NATIONAL ME/FM ACTION NETWORK
Charitable tax no. (BN) 89183 3642 RR0001 ISSN 1205-786X
Quest Newsletter
www.mefmaction.com Quest # 93, Winter 2013 mefminfo@mefmaction.com

Moving forward, and not going down the wrong road

There has been a lot of forward movement for ME/CFS and FM in the last few months. We touch on some important activity in this issue of Quest, including:

- The IACFS/ME Primer is now available in French.
- Questions about ME/CFS and FM have been raised in the Canadian House of Commons.
- The Network participated at the annual meeting of the Canadian Association on Suicide Prevention.
- The Network participated at a workshop organized by the Canadian Institute of Health Research to encourage the study of skeletal muscle health.
- A Network adviser was awarded the Queen's Jubilee Medal for his volunteer work.
- A homeowner with Environmental Sensitivities reached a settlement with the Canada Revenue Agency on a claim for home repair expenses.
- The Network started a scholarship fund for medical students, applied for funding from the federal government's disability program, and sponsored a proposal in the Aviva community fund contest.

Unfortunately, when we are dealing with ME/CFS and FM, moving forward isn't the only concern. We need to be vigilant that authorities don't go down the wrong roads. In this Quest, we touch on several issues that have arisen:

- The American Psychiatric Organization could be adding “Somatic Symptom Disorder” to the next revision of its Diagnostic and Statistical Manual (DSM-5). People could be saddled with a psychiatric diagnosis because they are worried about their symptoms.
- The Network has been working for changes to the 2012 Canadian Fibromyalgia guidelines discussed in Quest 92.
- The Network questioned the President of the Treasury Board on the classification of CFS as a psychiatric illness and has now received a reply.

Scottish health authorities developed guidelines for treating people with ME/CFS which included use of the Canadian criteria. A journal article, co-authored by UK psychiatrist Simon Wessely, was very critical of the Scottish recommendations and of the Canadian guidelines. He would have preferred that Scotland adopt the criteria he has long championed. The Network agrees with the article's main point – that bad guidelines can have serious consequences. We don't agree that the Scottish guidelines went “awry”.

There are several broader developments that are worth watching:

- The Supreme Court of Canada released a decision around special education that could be helpful to young people with ME/FM.
- A commission appointed by the Government of Ontario released a report looking at the future of welfare and disability services in Ontario.

For readers with email, some of this information will be familiar to you. Please keep in mind that some of our subscribers do not have internet, while others who have internet do not receive our email bulletins.

Note: Our old fax number has been reinstated. See contact information on page 15.

Contents

IACFS/ME Primer Now in French

The National ME/FM Action Network is pleased to announce that the IACFS/ME Primer is now available in French. The translation was done by Hélène Dion of Commuication Cinq sur Cinq inc. The IACFS/ME nominated Dr. Philippe Tournesac of Paris, France, to review the translation. Funding for the translation came from the Ontario Trillium Foundation funding for the IACFS/ME Conference and from donations to the Network.

The National ME/FM Action Network is working to build a library of key documents in French. The following information is now available in French.:

Syndrome de fatigue chronique / Encéphalomyélite myalgique

Petit guide pour la médecine clinique

(The IACFS/ME Primer)

Encéphalomyélite myalgique /syndrome de fatigue chronique :

Définition clinique et lignes directrices à l’intention des médecins

Abrégé du Consensus canadien

(The ME/CFS Overview)

Syndrome de fibromyalgie :

Définition clinique et lignes directrices à l’intention des médecins

Abrégé du Consensus canadien

(The FM Overview)

« TEACH-ME » Guide de Référence pour l'ensignement aux élèves souffrant d’encéphalomyélite myalgique / syndrome de fatigue chronique (EM/SFC) et/ou du syndrome de fibromyalgie (SFM)

(The Teach-ME Sourcebook for teachers)

Videos of the presentations at the 2011 Patient Conference of the IACFS/ME, Ottawa, 2011are also available in French.

Translation of the ME/CFS Overview was made possible by AQEM, the Quebec Association for ME/CFS. All the other translations have been organized by the National ME/FM Action Network.

Report on CASP Conference (Canadian Association for Suicide Prevention)

ME/CFS and FM are life changing illnesses and support can be hard to find. The idea of suicide crosses people's minds more often that we would like to think. From time to time, we hear of people with ME/CFS or FM taking their own lives. Due to the stigma attached to suicide, it is difficult to know exactly how many people actually do.

Here are some statistics from the 2005 Canadian Community Health Survey. Respondents aged 15 and over in 4 provinces were asked about suicidal thoughts.

- 11% of Canadians reporting a diagnosis of CFS said that that they seriously considered suicide in the past year.
- 6% f Canadians reporting a diagnosis of FM said that that they seriously considered suicide in the past year.
- 10% of the Canadians who said that they had seriously considered suicide in the past year reported a diagnosis of CFS, FM or both.
- 2.4% of the people responding to the questions about suicidal thoughts reported a diagnosis of CFS, FM or both, meaning that occurrence of recent suicidal thoughts is 4 times higher in the ME/FM population than in the general public.

To learn more about about suicide prevention and to create more awareness of the ME/FM community among specialists in suicide prevention, we asked Judi Day, one of our Directors, to attend the annual conference of the Canadian Association for Suicide Prevention in Niagara Falls in October 2012. The theme was “Stepping out of the Darkness”. Judi was very successful in drawing ME/FM issues to the attention of participants, especially the feelings of hopelessness and helplessness that people experience when they are dealing with being chronically ill and not being taken seriously by their physicians, insurance companies and sometimes even their families. This lack of belief can take a bigger toll on the quality of their lives than the illness itself.

The Network does not have the resources to provide counseling services, even though we are very good at listening, and providing information that may help. If people are experiencing suicidal thoughts, we would direct them to the health system or to crisis service. Most people are looking for hope and help, and you can be assured that the Network is working for a better recognition and services for ME/FM patients in Canada, and progress is being made.

Report on a CIHR Workshop

The Canadian Institutes of Health Research is the primary source of health research funding in Canada, handing out in the range of $1billion per year. Note that CIHR is divided up into 13 institutes, each taking a different perspective of the health system. A small percentage of funding is handed out by the institutes, while the rest is distributed in open competitions. Note also that CIHR funds research but does not do research, unlike the US National Institutes of Health which actually has researchers on staff.

The Network has argued strongly that ME/CFS and FM do not receive a fair share of CIHR funding. The Network has written to CIHR pointing out a number of barriers to funding and suggesting that special strategies are needed to address the lack of funding.

In a small but very appreciated step, the Institute for Musculoskeletal Health and Arthritis invited the Network to attend a workshop for researchers interested in skeletal muscle health in late November. Some of the research into ME/CFS and FM has focused on muscle health and exercise issues. We were pleased to send two delegates, Judi Day to represent the patient perspective, and Dr. Brian MacIntosh of the University of Calgary who has published an article on FM and who recently did some work with Dr. Stein on exercise issues in ME/CFS.

Judi elaborated on the fact that over fifteen years that she has volunteered first as a facilitator of a self-help group and then with the network, she has listened to hundreds of people, men and women, who give the same history of their illness as if they had all rehearsed together, but then they did not even know each other.

Judi also mentioned that while musculoskeletal health is a very important focus, she wonders if it is distorted transmission of signals from the brain that cause the muscular fatigue, pain and other systemic symptoms that our people with ME/CFS and FM have to live with. We cannot just focus on muscles. There are neurological-endocrinological issues and medicine and science have to consider the implications.

There are supposed to be more meetings to develop this area of research. Judi was assured that the National ME/FM Action Network would be kept in the loop.

— In another development, the Institute of Musculoskeletal Health and Arthritis has designated a $5,000 undergraduate scholarship for ME/CFS or FM. While this is a small amount, it is certainly a step in the right direction and very much appreciated.

2012 FM Guidelines – New Developments

In Quest 92, we reviewed the FM guidelines which have been endorsed by the Canadian Pain Society and the Canadian Rheumatology Association. We pointed out a number of issues. We wrote both organizations asking for them to suspend their endorsements until the issues are addressed. We have now heard back from the both the Canadian Pain Society and the Canadian Rheumatology Association. They defended the guidelines and did not even offer to meet with the Network. The MEFM Society of BC and MEAO (Ontario) recently contacted the CPS and the CRA echoing our concerns.

The Canadian Medical Association has linked to the documents, so the Network has contacted them as well.

Treasury Board President Responds

Treasury Board is the department of the federal government responsible for establishing public service salaries and benefits. One of the benefits that the public service provides is long-term disability coverage. Treasury Board has contracts out administration of Long Term Disability to Sun Life Financial.

An article in the Ottawa Citizen dated July 9, 2012 claimed that 48% of approved disability claims were mental health related. Chronic Fatigue Syndrome appeared on the list of mental health conditions. The Network wrote Tony Clement, President of the Treasury Board, pointing out that CFS did not belong on the list.

We received a reply from Ton Clement dated. September 12 2012. We would like to thank Mr. Clement for his quick response. He quotes Sun Life Financial as saying that they follow the 2012 ICD-10-CM Medical Coding Reference Database. Sun Life adds:

"However, it is most important to note that regardless of how claims are reported, it has no impact on how claims are managed and adjudicated. Sun Life's Disability Management philosophy is based on managing each absence according to the prognosis, duration and degree of functional impairment, not just the diagnosis. Sun Life categorizes each absence based on the person's likelihood of recovery within a given time frame. In other words, the disability is assessed and managed holistically, looking at many factors, including the medical information, the impact on functions as well as workplace and personal issues that may be influencing recovery."

Homeowner Settles with Canada Revenue Agency

The homeowner applied for the 'medical exemption tax credit' (METC) for a portion of the costs for the repairs made to a house purchased in 2005. The house turned out to have serious mold issues, plus asbestos. Every part of the house had been affected, including the heating, ventilation and plumbing systems. It cost over $200,000 to repair and/or rebuild the house. The homeowner applied for the METC for costs that were strictly and entirely linked to Environmental Sensitivities - Multiple Chemical Sensitivities issues. The homeowner thoroughly documented both the the house alterations and the medical rationale.

The CRA rejected the original claim. The homeowner argued that a safe house is the absolute precondition to stabilization and improvement for people with ES-MCS and that refusing this tax credit is discrimination against people with ES-MCS. The homeowner took the case through the tax appeal process as well as to the Canadian Human Rights Commission. The homeowner reports: "The amount of work involved in all these cases was, truly, monumental. I generated hundreds of pages of briefs. It cost us many thousands of dollars in out of pocket expenses, and one friend contributed very generously to obtain legal advice on my brief before it was submitted to the Tax Court. In truth, had I known what would be involved in this fight, I would never have started it. But as each outrageous action by the CRA unfolded, and as each decision by the CHRC [Canadian Human Rights Commission], CHRT [Canadian Human Rights Tribunal] and even Tax Court Judge came in on our side, and as the stakes -- not only for MCS, but for other sick and disabled Canadians -- grew higher, it just felt like we had to go on."

The homeowner, supported by Ecojustice (a Canadian environmental charity), ARCH (the legal clinic for Ontarians with disabilities) and the Canadian Human Rights Commission, had a mediation session with the CRA in December 2012. The homeowner reports: "The remedies I was seeking had to do with improving the medical expense claims process for people with ES-MCS, and by extension, for some other illnesses as well. We did reach a settlement, an 'agreement in principle' that should be finalized in January. The strict confidentiality clause (par for the course, alas) I had to sign prevents me from disclosing the details of the settlement. But I am permitted to say that I was satisfied with the terms of the settlement (mostly, to be precise), and I do believe that a real step forward was achieved by it."

DSM-5 - Somatic Symptom Disorder

[The DSM is the Diagnostic and Statistics Manual published by the American Psychiatric Association (APA). It defines psychiatric illnesses and is widely used. The fifth edition of the DSM is scheduled for publication in Spring, 2013. Here is a bulletin from Suzy Chapman who has been monitoring developments.

On December 8, Allen J. Frances, MD, blogged at Psychology Today on our shared concerns for the new DSM-5 category – Somatic Symptom Disorder. Dr Frances was chair of the DSM-IV Task Force and of the department of psychiatry at Duke University School of Medicine, Durham, NC. He is currently professor emeritus, Duke.

One in six people suffering from cancer, heart and other serious diseases risks being saddled with a psychiatric diagnosis just because they are worried about their illness or spending more time on the internet researching their symptoms than APA thinks good for them.

But many illness groups stand to be captured by these new criteria, assigned an additional mental health diagnosis or placed at risk of misdiagnosis.

The DSM-5 manual texts are still being finalized and the Somatic Symptom Disorder Work Group has been asked to reconsider its criteria and tighten them up before the next edition of DSM is sent to the publishers.

Please demonstrate to APA and the Somatic Symptom Disorder Work Group the level of concern amongst clinicians and allied health professionals, patients, caregivers and advocacy organizations by visiting the blog post and leaving a comment. You can read the commentary at the link, below.

If you share our concerns that these catch-all criteria will see thousands more patients tagged with a mental health label please forward the link on to your colleagues and contacts.

Thank you,

Suzy Chapman for Dx Revision Watch
(http://dxrevisionwatch.com)

http://www.psychologytoday.com/blog/dsm5-in-distress/201212/mislabeling-medical-illness-mental-disorder

Note: A big thank you to Suzy Chapman for monitoring developments around the DSM and the International Classification of Diseases (ICD).

Dates to Watch

January 28, 2013: Canadian government responds to question on the Order Paper (see next page).

February 2, 2013: US Food and Drug Administration rules on an application to approve the drug Ampligen as a CFS treatment.

April 1, 2013: The appeal process for Canada Pension Plan - Disability changes. The Review Tribunals and Pension Appeal Board will be replaced by a Social Security Tribunal.

March 20-23, 2014: The next conference of the IACFS/ME will be in San Fransisco and will be co-sponsored by Stanford University.

MP's Questions to the Federal Government

A set of question was placed on the Order Paper of the House of Commons by Dr. Carolyn Bennett, the Member of Parliament for St. Paul's (Toronto). The Order Paper is the written version of the daily Question Period. The government is scheduled to table the answers on January 28, 2013, the day that Parliament resumes after the holiday break. While the Network did not ask that the questions be tabled, we will be very interested in reading the answers

Q-10442 – October 30, 2012 – Ms. Bennett (St. Paul's)

With regard to Canadians diagnosed with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS):

a) what funding has been allocated to research this illness in the last two years;

b) how does the government propose to encourage Canadian research into ME/CFS so that the level of research into this complex, multi-system illness is commensurate with its extent and impact;

c) what is the government doing to develop strategies and programs to meet the needs of Canadians with ME/CFS;

d) how is the government ensuring that health professionals are aware of the following documents,

(i) the Canadian Consensus Document for ME/CFS (ME/CFS: A Clinical Case Definition and Guidelines for Medical Practitioners),

(ii) Canadian Consensus Document for Fibromyalgia (Fibromyalgia Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners);

e) when will the government perform the following tasks in relation to the Consensus Document for ME/CFS posted on the Public Health Agency of Canada's website,

(i) improve the location of the document on the website in order to facilitate location of this document,

(ii) post the French version of this document;

f) why is the Fibromyalgia Consensus Document not posted as a Guideline on the Public Health Agency of Canada's website;

Q-10442 – 30 octobre 2012 – Mme Bennett (St. Paul's)

En ce qui concerne les Canadiens atteints d'encéphalomyélite myalgique/syndrome de fatigue chronique (EM/SFC) :

a) combien a-t-on alloué à la recherche sur cette maladie au cours des deux dernières années;

b) comment le gouvernement entend-il encourager la recherche afin que le financement accordé pour traiter cette maladie complexe et multisystème soit proportionnel à sa prévalence et à son impact;

c) que fait le gouvernement pour élaborer des stratégies et des programmes en vue de répondre aux besoins des Canadiens atteints d'EM/SFC;

d) que fait le gouvernement pour s'assurer que les professionnels de la santé connaissent l'existence des documents suivants,

(i) le document canadien de consensus sur l'EM/SFC (ME/CFS: A Clinical Case Definition and Guidelines for Medical Practitioners),

(ii) le document canadien de consensus sur la fibromyalgie (Fibromyalgia Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners);

e) quand le gouvernement accomplira-t-il les tâches suivantes en rapport avec l'affichage sur le site Web de l'Agence de la santé publique du Canada du document de consensus sur l'EM/SFC,

(i) améliorer l'emplacement du document sur son site Web de façon à en faciliter la consultation,

(ii) afficher la version française du document;

f) pourquoi le document de consensus sur la fibromyalgie n'est-il pas affiché en tant que ligne directrice sur le site Web de l'Agence de la santé publique du Canada;

g) what steps is the government taking to ensure that health professionals, patients, and the public have access to science-based, authoritative and timely information on ME/CFS;

h) how soon will the government post other information related to ME/CFS on government websites;

i) what is the government doing to ensure access to ME/CFS knowledgeable physicians and appropriate health care on a timely basis and how are they working with the provinces, territories, professional organizations, educational institutions and other stakeholders to meet these needs;

j) how is the government working with stakeholders to deal with other needs of Canadians with ME/CFS shown by the 2005 Canadian Community Health Survey (CCHS) including,

(i) reducing the levels of unmet home care needs,

(ii) reducing the levels of food insecurity,

(iii) increasing the sense of community belonging experienced by Canadians with this condition;

k) how will the surveillance report on ME/CFS, prepared from analysis of data collected from the 2005 CCHS, be used to improve the situation for Canadians with ME/CFS; and

l) how will the government monitor the extent and impact of ME/CFS and these other conditions on an annual basis given that questions regarding ME/CFS, Fibromyalgia and Multiple Chemical Sensitivities were dropped from the CCHS after 2005?

g) quelles mesures le gouvernement entend-il prendre pour que les professionnels de la santé, les patients et le public aient accès à des renseignements qui sont scientifiques, font autorité et sont à jour sur l’EM/SFC;

h) quand le gouvernement affichera-t-il d’autres renseignements sur l’EM/SFC sur les sites Web du gouvernement;

i) que fait le gouvernement pour assurer un accès rapide à des médecins informés et à des soins de santé appropriés sur l’EM/SFC, et comment collabore-t-il avec les provinces, les territoires, les organismes professionnels, les établissements d’éducation et autres intervenants pour répondre à ces besoins;

j) comment le gouvernement travaille-t-il avec les intervenants pour tenir compte des autres besoins des Canadiens atteints d’EM/SFC, tels que signalés dans l’Enquête sur la santé dans les collectivités canadiennes (ESCC) de 2005, y compris

(i) réduire le niveau de besoins insatisfaits en matière de soins à domicile,

(ii) réduire l’insécurité alimentaire,

(iii) accroître le sentiment d’appartenance à la collectivité des Canadiens atteints de cette maladie;

k) comment le rapport de surveillance sur l’EM/SFC, préparé à partir d’analyses de données tirées de l’ESCC de 2005, sera-t-il utilisé pour améliorer la situation des Canadiens atteints de l’EM/SFC;

l) comment le gouvernement entend-il surveiller chaque année la prévalence et l’impact de l’EM/SFC et de ces autres maladies, étant donné que les questions concernant l’EM/SFC, la fibromyalgie et les polysensibilités chimiques ont été supprimées de l’ESCC après 2005?

Queen's Jubilee Medal Awarded to Network adviser

John Wodak started his important volunteer work on disability benefits in 1993 after his wife was diagnosed with ME/CFS and FM and after his retirement from the Alberta government. In the past two decades, John has advised and/or assisted more than 600 individuals on matters related to disability benefits, in particular CPP (disability) and its provincial counterparts. He accepted the role of adviser to the Network and co-authored the latest edition of the Network's CPP-Disability Guide. John is a also member of the CPP Disability National Round Table which provides the federal government with feedback on disability issues.

The Network greatly appreciates the work John has done on behalf of Canadians with ME/CFS and/or FM, individually and collectively, and congratulates him on receiving the Queen's Jubilee Medal.

He is seen receiving his medal from Linda Duncan, MP for Edmonton-Strathcona.

Fundraising and Volunteering

Do you remember the book, The Mouse the Roared? It is about a tiny country that faced superpowers and won. The Network is like that. We are a very small scale operation, but we are not afraid of big challenges and we have a number of accomplishments.

Currently, our funding comes from memberships and donations. The only government funding we have received over the past decade was a grant from the Ontario Trillium Foundation for special services related to the Ottawa conference. We very much appreciate the financial support we receive from members.

We would like to expand our funding so that we can make a bigger impact.

One project we initiated this summer is the “Alison Bested Scholarship Fund”. It was started as a going-away present for Dr. Bested as she moved from Toronto to Vancouver to take up her appointment at the new BC Clinic. The funds will be used to cover expenses of medical students who spend time at a clinic specializing in ME/CFS, FM and/or MCS. Med students work in hospitals or clinics for a few days to gain experience. It was thought that covering expenses would encourage more students to consider placements at ME/FM/MCS clinics and would have long-term benefits. Please feel free to designate your donations to this fund.

We received an inquiry from a someone who was interested in funding a new scholarship. Would the Network administer it? The answer is that we would certainly be interested. Such a proposal falls within our charitable mandate and aligns with our objectives.

Over the summer, we put together an application for funding from the disabilities program of the federal government. We asked for the maximum amount - $250k for each of three fiscal years (2012 to March 2015). We would use the funding to raise public awareness of disability issues facing Canadians with ME/FM and to encourage discussion about disability and disability services within the ME/FM community. Our application is posted on our website. We would like to thank everyone who contacted their Members of Parliament to make them aware of our request. As of December 31, 2012, we still have not been told if we will be receiving any funding from the program.

This fall, the Network sponsored a proposal to fund medical equipment at the new Complex Chronic

Disease Clinic in British Columbia in the Aviva Community Fund contest. Funding is given to the proposals that receive the most on-line votes. This proposal did well enough in the first round of voting to be included in the second round. The proposal did well in the second round and raised the visibility of ME/FM and the clinic, but the proposal did not receive enough votes to win any money.

We also appreciate the volunteer help we receive. For example, Lynda manages the website, Judi handles the phone messages, Lydia deals with the revenue and expenses, Alison and Charlotte manage Facebook, Sherri serves on the BC Clinic advisory committee, and Anne Marie helps with special projects. People aren't paid for this work. We would also like to recognize the very hard-working volunteers in organizations and support groups across the country. The Network is on the lookout for researchers and writers to help with correspondence, the newsletter, the website, informational material etc. If you are interested, please get in touch.

Feedback Regarding the Aviva Contest

Dear patients, supporters, volunteers,

From the bottom of my heart I would like to say thank you for all of your 12,600 some votes in the Aviva contest in support of the clinic that Dr Bested is building, from the ground up.

While we could not match the vote numbers of other teams and could not win the popularity contest, we have spread awareness for the most neglected diseases far and wide all around the world, but also locally with the governments, health agencies and local communities.

The BC Women's Foundation was very pleased with 100 views of the video of Dr Bested some 2 weeks ago. We now have over 1300 views. This contest is the propeller to a clinic which can look at how we treat and research ME, FM and Lyme, and how the patients can be treated better in their communities and perhaps where to source funding from, now. The good news is the BC Women's Foundation has the expertise to look at the problem, we won't be alone in doing this.

This awareness campaign has been, in my eye, very successful even though we would have loved to bring in some money to fund our project.

We can only move forward from here. There is a light at the end of the tunnel.

Thank you!

sincerely, Kati

Kati Debelic spearheaded the proposal to fund the BC Clinic. Thank you Kati!

International support to new medical clinic in Vancouver

This is written a few minutes before the closing of the Aviva contest 2012. The project 'ACF13624 Medical equipment for a new chronic diseases clinic in Vancouver´' has got around 12,600 votes, and it seems like it will take a miracle for this cause to be amongst the top 10 winners in the big prize category.

Anyway – we are happy, that we have been able to participate. Thank you so much to Aviva for giving us the opportunity to hope and work for Canadian biomedical research, into the neglected and misunderstood illnesses: ME (or Chronic Fatigue Syndrome), fibromyalgia, Multiple Chemical Sensitivity, and Lyme Disease.

I am living in Denmark and have had ME for 17 years now. So why am I supporting a Canadian clinic, you might ask. Well, in all the time I've been ill, not ONE Danish kroner has been granted to biomedical research into ME. The need for biomedical research into all these illnesses is an international need and not just a Canadian one. That shows by the international support, the idea has had.

This idea has made ripples in all corners of the world. On the supporting facebook page 'Help fund medical equipment for CCDC in Vancouver: An Aviva Contest' there have been supporters from not only Canada but also the USA, United Kingdom, Germany, Sweden, Denmark, Australia, Belgium, Spain, Norway, Netherlands, France, Malta, Iceland, Ireland, New Zealand, Finland, Czech Republic, South Africa, and Hong Kong.

So now, we wish Dr. Bested and her team all the best, when the Complex Chronic Diseases Clinic opens in 2013. Our hearts are with you!

Yours sincerely,

Helle Rasmussen

Denmark

Special Education Decision, Supreme Court of Canada

When a young person develops ME/CFS or FM, it can be very difficult for them to attend school on a full time basis. Many young people with ME/FM need part time or home based instruction.

A recent decision from the Supreme Court of Canada may be of assistance to students with ME/FM. It concerned a child who was diagnosed with severe learning disabilities. He was slated to attend a special program, but that program was cut in a time of financial constraint. There was no other program meeting his needs. The parents enrolled him in a private school, then claimed reimbursement of his tuition fees from the school board and the BC provincial government.

The court did not find against the province since responsibility for learning disabled students had been downloaded to school boards.

The school board argued that the student should have comparable access to education as other special needs students. The court disagreed saying that, under this logic, school boards could eliminate all special education programs entirely and all special needs students would be treated equally. Instead, special needs students need to have comparable access as regular students. The court found that the child did not have any publicly provided options which would allow him to access educational services and the school board had not given sufficient thought to this when cutting the program. Therefore the school board had to provide reimbursement.

I don't know about other provinces, but here in Ontario the school boards have not given much thought to educational services for young people whose attendance is affected by health. Even more interestingly, the province has not made school boards responsible for providing access to education to these students. Both the province and the school boards are leaving themselves vulnerable.

Future of Social Assistance in Ontario

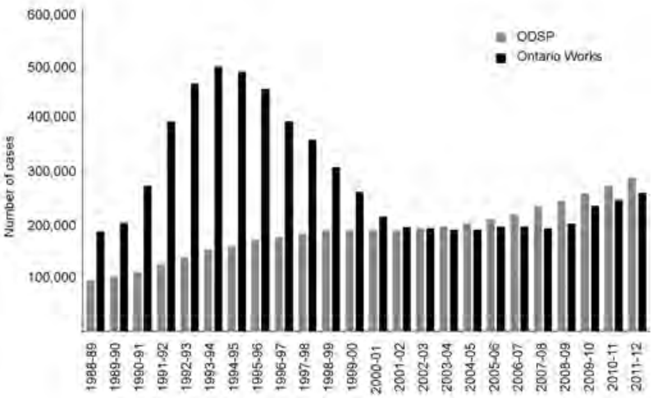
“In November 2010, the Ontario government appointed us to lead a comprehensive review of social assistance in this province and to make recommendations to improve the system. Our review was established as part of the government's 2008 Poverty Reduction Strategy. The overaching goal of the review was to identify ways to remove barriers and help people move into employment.”

This is the opening paragraph of a the report of the Social Assistance Review Commission released in October 2012. The report is 181 pages long and makes 108 recommendations.

There are a number of income support programs for people of working age and their dependents in Ontario. Programs include Ontario Works (OW), the Ontario Disability Insurance Plan (ODSP), Employment Insurance, Worker's Compensation, CPP-Disability and private workplace insurance. The social assistance review commission looked at OW and ODSP. People can qualify for social assistance only if they have little or no income and few if any assets. If one can demonstrate disability, one can be reclassified from OW to ODSP which offers higher monthly payments. Currently, OW is administered at the municipal level while ODSP is administered provincially.

The report recommended merging OW and ODSP. The new combined program would be administered at the municipal/first nations level in the same organizations that administer employment, housing and child care services. Benefit recipients would be expected to have an employment or participation plan.

To understand the Commission's logic, it is helpful to look at Appendix F “Trends in Social Assistance Reform” which interprets provincial, national and international experience. The appendix refers to many studies including work done by the Organization for Economic Co-operation and Development (OECD) which brings together 34 of the world's most developed countries.



Trend in Cases Receiving Ontario Works and ODSP

Appendix F starts with a graph of Ontario social assistance caseloads over the last two decades. ODSP cases showed a slow and steady growth over the period. OW cases, on the other hand, peaked at around 500,000 cases in the early 1990's, dropped to about half that level over the next ten years and then started a slow gain.

What led to the drop in OW cases in that ten year period? The appendix provides three main explanations:

- a robust period of job growth
- a range of income support policy reforms. “Changes included the introduction of 'work-first' employment strategies that incorporated new or enhanced employment expectations of recipients and improved access to job search and related employment services” (Among the strategies was a 22% cut in OW payments, making OW an unattractive option.)
- benefits for low income workers were enhanced so that people did not lose ground when moving from social assistance into low-paying jobs.

Even with these initiatives, the report notes that “recipients who experience significant and multiple barriers to participation in employment continued to need income support.” In other words, these strategies got some people into the workplace, but did not lead to employment for everyone.

What are the “significant or multiple barriers” that are still keeping people out of the workforce? The classic ones – having young children, low education, being an immigrant and being located in a high-unemployment region – was found to explain only 10% of the phenomenon in one study. Other factors are obviously very important, but what they are is not yet clearly understood. One study that was cited suggested these factors include “significant levels of social isolation, feelings of low self-esteem, significant levels of mental illness, including depression and anxiety, and significant functional limitations due to physical and mental health problems.”

The appendix then notes that “most OECD countries...have experienced an increase in disability income support beneficiary rates over the last 10-15 years”. The national rates are around 6%-10% of the working-age population in a number of countries. The OECD notes that “working-age disability policy today is one of the biggest social and labour market challenges for policy makers”.

Why are the number of disability cases growing? Research has attributed about a third of the growth to the aging of the population. Other suggestions put forward include:

- people who would have been classified as welfare are now more likely to be classified as disabled
- barriers to employment for people with disabilities
- lower educational levels for people with disabilities
- for people with disabilities, work “may not pay”

Looking from a different perspective, the appendix notes particular growth in new ODSP grants for people with mental disorders and for people with musculoskeletal issues. The OECD has also observed a growth in mental illness claims in other countries. (Overall, there seems to be agreement that disability cases are growing, but the reasons behind the growth don't appear to be well understood.)

The appendix then turns to the benefits structures for people with disabilities. One report says that people with disabilities who cannot reasonably be expected to obtain an adequate income through employment should get additional benefits. Another reports says that people with disabilities should not be treated differently than the rest of the population. The second report seems to be arguing that one person can be medically very disabled and yet still work productively while another person may appear fine and yet have great difficulty working. (The second report appears to be assuming that the traditional model of disability focusing on the standard impairments – deaf, blind, wheelchair etc. - equates to disability in the workplace.)

The appendix returns to the concept of “work-first” policies. It notes that, while initially appearing successful, the weaknesses of the model emerged over time. Researchers are now suggesting a mixed model combining work-first strategies and support strategies that are tailored to the client.

The way to tailor strategies is to develop individual employment or participation plans. Research has found that the better the plan, the more chance of success. “This highlights the need for both well-trained and supported caseworkers, who have the time to work with clients, and the availability of good-quality labour market information that is accessible to recipients and caseworkers as they prepare individual plans”.

Next, the appendix notes that "another key trend is to integrate the delivery of human services, such as employment child care and housing." While citing studies that show benefits from integrated services, the appendix warns that the challenges and costs of integration have not been assessed.

Finally, the appendix notes that the international community is grappling with performance measurement. This is a factor in how to pay for the organizations that help people get back to work. For example, if they are funded by the number of returns-to-work, the incentives would be to select the easiest clients and to focus on getting people jobs rather than maintaining them in jobs.

The report starts with the assumption that "all social assistance recipients, including people with disabilities, should be supported to participate in the workforce to the maximum of their abilities and that income security should be guaranteed for those who cannot work."

That is a top-down approach. Social assistance in Ontario was costed at $8.1billion a year. With about 600,000 social assistance "cases" (singles and families), the average case is costing social assistance about $13,000 a year. This includes income, extended medical benefits and administration. There is little room to cut per capita costs, so the province is motivated to remove as many people as possible off the rolls.

Now let's take a bottom-up approach from the perspective of people with ME/CFS and/or FM.

It is our experience that people with ME/FM want to work, participate and contribute. Unfortunately, their health can get in the way. Nevertheless, it is our experience that many people with very limited functioning are making remarkable contributions to their families and communities.

We know that it is very important for people with ME/FM to operate at their functional level. If one's functional capacity is at level 3, the person should be operating at level 3. Going above that puts one's health at risk. Going below that level is a failure to optimize functioning.

Therefore, supporting ME/FM people "to participate in the workforce to the maximum of their abilities" means:

- ensuring an accurate assessment of their functional capacity
- finding employment that matches the functional capacity level
- monitoring over time to ensure that the demands of the job continue to match the functional capacity of the employee

Including ME/FM people in the workplace brings out a number of challenges.

- accurate assessment of functional capacity, which means looking honestly and objectively at their medical situation and monitoring it over time
- thinking of employment flexibly and creatively to include part-time and housebound work. Part of this could be looking at the roles that people are currently undertaking as work or participation.
- Recognizing that some people with ME/FM will not be able to financially support themselves because of their health challenges and ensuring that they are adequately supported financially.

There is a fundamental issues that needs to be considered. The commission focused on getting people into the workforce. Is including ME/FM people in the workforce a good strategy in all cases? Are there times when it is more important for people to take care of their health than to participate in the workforce? Can pressure to work be detrimental?

It is not clear how the proposals are going to move forward for several reasons:

- Ontario has a minority government and the there will be a change in premiers in January 2013; at this time the government's direction is not clear.
- the report itself is confusing, with so much nuance that it can be interpreted in different ways
- The document has received a low profile, and the reactions that can be found do not seem to be consolidated, so it is difficult to determine the public mood.

Nevertheless, this report gives a glimpse into the direction that social assistance may take in Ontario and, indeed, all across the country.

Open Letter to Simon Wessely

J Neurol Neurosurg Psychiatry Published online November 17,2012

Doi: 10.1136/jnnp-2012-303208

I am rather flattered that you feel threatened by the National ME/FM Action Network

Background: Professor Simon Wessely, the British psychiatrist who claims that ME/CFS can be cured by cognitive behaviour therapy and graded exercise therapy, has co-authored a recent journal article. The thesis of his article is that there is a discrepancy between what he calls "evidence-based medicine" around ME/CFS (i.e. explaining, diagnosing and treating ME/CFS his way) and what he calls the "narrative and individual accounts" (i.e. explaining, diagnosing and treating ME/CFS other ways). He is particularly upset that the Scottish Public Health Network developed guidelines for ME/CFS that use the Canadian definition and do not adopt his preferred model of care. He warns us that, if followed, the Scottish guidelines would lead "to the adoption of dangerous diagnostic criteria for ME/CFS, as well as preventing patients from making informed decisions about treatment options, and discouraging clinicians from following evidence-based medicine and recommending proven treatments for ME/CFS." Of course, we have never thought that Professor Wessely's model of ME/CFS, which has been widely implemented, was based on valid evidence. We have argued that following his model leads to these exact consequences. Now the shoe is on the other foot.

The Scottish guidelines adopt the Canadian Consensus definition for ME/CFS. In his critique of the Scottish guidelines, he lashes out at the Canadian Consensus Document.

To: PROFESSOR WESSELY

METHINKS THOU DOST PROTEST TOO MUCH

December 3, 2012

It is rather regrettable that you never bothered to check your information by contacting the National ME/FM Action Network. If you had, you could have based your opinion on the facts rather than fantasy.

It is even more regrettable that you are insinuating that the scientific community and the health and social professionals working so diligently to understand, diagnose, treat and support ME/CFS and FM patients are all on the wrong path and only you know the correct approach. That is, to say the least, the height of arrogance.

When the Expert Panel met, they decided to adopt the term Myalgic Encephalomyelitis / Chronic Fatigue Syndrome simply because some countries used one of the terms while some countries used the other. The research community published under both names and the panel did not want to lose the research published under the name that was dropped.

Under the Canadian Definition, ME and CFS are one and the same. However, people who experience chronic fatigue, without the additional required symptoms, would not qualify for a diagnosis. Equating chronic fatigue with chronic fatigue syndrome, as one physician stated, would be like saying that everyone with a chronic cough has pneumonia.

The Journal in which the material was published may have gone out of circulation but that does not eliminate the valuable research that it contained. In fact, the Overviews of the Canadian Consensus document are available in 6 languages and the Canadian model has found support around the world.

I am rather flattered that you feel threatened by the National ME/FM Action Network but at the same time wonder why you took your valuable time to criticize rather than help.

Lydia E. Neilson, MSM
Chief Executive Officer
NATIONAL ME/FM ACTION NETWORK

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THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter – Free with annual membership of $30.00

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ME/CFS and FM Brochures - FREE

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

Consensus Documents for ME/CFS and FM

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

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

ME/CFS and FM Overviews - $2.50 each

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

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

ABREGE DU CONSENSUS CANADIEN SUR LE SFC: DEFINITION CLINIQUE ET LIGNES DIRECTRICES A L'INTENTION DES MEDICINES - 2.50 $ chacun

To order, please contact AQEM, 7400 Boul. Les Galeries, Box 410, Anjou, QC H1M 3M2 Canada or call 514.369.0386 or via email at aqem@spg.qc.ca

TEACH-ME (Second Edition) - $22.00 - Discount on bulk orders
TEACH-ME (TRADUCTION FRANCAISE): 22 $

Our TEACH-ME Resource Book is for Parents and Teachers of children and youth with ME/CFS and/or FM.

QUEST COLLECTION: 1993 TO 2003 - $38.00
QUEST COLLECTION: 2004 TO 2008 - $38.00

These are a collection of medical and legal articles that appeared in our newsletters for the periods indicated and combined for easy reference.

CANADA PENSION PLAN DISABILITY GUIDE - $10.00

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

LEGAL & DISABILITY MANUAL - Out of Print

This manual consists of court case references and disability matters relevant to ME/CFS and FM matters.

NATIONAL LAWYERS' ROSTER

A roster of lawyers and legal advocates who are knowledgeable about ME/CFS and FM. This roster is a guide only and the National ME/FM Action Network plays no role in any decisions made by the individual or in the legal professional selected. Please contact us for more information.

NATIONAL ME/FM ACTION NETWORK WEBSITE http://www.mefmaction.com

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