NATIONAL ME/FM ACTION NETWORK

Quest Newsletter

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In this edition of Quest, we would like to share with you pictures and stories from May 12th Awareness Day for Chronic Immunological and Neurological Diseases like ME/CFS and FM. It was thrilling to see how many activities took place. There is a lot more work to be done in raising awareness, but the May 12th events demonstrate the growing strength and solidarity of the community in Canada and internationally.

We would like to draw your attention to an art contest for young people (see page 12). The IACFS/ME is preparing a pediatric primer for release at its next conference (now scheduled for October 27-30, 2016 in Ft. Lauderdale). The IACFS/ME is looking for a picture from a young person with ME/CFS to go on the front cover. And yes, the submission deadline is a year from now.

Awareness event in Calgary, Ab

May 12th Light Up the Night

On May 12, 2015, participants from around the world joined in the 2nd Annual International Light Up the Night Challenge. The challenge is a competition between countries to see which country can get the most landmarks or the most private homes to light up on May 12th. Public buildings, landmarks and homes were lit up in Blue, Purple and Green to raise awareness for Myalgic Encephalomyelitis, Fibromyalgia and Multiple Chemical Sensitivity. Photos are posted at: *https://www.facebook.com/may12th.awareness*.

Canadian landmarks that were lit up on May 12th include:

BC Place Stadium, Vancouver

Canada Place - Sails of Light, Vancouver

Convention Center, Vancouver

Olympic Cauldron at Jack Poole Plaza, Vancouver

Science World, Vancouver

Langevin Bridge, Calgary

109th St Bridge, Edmonton

ATB Building, Edmonton

Peace Bridge - between Windsor and Detroit

Niagara Falls

CN Tower, Toronto

Farmers Market and Central Library, Hamilton

Olympic Stadium, Montreal

City halls in Toronto, Mississauga, Brampton, Ottawa, Halifax and Charlottetown

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May 12th Events in Canada

Vancouver – Tour de Force, May 16

Opera Mariposa presented Tour de Force, *An Evening of Broadway Showstoppers*. The show was a huge hit. The house was packed and the performers received a standing ovation. Review Vancouver published an extremely complimentary review describing the performance as "spell-binding," "awe-inspiring" and "phenomenal". The full review can be read at *http://reviewvancouver.org/op_tourdeforce2015.htm*. A portion of the ticket sales will go to the National ME/FM Action Network, to support education of health care professionals in diagnosing and treating patients with Myalgic Encephalomyelitis and Fibromyalgia.

Vancouver - MEBC, May 24th

The MEFM Society of BC, in collaboration with the National ME/FM Action Network and the BC Complex Chronic Diseases Program, hosted an awareness event featuring special guests, Dr. Daniel Peterson, Staci Stevens and Dr. Ian Hyams.

BC

A radio station in BC, CKVS-FM 93.7 Voice of the Shuswap, did a show on May 11th talking about May 12th and other ME/FM issues. The National ME/FM Action Network participated in the program.

SOFA (Sunny Okanagan FM-ME Association) encouraged people to go to AMAZON to purchase the book "Blue Highway Sunshine Route: Spring: Daily Reader for Those with Fibromyalgia and Chronic Fatigue", just released by Penticton author Sheryl Ann Wilson. Daily readers for Summer, Fall and Winter are planned.

Edmonton

May 2. The Fibromyalgia Society of Edmonton held an awareness event with guest speakers, education sessions, bake sale, book sale and much more.

The ME Society of Edmonton held an event on May 9th. Special guest speaker was Dr Eleanor Stein. She spoke about Exercise and M.E./CFS and the latest developments in M.E./CFS/SEID

Calgary

On May 19th in Calgary, Dr Eleanor Stein hosted a webcast with guest speakers Rory Hornstein RD, BEd and Lucinda Bateman, MD.

An information table was set up on May 11 and 12 at Planet Organic in Calgary.

Toronto

MEAO held an awareness event at Queen's Park, Toronto, on May 12th. Representatives from all three political parties made supportive statements in the legislature. There was a reception afterwards and the Ontario Minister of Health made an appearance!

The National ME/FM Action Network sponsored an event May 16th in conjunction with the Mississauga, North Toronto, Scarborough and York Region support groups. Dr Alison Bested and Dr Michelle Skop were speakers. There were body map artwork displays, information booths & refreshments.

Ontario

In Brockville on May 12th, 3 ME-FM Awareness tables were set up. The local radio stations told people about the severity of the disease, the name change and the awareness tables.

London, Ontario held a Fibromyalgia Awareness & Information Day event at the Beacock Library on May 9 featuring Dr. Manfred Harth. On May 12, there was an event featuring Kevin White, author of "Breaking Thru The Fibro Fog".

Sudbury Ontario held a Mother's Day tea on May 9th.

MESH Ottawa hosted a panel discussion and Q & A on insurance titled "Are You Covered". Speakers were from the law firm RavenLaw. Margaret Parlor from the National ME/FM Action Network provided some opening remarks.

Quebec

The fibromyalgia associations for Quebec City and for Chaudiere-Appalaches held a conference on May 12th.

Groupe envolée bleue actions (Blue ribbon action group), which brings together ME and FM associations in Quebec, held a photo display, a dinner and a group picture-taking in front of the Olympic Stadium. Featured guest was Montreal mountain-climber Monique Richard who has climbed the seven summits (including Everest) and is fundraising to climb K-2 this year. She wants to display a Montreal flag, a Quebec flag, a Canada flag and a Fibromyalgia flag on the world's second highest summit.

Proclamations

May 12th has been proclaimed International Awareness Day for Myalgic Encephalomyelitis , Fibromyalgia and Multiple Chemical Sensitivity in the following cities: Ottawa, Toronto, Mississauga, Brampton, Ramara, Brockville in Ontario; Victoria, Nanaimo Kelowna and Port Moody in British Columbia. In Vancouver, the day has been proclaimed in perpetuity. The BC province has also proclaimed the day.

Letters

All across the country constituents have sent emails or letters to their MPs, MLA, MPPs asking for their support on May 12th to raise awareness.

More details about May 12th awareness events can be found at *www.bit.ly/May12th2015*

International Events

Some of the many events held on May 12th are listed below

Online Everywhere

- M.E.Again organized a juried art show and media campaign. Artists with ME and FM were invited to participate. The selected artwork, along with interviews with the artists, is shown at *www.meagain.org.* It is powerful.
- People who can't get out were invited to a virtual vintage tea party, or to participate in a big sleep event.

Australia

- City of Perth Council House, Melbourne's AAMI Park stadium, the Adelaide Oval stadium and the National Centre for Neuroimmunology and Emerging Diseases at Griffiths University were lit up.

Italy

- AISF ONLUS (the Italian Association For Fibro and CFS) held an event on May 10th in Verona.

Japan

- Dr. Kuratsune, a Japanese leading expert on Chronic Fatigue Syndrome, introduced CFS Awareness Day on this video: *youtube.com/watch?v=hKy8WAldsY0*
- A lecture by Dr.Kuratsune was held at the Institute of Aomori chuo Gakuin University School of Nursing.
- In Akita Prefecture, there was a blue light up event happening for the first time at ME/CFS doctor, Dr. Miura`s satellite clinic in Sotoasahikawa on May 12,13th. Pumpkin artwork of Yayoi Kusama was decorated on the hospital roof. Dr.Miura held a lecture titled chronic fatigue and chronic pain that prevent the daily life,on May 9th.
- Aomori Prefecture Tourist Center, Aspam, was blue on May 12th.

Malta

- The following places were lit up on May 12th: The President's Palace, officially named The Grandmaster's Palace in Valletta, the Couvre Porte in Vittoriosa, the Chapel of Our Lady of Sorrows in Mqabba, a fountain in Kalkara promenade, the facade of the building of Cospicua Local Council and the facade of the edifice of Naxxar Local Council.

Northern Ireland

- The Newry Reporter newspaper did a story on ME and mentioned global May12th awareness day.
- Bangor Town Hall, BanBridge, Craigavon Civic Centre and Armagh Gaol were lit up May 12th.
- Fibromyalgia Awareness Bangor/Ards & North Down Support Group arranged for a garden display.

Netherlands

- ME Vereniging Nederland held their yearly ME Information Day in Breda this year. On May 12 they published all tweets using #12MEi.

Republic of Ireland

- The Irish ME/CFS Association is pleased to announce two talks as part of its ME Awareness Month activities in May by Dr. Abhijit Chaudhuri from the UK.
- Dublin's Mansion House and Mullingar's Market House were lit on May 12.
- An event was held at Bewley's Hotel Newlands Cross.
- Fibromyalgia Awareness and Advocacy Forum Ireland sold ribbons and they produced a booklet on Fibromyalgia to raise awareness.
- FMANI Charity Organization held an FM Awareness Day May 9th at the Civic Centre Drumceatt Square, Limavady.
- Cork Fibromyalgia group held an event May 9th at Wilton Shopping Centre.

South Africa

- A member of www.fibromyalgiasa.co.za appeared on radio and it's hoped a newspaper article will be written.

Sweden

- Sweden has produced a Facebook cover photo and profile photo you can use on May 12th and a "wear something blue" day was planned.
- In Borås City, the big accumulator tank for warm district heating water was lighted blue on the 12th of May. The accumulator tank has 5,000 led lights.

United Kingdom (UK)

- Invest in ME's 10th International ME Conference 2015 took place on 29th May 2015 in Westminster, London. A research conference took place on the two preceding days. Cordon bleu for ME helped raise funds for the conference. There was also an online party and sale of cards/stationary to fundraise for Invest in ME.
- Fibroduck Foundation arranged for the Blackpool Tower to be lit PURPLE, and the Heart BLUE, with FIBRODUCK text scrolling through the heart. 300 patients and family members showed up! They invited the press along and gave out information flyers to passers by. The event was filmed.
- Tymes Trust held an event May 11th at Ingatestone Hall.
- The 25% Group provided a draft letter to be sent to MP's.
- Number 12 in Norwich England held a Pub Quiz in aid of Fibromyalgia.
- The Gatgeshead Millennium Bridge was lit blue on the 12th.
- In invitation was extended for Tea and Coffee 157, Hemerdon Heights, Plympton.
- Starfish Craft Studio held an event at their business with a raffle, making awareness jewelry, a cake sale, a chance to meet and join the local support group and a holistic therapist offering demonstration.
- Other buildings and landmarks that were lit include Wainhouse Tower, Halifax, West Yorkshire, the Brighton Wheel, the Sea Life Centre in Brighton, The Gateshead Millennium Bridge, the Newcastle Tyne Bridge, the Birmingham library, the South Shields town hall clock tower and the Titan Crane at Clydebank.

United States (US)

- New York City's Caterpillar Walk program is a fundraising campaign designed to raise awareness and support for Fibromyalgia and Chronic Pain.
- Washington DC MEadvocacy.org had a demonstration on April 28.
- The following places have proclaimed May 12th: Sumter County, Kissimmee and Haines City, Florida, Springfield, OH and Anaheim, CA.
- #OccupyTheUSDOJ #June2015 was held in Washington DC on June 1st.
- The Peace Bridge between Canada and the US will be lit with all 3 colours on May 12th.
- Anne Keith went to Washington DC to lobby Congress for funding and for greater HHS oversight.
- Port Washington Town Dock NY Fibromyalgia Walk May 17 at 1pm.
- Houston Texas City Hall was lit up with three colours on May 12th.

More information about May 12th awareness can be found at may12th.org

This article was written by staff at RavenLaw, the law firm that spoke at the Ottawa Awareness Event. The topic of accommodation at work will be most applicable to people at functional capacity 7 or 8 - those still able to participate in the workforce but struggling to do so.

How to request accommodation at work?

Human rights law requires employers to take steps to ensure that all employees can participate fully in the workplace despite any limitations they may have that are linked to their disability.

What is the duty to accommodate?

Human rights laws in Canada do not simply prohibit employers from taking discriminatory actions against individuals. These laws, such as the Ontario Human Rights Code or the Canadian Human Rights Act, also require an employer to take positive steps to eliminate or reduce barriers in the workplace. In some cases, this may require the employer to meet a duty to accommodate an employee.

In the employment context, an employee may be in need of accommodation while at work or while attempting to return to work after a leave of absence. In such cases, an employer may be required to accommodate the employee by providing additional assistance or making changes to the physical environment or workplace culture, or even by providing the employee with an exemption from a workplace rule or standard. Whether or not your employer must accommodate you in such a manner will depend on your particular situation and your particular needs.

For example:

- An employer may be required to make physical changes to the workplace to accommodate an employee's mobility issues.
- An employer may be required to provide employees with modified duties, or specialized work equipment, if they can no longer perform their original work duties due to a disability.
- An employer may be required to modify productivity or work performance standards where an employee cannot meet existing standards due to a disability.

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Comment demander un accommodement au travail?

Les droits de la personne obligent les employeurs à prendre des mesures pour veiller à ce que tous les employés puissent participer pleinement au travail malgré des limitations liées à un handicap ou une incapacité.

Qu'est-ce que l'obligation d'accommodement?

Les lois sur les droits de la personne au Canada n'interdisent pas seulement aux employeurs de ne pas discriminer contre des individus, ces lois, comme le Code des droits de la personne de l'Ontario ou la Loi canadienne sur les droits de la personne, exigent également qu'un employeur prenne des mesures positives pour éliminer ou réduire les obstacles en milieu de travail. Dans certains cas, ceci peut vouloir dire qu'un employeur doit accommoder son employé.

Dans le contexte du travail, un employé peut avoir besoin d'un accommodement au cours de son emploi, ou avant un retour au travail après un congé de maladie. Dans de telles situations, un employeur peut être tenu d'accommoder l'employé en fournissant une assistance supplémentaire, en apportant des modifications à l'environnement au travail ou même en appliquant une règle de travail de façon différente. Votre droit à un accommodement dépendra de votre situation particulière et de vos besoins particuliers.

Par exemple:

- Un employeur peut être obligé de faire des changements physiques dans le lieu de travail pour répondre aux limitations de mobilité d'un employé.
- Un employeur peut être tenu de modifier les responsabilités de l'employé, ou de fournir de l'équipement de travail spécialisé, si l'employé ne peut plus exercer ses fonctions originales en raison d'un handicap.
- Un employeur peut être tenu de modifier les normes de productivité ou de performance, dans le cas où un employé ne peut pas remplir les normes existantes en

- An employer may be required to allow for alternative work arrangements, such as compressed hours, flexible hours or a flexible place of work to accommodate an employee's disability.

How do I request accommodation from my employer?

The nature of the accommodation required and the ways in which an employer can fulfill its duty will vary according to each individual's unique needs, which must be assessed and accommodated on an individualized basis.

There are a number of steps you should take in order to request appropriate accommodation from your employer:

- While employers will sometimes be under an obligation to inquire into whether an employee needs accommodation, it is generally your responsibility, as the employee, to communicate your need for accommodation to the employer. Ideally, you should make this request for accommodation in writing, explaining why you need accommodation. In your request, you should also provide information regarding your medical restrictions and limitations.
- As an employee requesting accommodation for a disability, you have an obligation to provide medical documentation explaining your medical restrictions and limitations to your employer. But employers are entitled to only the information necessary to determine what accommodation is required, not your entire medical file.
- After you have made your request, you are required to participate and cooperate with your employer in identifying the best ways to accommodate your medical restrictions and limitations. This may involve providing additional information to help the employer understand what it needs to do to provide accommodation.
- Finally, employees may be required to accept accommodations that appropriately address their needs, even if the accommodations are not ideal or exactly what the employee has asked for.

raison d'un handicap.

- Un employeur peut être tenu de permettre des conditions de travail flexibles, telles que les heures comprimées, des horaires flexibles ou un lieu de travail flexible pour accommoder l'incapacité de l'employé.

Comment puis-je demander un accommodement de mon employeur?

La nature de l'accommodement qu'un employé requiert et les moyens par lesquels l'employeur peut remplir son obligation varieront selon les besoins uniques de chaque individu, et ceci doit être évalué cas par cas.

Il y a plusieurs étapes que vous devez prendre pour demander un accommodement approprié de votre employeur:

- Alors que les employeurs seront parfois dans l'obligation de se renseigner quant au besoin d'accommodement de l'employé, il est généralement votre responsabilité, en tant qu'employé, de communiquer votre besoin d'accommodement à l'employeur. Idéalement, vous devriez faire cette demande à l'écrit, en expliquant pourquoi vous avez besoin de l'accommodement. Dans votre demande, vous devez également fournir l'information sur vos restrictions et limitations médicales.
- En tant qu'employé qui demande un accommodement à son employé, vous avez l'obligation de fournir de l'information médicale expliquant vos restrictions et limitations. Par contre, les employeurs ont uniquement droit à l'information nécessaire pour déterminer quel accommodement est requis dans votre situation, et non pas l'ensemble de votre dossier médical.
- Une fois que vous avez fait votre demande, vous êtes tenu de participer et de coopérer avec votre employeur en identifiant les meilleures façons de répondre à vos restrictions et limitations médicales. Ceci peut impliquer devoir fournir plus d'information pour aider l'employeur à mieux comprendre ce qu'il doit faire pour fournir un accommodement.
- Finalement, les employés peuvent être tenus d'accepter un accommodement qui remplis les besoins de l'employé, même si ces accommodements ne sont pas idéales ou exactement ce que l'employé recherchait.

What if the employer won’t accommodate me?

The duty to accommodate is not limitless. Even where it seems like the employer may have failed to provide necessary accommodation, the employer may nonetheless justify its policy, practice or expectation. For instance, employers may be able to establish that accommodating an employee would cause the employer such significant hardship that it should not be required to provide accommodation.

Examples of undue hardship can include changes that endanger your health and safety or the health and safety of others, or changes that impose a financial cost that is so significant that it threatens the viability of the employer’s business. That being said, the standard on the employer is high and will usually not be met unless the employer has exhausted every reasonable, available step it could take to provide accommodation.

Conclusion

Whether your employer has fulfilled its duty to accommodate your needs – and whether it will be able to establish a defense if it has not – is a very individualized and fact-based inquiry. If, after requesting accommodation for your disability and providing your employer with the necessary information, you believe that your employer has failed to accommodate you on the basis of your disability, you may have been subject to discrimination, and you should seek advice from a lawyer.

If you have questions regarding this or other disability/employment-related legal matters, please do not hesitate to contact our experienced lawyers at *Raven, Cameron, Ballantyne & Yazbeck*. Our firm provides advice and representation to employees, unions, and public interest organizations involved in human rights, disability, employment law, wrongful dismissal and accommodation matters.

[*This article is for informational purposes only and does not constitute legal advice, which cannot be given without consideration of your individual circumstances. If you are a unionised employee, we advise you to contact your union representative to request assistance in getting appropriate accommodation.*]

Que faire si l’employeur ne veut pas m’accommoder?

L’obligation d’accommodement n’est pas illimitée. Même dans les cas où il semble que l’employeur a manqué à son obligation d’accommodement, il se peut que l’employeur puisse justifier sa politique, sa pratique, ou ses règles de pratique. Par exemple, les employeurs peuvent être en mesure de démontrer que l’accommodement causerait une contrainte excessive de sorte qu’il ne devrait pas être tenu d’accommoder son employé.

Des exemples de contraintes excessives peuvent inclure des changements qui mettent en danger la santé et la sécurité des autres employés, ou des coûts financiers importants qui menacent la viabilité de l’entreprise de l’employeur. Cela étant dit, l’obligation de l’employeur d’accommodement est élevée et ne sera généralement pas satisfaite que si l’employeur a épuisé toutes les mesures disponibles et raisonnables qu’il aurait pu prendre pour fournir un accommodement à son employé.

Conclusion

La détermination à savoir si votre employeur a rempli son obligation d’accommodement - et s’il sera en mesure de faire valoir une contrainte excessive s’il ne l’a pas fait - est basée sur les faits spécifiques à votre cas. Si, après avoir demandé un accommodement pour votre handicap et après avoir fourni les informations nécessaires, vous croyez que votre employeur a manqué à son obligation d’accommoder votre handicap de façon adéquate, il est possible que ceci constitue de la discrimination. Si ça vous arrive, vous devriez consulter un avocat.

Si vous avez des questions à ce sujet ou d’autres questions liées à l’emploi ou à l’accommodement, s’il vous plaît n’hésitez pas à communiquer avec nos avocats expérimentés à *Raven, Cameron, Ballantyne & Yazbeck*. Notre cabinet fournit des conseils et de la représentation aux employés, aux syndicats et aux organisations d’intérêt public sur les sujets tels que les droits de la personne, l’incapacité, le droit de l’emploi, le congédiement injustifié et les questions d’accommodement.

[*Cet article est à titre informatif et ne constitue pas un conseil juridique, qui ne peut être donnée sans tenir compte de votre situation personnelle. Si vous êtes un employé syndiqué, nous vous conseillons de contacter votre représentant syndical pour demander de l’aide à obtenir un accommodement approprié.*]

CIHR Fellowship

The Canadian Institutes of Health Research announced that is would give priority designation for a fellowship in the area of ME, CFS or FM. That fellowship has now been awarded to Santiago Herrera Monroy. Mr Herrera will be working under the direction of Dr Patrick McGowan at University of Toronto (Scarborough). The topic of the study is Genotypic influences on epigenetic variability in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.

Epigenetic changes constitute important response mechanisms in individuals to environmental changes during their lifetime. Differences in environmental conditions have been the main research focus to explain this variability. However recent evidence has indicated that these differences in environmental conditions alone cannot explain all the epigenetic responses we observe, but that underlying genetic variability is also an important factor. Understanding the biological basis of complex traits and diseases remains one of the biggest challenges in biology and medicine. Human Chronic Fatigue Syndrome (CFS) (also known as Myalgic Encephalomyelitis - ME) is clear example of a complex disease with multiple symptoms that vary substantially among diagnosed patients. Recent exploratory studies have found that epigenetic and genetic factors are involved in this disease. Understanding the association between genetics and epigenetics in CFS/ME will help elucidate the causes for this disease, and thus provide new tools to identify risk factors and potential therapeutic treatments. CFS/ME constitutes an excellent study model that can help enhance our understanding of complex diseases, and, more broadly, of the biological mechanisms that are involved in phenotypic responses. This research proposal aims to investigate the role that genetic variation has on the DNA epigenetic variation related to CFS/ME. The main objectives of this research are to i) Identify the genetic and epigenetic variation associated with CFS/ME; and ii) Test associations between genetic and epigenetic variation, and symptom severity in CFS/ME diagnosed patients

Study from UBC

Wouldn't it be nice if there were a test for post-exertional malaise that did not exhaust the patient! A study by Dr Ruth Miller and others at UBC for the Journal of Translational Medicine suggests that it may be possible in the future.

Background

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a debilitating illness. Symptoms include profound fatigue and distinctive post-exertional malaise (PEM). We asked whether a submaximal exercise test would prove useful for identifying different patterns of tissue oxygen utilization in individuals with ME/CFS versus healthy subjects. Such a test has potential to aid with ME/CFS diagnosis, or to characterize patients' illness.

Methods

A case-control study of 16 patients with ME/CFS compared to 16 healthy controls completing a 3-min handgrip protocol was performed. Respons was measured using near-infrared spectroscopy, resulting in measurements of oxygenated (O2Hb) and deoxygenated hemoglobin (Hhb) over wrist extensors and flexors. Changes in O2Hb (delta (d)O2Hb) and HHb (dHHb) absorbance between the first and last contraction were calculated, as were the force-time product of all contractions, measured as tension-time index (TTI), and ratings of perceived exertion (RPE)

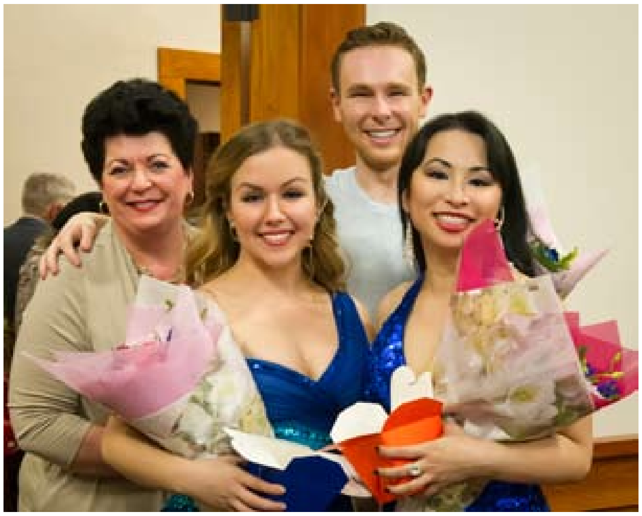
Results

Individuals with ME/CFS demonstrated smaller dO2Hb and dHHb than controls. However, after adjusting for TTI and change in total hemoglobin (delta (d)tHb), differences in dO2Hb and dHHb were reduced with large overlapping variances. RPE was significantly higher for cases than controls, particularly at rest.

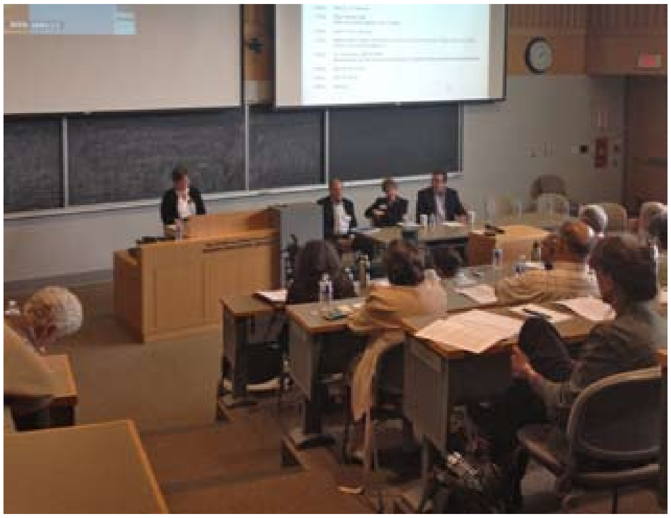
Conclusions

Relative to controls, participants with ME/CFS demonstrated higher RPE, lower TTI, and reduced dO2Hb and dHHb during repetitive handgrip exercise, although considerable variance was observed. With further study, submaximal exercise testing may prove useful for stratifying patients with a lower propensity for inducing PEM, and have the ability to establish baseline intensities for exercise prescription.

Images from May 12th

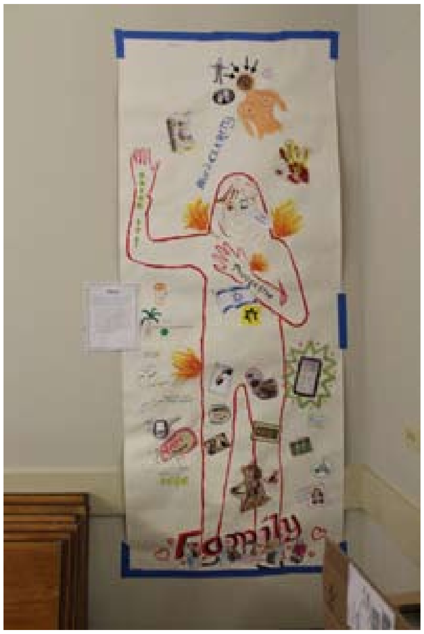


Sherri Todd of the National ME/FM Action Network with performers Kyle Preston Oliver, Robin Eder-Warren and Jacqueline Ko of Opera Mariposa. The *Tour de Force* production was a fundraiser for ME and FM

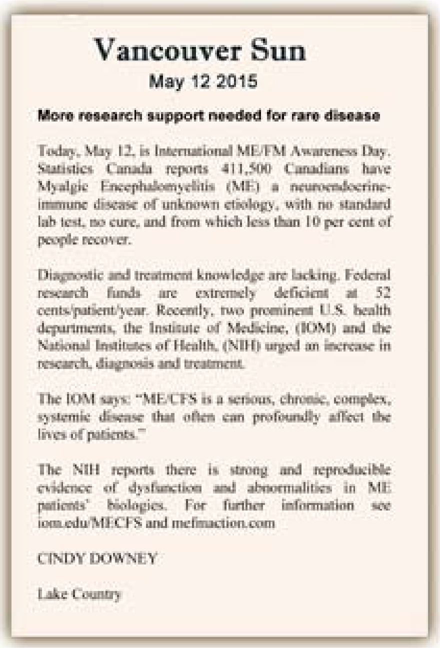


The MEFM Society of BC hosted a special awareness day event with guest speakers Dr Daniel Peterson, Staci Stevens and Dr Ian Hyams.

The "Light up the Night Challenge" was a huge success with buildings, landmarks and private homes lit up around the world.



Body Map on display at Toronto awareness event.



Vancouver Sun

May 12 2015

More research support needed for rare disease

Today, May 12, is International ME/FM Awareness Day. Statistics Canada reports 411,500 Canadians have Myalgic Encephalomyelitis (ME) a neuroendocrine-immune disease of unknown etiology, with no standard lab test, no cure, and from which less than 10 per cent of people recover.

Diagnostic and treatment knowledge are lacking. Federal research funds are extremely deficient at 52 cents/patient/year. Recently, two prominent U.S. health departments, the Institute of Medicine, (IOM) and the National Institutes of Health, (NIH) urged an increase in research, diagnosis and treatment.

The IOM says: "ME/CFS is a serious, chronic, complex, systemic disease that often can profoundly affect the lives of patients."

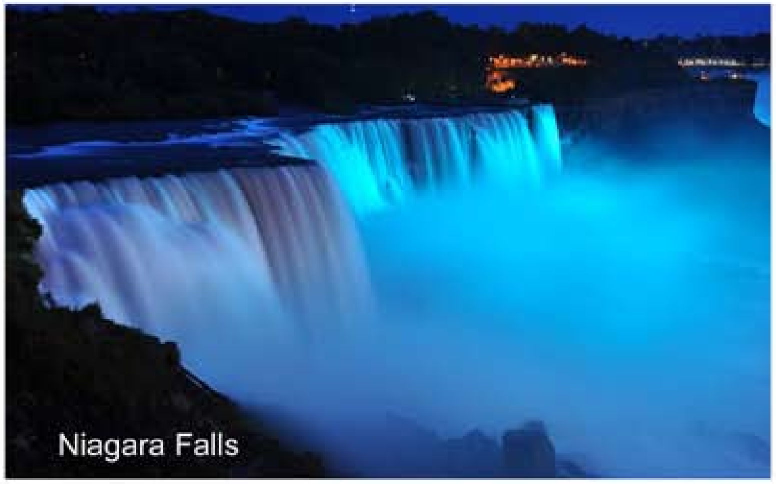
The NIH reports there is strong and reproducible evidence of dysfunction and abnormalities in ME patients' biologies. For further information see iom.edu/MECFS and mefmaction.com

CINDY DOWNEY

Lake Country

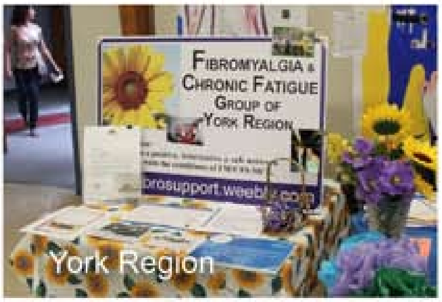
Newspaper articles and radio programs promoted awareness on May 12th


Information Table, Toronto


Niagara Falls

Central Bank of Malta

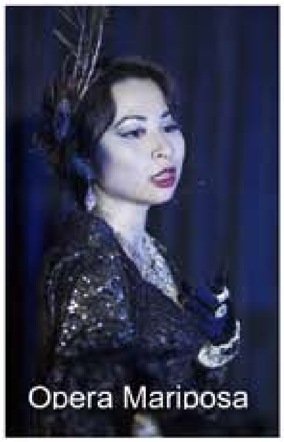

Brighton Wheel, UK



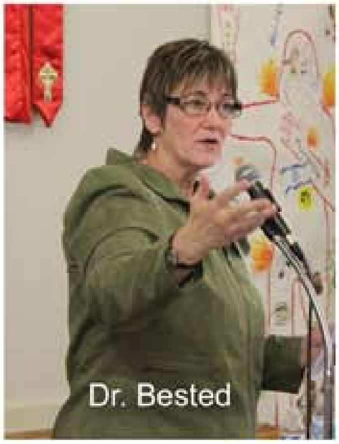
York Region

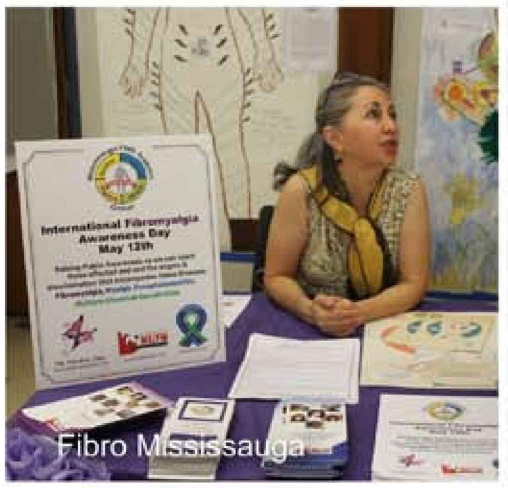

Toronto Presentations


Science World, BC


Opera Mariposa

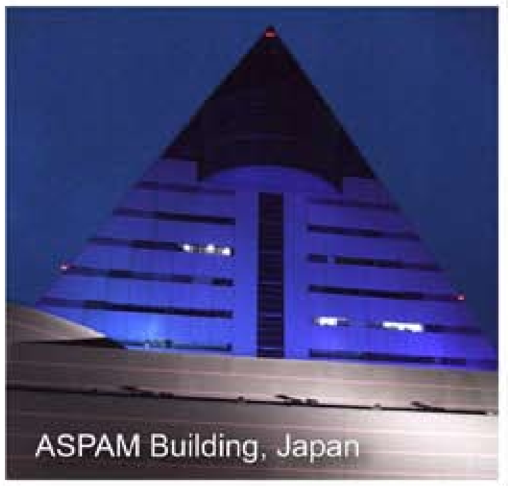

Peace Bridge between Canada and USA


Dr. Bested

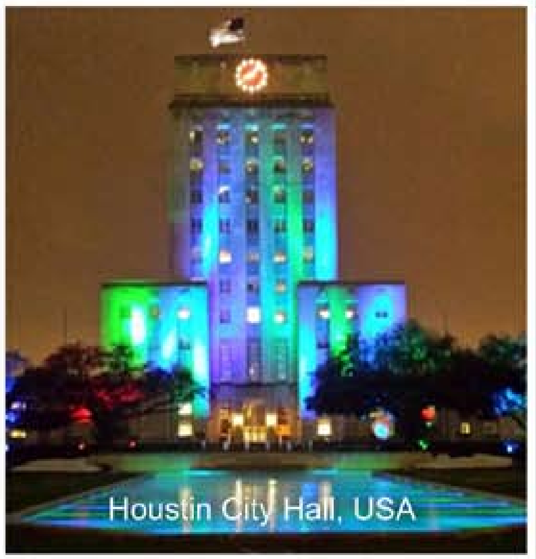


Fibro Mississauga

Canada Place Sails of Light, BC

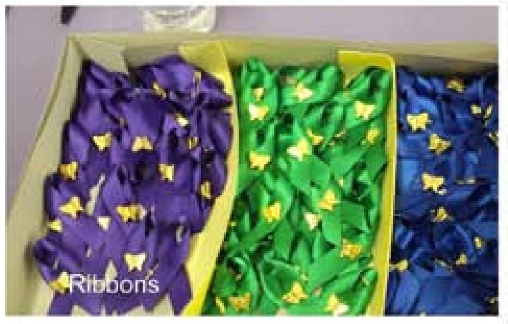


ASPAM Building, Japan



Houstin City Hall, USA

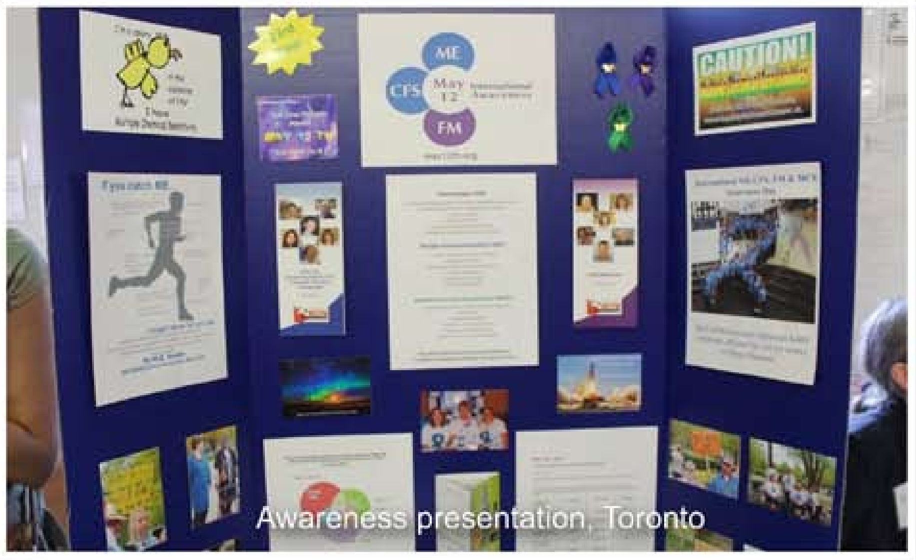
Opera Mariposa



Ribbons

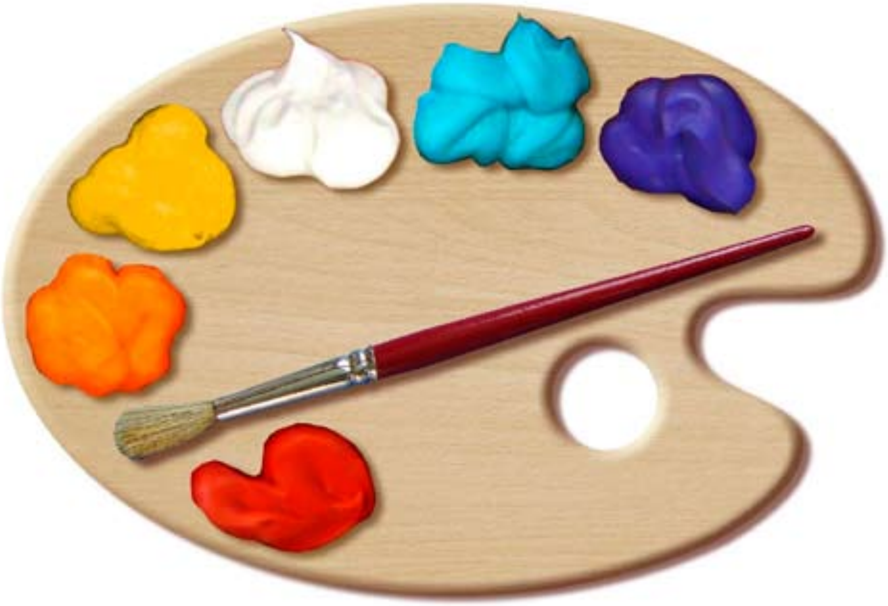
May 12, 2015

Perth, Australia



Awareness presentation, Toronto

International Art Contest
for
Young Artists with ME/CFS



We wish to showcase the artwork of a young patient with ME/CFS, and demonstrate that although seriously ill, these young patients are still capable of great accomplishments

Young artists currently diagnosed with, or recovered from, ME/CFS, and are aged 17 and younger, are invited to submit artwork to be placed on the cover of a new Primer for doctors looking after young people with ME/CFS.

The new Primer will assist pediatricians and primary care physicians in the diagnosis and management of ME/CFS in children and young adults.

Further information and an application form can be obtained from Dr. Kenneth J. Friedman at Kenneth.j.friedman@gmail.com

Contest closing date is June 30, 2016.

ME/CFS–An Invisible Illness No More

Thirty Years of Disdain: How HHS buried M.E.

A thought-provoking document was released for discussion and comment in May 2015. It brings to the surface the interrelationship between US government health policy and health services. h*ttp://bit.ly/The_Burial_of_ME*

The document was written by a mother (Mary Dimmock) and son (Matthew Lazell-Fairman) in the US. The son completed university and launched into adult life. Then at the age of 23 he was stricken with ME. The authors discovered to their dismay how little understanding and support there is for this illness despite the fact that it has been on the US government's radar screen for a full 30 years and despite the fact that it is imposing a huge burden on individuals, their families, and the country.

This document explores why so little is known about or done for ME in the US. The authors place most or all of the blame on the policies of the US Department of Health and Human Services (HHS). They talk about the need for leadership and for the following components (page 136):

1. appropriate engagement of patients, caregivers and supporters
2. strategy and oversight
3. good quality definition
4. funding commensurate with disease impact
5. treatment centers
6. active recruiting of researchers and clinicians
7. education of health professionals
8. attention to social issues associated with the illness

They also scratch behind these components to figure out why this situation has been allowed to happen. They identify a number of cultural tendencies such as a willingness to allow sloppy science, an undervaluing of diseases that primarily affect women, and a discomfort with problems that don't align with pre-existing institutional structures. (page 135)

The authors demonstrate an extraordinary lack of confidence in the professionalism of HHS:

Fixing this problem is going to require sweeping changes in every aspect of HHS's policies and actions toward this disease. But HHS is not going to make the magnitude of changes needed unless pressured to do so by those outside of HHS, particularly the media, the public and Congress. (page 5)

One sad observation is that many reasonable people have arrived at the same conclusions as the authors. Another sad observation is that, even though HHS does not operate in Canada, the same lack of support plagues ME patients here.

Priority Setting Partnership on Adult Fibromyalgia

The Canadian Institutes of Health Research is continuing its project to identify the top 10 treatment uncertainties around Adult-Fibromyalgia. The project supposedly follows a process developed by the James Lind Alliance (JLA) in the UK. The JLA process has been used for other medical conditions like asthma, eczema, Parkinson's and schizophrenia.

The National ME/FM Action Network has been asked to promote the project and to distribute survey questionnaires. We will not be doing so. The project does not meet components 1-3 of the Dimmock/Lazell Fairman list – community engagement, strategy and definition (see previous article):

1. The project has not engaged the FM community in an appropriate way. It was not built as a partnership but rather as people telling the community what the community should want.
2. The project does not meet a current strategic need. The JLA process asks front-line clinicians and their patients to identify "treatment uncertainties" in order to motivate funders and researchers to pay attention to those issues. This implicitly assumes that funding, research and treatment are already in place (components 4-8 above). This is not the case for FM.
3. The scope of "Fibromyalgia" has not been specified for this project though indicators suggest that that a broad chronic pain definition is being used.

The Network has contacted the James Lind Alliance pointing out that the project was not following the proper protocols, notably the oversight by partners.

We would like to extend congratulation to Michelle Skop for completing her PhD and to thank her for her participation at the Toronto awareness event. Here is a summary of her thesis.

Maps of Marginalization:
Exploring the Healthcare Experiences of Men and Women with Fibromyalgia

Dissertation Study: Executive Summary
May 11, 2015
Michelle Skop, MSW, RSW, PhD Candidate
Faculty of Social Work, Wilfrid Laurier University

Introduction

This dissertation study was conducted by a PhD Candidate in the Faculty of Social Work at Wilfrid Laurier University and received approval from Laurier's Research Ethics Board. The purpose of the study was to explore the retrospective and ongoing healthcare experiences of men and women with a diagnosis of fibromyalgia (FM). FM is a chronic, gendered, and contested condition of unknown origin and is prevalent in children and adults in both industrialized and non-industrialized countries (Clauw, 2014). In Canada, 1.5% of the population – 437,550 people -- has a diagnosis of FM, and 79% of those diagnosed are women (Statistics Canada, 2011). People with FM experience a constellation of symptoms including chronic widespread pain, fatigue, sleep disturbances, memory loss, and sensitivity to sensory stimuli (Clauw, 2014). These symptoms, which can unpredictably shift in frequency and severity, impact people's global functioning, quality of life, and socioeconomic status (Sim & Madden, 2008).

Methods

The study's central research question was: "How do men and women who have a diagnosis of FM experience interactions with healthcare providers?" This question was answered through interviews, focus groups, and an arts-based research methodology called body-map storytelling (Gastaldo, Magalhaes, Carrasco & Davy, 2012). Body maps are life size drawings, which depict people's inner-worlds within their social contexts (MacGregor, 2009). In this study, participants created body maps to both verbally and visually express their healthcare journeys.

Thirty women and five men, living in the Greater Toronto Area (GTA) and the region of Kitchener-Waterloo, provided informed consent to participate in this study. Out of these 35 participants, 11 completed individual interviews and 24 participated in focus groups. The 24 participants were divided into four different focus groups based on geographical region. Each focus group contained five to seven participants, was held in a different location across the GTA and Kitchener-Waterloo, and involved up to six two-hour sessions. In these sessions, participants shared their healthcare experiences and created body maps through a series of activities. All sessions were audio-recorded and then transcribed for the purpose of data analysis.

Both the individual interviews and focus group sessions generated a large amount of rich data. As such, the dissertation study reported the findings from the focus group sessions. Future articles, which will be published in academic journals, will report the interview findings.

Summary of Key Findings

Five key findings emerged through the process of analyzing the focus group participants' verbal narratives and body maps.

1. Most participants experienced compromised healthcare. The term compromised healthcare refers to the ways in which the provision of ethical, equitable, and adequate healthcare services was impeded by barriers at both the structural-level of institutions and within patient-provider interactions.
    a. Structural-level barriers included the restricted time of medical appointments, the absence of a clear path for finding and navigating FM healthcare services, and the lack of continuity of care.
    b. Barriers within patient-provider interactions included the stereotype that FM was an illegitimate condition. This stereotype appeared in healthcare providers' negative attitudes towards patients with FM. Negative attitudes -- ranging from moral judgment to paternalism, apathy to verbal abuse -- were manifested in punitive healthcare practices (i.e., threatening to withhold medical services or actually withholding said services).
2. Some participants' experiences of compromised healthcare were impacted by their diverse identities (e.g., differences in gender, age, class, culture, and race, etc.). For example, some female participants reported that doctors explained away their FM as a

symptom of the stress of balancing multiple roles, such as being a spouse and/or parent.

3. Most participants resisted the system of compromised healthcare through strategies of self-management. Self-management strategies included:
   a. Advocacy and asserting the human right to receive unbiased care;
   b. Educating healthcare providers and the public about FM;
   c. Seeking treatment outside of the mainstream medical system;
   d. Adopting practices of self-care, which combined gentle exercise, nutrition, meditation, and sleep hygiene;
   e. Learning to experience self-efficacy, a form of empowerment that involved feeling in control of and gaining mastery over FM;
   f. And, finding peace and strength through spirituality.
4. Some participants experienced positive interactions with healthcare providers. Positive interactions involved receiving comprehensive care based on providers' abilities to: collaborate, be held accountable for their actions, spend time with patients, and foster a therapeutic alliance. All narratives of positive interactions had a common theme: providers legitimized the reality of FM.
5. Most participants shared their strategies for changing the healthcare system. They envisioned a patient-centered, transdisciplinary, cost-effective, integrated, and centralized healthcare system. They also emphasized the importance of increasing knowledge about FM by promoting research.

Implications

The findings of this study have led to a better understanding of the healthcare experiences of men and women with FM. These findings have contributed crucial information for the future development of healthcare policies, programs, and clinical practices for the FM patient population. For example, these findings could be used to develop programs for healthcare providers about communication strategies that foster supportive and legitimizing interactions. As a form of applied research, the study has also helped give voice to a marginalized population.

The study findings have illuminated a multitude of future directions for research. For example, a limitation of this study was that it did not explore the experiences of healthcare providers. Further research is required to examine providers' attitudes towards and practices for patients with FM. Studies about providers should compare the experiences of male and female providers working in different healthcare fields. It would also be helpful compare the experiences of patients and providers, bringing both groups together in order to dialogue about what it is like to both obtain and deliver healthcare services. In addition, future research should examine: how the policies and practices of insurance companies impact people with FM who are on work leave; how people with FM cope with social isolation; and how body-mapping could be utilized as a therapeutic intervention for people with chronic conditions.

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Statistics Canada. (2011). *Canadian Community Health Survey*. Public Use Microdata File (2009/2010, Released November 7, 2011), Statistics Canada Catalogue no. 82M0013XCB. *http://www5.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=82M0013X&chropg=1&lang=eng*

Samples of the body maps produced can be found in our photo album at: *https://www.facebook.com/media/set/?set=a.977620768924533.1073741829.119761554710463&type=3*

Statistics on Mobility

The issue of mobility has been identified as a priority by the Canadian Institutes of Health Research.

The Canadian Community Health Survey (CCHS) 2010 questionnaire asks about mobility using the following question:

Are you usually able to walk around the neighbourhood without difficulty and without mechanical support such as braces, a cane or crutches? Yes / No

As you can see, the question is imprecise, leaving it to the respondent to interpret “usually”, “the neighbourhood” and “without difficulty”. The data is based entirely on the answer given by the respondent.

The following tables divide the respondents into two groups, those aged 12 to 69 and those aged 70 or older.

About 600,000 Canadians aged 12 to 69 (2% of that population) reported usually having difficulty walking around their neighbourhood. For people reporting a

Table 1: Canadian population aged 12 to 69 with chronic conditions having mobility problems, 2010 CCHS

Chronic Condition	% with Mobility Problem
Effects of a stroke	24.5[E]
Urinary incontinence	17.7
CFS	17.5
COPD	15.6
FM	15.3
Cancer	11.0[E]
Arthritis	10.6
Heart disease	10.0
Diabetes	9.6
Mood disorder	9.0
MCS	8.1
Ulcers	8.1
Anxiety disorder	7.7
Bowel disorder	7.1
Back problems	6.5
High blood pressure	6.5
Asthma	4.5
Migraines	3.8
Total population	2.3

Table 2: Canadian population aged 70 and older with chronic conditions having mobility problems, 2010 CCHS

Chronic Condition	% with Mobility Problem
Effects of a stroke	50.1
CFS	41.6[E]
Urinary incontinence	41.3
Mood disorder	39.5
FM	38.4[E]
Bowel disorder	34.6
Anxiety disorder	34.6
Back problems	33.3
COPD	32.9
Heart disease	30.5
MCS	30.0[E]
Arthritis	29.6
Asthma	29.0
Ulcers	27.9[E]
Diabetes	27.8
Cancer	26.8
High blood pressure	23.3
Migraines	22.4[E]
Total population	20.4

Source: Statistics Canada, Canadian Community Health Survey, 2010, Public Use Microdata File

[E] Use with caution (Coefficient of Variation between 16.6 and 33.3)

Arthritis = ages 15+; COPD = ages 35+; Urinary incontinence = ages 25+

Chronic Fatigue Syndrome is the term used in the survey.

Table prepared by The National ME/FM Action Network. This analysis is based on the Statistics Canada Canadian Community Health Survey Public Use Microdata File, 2010. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network.

diagnosis of Chronic Fatigue Syndrome the rate was 18%. and for people reporting a diagnosis of Fibromyalgia the rate was 15% (Table 1).

About 600,000 Canadians aged 70 or older (20% of that population) reported usually having difficulty walking around their neighbourhood. For people reporting a diagnosis of Chronic Fatigue Syndrome the rate was 42%. and for people reporting a diagnosis of Fibromyalgia the rate was 38% (Table2).

Of people aged 12 to 69 reporting mobility problems, 17% reported a diagnosis of CFS and/or FM (Table3). The rate drops to 7% for people aged 70 or older (Table 4). One possible explanation for the drop is under-diagnosis of CFS and FM in older people.

Mobility is a complicated issue and more investigation is needed to understand the factors at play. Any investigation needs to consider the high rates of mobility problems experienced by Canadians with CFS and FM.

Table 3: Canadian population aged 12 to 69 with mobility problems having chronic conditions, 2010 CCHS

Chronic Condition	% with Chronic Condition
Arthritis	54.7
Back problems	51.0
High blood pressure	36.9
Mood disorder	26.3
Diabetes	20.9
Migraines	18.0
Anxiety disorder	18.0
Asthma	16.9
CFS and/or FM	16.7
COPD	16.7
Urinary incontinence	15.6
Heart disease	13.1
Bowel disorder	12.4
CFS	10.2
FM	10.0
MCS	9.5
Ulcers	9.4
Effects of a stroke	6.7^E
Cancer	6.0^E

Table 4: Canadian population aged 70 and older with mobility problems having chronic conditions, 2010 CCHS

Chronic Condition	% with Chronic Condition
Arthritis	67.1
High blood pressure	58.0
Back problems	44.0
Heart disease	32.3
Urinary incontinence	28.4
Diabetes	24.8
COPD	12.5
Effects of a stroke	12.2
Bowel disorder	11.6
Cancer	9.9
Asthma	9.8
Mood disorder	9.6
CFS and/or FM	7.4^E
Anxiety disorder	6.7^E
Ulcers	5.4^E
MCS	5.3^E
CFS	4.6^E
Migraines	4.4^E
FM	3.3^E

Source: Statistics Canada, Canadian Community Health Survey, 2010, Public Use Microdata File

^E Use with caution (Coefficient of Variation between 16.6 and 33.3)

Arthritis = ages 15+; COPD = ages 35+; Urinary incontinence = ages 25+

Chronic Fatigue Syndrome is the term used in the survey.

Table prepared by The National ME/FM Action Network. This analysis is based on the Statistics Canada Canadian Community Health Survey Public Use Microdata File, 2010. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network.

Pathways to Prevention Report (US)

The draft P2P report on fixing ME research was released last December and the public was given one month to comment. The next step was a review of the comments by the panel members. The review has not gone smoothly. A patient advocate submitted an access-to-information request and discovered that the panel members had not been given all the submissions. A subsequent access-to-information request discovered that the panel members had received some but not all the missing submissions. The final P2P report is now scheduled for release on June 16. We will see what happens.

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THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter—Free with annual membership of $30.00

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

ME/CFS and FM Brochures - FREE

Coloured pamphlets on ME/CFS and FM are available in English and French. You can view them on our website

Consensus Documents for ME/CFS and FM

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols [Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004 ISBN:0-7890-2207 9]
- The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4]

The consensus documents are available at Amazon.ca or at Chapters.ca or view them on our website.

ME/CFS and FM Overviews - $7.00

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents.

- You can view the ME/CFS Overview in English, French, Spanish, German, Italian and Dutch on our website. English versions of the ME/CFS Overviews are available for purchase from the National ME/FM Action Network. French versions of the ME/CFS Overview are available for purchase from Quebce Association for ME, AQEM (aqem.ca)- call (514) 369-0386 or 1-855-369-0386 or email info@aqem.ca.
- You can view the FM Overview in English, French, Spanish and Italian on our website. English versions of the FM Overview are available for purchase from the National ME/FM Action Network.

TEACH-ME (Second Edition) - $25.00

Our TEACH-ME Source Book is for Parents and Teachers of children and youth with ME/CFS and/or FM. This document is available in English and French.

CANADA PENSION PLAN DISABILITY GUIDE 2015 Edition- $10.00

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

Chronic Fatigue Syndrome / Myalgic Encephalomyelitis - Primer for Clinical Practitioners

Syndrome de fatigue chronique Encéphalomyélite myalgique - Petit guide pour la médecine clinique - $25.00

The ME/CFS Primer was produced by the International Association for Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (IACFS/ME). It was translated into French by the National ME/FM Action Network. You can view both the English and the French on our website. Bilingual versions are available for purchase from the National ME/FM Action Network.

All of the above resources can be viewed on the

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