NATIONAL ME/FM ACTION NETWORK

Quest Newsletter

www.mefmaction.com Quest 105, Winter 2015 mefminfo@mefmaction.com

A Short History of the National ME/FM Action Network

The National ME/FM Action Network was founded in 1993 by Lydia Neilson. Prior to that, Lydia had started a local ME/FM patient support group and had volunteered with a ME/FM research foundation. Lydia noted a gap in service – the lack of a patient-focused ME/FM organization for Canada. She started the Network to become the eyes, ears and voice of the ME/FM community at the national level.

The organization has evolved over time as needs have changed. The story can be broken down into phases of about 5 years each:

Phase 1: Reaching out (1993-98)

In the early years, the Network focused on identifying and developing connections in Canada and internationally. It reached out to ME/FM patients and support groups, identified and reached out to health professionals and lawyers who were supportive of ME/FM patients, and monitored international developments because we are working within an international context.

Very importantly, the Network started the Quest newsletter and the national website to share information and discuss issues.

The Network was instrumental in establishing May 12 as International ME/FM Awareness Day. May 12th was chosen as it was Florence Nightingale's birthday and she may have had ME/CFS or FM.

Even at this early stage, the Network applied for intervenor status in a court case of national significance dealing with fibromyalgia.

Phase 2: Developing Resources (1998-2003)

The years 1998-2003 were focused on compiling resources to respond to the needs of the community.

A survey conducted by the Network found that health professionals wanted and needed diagnostic and treatment protocols for ME/CFS and FM. The Network asked Doctors Anil Jain and Bruce Carruthers, two experts in the illnesses, to develop draft documents. The Network also convinced Health Canada to appoint panels of international experts to review the documents. Both panels came to unanimous agreements. The consensus criteria for ME/CFS and FM were published in peer reviewed journals in 2003.

Recognizing that young people can be affected by ME/CFS and FM, the Network supported a team which published the Teach-ME Sourcebook for Teachers of students with ME/CFS and/or FM.

Recognizing the challenges of applying for disability benefits, the Network wrote the first edition of the CPP-Disability Application and Appeals Guide.

Recognizing the legal issues around the illnesses, the Network published a manual for lawyers compiling important legal cases.

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Phase 3: Sharing Resources (2004-2008)

The focus of this period was on sharing the information as widely as possible. The consensus documents and the shorter Overviews were sent to patients, doctors, medical schools and libraries. The Sourcebook was sent to schools, school boards and children's aid societies. The Overviews and Sourcebook have been translated into French to reach a wider audience.

During this period, the Network appeared as an intervenor before the Supreme Court of Canada. The Supreme Court found that an employer had wrongful dismissed an employee with ME/CFS.

Also during this period, Lydia was awarded the Meritorious Service Meal by the Governor-General for her contributions to the ME/FM community.

Phase 4: Building Evidence/ Proposing solutions (2009 – 2015)

During this period, the Network put together evidence of the situation facing Canadians with ME/CFS. A major source of information was the Canadian Community Health Survey which showed that ME/CFS and FM are frequently diagnosed and that these conditions entail a high degree of disability and disadvantage. The questions on CFS, FM and MCS had been removed from the survey after 2005. The ME/FM/MCS community spoke up and the questions were reinstated for 2010, 2014 and for additional years in the future.

Also during this period, the Network hosted the biennial conference of the IACFS/ME. This meeting brought world experts to Ottawa to look at the state of research and clinical care.

The Network has brought to light issues in Canada's health research program, health delivery system, and disability system and has suggested ways that these issues could be resolved.

The Future

The fact that the government of BC has begun addressing issues, the fact that collaboration is starting to happen in other countries and the stated intentions of the Liberal Party of Canada gives us hope that more doors will open here in Canada. The Network will be ready. In the meantime, we have identified upgrading our website as a high priority project. Through the website, we can speak to many people.

We are thankful to everyone who has supported our organization over the years. We would like to give special recognition to the provincial and local organizations across Canada supporting Canadians with ME/CFS and/or FM. They serve the ME/FM community in different but very important ways.

The Network's task is a difficult one. However, like our Logo - the Canada Geese flying in 'V' formation making their trek easier - our task is made easier by working together.

Alison Bested Scholarship Recipients

To the Members of the National MEFM Action Network,

I would like to thank you for supporting my elective in Environmental Medicine at the Women's College clinic in Toronto. This unique clinic directs the care for patients who come for assessment for fibromyalgia (FM) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), as well as other similar conditions. Patients are given incredibly detailed assessments at this clinic, and often feel very validated at the end of their visit. If one thing was made clear with this elective, it is that patients who come to their practitioners with these conditions often do not feel as though they were adequately listened to in previous interactions with physicians.

During this elective I learned how to take a very thorough environmental exposure history. I also learned about treatment options for people suffering from pain or fatigue, but mostly I learned about how the symptoms of FM and ME/CFS can affect people's function. It is amazing how people's work and personal lives are impacted when suffering from long-standing pain or fatigue. Working with these patients gave me a better understanding of how important it is for them to be heard, and how desperate they can be for some form of help.

While this elective was too short to more than begin to understand these complex conditions, it was helpful to meet people who live with them so I can begin to form an approach for when I begin my own medical practice.

Thank you again,

Sarah Stewart
Senior Year Medical Student
College of Medicine
University of Saskatchewan

I spent a two-week elective at the Environmental Health Clinic in the Women's College Hospital, located in Toronto, Ontario. In my time there, I saw several patients with Fibromyalgia. In seeing these patients, we spent several hours gathering their history. Throughout medical school, we are taught how to take a history; however, the in-depth histories that I observed (and was involved in) were much more comprehensive than I had ever seen. Most clinics focus on area or organ-specific disorders, whereas the environmental medicine clinic took a holistic approach to the patient's disease. The history covered an exposure history, birth-present medical history, psychological history, as well as physical exam. On top of learning the comprehensive history, I also learned other treatment methods that are not used in most areas of medicine.

When I work as a family physician, I plan to incorporate several aspects from this clinic into my practice. First, I will use consecutive clinic visits to gather a comprehensive patient history. Second, I will use a holistic approach to treating my patients, such as decreasing exposure to mold, optimizing sleep hygiene, augmenting with vitamins, physiotherapy, and pain control. Most importantly, I will take away the lesson that Fibromyalgia is a chronic disease that can only be treated with a multi-faceted approach. It is a debilitating disease which affects the function of so many Canadians; as a future physician, this experience will make me better able to help my patients with Fibromyalgia.

Karl Ayton, BSc

MD Candidate, Class of 2016
Faculty of Medicine and Dentistry
University of Alberta

Relying on Your Initial Diagnosis Can be Dangerous

In the past few months, I was reminded again how important it is that when you experience a new symptom, all avenues are explored before concluding your illness has added a new symptom.

I just lost a friend who for the past year was going to doctors for an ever-present headache. As she had been diagnosed previously with a medical condition, not much was made of her new symptoms and no tests were done. Finally, her headaches were so severe she was rushed to the hospital where tests were finally made. It was a dire diagnosis and her family was told she had only weeks to live. Tests indicated brain and stomach cancer but it was so advanced, there was nothing that could be done. Four days later she passed away.

Another friend of mine has had Lupus since she was a teenager. She is used to the flare ups and saw her rheumatologist on a regular basis. She then started having problems with her energy levels to such a degree that she was spending more time sleeping than staying awake. Her rheumatologist advised her that her Lupus was acting up and she would get over it.

Fortunately for her, the Rheumatologist retired and she got to see a replacement. When she related what had been happening to her, he immediately sent her for tests for her kidneys as well as her heart. Her heart turned out to be the culprit and without intervention she would have been dead in a few months.

Although these were extreme cases, there is also the possibility that a new symptom may be treatable and relying upon it being related to your present illness or condition may obscure any chance of getting relief.

It is important to remember that no matter what illness you have, it does not make you immune from getting anything else. To be safe, first get the new symptom checked out. Neither you or your doctor should feel confident that it is related to your present condition or illness.

Lydia

Media Release from NIH

NIH Takes Action to Bolster Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

The National Institutes of Health is strengthening its efforts to advance research on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), a disease for which an accurate diagnosis and effective treatment have remained elusive. The actions being taken include launching a research protocol at the NIH Clinical Center to intensely study individuals with ME/CFS and re-invigorating the efforts of the long-standing Trans-NIH ME/CFS Research Working Group with the National Institute of Neurological Disorders and Stroke (NINDS) as the lead of a multi-institute research effort.

“Of the many mysterious human illnesses that science has yet to unravel, ME/CFS has proven to be one of the most challenging,” said NIH Director Francis S. Collins, M.D., Ph.D. “I am hopeful that renewed research focus will lead us toward identifying the cause of this perplexing and debilitating disease so that new prevention and treatment strategies can be developed.”

NIH’s direction on the disease is being guided by a recent Institute of Medicine report (http://iom.nationalacademies.org/reports/2015/me-cfs.aspx), that recommended new diagnostic criteria and a new name for the disease (Systemic Exertion Intolerance Disease), and an NIH-sponsored Pathways to Prevention meeting that generated a position paper and report with recommendations for research strategies.

According to the Centers for Disease Control and Prevention, ME/CFS is estimated to affect more than 1 million Americans, and has been reported in people younger than 10 years of age and older than age 70. ME/CFS is an acquired, chronic multi-system disease characterized by systemic exertion intolerance, resulting in significant relapse after exertion of any sort. The disease includes immune, neurological and cognitive impairment; sleep abnormalities; and dysfunction of the autonomic system, which controls several basic bodily functions. These symptoms result in significant functional impairment accompanied by profound fatigue. Additional symptoms may include widespread muscle and joint pain, sore throat, tender lymph nodes and headaches. Effects of the illness can range from moderate to debilitating, with at least one-quarter of individuals with ME/CFS being bedbound or housebound at some point in the illness and many individuals never regaining their pre-disease level of functioning. Because the pathology of ME/CFS remains unknown and there is no test to diagnose the disease, studies to date have used different criteria for diagnosis, which has limited the ability to compare results across studies. Additionally, many of the published studies are based on small study populations and have not been replicated.

In an effort to remedy this situation, NIH will design a clinical study in the NIH Clinical Center with plans to enroll individuals who developed fatigue following a rapid onset of symptoms suggestive of an acute infection. The study will involve researchers from NINDS, the National Institute of Allergy and Infectious Diseases, National Institute of Nursing Research and National Heart, Lung, and Blood Institute. The primary objective of the study is to explore the clinical and biological characteristics of ME/CFS following a probable infection to improve understanding of the disease's cause and progression.

NIH will also be considering additional ways to support ME/CFS research in the extramural research community. Since the root cause of ME/CFS is unknown and the manifestations of the disorder cut across the science interests of multiple NIH institutes and centers, a trans-NIH working group will be needed to assist that plan. NINDS Director Walter J. Koroshetz, M.D., will chair the Working Group along with Vicky Holets Whittemore, Ph.D., the NIH representative to the U.S. Department of Health and Human Services' Chronic Fatigue Syndrome Advisory Committee. One goal of the group will be to explore how new technologies might shed light on what causes ME/CFS. The Working Group includes representation from 23 NIH institutes, centers and offices.

About the National Institutes of Health (NIH): NIH, the nation's medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

Recording of Expert Examinations: The Time Has Come!

More and more litigation is coming to depend on expert witnesses. This is the impetus behind the recent amendments to the *Rules of Civil Procedure*, which require all experts to sign an acknowledgement of the expert's duty - a duty that includes, among other things, a duty "to provide opinion evidence that is fair, objective and non-partisan" .

However, the reality is that experts are often hired by parties not only for their expertise but for their partisanship. One solution, in the medical context, that has been advocated by plaintiff's counsel for over twenty years is the recording of defence medical examinations. Our courts, however, have been less than enthusiastic about such steps - at least partially because of the fact that there is no corresponding duty on plaintiff medical examinations. However, there are indicia that suggest that this atmosphere of reluctance may be changing.

In Ontario, the governing law on the issue is the Ontario Court of Appeal decision in *Bellamy v. Johnson,* 1992 CarswellOnt 1712. In *Bellamy*, the Master had ordered the use of audiotape recording because of a perceived 'defence orientation' on the part of the medical expert examining. The Court of Appeal agreed that the courts did have the jurisdiction but found that there was no evidence of a defence-oriented bias. Doherty J.A., writing in a concurring decision noted three factors that a court should consider in making a decision on the recording of an examination; namely:

1. The opposing party's ability to learn the case it has to meet by obtaining effective medical evaluation;
2. The likelihood of achieving a reasonable pretrial settlement; and,
3. The fairness of the trial.

Doherty J.A. further found that the first factor is the predominant factor to consider.

Since *Bellamy*, our courts have struggled with this test and have been reluctant to grant orders for the recording of defence medical examinations. They have allowed such orders in cases where they found that there were genuine cognitive or memory problems which would handicap the plaintiff's ability to challenge the defending expert. However, the courts have been less forthcoming where the recording was requested as a result of an alleged bias on the part of the examiner (see, for example, *Worrall v. Walter*, 2009 CarswellOnt 101).

The Court of Appeal recently reviewed its decision in *Bellamy*. In *Adams v. Cook*, 2010 ONCA, a five member panel of the Court was invited to revisit *Bellamy* in a case where the plaintiff's counsel argued that there existed a systemic bias requiring the recording of examinations. While the majority refused to revisit *Bellamy*, a strong dissent argued that the nature of the relationship between the plaintiff and the examiner, the changes in the approach to expert reports, advances in technology and the advantages gained by an accurate record all advocate in favour of recording "absent any adverse impact on the examiner's ability to conduct an effective examination".

Shortly after the Court of Appeal's decision in *Adams*, Master Short in *Bakalenikov v. Semkiw*, 2010 ONSC 4928 argued that the then new Rules of Civil Procedure had changed the environment such that, although he was bound by the majority decision in *Adams*, the changed requirement of "frank and unbiased opinions" had changed the environment. Master Short suggests a presumption in favour of recording unless the Defence was able to give "evidence that this would be impractical, intrusive or an obstacle to their chosen expert conducting his interview and examination". The expert's preference or refusal to perform an examination under recording is irrelevant. Master Short hypothesizes that in the future all corresponding examinations will be recorded and concludes that:

> I believe the national trend is clearly towards allowing such records as quality control 'check on the process. I can see much benefit to the parties and the court. The court and ultimately the public have a right to be confident in the independence and competence of experts reporting on matters before the court.

However, to date, Master Short's analysis has not been tested in a higher court and, when reviewed, has not been seen as changing the current regime.

Bellamy, as supported by the majority in *Adams* remains the law in Ontario. However, both the dissent in *Adams* and Master Short's decision in *Bakalenikov* suggest that the environment is changing. It is submitted that Master Short is correct in his analysis that the environment has changed, particularly in light of the impact of the amendments to the *Rules of Civil Procedure*. It remains uncertain how the courts will develop this line of reasoning.

* Hugh Scher is a Toronto lawyer who practices disability insurance, labour, employment and human rights law with a focus on complex terminations of disabled employees, disability insurance claims and workplace accommodation and harassment disputes. He is past Chair of the Labour and Employment Law Section of the OBA and was also counsel in the landmark case of *Keays v. Honda* where he obtained the largest employment trial award of punitive damages in Canadian history, in a case that went up to the Supreme Court of Canada.

*Jeff Childs is a Toronto lawyer who practices disability insurance, employment and human rights law with a focus on complex terminations of disabled employees, disability insurance claims and CPP claims.

Scher Law Professional Corporation
Barristers & Solicitors
175 Bloor Street East, South Tower, Suite 1803
Toronto, Ontario, Canada, M4W 3R8
Telephone (416) 515-9686
Facsimile (416) 969-1815
Email: hugh@sdlaw.ca
Website: www.lostjobs.ca

New Publications by Network Advisers

Alison C Bested and Lynn M Marshall

Review of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: an evidence-based approach to diagnosis and management by clinicians

Reviews on Environmental Health 2015; 30(4) 223-249

The review was written for treating clinicians. The article talks about diagnosing ME/CFS and about its etiology, pathophysiology, management approach, long-term prognosis and economic cost.

Dr Bested was, of course, a member of the expert panel that developed the Canadian Consensus Criteria and a member of the panel that developed the IACFS/ME Primer. This article builds on those two documents and incorporates developments since the Primer was released. The material is presented in a fashion that is extremely professional and at the same time very approachable. Treating clinicians should find this article a treat to read.

http://www.ncbi.nlm.nih.gov/pubmed/26613325

Abdolamir Landi, David Broadhurst, Suzanne D Vernon, D Lorne J Tyrrell, Michael Houghton

Reductions in circulating levels of IL-16, IL-7 and VEGF-A in myalgic encephalomyelits/chronic fatigue syndrome

Cytokine 78 (2016) 27-36

This study was conducted at the University of Alberta (Edmonton) using samples from the Solve ME/CFS BioBank. The study tested for 34 cytokines, chemokines and growth factors in 100 long-term ME/CFS patients and in 79 matched controls.

The study found that people with long-term ME/CFS had highly significant reductions in 3 analytes (IL-16, IL-7 and VEGF-A). They found that these three reductions were statistically related, suggesting a biological pattern. They explored whether their findings could eventually form the basis of a diagnostic test and they found several mathematical formulas that had good specificity though not-as-good sensitivity. They also discussed what is known about IL-16, IL-7 and VEGF-A and found that these corresponded with symptoms often experienced by patients, providing evidence that their findings have clinical significance.

To put the key findings in the researchers' own words:

- Abnormal cytokine/chemokine profile in ME/CFS associated with clinical symptoms.
- A cluster of IL-16, IL-7 and VEGF-A that may suggests neuro-inflammation as the pathogenesis mechanism in ME/CFS.
- Potential diagnostic biomarkers proven by vigorous mathematical/statistical analysis.

http://www.sciencedirect.com/science/article/pii/S1043466615301071

M. Oldfield, E. MacEachen, B. Kirsh & M. MacNeill

Impromptu everyday disclosure dances: how women with fibromyalgia respond to disclosure risks at work

Disability and Rehabilitation DOI:10.3109/09638288.2015.1103794

Dr Oldfield interviewed working women with fibromyalgia, family members and work associates and found that disclosing one's medical situation at work was not straightforward, that women would "dance" around the topic. The study proposes the following implications for rehabilitation staff:

- For women with fibromyalgia, disclosing illness and impairments at work may entail risks to their jobs and workplace relationships.
- Rehabilitation professionals need to consider these risks when advising women with fibromyalgia about disclosing their illness and impairments at work.
- Professionals may first want to learn from clients about their workplace cultures and relationships, and their perceptions of disclosure risk.
- Professionals can then suggest a range of disclosure responses, depending on the relationship and risk

http://www.tandfonline.com/doi/full/10.3109/09638288.2015.1103794

Letter From the Liberal Party of Canada / Parti libéral du Canada

Prior to the election we sent letters to each of the federal parties asking for a response to our submission to the House of Commons Finance Committee. We received the following letter from the Liberal Party of Canada, too late for our fall Newsletter but before the election date.

Liberal Party of Canada
350 Albert, Suite 920
Ottawa, Ontario K1P 6M8

October 14, 2015

Lydia E. Neilson
Founder and Chief Executive Officer
National ME/FM Action Network
512-33 Banner Road
Nepean, ON K2H 8V7

Dear Ms. Neilson,

Thank you for your submission regarding you budget priorities for sufferers of ME/CFS and FM. The Liberal Party of Canada recognizes that these are complex illnesses that negatively affect the lives of thousands of Canadians.

A Liberal government will ensure the federal government rebuilds its capacity to deliver on evidence-based decision-making. Without evidence, government makes arbitrary decisions that have the potential to negatively affect the daily lives of Canadians. We need reliable economic indicators and data for sound economic policy, and to provide other governments, businesses, and civil society with the tools to enrich our national life. This commitment to scientifically driven, evidenced-based policy will help to restore Canada to the forefront of health research. Sound science, not ideology, will drive our funding and programming in health research.

We are deeply concerned about cuts this government has made to scientific research, such as the CIHR. Stable, predictable funding is necessary for the CIHR to perform its work, and address complex, multifaceted health issues such as ME/CFS and FM.

A Liberal government believes that a collaborative approach is required to deliver health care in Canada. The federal government must collaborate with the provinces, territories, stakeholders and experts on a real plan to improve research into these diseases, as well as the services and supports for those who live with these conditions and their caregivers. As an immediate commitment, a Liberal government will invest $3 billion over the next four years to prioritize additional and improved home care services for all Canadians.

Our commitment is nothing less than ensuring an integrated primary care system in Canada that is multidisciplinary, patient-centered, and committed to managing chronic disease within community, home, and long-term care settings. We will work with the provinces and territories to ensure all Canadians have access to high-quality in-home caregivers, financial supports for family care, and, when necessary, palliative care. As already announced, as part of a Liberal government's commitment to a new, ten-year investment of nearly $20 billion in social infrastructure, including long-term care facilities. We will also expand access to the Employment Insurance Compassionate Care Benefit, so that it is available for more than only end-of-life care.

Further, the Liberal Party knows we must do a better job supporting caregivers in the important work they do. Caring for each other is an essential part of what it means to be Canadian. Nearly every Canadian family is confronted at some point with the important responsibility of caregiving. Under our current framework, many of those providing care for loved ones do not qualify for benefits, nor do they have job security while they are providing care. The result is that people are too often forced to leave their jobs and drain their personal savings to provide essential care. This is not only unfair, but it hurts our economy and our middle class.

That is why a Liberal government will introduce a more flexible and accessible Employment Insurance Compassionate Care Benefit, available to any Canadian who provides care to a seriously ill family member. Though applicants will still be expected to submit a medical certificate in order to qualify, the benefit will have more inclusive eligibility requirements. Canadians who are caring for a seriously ill adult family member who needs significant care over and above what can be provided during evenings and weekends - or a seriously ill child who cannot attend school for an extended period of time - will no longer be excluded from the benefit.

We look forward to working in partnership with organizations like yours moving forward and value your interest in the Liberal Party of Canada's policies as they relate to these critical issues.

Yours sincerely,

Anna Gainey, President
Liberal Party of Canada

Parti Libéral du Canada
350 rue Albert, Suite 920
Ottawa (Ontario) K1P 6M8

14 octobre 2015

Lydia E. Neilson
Fondateur et directeur Général
Réseau d'action national du ME/FM
512-33, rue Banner
Nepean (ON) K2H 8V7
Chère Mme Neilson,

Nous vous remercions d'avoir communiqué avec nous pour connaître nos priorités budgétaires en faveur des personnes qui souffrent du syndrome de fatigue chronique (SFC)/encéphalopathie myalgique (EM) et de fibromyalgie (FM). Le Parti libéral du Canada reconnaît que ces maladies complexes perturbent profondément la vie quotidienne de milliers de Canadiennes et Canadiens.

Un gouvernement libéral rétablira la capacité du gouvernement fédéral de prendre des décisions basées sur des faits. En l'absence de faits, les gouvernements prennent des décisions arbitraires qui peuvent nuire à la vie quotidienne des Canadiennes et des Canadiens. Nous avons besoin d'indicateurs et de données économiques fiables pour élaborer des politiques économiques judicieuses, et pour offrir aux autres paliers de gouvernement, aux commerces et à la société civile les outils dont ils ont besoin pour enrichir notre vie nationale. Cet engagement à adopter des politiques fondées sur des données scientifiques et factuelles contribuera à redonner au Canada les moyens d'être à l'avant-garde de la recherche en santé. Des données scientifiques fiables, et non une idéologie, orienteront nos décisions concernant le financement et les programmes touchant la recherche en santé.

Nous jugeons très préoccupantes les compressions budgétaires du gouvernement actuel freinant les recherches scientifiques effectuées, par exemple, par les IRSC. Il est essentiel que ces instituts de recherche disposent d'un financement stable et prévisible pour mener leurs travaux et trouver des solutions à des problèmes de santé complexes et multiformes comme l'EM/SFC et la FM.

Les libéraux sont convaincus que la prestation des soins de santé au Canada doit reposer sur la collaboration. Le gouvernement fédéral doit coopérer avec les provinces et les territoires, les intervenants et les spécialistes pour élaborer un plan concret visant à améliorer les recherches sur ces maladies, ainsi que les services et les mesures de soutien pour les personnes qui en souffrent et celles qui leur prodiguent des soins. Comme mesure immédiate, un gouvernement libéral investira immédiatement trois milliards de dollars au cours des quatre prochaines années pour offrir en priorité des soins à domicile supplémentaires améliorés à toutes les Canadiennes et tous les Canadiens. Notre engagement ne vise rien de moins que la mise en place d'un système de soins primaires intégrés au Canada – un système multidisciplinaire, axé sur le patient et prenant en charge les maladies chroniques dans le cadre des soins communautaires, des soins à domicile et des soins à long terme. Nous travaillerons avec les provinces et les territoires pour faire en sorte que tous les Canadiens et Canadiennes aient accès à des fournisseurs de soins à domicile compétents, à de l'aide financière lorsqu'ils doivent prendre soin d'un être cher, et au besoin, à des soins palliatifs. Comme nous l'avons déjà annoncé, dans le cadre de l'engagement d'un gouvernement libéral à faire un investissement historique de presque 20 milliards de dollars sur dix ans dans les infrastructures sociales, nous accorderons la priorité à l'investissement dans les logements abordables et les résidences pour personnes âgées – incluant les établissements de soins de longue durée. Nous élargirons aussi l'accès aux prestations de compassion au titre de l'assurance-emploi afin que celles-ci ne soient pas uniquement réservées aux soins de fin de vie.

En outre, le Parti libéral est conscient qu'il faut faire mieux pour soutenir les aidants naturels dans l'important travail qu'ils accomplissent. L'entraide et la compassion s'inscrivent au coeur de l'identité canadienne. Presque toutes les familles canadiennes, à un moment ou à un autre, sont confrontées à l'importante responsabilité de prendre soin d'un proche malade. Présentement, trop d'aidants naturels ne sont pas admissibles aux prestations, et n'ont pas de sécurité d'emploi lorsqu'ils viennent en aide à un membre de leur famille atteint d'une maladie grave. Par conséquent, les aidants naturels sont trop souvent forcés de quitter leur emploi et de puiser dans leurs économies pour prodiguer ces soins indispensables. Cela est non seulement injuste, mais aussi néfaste pour notre économie et notre classe moyenne.

Voilà pourquoi un gouvernement libéral investira dans la classe moyenne et mettra en place des prestations de compassion aux aidants naturels plus souples et plus accessibles. Ces prestations seront offertes à toutes les Canadiennes et tous les Canadiens qui prodiguent des soins à un membre de leur famille atteint d'une maladie grave. Les aidants naturels devront toujours présenter un certificat médical pour bénéficier des prestations, mais les exigences d'admissibilité seront plus inclusives. Les prestations n'excluront plus les aidants naturels qui prennent soin d'un membre adulte de leur famille gravement malade nécessitant des soins importants au-delà de ceux pouvant être prodigués en soirée et en fin de semaine, ou encore d'un enfant gravement malade qui ne peut se rendre à l'école pendant une période prolongée.

Nous somme prêts à collaborer avec des organisations comme la vôtre et nous vous remercions vivement de l'intérêt que vous portez aux politiques du Parti libéral du Canada concernant ces questions cruciales.

Bien cordialement,

Anna Gainey, Présidente
Parti libéral du Canada

"It's curiosity."

Call for Review of Pace Trial

Twelve U.S.organizations have signed a letter asking the heads of the Centers for Disease Control (CDC) and the Agency for Healthcare Research and Quality (AHRQ) to examine the issues raised by journalist David Tuller's analysis of the U.K.'s £5 million PACE trial for ME/CFS. The letter is below:

To: Dr. Thomas Frieden and Dr. Richard Kronick
CC: Dr. Ermias Belay, Dr. Beth Unger, Dr. Suchitra Iyer, Dr. Walter Koroshetz, Dr. Nancy Lee, Dr. Susan Levine
Subject: PACE Trial for Chronic Fatigue Syndrome
Date: November 15, 2015

On October 21-23, David Tuller, DrPH, published a three-part article on Columbia University's Dr. Vincent Racaniello's Virology Blog[1] outlining fundamental flaws in the conduct and results of the U.K. £5 million PACE trial for chronic fatigue syndrome. The multiple flaws in this study call into question the validity of the 2014 AHRQ ME/CFS Evidence Review and CDC's clinical guidelines for ME/CFS, both of which rely upon PACE in their recommendations for cognitive behavioral therapy (CBT) and graded exercise therapy (GET). We ask that the validity of the PACE trial be investigated and appropriate steps taken to protect patients.

Echoing the analyses done by advocates and reiterated by other writers since, Dr. Tuller's article identified numerous problems with the design, conduct and analysis of the PACE trial and subsequent publications, including:

1. PACE subjects were selected using the Oxford definition of CFS,[2] which requires only six months of fatigue but no additional symptoms. The NIH's 2015 Pathways to Prevention Panel on ME/CFS recommended that the Oxford definition be discarded

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[1] David Tuller. "TRIAL BY ERROR: The Troubling Case of the PACE Chronic Fatigue Syndrome Study." Virology Blog. October 21-23, 2015.
First installment:
http://www.virology.ws/2015/10/21/trial-by-error-i/
Second installment:
http://www.virology.ws/2015/10/22/trial-by-error-ii/
Third installment:
http://www.virology.ws/2015/10/23/trial-by-error-iii/

[2] PACE selected patients by Oxford first, then subgrouped by modified ME and CDC CFS criteria. One PACE publication noted that CDC CFS criteria modifications could result in inaccurate patient characterizations but did not discuss impact of ME criteria modifications.

because it is overbroad and includes patients who do not have the disease.

2. Entry criteria, improvement/recovery criteria, and data analysis methods were all changed after the trial began. This is especially problematic as the trial was completely unblinded, and no analysis of the effect of these changes has been published.
3. The change in recovery criteria meant that patients could worsen from their entry scores and still be counted as "recovered" on two key outcome measures. Thirteen percent of PACE subjects met one of these modified recovery criteria when they entered the trial.
4. None of the objective measures set forth in the study protocol supported trial claims of successful treatment and recovery.
5. During the trial, a newsletter was posted on the trial website that included positive testimonials from other patients, and government endorsement of the therapies under investigation. This is, at best, highly irregular in an unblinded trial that is at serious risk of participant bias.
6. PACE trial participants did not receive disclosure of the financial conflicts of interest of some of the study investigators, despite those investigators having previously agreed to disclose the conflicts.

Many prominent US-based ME/CFS researchers have voiced their strong concern about the PACE study quality, content and methodology. Numerous patient surveys have reported physical harm from these therapies. Dr. Arthur Reingold, University of California, Berkeley told Dr. Tuller, "Under the circumstances, an independent review of the trial conducted by experts not involved in the design or conduct of the study would seem to be very much in order." We agree, as do six prominent researchers, who have already called on *The Lancet* to seek an independent re-analysis of the PACE trial data.[3]

The multiple and fundamental flaws of the PACE trial would be problematic in any field. However, the PACE trial is the largest study of this treatment approach and is used in the formulation of numerous clinical guidelines and medical-provider education efforts for ME/CFS today. There is great potential for harm to patients arising from the broad use of such a questionable and compromised study, particularly when that study includes patients who do not have ME/CFS.

Therefore, we ask that you examine the issues identified in Mr. Tuller's analysis, along with subsequent analyses of PACE. Given the implications for both the PACE study itself and for the AHRQ Evidence Review and for all U.S. clinical guidelines that currently rely upon PACE and/or the AHRQ Evidence Review, we ask that:

- CDC remove all recommendations and risk and prognosis statements based on PACE and other Oxford studies from its current and planned medical education material;
- AHRQ issue a revision of its Evidence Review in light of the concerns with PACE and with the Oxford definition studies as noted by NIH's Pathways to Prevention report;
- HHS use its leadership position to communicate these concerns to other U.S. mainstream clinical guidelines providers; and,
- HHS call upon The Lancet to ensure an independent re-analysis is conducted.

We respectfully ask for feedback on the results HHS's analysis and what HHS plans to do as a result. Feedback can be sent to Mary Dimmock.

Thank you.
Signed,

Massachusetts CFIDS/ME & FM Association
MEAction
MEadvocacy.Org
New Jersey ME/CFS Association, Inc.
Open Medicine Foundation
Pandora Org
Phoenix Rising
ProHealth
Solve ME/CFS Initiative
Speak Up About ME
Vermont CFIDS Association, Inc.
Wisconsin ME and CFS Association, Inc.

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[3] "An open letter to Dr. Richard Horton and The Lancet." November 13, 2015. http://www.virology.ws/2015/11/13/an-open-letter-to-dr-richard-horton-and-the-lancet/

Network Writes Federal MPs

Nov 16, 2015

The Honourable Jane Philpott
Minister of Health

Dear Dr Philpott:

Moving forward on behalf of Canadians with ME/CFS and FM

The National ME/FM Action Network would like to congratulate you on your election to Parliament and on your appointment as Minister of Health.

We are a registered charity that has been supporting Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and/or Fibromyalgia for over 20 years. These diseases are far from rare. The Canadian Community Health Survey, conducted by Statistics Canada, estimated that there were over 800,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia, or both in 2014.

There are three sets of issues challenging our community: little biomedical research, little medical system support, and difficulty accessing disability programs such as home care. This letter focuses on the first two. We have raised the accessibility issues with your colleague Ms Qualtrough.

Canadians with ME/CFS and FM have been badly served by the Canadian health system for years. Our organization knows this from our ongoing contact with patients. This neglect has been confirmed by Statistics Canada's Canadian Community Health Survey. Chronic Fatigue Syndrome and Fibromyalgia have been on the survey five times since 2001. Each time they have had the highest and second highest rates of unmet health care needs among the chronic conditions listed.

One would think that this evidence of ongoing under-service would trigger federal government investigation and action. We have called attention to the situation and we have been supported by three Liberal MP's who each put questions on the Order Paper. There was little meaningful action taken by the previous government. We hope that things are about to change.

Many health care providers have an unrealistic and potentially harmful approach when dealing with ME/CFS patients, telling them to change their attitude and be more active. Patients experience dismissal and invalidation of their physical symptoms – creating undue distress on already ill patients. Further, the patient may be intolerant of exertion, a point made clear in a recent report by the US Institute of Medicine.

Other health care providers are more sympathetic but have no ME/CFS or FM training, little research to refer to, and nowhere to turn for guidance. There has never been a specialty for ME/CFS and the specialty that dealt with FM (rheumatology) is abandoning the illness and, by extension, the patients.

Meanwhile, there is little biomedical research going on in Canada or internationally to understand the etiology or develop treatments. However, much is changing internationally, especially on the ME/CFS side, as leading scientists are developing a better understanding of the illnesses, are criticizing the pseudo-science that has held sway and are calling for biomedical research.

Fixing the situation here in Canada will take more than money. There needs to be a fundamental paradigm shift in attitudes, priorities, and collaboration to bring ME/CFS and FM, currently on the outside, into the research and clinical systems. This paradigm shift needs leadership to ensure effective ramp up and roll out.

This is why we are disappointed that these issues were not mentioned in the PM's mandate letter. Your overarching goal is to strengthen the publicly-funded universal health care system and ensure that it adapts to new challenges – that is precisely what ME/CFS and FM illnesses and our community needs. The letter identifies particular priorities, yet none directly address our issues or our community. The ME/FM community fears that it will be ignored once again, just when focused attention by leadership is required.

We note the Mandate letter gives you the authority to add priorities to your agenda. We hope that the under-service of the ME/FM community is one of your additions.

We look forward to working with you to address the concerns of the community. We know how busy you are so would suggest a 15 minute get-together this month here in Ottawa to start the ball rolling. Let me also mention that our winter newsletter will be published in the next month or so and we would like to give a message of hope to our readers.

Yours truly,

Margaret Parlor
President
National ME/FM Action Network

Nov 16, 2015

The Honourable Carla Qualtrough
Minister of Sport and Persons with Disabilities

Dear Ms Qualtrough:

Moving forward on behalf of Canadians with ME/CFS and FM

The National ME/FM Action Network would like to congratulate you on your election to Parliament and on your appointment as Minister of Sport and Persons with Disabilities.

We are a registered charity that has been supporting Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and/or Fibromyalgia for over 20 years. These diseases are far from rare. The Canadian Community Health Survey, conducted by Statistics Canada, estimated that there were over 800,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia or both in 2014.

ME/CFS and FM can involve a high degree of disability. The disability shows up primarily as reduced physical and mental stamina. This affects people's ability to participate in school, work, family, social and recreational activities. Patients may be housebound or even bedbound for years.

Here is a statistic from the 2010 Canadian Community Health Survey that gives a perspective on the extent of the problem: 20% of working age Canadians who were permanently unable to work had a diagnosis of CFS, FM or both.

People with ME/CFS or FM often have difficulty accessing programs intended for people with disabilities. Barriers to access include:

- many disability programs were designed without ME/CFS or FM in mind
- the seriousness of the disability is under-appreciated
- disability around ME/CFS and FM can be hard to describe, measure and prove
- many people with ME/CFS or FM have difficulty finding a health professional to complete application forms.

We have identified a number of programs that need review to ensure equitable access for persons with ME/CFS and FM. These include CPP-Disability, the Disability Tax Credit, home care, and work accommodation initiatives. Even Elections Canada was not forthcoming about the option of voting from home. Fixing these programs would have a very positive impact on the lives of many Canadians.

Your mandate letter sets an overall goal of ensuring greater accessibility and opportunities for Canadians with disabilities. The letter identifies just one activity in relation to disability issues - development of a Canadians with Disabilities Act. Our specific issues are not mentioned but the mandate letter gives you the authority to add priorities to your agenda.

The ME/FM community would like to be included in discussions around the new Canadians with Disabilities Act. The community would also like your assurance that ME/FM issues, while not specified in your mandate letter, will be added your agenda.

I would welcome the opportunity to sit down with you to discuss how we can work together for the benefit of Canadians with ME/CFS and FM. Let me mention that we are in the process of preparing our winter newsletter and would like to be able to bring news of progress to our readers.

Yours truly,

Margaret Parlor
President
National ME/FM Action Network

We regret to inform you that Dr Martin Lerner, 86, of Michigan died in October. Dr Lerner was an early pioneer in the study of ME/CFS, a member of the expert panel that developed the Canadian Consensus Criteria, an advisor to the Network, and a genuinely nice person.

We would like to welcome three new advisors to the Network, Dr Gordon Broderick, Dr Margaret Oldfield and Dr Michelle Skop

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NATIONAL ME/FM ACTION NETWORK

512-33 Banner Road, Nepean, ON K2H 8V7 Canada
Phone: 613-829-6667 • Fax: 613-829-8518
Email: mefminfo@mefmaction.com • www.mefmaction.com
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THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter—Free with annual membership of $30.00

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

ME/CFS and FM Brochures - FREE

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

Consensus Documents for ME/CFS and FM

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

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

ME/CFS and FM Overviews - $7.00

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

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

TEACH-ME (Second Edition) - $25.00

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

CANADA PENSION PLAN DISABILITY GUIDE 2015 Edition- $10.00

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

Chronic Fatigue Syndrome / Myalgic Encephalomyelitis - Primer for Clinical Practitioners
Syndrome de fatigue chronique Encéphalomyélite myalgique - Petit guide pour la médecine clinique - $25.00

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

All of the above resources can be viewed on the

National ME/FM Action Network website at **http://mefmaction.com**

NATIONAL ME/FM ACTION NETWORK

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