Two important breakthrough for ME/CFS this summer:

- the CBT/GET model of ME/CFS got undermined *... page 2*
- research suggests a mechanism for ME/CFS... *page 5*

Two reminders that there is still a long way to go

- CIHR turned down a grant application because ME/CFS "is not a real disease". *... page 3*
- statistics from the 2014 Canadian Community Health Survey show very serious problems facing the ME/CFS and FM communities. *... centre insert*

Two upcoming activities that you should know about

- the IACFS/ME biennial conference takes place in October *... page 1*
- the Canadian government is holding consultations on accessibility and inclusion for people with disabilities. *... page 2*

Deux documents sont maintenant disponibles en français *... page 6*

- the CPP-Disability Guide
- the article by Dr Bested and Marshall

Note to people without internet access: If you are interested in any of the supplementary material, please contact us.

Special Insert:

The results of the 2014 Canadian Community Health Survey

See the 12 page insert in the centre of this newsletter.

IACFS/ME Conference

October 27-30, 2016, Florida

Daily reports will be available on Facebook. There will also be a report from the Nova Southeastern University pre-conference held on October 26.

Canadians on the IACFS/ME conference agenda:

Dr Alison Bested will be leading a professional workshop on Review of ME/CFS, FM and MCS/ES: Office Assessment and Management

Dr Gordon Broderick will be speaking on Exploring the role of sex hormones in driving symptom severity in ME/CFS

Margaret Parlor will be co-leading a professional/patient workshop on Moving Forward Internationally

Dr David Patrick (UBC)will be speaking on Potential for an immunosignature assay to aid in classification and prediction of rituximab response in ME/CFS. He will also be moderating a lunchtime discussion on International Research Networks

Dr Peter Rowe will be leading a workshop, moderating a panel, and speaking on several panels.

Wilfred de Vega (PhD candidate, UofT) will be speaking on Epigenetic modifications and glucocorticoid sensitivity in ME/CFS.

Judy-Anne Wilson (ME Edmonton) will be leading a patient workshop on Mindfulness, Meditation, Movement, and Merriment

Further reading:

http://iacfsme.org

http://www.nova.edu/nim/iacfs-2016-preconference/

CBT/GET Model Undermined

The psycho-social model for ME/CFS somehow concludes that ME/CFS can be overcome using Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET). Support for that conclusion has been based on a number of published studies, with major support coming from the UK "PACE trial".

The Agency for Healthcare Research and Quality, a major US government agency, did a literature review about 2 years ago and concluded that there is evidence that CBT and GET benefit patients. Advocates pointed out that some of the studies relied on the "Oxford" definition of ME/CFS which does not include the key symptom of post-exertional fatigue, and therefore these studies cannot be used to draw conclusions about ME/CFS. This summer, AHRQ went back and reviewed the literature, this time leaving out studies based on the Oxford definition. Lo and behold, there was no evidence supporting the GET, and only very slight evidence around CBT.

The PACE trial was not excluded from AHRQ's second look at the evidence. But the PACE publications have been under scrutiny since their release. A number of methodological problems have been raised, notably that the test for recovery was changed part way through the trial. People asked for release of the raw data so that results could be calculated using the method originally proposed. The study managers were opposed to releasing the data. The issue wound its way through a legal process. This summer, a tribunal decided that the data should be released. Very shortly after the data was released, independent researchers published the results using the PACE researchers original methods. The success rates of CBT and GET were much lower under the new calculations. In fact, the recalculated numbers showed that CBT and GET did not make a statistically significant difference.

All in all, research has spent decades looking at CBT and GET, often to the exclusion of biological research. After all this time and effort, there is essentially no proof of their value. Isn't it time to focus on biological research?

Further reading

http://www.meaction.net/2016/08/18/ahrq-agrees-get-useless-cbt-ineffective/

http://nymag.com/scienceofus/2016/09/a-big-chronic-fatigue-syndrome-study-has-been-discredited.html

Participating in Disability Consultations

The federal Minister responsible for disability issues is conducting consultations on the content of a new disabilities act. Public meetings will be held in some Canadian cities. Alternatively, people can submit comments by phone, fax, mail or email between now and February. The government prepared a discussion paper but we find it confusing and suggest that people simply relate their disability experience and propose ways of moving forward.

Information about the public meetings and ways to submit comments are found here

http://www.esdc.gc.ca/en/consultations/disability/legislation/index.page

or you can phone the government at 1-844-836-8126

The National ME/FM Action Network has made a submission emphasizing the following points.

- *ME/CFS and FM are chronic disabling illnesses that impact many Canadians.*
- *The ME/FM community brings a important perspective to disability discussions – having a disability that is not well-established.*
- *The CRPD [United Nations Convention on the Rights of Persons with Disabilities] provides a definition of disability, but putting too little emphasis on participation restrictions and too much emphasis on impairments can be exclusionary.*
- *The discussion paper uses other disability legislation as the main models for moving forward. Much can be learned from experiences around building inclusion for other excluded groups.*
- *The discussion paper seems to be defining accessibility in a very narrow sense, the way it is used in article 9 of the CRPD. All rights within the CRPD need to be considered, including health education and income adequecy.*
- *Our experience is that federal government employees know little about disability issues. A key priority of the new legislation should be building federal competency.*
- *The federal government should be taking leadership on disability issues as there are many stakeholders.*

- *The federal government needs to understand the value of disability organizations like ours.*
- *Amendments to the Disability Tax Credit provisions should be included in the new legislation.*
- *Statistics and evaluation are extremely important.*

Changes needed to the Disability Tax Credit

The National ME/FM Action Network reviewed the Disability tax credit and found the following problems:

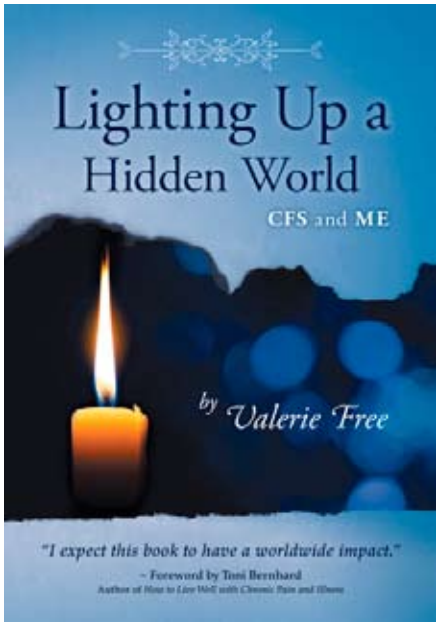
Highly-selective qualification criteria. The theoretical foundation of DTC is weak. The legislation needs to be reviewed and rewritten.

Confusing qualifiers. Form 2201 is difficult to interpret and should be clarified.

Need for medical practitioner certification. Requiring medical certification makes it very difficult for may people with ME/CFS or FM to apply.

Because amendments to the Income Tax Act are needed to resolve some of these problems, we asked that the new disability legislation include those amendments.

The full version of this document is available on our website.
http://mefmaction.com/index.php?option=com_content&id=527&catid=69&Itemid=287



Lighting Up a Hidden World

by Valerie Free

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ValerieFree.org

CIHR Turns Down Catalyst Grant

The federal Minister of Science appointed a panel of scientific experts to look at the funding of fundamental science in Canada. We sent the panel the following letter describing how the one and only application for a catalyst grant in ME/CFS was turned down and what it says about science funding in Canada.

Unfunded science: A case study

On August 25, 2016, CIHR announced that a review committee had rejected the only application CIHR had received in its funding competition for a Canadian research network focused on ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome).

The review committee, made up of only a few people, assumed a psycho-social model for ME/CFS, criticized the application for focusing on physical pathology and biomarkers, and went as far as to say that the "there is no evidence that CFS is a real disease". This is reminiscent of a 2013 book by a Canadian academic referring to CFS as a quasidelusional disorder.

CIHR has chosen to stand behind the review committee decision. Nobody in the federal government has stated what should be obvious - that the committee's evaluation does not stand up to scientific scrutiny.

According to Statistics Canada's Canadian Community Health Survey, there are over 400,000 Canadians with a diagnosis of ME/CFS and over 500,000 with a diagnosis of Fibromyalgia. The data shows that these Canadians have high degrees of disability, high levels of health care utilization, high levels of unmet health and home care needs, high levels of socioeconomic disadvantage, and high levels of social isolation.

According to the prestigious US Institute of Medicine in February 2015, "ME/CFS is a serious, chronic, complex, systemic disease that often can profoundly affect the lives of patients". The IOM added that "remarkably little research funding has been made available to study the cause of ME/CFS, mechanisms associated with the development and progression of the disease, or effective treatment, especially given the number of people affected" [emphasis mine].

Esteemed researcher Dr Ronald Davis describes ME/CFS as probably one of the last major diseases we know nothing about. It has been speculated that discoveries

into ME/CFS will not only benefit the patient population, but would open up our understanding of a number of other unexplained illnesses. In other words, fundamental science into ME/CFS could not only enrich the lives of Canadians with this complex chronic and disabling disease, it could have far wider impact.

CIHR is mandated to develop health research in emerging areas. Patients have been asking CIHR for years for help in building research capacity for both ME/CFS and Fibromyalgia. Currently, there is only one project being funded by CIHR which even mentions ME/CFS for a total of $45k this fiscal year. There are two studies that mention Fibromyalgia for a total of $152k. We have suggested the establishment of a new institute, pointing out that an institute was the strategy used to develop aboriginal research. Failing an institute, we suggested multi-year designated funding to attract researchers. We conservatively suggested that funding should be about $10M/year for ME/CFS and the same for Fibromyalgia, not taking into account retroactive entitlement. Note that $20M/year is typical institute funding.

In early March 2016, CIHR announced a competition for a catalyst grant to build a ME/CFS research network in Canada. Funding was set at $200k per year for three years. There was no commitment to any additional or ongoing funding and there was no support offered in putting together the application.

Despite the paltry offering, a dream team came together – Canadian researchers who have become interested in ME/CFS, public health academics, supportive clinicians, and patients representatives.

The major focus of the application was on the physical pathology of ME/CFS and biomarkers.

The ME/CFS community has suffered from decades of scientific abuse and scientific neglect as biological research was pushed aside in favour of the psycho-social approach favoured by the review committee. With the announcement of the catalyst grant competition, the community found new hope. With the rejection of the application, the community felt abused and abandoned once again.

Ironically, just before this decision was announced, the psycho-social approach was seriously undermined in two separate ways, no surprise to anyone following events. Several days after this decision, a study came out of a US university that found a metabolite signature for ME/CFS and suggested that ME/CFS could represent a hypometabolic state caused by the activation of an evolutionary cell protection mechanism. While the study needs to be debated and replicated, the study provides a very promising way of looking at ME/CFS.

Fundamental research into ME/CFS is already happening and much more is going to happen. Europe recently established a research network and the US NIH is moving in this direction. Canada missed this opportunity to get off the ground in a coordinated fashion, though individual researchers are involved in ME/CFS research.

From Canada's point of view, it cannot be a leader in all areas of science. From the patient perspective, it does not matter if discoveries are made in Australia or Norway or the US. So what is the problem?

The problem is that Canadian public policy is based on false science. For years, public policy has ignored evidence that ME/CFS is real, is having a major impact on Canadians, and is not being properly addressed by the health and social systems. For CIHR to reject an application because there is no evidence that CFS is a real disease sends the message that it is okay to blame patients for their misfortune and that there is no need for clinical care or social policy to change.

Maybe Canada cannot be a leader in all areas of science, but it must be involved in this area of science. Otherwise, patients will continue to suffer from neglect.

What would we like the Science Panel to do? We would like it to look carefully at the measures of success for CIHR. As far as we can see, the current measures of success include avoiding controversy and not getting involved in stigmatized areas. We would like the measures of success to change to include resolving scientific conflicts, exploring new areas, confronting stigma, and focusing on high needs areas. More broadly, a measure of scientific success would be public policy based on a solid foundation.

Yours truly

Margaret Parlor

President

The full text (with notes) is available on our website

http://mefmaction.com/images/stories/News/NetworkNews/SciencePanel-MECFS-CIHR.pdf

Research Proposes a New Mechanism for ME/CFS

Dr Robert Naviaux is a researcher at the University of San Diego who specializes in human genetics, inborn errors in metabolism, metabolomics, and mitochondrial disease. He was lead author of a study on ME/CFS that was published in August that proposes a new way of thinking about ME/CFS. Of course, the study needs to be replicated so we have to be careful not to get too excited.

We report that targeted, broad-spectrum metabolomics of plasma not only revealed a characteristic chemical signature but also revealed an unexpected underlying biology. Metabolomics showed that chronic fatigue syndrome is a highly concerted hypometabolic response to environmental stress that traces to mitochondria and was similar to the classically studied developmental state of dauer.

In a question and answer, Dr Naviaux writes:

Q. How does chronic fatigue syndrome fit in with other kinds of hypometabolic states or syndromes?

All animals have ways of responding to changes in environmental conditions that threaten survival. We discovered that there is a remarkable uniformity to this cellular response, regardless of the many triggers that can produce it. We have used the term, the cell danger response (CDR) to describe the chemical features that underlie this response. Historical changes in the seasonal availability of calories, microbial pathogens, water stress, and other environmental stresses have ensured that we all have inherited hundreds to thousands of genes that our ancestors used to survive all of these conditions.

The body responds differently to the absence of resources (eg, caloric restriction or famine) than to the presence of pathogens and toxins. We can classify two responses: a single-step response to the absence of resources, and a two-step process in response to the presence of a threat. Both responses are completed by a return to normal metabolism and function.

When resources are severely curtailed or absent, the full CDR is bypassed, and the flow of nutrients through metabolism is decreased to conserve limited resources in an effort to "outlive" the famine. This is often called a caloric restriction response.

On the other hand, when the cell is faced with an active viral, bacterial, or fungal attack, or certain kinds of parasitic infection, severe physical trauma, or even chronic psychological trauma (which produces a similar chemical change in metabolism), this activates the two-step response. The first step is to acutely activate the CDR. Innate immunity and inflammation are regulated by the metabolic features of the CDR. Activation of the CDR sets in motion a powerful sequence of reactions that are tightly choreographed to fight the threat. These are tailored to defend the cell against either intracellular or extracellular pathogens, kill and dismantle the pathogen, circumscribe and repair the damage, remember the encounter by metabolic and immunologic memory, shut down the CDR, and to heal. In most cases, this strategy is effective and normal metabolism is restored after a few days or weeks of illness, and recovery is complete after a few weeks or months. For example, only a small percent of people who are acutely infected with Epstein-Barr virus (EBV) or human herpes virus 6 (HHV6), or Lyme disease go on to develop chronic symptoms.

If the CDR remains chronically active, many kinds of chronic complex disease can occur. In the case of CFS, when the CDR gets stuck, or is unable to overcome a danger, a second step kicks in that involves a kind of siege metabolism that further diverts resources away from mitochondria and sequesters or jettisons key metabolites and cofactors to make them unavailable to an invading pathogen, or acts to sequester toxins to limit systemic exposure. This has the effect of further consolidating the hypometabolic state. When the hypometabolic response to threat persists for more than 6 months, it can cause CFS and lead to chronic pain and disability. Metabolomics now gives us a way to characterize this response objectively, and a way to follow the chemical response to new treatments in systematic clinical trials.

Q. You talk about the chemical signature being similar to a state of hibernation. What sort of animals exhibit a similar signature in hibernation?

I wouldn't use the term hibernation to describe chronic fatigue syndrome. Humans do not hibernate. Hibernation is just one of a handful of hypometabolic states that has been studied in different animals. There are many others that go by names like dauer, diapause, torpor, estivation, caloric restriction, etc. Many environmental stresses will trigger hypometabolism in humans. In our experience, the metabolic signature of dauer is more similar to CFS than some of the other hypometabolic states that have been studied....

Further reading:
http://www.pnas.org/content/113/37/E5472.abstract (ME/CFS study)

http://www.sciencedirect.com/science/article/pii/S1567724913002390 (cell danger response)

http://www.openmedicinefoundation.org/expanded-mecfs-metabolomics-study/

Maintenant disponible en français

GUIDE DE DEMANDE ET D'APPEL POUR LES PRESTATIONS D'INVALIDITÉ DU RÉGIME DE PENSIONS DU CANADA


Encéphalomyélite myalgique/syndrome de fatigue chronique : une approche basée sur les preuves pour le diagnostic et la gestion dans la médecine clinique

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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

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