic Fatigue Syndrome" and "CFS" must be permanently abandoned along with the overly broad, two-decades old Fukuda and Oxford definitions. By using non-specific criteria that have become associated with such a diverse set of unrelated conditions, these terms and the accompanying definitions have become medically and scientifically meaningless. They are impeding forward progress and DHHS should discontinue their use. DHHS should also discontinue the dissemination of "CFS" clinical information, like the 'one size fits all' CDC CFS Toolkit, that uses a non-specific disease description and includes clinical findings and recommendations for all patients based on Oxford, Empirical or chronic fatigue studies.
3. **Manage the transition to the Canadian Consensus Criteria:** This includes the adoption and proactive dissemination of appropriate medical guidance like the International Association for CFS/ME Primer, available through DHHS' Guidelines.gov. It also includes the establishment of a research program focused on ME, updated insurance guidelines for Medicare/Medicaid, the establishment of disability guidelines for ME and similar transition activities. Most importantly, it must include a plan to care for those patients who have received a diagnosis of "CFS" but do not meet the CCC criteria for ME. These individuals should be properly evaluated and diagnosed where possible. If unexplained conditions remain, additional studies will be needed to understand these conditions and establish more appropriate names and definitions. The continued use of the overly broad "CFS" and Fukuda for these patients is not appropriate.
4. **Engage ME stakeholders in the planning and implementation**: In keeping with President Obama's commitment to Open Government, the key stakeholders – ME patients and ME experts – must be engaged in a full and open partnership to plan for and ensure implementation of this change. We are the ones that best understand this disease and will provide valuable input to these activities.



May 12 on Parliament Hill. L-R Maureen MacQuarrie, Lisa Schneiderman, Margaret Parlor, Dr Gordon Broderick, Christiane Garcia. Photo by Anne Marie MacIsaac

Online Tool to Save British Columbians Money on their Prescription Drugs

Monday, December 03, 2012

Pacific Blue Cross today announces the launch of the Pharmacy Compass, a free online tool developed for the public. The tool helps consumers find better value for their medications by comparing the price at different pharmacy locations across B.C.

Prescription drugs represent the most significant cost of health coverage in the province. Seventeen per cent of B.C. residents do not adhere to their prescriptions due to cost, a rate nearly twice the national average of 9.6 per cent. Drug costs affect consumers with and without insurance.

"At Pacific Blue Cross, one of our primary goals is to ensure British Columbians have access to affordable health care," says Ken Martin, President and CEO of Pacific Blue Cross. "Our aim with the Pharmacy Compass is to lower out-of-pocket costs for prescription drugs for all consumers."

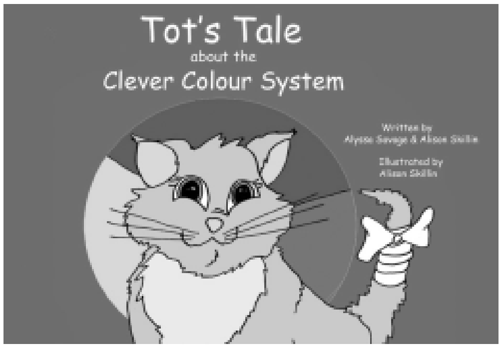
To further cost savings the Pharmacy Compass also provides the generic equivalent of any brand name drug and the cost difference between them. Generic drugs listed with PharmaCare typically cost 35 per cent of brand-name drugs in B.C.

However, the organization cautions that price is only one aspect to consider when selecting a pharmacy. Consumers also need to consider the value-added services provided by a pharmacy, the convenience of the pharmacy's location and its business hours.

The Pharmacy Compass is updated monthly. The drug prices shown are calculated based on prescription claims submitted by pharmacies to Pacific Blue Cross over the previous three months.

The Pharmacy Compass can be accessed at: www.pharmacycompass.ca

A Children's Book



"Tot's Tale about the Clever Colour System" is a book for young children. Mother Cat has been hurt. A youngster explains to its kitten that the child's mother is also dealing with pain and that she has red days, yellow days and green days. They do different things depending on the colour of the day, but all are good. The authors Alison Skillin and Alyssa Reid write in a very sensitive fashion. The book could be helpful for any adult dealing with pain that has young children in their lives. It is available from Amazon.ca

Employment and Disability

Hugh Scher, the Network's legal advisor, sent us an article explaining how the courts have handled cases when employees become disabled after they were given notice of termination but before the lay-off period ended. What is clear is that the issues are very complex. If you find yourself in such a situation, you need expert advice that is familiar with employment, insurance and human rights law. If you would like a copy of the article, please contact us and we will send you a copy. Thanks to Hugh for introducing us to this very challenging area.

Jaqueline Ko (centre), founding Artistic Director for Opera Mariposa presents a cheque for $10,000.00 to the Complex Chronic Disease Program. On the left is Laurie Clarke, the CEO of the BC Women's Hospital + Health Centre Foundation. On the right is Dr. Alison Bested, the Medical Director of the CCDP.

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Thank You to Lynda

Lynda Cregan has stepped down from her positions of the Network including Vice-President and Webmaster. We would like to thank Lynda very much for the contributions she has made over the years. She did a beautiful job on the Quest Collection Books 2 and 3. She put together the Accomplishments that you can view on our website. She designed the graphs in Quest 80. Some of you may have had the opportunity to talk to Lynda when she handled our phone. She has maintained the website and done behind the scenes work. Best wishes Lynda. You will have more time for yourself and your family, including your new granddaughter.

NATIONAL ME/FM ACTION NETWORK

512-33 Banner Road, Nepean, ON K2H 8V7 Canada
Phone: 613-829-6667 • Fax: 888-522-8006
Email: mefminfo@mefmaction.com • www.mefmaction.com
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Thank You

THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter - Free with annual membership of $30.00

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

ME/CFS and FM Brochures - FREE

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

Consensus Documents for ME/CFS and FM

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

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

ME/CFS and FM Overviews - $7.00 each

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

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

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

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