



Quest

Newsletter



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2015 CCHS Statistics

On March 22, Statistics Canada released statistics from the 2015 Canadian Community Health Survey. Here are prevalence figures for CFS, FM and MCS (obtained from Statistics Canada on request).

	Number, 2015	% of target population
Fibromyalgia		
Total	493,600	1.6%
Males	97,200	0.7%
Females	396,400	2.6%
Chronic Fatigue Syndrome		
Total	561,500	1.9%
Males	195,100	1.3%
Females	366,400	2.4%
Multiple Chemical Sensitivities		
Total	940,500	3.1%
Males	284,900	1.9%
Females	655,600	4.3%

The figures came with a caution against making comparisons between 2014 and 2015 data because of changes to the data collection strategy and to the questionnaire in 2015. One always has to keep sampling issues in mind as well when interpreting data.

Of course, the first thing I did was to compare the 2014 and 2015 numbers. The FM figure dropped a little between 2014 and 2015, but it had jumped considerably between 2010 and 2014 so this could be a sampling correction. The MCS figure surged between 2014 and 2015, but it had dropped between 2010 and 2014 so some of the jump could be correcting for this. The figure for CFS took a big 38% jump between 2014 and 2015.

There was little change between 2010 and 2014, but sampling might still be partially at play, especially if the 2015 figure is overstated. The new survey design might be partly responsible for the jump though it is not clear why that would be the case. Perhaps the CFS jump is real. Could it be tied to the release of the IOM report in February 2015 and increased acceptance of ME/CFS in the medical profession? We will have more clues if someone analyses the 2015 data (note: the Network does not have access to the master or share file and there is no 2015 public use file) or when the 2016 data is released in the autumn.

Bio-Research

Reasons to be Optimistic: Notable Recent ME/CFS Research Progress

Scot Merriam March 2017

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), also known as Post Viral Fatigue Syndrome, Systemic Exertional Intolerance Disease and other names, is a disease recognized by the World Health Organization (WHO) as a neurological disorder. It affects millions of people worldwide and over 400,000 people in Canada alone (2014 stats). These numbers are similar to the numbers of people affected by MS and Rheumatoid Arthritis.

Despite the above facts, it's easy for us ME/CFS sufferers to feel invalidated when we encounter ME/CFS ignorance in the general public or with our own front line health care professionals. Further, after fighting a several decade's long battle for recognition it's not surprising that some conclude we are fighting a losing battle. But we are making progress and there is reason to be optimistic. Here's why:

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The state of ME/CFS research is vastly different today than it was 20 years ago and significantly different from even 5 years ago.

- The frequency of publishing about ME/CFS, particularly with respect to biological abnormalities, has been accelerating over the last few years. We're seeing release of very significant research papers every month or two now where in the past we would see release of similar grade research papers once every year or two;
- The biological abnormalities being discovered are becoming more consistent and links between research observations are becoming apparent. In other words, ME/CFS research results are beginning to converge, which is contributing to the development of robust themes and helping to pinpoint where new research is needed;
- There are more dedicated ME/CFS research labs now than ever before in history. This has in part been fueled by increases in private donations arising from the realization in the ME/CFS community that waiting for governments to take the lead was getting us nowhere;
- ME/CFS research is becoming sexy(!) That's right; within the last few years we've seen a number of bright young researchers specifically choose to dedicate their career to unraveling the ME/CFS mystery. This demonstrates that those who are on the cutting edge can see that ME/CFS is a valid and serious biological illness and that whoever discovers the root cause(s), biomarkers and affordable diagnostic test(s) and treatment(s) will claim a significant place in medical history.
- While the Canadian Institute for Health Research has been slow to respond to the international research confirming that ME/CFS is real, the US National Institute of Health has recognized ME/CFS as a serious disease in their paper titled *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness* (2015 DOI: 10.17226/19012);
- Thanks to journalist David Tuller and many others, faulty research proclaiming ME/CFS as a psychological illness (such as the PACE study) is being identified and soundly rebutted.

Respected medical professionals are now routinely stating that there is no question that ME/CFS is a biological disease: Please refer to a YouTube® published March 26, 2014 Stanford lecture titled *The Biology of Chronic Fatigue Syndrome* by Dr. Anthony Komaroff, a professor at Harvard Medical School who has over 3 decades of

experience with ME/CFS. The lecture video provides a clear and comprehensive summary of the biological abnormalities that make ME/CFS a real disease.

On November 10, 2016, Dr. Komaroff also presented what he feels are the *Hot Areas in ME/CFS Research* and on February 21, 2017 Dr. Ron Davis of the Open Medicine Foundation gave an *Update on ME/CFS Research* taking place at Stanford University (both available on YouTube®)

While we can't include all the great ME/CFS research that has been published over the last few years, here is a selection of some of the latest research that we feel is particularly noteworthy:

Most recently, an Australian research team announced they believe they have identified a practical biomarker for ME/CFS. While these preliminary findings must be validated by other researchers, if true, it could radically change attitudes and patient care. Read more here:

Activin B is a Novel Biomarker for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) Diagnosis: a Cross Sectional Study (2017 DOI: 10.1186/s12967-017-1161-4)

Late last year a USA research team detected what appears to be a unique immuno-signature with ME/CFS using test subjects from the UK as well as USA:

Humoral Immunity Profiling of Subjects with Myalgic Encephalomyelitis Using a Random Peptide Microarray Differentiates Cases from Controls with High Specificity and Sensitivity (2016 DOI: 10.1007/s12035-016-0334-0)

Then early this year an Australian research team reported they have discovered altered metabolism specific to natural killer cells in patients with ME/CFS:

Impaired Calcium Mobilization in Natural Killer Cells from Chronic Fatigue Syndrome/Myalgic Encephalomyelitis Patients is Associated with Transient Receptor Potential Melastatin 3 Ion Channels (2017 DOI: 10.1111/cei.12882)

Several other recent studies by US, Norwegian and Australian researchers have also demonstrated significant general cellular metabolic problems in ME/CFS:

Metabolic Features of Chronic Fatigue Syndrome (2016 DOI: 10.1073/pnas.1607571113)

Metabolic Profiling Indicates Impaired Pyruvate Dehydrogenase Function in Myalgic Encephalopathy/Chronic Fatigue Syndrome (2016 DOI:10.1172/jci.insight.89376)

Metabolic Profiling Reveals Anomalous Energy Metabolism and Oxidative Stress Pathways in Chronic Fatigue Syndrome Patients (2015 DOI: 10.1007/s11306-015-0816-5)

Interestingly, Fluge and Mella's work was sparked when they discovered, much by accident, that attenuating the immune system of people with ME/CFS can result in a significant decrease in symptoms:

B-Lymphocyte Depletion in Myalgic Encephalopathy/Chronic Fatigue Syndrome. An Open-Label Phase II Study with Rituximab Maintenance Treatment (2015 DOI:10.1371/journal.pone.0129898)

In cellular metabolism related research, Dr. Maureen Hanson of USA uncovered a potential genetic factor which may be related to mitochondrial malfunction in ME/CFS:

Mitochondrial DNA Variants Correlate with Symptoms in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (2016 DOI: 10.1186/s12967-016-0771-6)

Canadian researchers have also been probing for potential epi-genetic markers in ME/CFS and have found 12,608 sites with different methylation between ME/CFS patients and healthy controls:

Epigenetic Modifications and Glucocorticoid Sensitivity in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) (2017 DOI: 10.1186/s12920-017-0248-3)

There are striking differences in the gut microbiome of those with ME/CFS compared to the general population as revealed in the following studies:

Reduced Diversity and Altered Composition of the Gut Microbiome in Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (2016 DOI: 10.1186/s40168-016-0171-4)

Changes in Gut and Plasma Microbiome following Exercise Challenge in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (2015 DOI: 10.1371/journal.pone.0145453)

Potentially part of the web of the above findings, the Australians have also demonstrated a link between an altered gut microbiome and host energy metabolism:

The Association of Fecal Microbiota and Fecal, Blood Serum and Urine Metabolites in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (2016 DOI:10.1007/s11306-016-1145-z)

There are indications of brain connectivity problems and deterioration in those with ME/CFS as published in the following studies:

Progressive Brain Changes in Patients with Chronic Fatigue Syndrome: A Longitudinal MRI Study (2016 DOI: 10.1002/jmri.25283)

Autonomic Correlations with MRI are Abnormal in the Brainstem Vasomotor Centre in Chronic Fatigue Syndrome (2016 DOI: 10.1016/j.nicl.2016.03.017)

In addition, there are dramatic immune system differences in the spinal fluid of those with ME/CFS compared to the general population as uncovered in *Cytokine Network Analysis of Cerebrospinal Fluid in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (2015 DOI: 10.1038/mp.2015.29)*.

While viruses may or may not be involved in sustaining ME/CFS, it remains plausible that a virus(s) can initiate ME/CFS as discussed in *Viruses and CFS: Statements by Dr. Ron Davis and Dr. Bob Naviaux (Open Medicine Foundation September 9, 2016)*

The above recent papers clearly support a biological basis for the symptoms those with ME/CFS experience.

Why Can't We Rely on the Validity of Old ME/CFS Research?

Because ME/CFS has been a medical mystery for so many years, the diagnostic criteria have changed several times over the decades as the knowledge base has been refined. Examples of old diagnostic screening criteria include the 1988 Holmes, 1991 Oxford, 1994 Fukuda and 2005 Reeves definitions, which are too loose and subjective and can include people who do not really have ME/CFS.

Accordingly, most research completed pre 2005 likely included people who do not have ME/CFS, meaning the conclusions reached are questionable.

More objective diagnostic screening criteria, such as the 2003 Canadian Consensus Criteria (thanks to the National ME/FM Action Network!) or the refined 2011 International Consensus Criteria are required for ME/CFS research to have reliable conclusions. For a more detailed discussion of this please refer to *Contrasting Case Definitions for Chronic Fatigue Syndrome, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Myalgic Encephalomyelitis (2011)*.

Summary

Yes, for some of us it has been a long and exhausting road – but when we objectively look at what has been happening in the world with ME/CFS research, and how quickly things are moving, there are reasons to be

optimistic. Recognition and validation, biomarkers and practical diagnostic tests and treatments are around the corner. As Arthur Schopenhauer observed with regard to society's acceptance of the truth:

All truth passes through three stages. First, it is ridiculed. Second, it is violently opposed. Third, it is accepted as being self-evident.

We are almost there!

About the author: Scot Merriam has been living with ME/CFS since 1990 and resides in Nanaimo, British Columbia. He has been a member and supporter of the ME/FM Action Network since 1993.

Chronic Fatigue IS a Real Disease

Fiona MacDonald

22 FEB 2017

Thanks to ScienceAlert for permission to reprint this article:

Chronic fatigue syndrome (CFS) or Myalgic Encephalomyelitis (ME) is one of the most perplexing conditions out there. It affects up to 1 million Americans and as much as 2.6 percent of the global population, often triggering exhaustion so severe that patients can't work or study.

But for decades, researchers have struggled to find an underlying cause, leading to an assumption by many doctors that it's 'not a real disease'. Now, Australian researchers have blown that myth wide open, showing for the first time that CFS is linked to a faulty cell receptor in immune cells.

"This discovery is great news for all people living with Chronic Fatigue Syndrome (CFS) and the related Myalgic Encephalomyelitis (ME), as it confirms what people with these conditions have long known - that it is a 'real' illness - not a psychological issue," said LeeAnne Enoch, the Science Minister of Queensland - the Australian state that's supporting the research.

"CFS and ME are notoriously difficult to diagnose, with sufferers often going for years without getting the proper care and attention they need."

Not only is this the first research to show how the faulty cell receptor causes the immune system changes seen in CFS/ME, it also offers researchers a long-sought-after target for future treatments and tests....

The breakthrough came after researchers from Griffith

University identified that patients with CFS/ME were far more likely to have single nucleotide polymorphisms - DNA typos - in the genetic code for a certain cell receptor.

This cell receptor is known as transient receptor potential melastatin 3 (TRPM3), and in healthy cells it plays a crucial role - transferring calcium from outside the cell to the inside, where it helps regulate gene expression and protein production.

But in several peer-reviewed papers published by the Griffith team last year, they showed that in CFS/ME patients, something seemed to be going wrong with TRPM3.

In the latest study, the team looked at blood samples 15 CFS/ME patients and 25 healthy controls, and found that immune cells in chronic fatigue patients had far fewer functioning TRPM3 receptors than those of healthy participants.

As a result, calcium ions weren't making it inside the cell like they should be, meaning cell function was impaired.

What makes matters worse is that TRPM3 isn't just found in immune cells. The team tested its presence on immune cells as they're easy to access in blood samples, but the receptor is found on every single cell in the body, which not only explains why CFS/ME has been so difficult to diagnose, but also why it's so severe.

"This is why it's such a devastating illness, and why it's been so difficult to understand," one of the researchers, Don Staines, co-director of Griffith University's National Centre for Neuroimmunology and Emerging Diseases, told ScienceAlert.

"This dysfunction affects the brain, the spinal cord, the pancreas, which is why there are so many different manifestations of the illness - sometimes patients will suffer from cardiac symptoms, sometimes it will be symptoms in the gut."

It's something that's confused doctors for decades, and has lead to much of the misdiagnosis of the condition - but the new research suggests that all of the common CFS/ME symptoms can be explained by these faulty calcium ion channels.

"We now know that this is a dysfunction of a very critical receptor and the critical role that this has, which causes severe problems to cells in the body," said Staines.

To be clear, the research is still in its early phases - all we know for now is that these dysfunctional TRMP3 receptors are involved in the disease, and there's a lot more work to be done.

But Staines suggests that the involvement of TRPM3 receptors could explain why so many patients appear to experience CFS/ME following a traumatic event or serious infection.

The class of receptors TRPM3 belongs to are also known as 'threat receptors', because they're upregulated when the body is under any kind of threat, such as infection, trauma, or even childbirth.

Staines and his colleagues predict that it's this upregulation that causes the the faulty genetic receptors to get over-expressed and then take over, messing up the calcium transfer in a range of cells.

For now, that's just a hypothesis. But it's a much-needed starting point for researchers to look into further.

Already, Staines and his team are working to figure out the best markers that can be used to test for these faulty receptors, so they can begin to create a CFS/ME test.

They're also looking for medications that act on these specific calcium ion channels in the hopes of finding potential treatments for the disease.

"We don't know that we can necessarily cure the illness but we can help people lead a normal life," Staines explained.

In the meantime, the research is a stark reminder of how serious CFS/ME can be - and how useless, and potentially even damaging, current treatment options are.

"This is a much more debilitating illness than people have realised - people die from CFS/ME because they're not taken seriously," Staines told ScienceAlert.

"The new research also suggests that [prescribing] exercise is just unbelievably bad as it can put the body under further stress," he added.

"This is why we're working day and night to develop a test - so that people start taking the disease seriously."

The latest research has been published in *Clinical Experimental Immunology*.

<http://www.sciencealert.com/one-of-the-biggest-myths-about-chronic-fatigue-syndrome-just-got-destroyed>

Epigenetic modifications and glucocorticoid sensitivity in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

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Abstract

Background: Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) is a debilitating idiopathic disease characterized by unexplained fatigue that fails to resolve with sufficient rest. Diagnosis is based on a list of symptoms and exclusion of other fatigue-related health conditions. Despite a heterogeneous patient population, immune and hypothalamic-pituitary-adrenal (HPA) axis function differences, such as enhanced negative feedback to glucocorticoids, are recurring findings in ME/CFS studies. Epigenetic modifications, such as CpG methylation, are known to regulate long-term phenotypic differences and previous work by our group found DNA methylome differences in ME/CFS, however the relationship between DNA methylome modifications, clinical and functional characteristics associated with ME/CFS has not been examined.

Methods: We examined the DNA methylome in peripheral blood mononuclear cells (PBMCs) of a larger cohort of female ME/CFS patients using the Illumina HumanMethylation450 BeadChip Array. In parallel to the DNA methylome analysis, we investigated in vitro glucocorticoid sensitivity differences by stimulating PBMCs with phytohaemagglutinin and suppressed growth with dexamethasone. We explored DNA methylation differences using bisulfite pyrosequencing and statistical permutation. Linear regression was implemented to discover epigenomic regions associated with self-reported quality of life and network analysis of gene ontology terms to biologically contextualize results.

Results: We detected 12,608 differentially methylated sites between ME/CFS patients and healthy controls

predominantly localized to cellular metabolism genes, some of which were also related to self-reported quality of life health scores. Among ME/CFS patients, glucocorticoid sensitivity was associated with differential methylation at 13 loci.

Conclusions: Our results indicate DNA methylation modifications in cellular metabolism in ME/CFS despite a heterogeneous patient population, implicating these processes in immune and HPA axis dysfunction in ME/CFS. Modifications to epigenetic loci associated with differences in glucocorticoid sensitivity may be important as biomarkers for future clinical testing. Overall, these findings align with recent ME/CFS work that point towards impairment in cellular energy production in this patient population.

<http://bmcmmedgenomics.biomedcentral.com/articles/10.1186/s12920-017-0248-3>

Metagenomic Investigation of Plasma in Individuals with ME/CFS Highlights the Importance of Technical Controls to Elucidate Contamination and Batch Effects

Citation: Miller RR, Uyaguari-Diaz M, McCabe MN, Montoya V, Gardy JL, Parker S, et al. (2016) Metagenomic Investigation of Plasma in Individuals with ME/CFS Highlights the Importance of Technical Controls to Elucidate Contamination and Batch Effects. PLoS ONE 11(11): e0165691. doi:10.1371/journal.pone.0165691

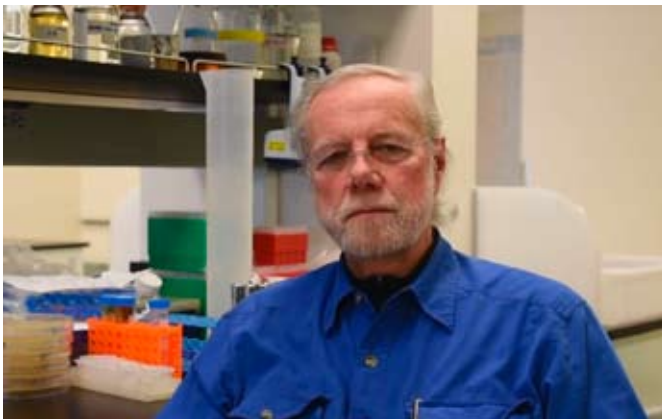
[Note: this article from UBC emphasizes the need for caution in performing and interpreting research]

Abstract

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a debilitating disease causing indefinite fatigue. ME/CFS has long been hypothesised to have an infectious cause; however, no specific infectious agent has been identified. We used metagenomics to analyse the RNA from plasma samples from 25 individuals with ME/CFS and compare their microbial content to technical controls as well as three control groups: individuals with alternatively diagnosed chronic Lyme syndrome (N = 13), systemic lupus erythematosus (N = 11), and healthy controls (N = 25). We found that the majority of sequencing reads were removed during host subtraction, thus there was very low microbial RNA content in the plasma. The effects of sample batching and contamination during sample processing proved to outweigh the effects of study group on microbial

RNA content, as the few differences in bacterial or viral RNA abundance we did observe between study groups were most likely caused by contamination and batch effects. Our results highlight the importance of including negative controls in all metagenomic analyses, since there was considerable overlap between bacterial content identified in study samples and control samples. For example, Proteobacteria, Firmicutes, Actinobacteria, and Bacteroides were found in both study samples and plasma-free negative controls. Many of the taxonomic groups we saw in our plasma-free negative control samples have previously been associated with diseases, including ME/CFS, demonstrating how incorrect conclusions may arise if controls are not used and batch effects not accounted for.

Interview with Dr. Ronald W. Davis



Q & A Regarding 21-Feb-2017 Research Update Video

00:18 - Ron Davis: Hello. This video is a follow up to a video that was done a little over a week ago, where I'm going to answer questions that were submitted about the previous video.

00:32 - Janet Dafoe reads a question: With the red and blue chart of metabolic pathways, you implied that ME/CFS is not like conventional mitochondrial disease, but more like a supply problem. Is that right? Like, if the mitochondria are a factory, it's the factory itself which is broken, and usable fuel piles up outside; whereas with ME/CFS the factory itself is in working order, but it's just not getting any fuel supplies delivered. Have I understood that right?

01:02 - Ron Davis: Yeah, I think that's a really good analogy of what's going on in this disease. It's clear from Dr Naviaux's work, and others', that it's a hypometabolic disease with a large number of things that are very low.

Some of those things are the raw materials that go into the mitochondria to generate energy – and that's what we think is the primary problem in causing the fatigue.

01:30 – Janet Dafoe reads a question: Is it still the case that the problem could also be not having enough of something in the blood, that should be there ?

01:39 – Ron Davis: So we've tested serum from patients, that show a change in impedance – we don't know exactly what it is that causes that change – it could be something that's in the blood, that's a positive thing that causes the change – or in fact, you're right, it could be something that's insufficient. Now, one of the likely cases is the fact that it might be a metabolite, or several metabolites – because this is a hypometabolic disease. So we have done another experiment, where we have actually filtered the serum, to see whether the signal is in the material that goes through the filter, or something that is retained by the filter. These filters are filtering out molecular species. What we've found is that most of the signal is filtered out – which means that it's very large, which means it's probably a protein. If it were a metabolite, we would probably have seen it's the filtrate causing the problem – which we did not.

02:45 – Janet Dafoe reads a question: Would blood from patients suffering from other forms of chronic fatigue, also show a similar impedance signature, or is the ME/CFS signature unique and distinguishable from other kinds of chronic fatigue, and therefore viable as an unambiguous diagnostic for ME/CFS ?

03:05 – Ron Davis: Well, we haven't done enough tests at the moment, to understand that. We will look at a number of fatigue situations, other diseases that show fatigue, as well as sports fatigue, and see if we see similar signals. This signature can still be quite useful, if in fact it shows up in all different types of fatigue. We would then have to work out some way to distinguish the types of fatigue, and one way to do that distinguishing, is to look at chemical reagents that will change the signal. And if, for example the pyruvate that we've used, causing the signal to go away, we would look at whether the signal goes away in these other fatigues. So this gives us a lot of dimensionality to actually do a fairly complex test that may be very specific for Chronic Fatigue Syndrome...

View the video at <http://www.openmedicinefoundation.org/2017/03/07/dr-ronald-w-davis-answers-patient-questions-q-and-a-follow-up-to-22117-research-update/>

Other Research

Summary: Estimating the Disease Burden of ME/CFS in the United States and its Relation to Research Funding.

Myalgic Encephalomyelitis, also called chronic fatigue syndrome or ME/CFS, is a very debilitating disease affecting more than one million Americans. A 2015 report by the National Academy of Medicine (NAM) characterized ME/CFS as a “serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities” of patients and in its severe form “can consume the lives of those whom it afflicts.” ME/CFS can leave patients with less function and a lower quality of life as compared to patients with congestive heart failure, multiple sclerosis, and end-stage renal disease. Less than 10% of patients recover and most are unable to work, resulting in an economic impact to our country of 18-24 billion dollars a year in lost productivity and medical costs. Patients are at a higher risk of premature death due to cancer, heart disease, and suicide.

In spite of the disability and increased risk of premature death, the NAM report cited a “paucity of research” and “remarkably little research funding,” averaging only five million dollars annually between 1995 and 2014. Estimated funding for 2016 has increased to seven million dollars,

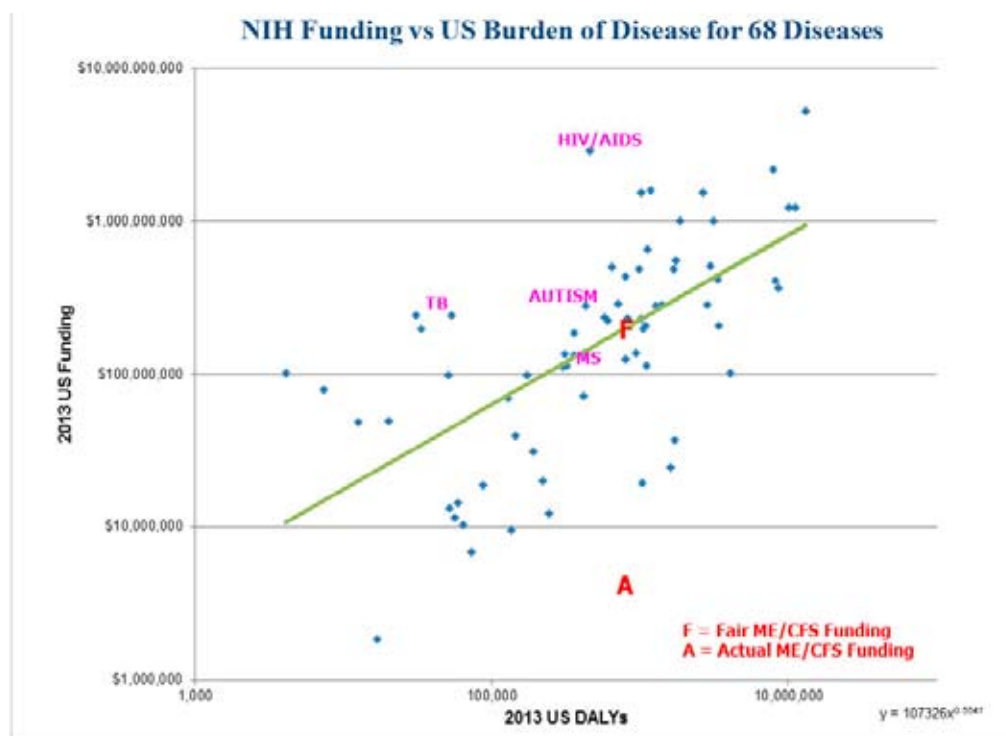
but this is still less than 0.04% of the yearly economic impact and leaves ME/CFS near the bottom of all disease areas funded by National Institutes of Health (NIH). By comparison, AIDS received three billion dollars and multiple sclerosis received \$98 million.

NIH considers disease burden when making funding decisions. The World Health Organization has pioneered a single measure of disease burden, disability adjusted life years (DALY), which combines the number of years of premature death (its mortality) with the degree of disability (the morbidity) caused by that disease. This quantifiable measure of suffering and death helps policy makers compare the impacts of different diseases.

The DALY is defined as the sum of the years lost due to the disability (YLD) and the years lost due to premature death (YLL). The estimate of YLD is based on the prevalence of the disease and the level of disability. The estimate of YLL is based on the number of deaths in a year and the number of years of life expectancy lost per death.

The DALY has been estimated for many diseases in the U.S. In 2013, NIH conducted an analysis that compared disease burden for 68 diseases to the research funding provided for each.¹ NIH then identified areas of underfunding relative to disease burden. NIH did not include ME/CFS in this analysis because its DALY had not been estimated.

A study published in December 2016² finally provides an



estimate of the DALY for ME/CFS in the United States. The DALY estimate includes both the years of life lost due to the disability experienced in ME/CFS (YLD) and the elevated risk of premature death due to cancer, cardiac disease and suicide (YLL). The YLD of 0.488 million is estimated using the U.S. prevalence of 1.06 million people and the disability weight of 0.46. The disability weight is a measure of the level of disability, and ME/CFS has one of the highest disability weights among a number of better-known diseases.

The study estimates a YLL of 0.226 million as a result of premature deaths due to heart disease, cancer, and suicide. The resultant DALY, which is the combination of the measures of YLD and YLL, comes out to 0.714 million.

This study adds ME/CFS to the NIH's 2013 analysis of funding and disease burden. As shown in the figure below, in 2016, ME/CFS was funded at about seven million dollars per year (point A). To achieve funding parity with other illnesses, the ME/CFS DALY suggests NIH funding of approximately \$188 million per year (point F). This is roughly twenty-seven-fold greater than the 2016 NIH funding level. The figure illustrates how ME/CFS has a disease burden greater than that of both HIV/AIDS and MS, yet in 2016, received about 400 times less funding than HIV/AIDS and 14 times less funding than MS.

The one million plus Americans who are afflicted with ME/CFS deserve as much consideration as those with more highly publicized diseases such as HIV/AIDS or multiple sclerosis. It is imperative that NIH funding for ME/CFS be substantially increased so that the necessary studies can take place to help restore the quality of life to those who have lost years and sometimes decades of their lives due to severe debility and premature death.

For questions, contact Mary Dimmock at medimmock@gmail.com, Dr. Arthur Mirin at aamirin@comcast.net, or Dr. Leonard Jason at ljason@depaul.edu

¹ Rockey S, Wolinetz C., 2015. "Burden of Disease and NIH Funding Priorities." Rock Talk. National Institutes of Health. June 19, 2015. Available at <https://nexus.od.nih.gov/all/2015/06/19/burden-of-disease-and-nih-funding-priorities/>

² Dimmock ME, Mirin AA, Jason LA (2016). "Estimating the disease burden of ME/CFS in the United States and its relation to research funding". J Med Therap 1: DOI: 10.15761/JMT.1000102, <http://bit.ly/2mR7yG4>

To see the disease burden for 68 diseases, go to: https://report.nih.gov/info_disease_burden.aspx and click on download source data at the bottom of the page.

Fibromyalgia Treatment Priorities

In September 2014, CIHR announced that it would be supporting a "James Lind Alliance" process for Fibromyalgia. The James Lind Alliance believes that:

- addressing uncertainties about the effects of a treatment should become accepted as a routine part of clinical practice
- patients, carers and clinicians should work together to agree which, among those uncertainties, matter most and deserve priority attention.

The idea is to come up with the top ten priority research studies.

The National ME/FM Action Network was critical of the announcement for several reasons. We believed that FM issues go well beyond treatment uncertainties into causality and service provision, that the discussion needs to include researchers and health systems administrators as well as patients carers and clinicians, and that enough was known about priorities to start research immediately.

The process went ahead despite our concerns. We were not invited to participate on the working group. The top ten research studies, along with 13 additional studies, were released recently. We are showing them for your interest. (From the James Lind Alliance website)

Fibromyalgia (Canada) Top 10

1. Can early targeted/personalised treatment plans based on sub-grouping and/or staging of severity improve outcome for people living with fibromyalgia?
2. What evidence is there to support the use of lifestyle interventions (i.e. nutrition, exercise, take more breaks, general lifestyle interventions) for the management of fibromyalgia symptoms?
3. What are the best ways to manage sleep problems in people living with fibromyalgia?
4. What are the effective methods for educating patients living with fibromyalgia to take an active role in their care?
5. What are the health care settings for persons with fibromyalgia that would allow for the best health care professional and optimal care pathway, and for appropriate follow-up?
6. What innovative self-management strategies, including social media and on-line tools, may be used in fibromyalgia care and do they impact outcome?

7. What are the best methods to treat and manage cognitive symptoms of fibromyalgia?
8. How safe and effective is the use of cannabinoids and opioids in treating fibromyalgia?
9. Does improving patient health literacy (i.e. education on medications, neuroscience of pain mechanism) help improve patient health outcomes in people with fibromyalgia?
10. What is the most effective treatment for hypersensitivity (e.g. touch, noise, odour, light, hypervigilance) in fibromyalgia patients?

The following questions were also discussed and put in order of priority at the workshop:

11. To what extent does physical environment (i.e. living/working space) affect fibromyalgia symptoms and influence disease management?
12. By what methods can a health care professional safely and effectively wean a person with fibromyalgia off a medication?
13. How prevalent is polypharmacy (or simultaneous use of multiple medications to treat a single condition) in fibromyalgia patients and are lower doses of more drugs better than high doses of fewer drugs?
14. What are effective methods in educating health care professionals to reduce the stigma that patients living with fibromyalgia experience?
15. How does fibromyalgia impact patients' concurrent medical conditions (e.g. diabetes, arthritis, cancer, myalgic encephalomyelitis) and vice versa? (i.e. diagnosis of new conditions, treatment of concurrent conditions, symptoms, success of treatment)
16. What workplace accommodations can be made to best allow people with fibromyalgia to continue working and manage their disease symptoms throughout the life course?
17. What factors (e.g. personality, socio-economic status, type of program, type of treatment) affect adherence to treatments for people living with fibromyalgia?
18. How effective are different medications including drugs given by novel routes of administration (injection, topical, mucosal) in fibromyalgia patients and how do they affect quality of life and ability to work?
19. What community-based resources would be effective methods of disease management for people with fibromyalgia (e.g. support groups, health literacy

coaches)

20. What are effective methods in educating the public (i.e. family, friends, co-workers, employers) to reduce the stigma that patients living with fibromyalgia experience?
21. Can a treatment algorithm or guidelines recommending the best treatment for symptoms be developed for people living with fibromyalgia?
22. Can the benefits of medication be maintained after the medication has been withdrawn from the patient's treatment?
23. How can people living with fibromyalgia be screened and managed to detect risk for addictions and prevent the development of outcomes such as medication misuse.

Medically unexplained physical symptoms (MUPS) among adults in Canada: Comorbidity, health care use and employment

This article by Jungwee Park and Heather Gilmour was released in March 2017 Statistics Canada's Health Reports, Volume 28, Number 3. MUPS is the term they use to cover ME/CFS, FM and MCS. The authors chose to exclude people aged 25+, so the numbers differ a little from what we have already published. Despite using different age ranges, the report supports our findings that ME/CFS, FM and MCS are widespread, that they are associated with high use of the medical system and yet patients express low satisfaction, and that they have great impact on employment.

Abstract

...In 2014, 5.5% of Canadian adults—an estimated 1.3 million – reported having chronic fatigue syndrome (1.6%), fibromyalgia (2.0%) and/or multiple chemical sensitivity (2.7%). Half (51%) of people with MUPS reported other chronic physical conditions, compared with 8% of those without MUPS. Similarly, mental comorbidities were more prevalent among those with MUPS. Higher health care use was observed among people with MUPS, but 25% of them reported unmet health care needs, compared with 11% of those without MUPS. People with MUPS were more likely than those without MUPS to be permanently unable to work or to not have a job; fewer than half (45%) were employed. Among those who were employed, 18% had missed work because of a chronic condition, compared with 5% of workers without MUPS.

Symptômes physiques médicalement inexpliqués chez les adultes au Canada : comorbidité, recours aux soins de santé et emploi

par Jungwee Park et Heather Gilmour

Résumé

...En 2014, 5,5 % des adultes canadiens, soit environ 1,3 million de personnes, ont déclaré souffrir du syndrome de fatigue chronique (1,6 %), de fibromyalgie (2,0 %) ou de sensibilités aux agresseurs chimiques (2,7 %). La moitié (51 %) des personnes ayant des SPMI ont déclaré avoir d'autres troubles physiques chroniques, par rapport à 8 % des personnes n'ayant aucun SPMI. Dans le même ordre d'idées, les comorbidités mentales étaient plus répandues chez les personnes ayant des SPMI. Un recours plus important aux soins de santé a été observé chez les personnes ayant des SPMI. Cependant, 25 % de celles-ci ont déclaré qu'elles ont des besoins insatisfaits en fait de soins, par rapport à 11 % des personnes n'ayant pas de SPMI. Les personnes ayant des SPMI étaient plus susceptibles que celles n'en ayant pas d'être incapables de travailler de façon permanente ou de ne pas avoir d'emploi; moins de la moitié de ces personnes (45 %) avaient un emploi. Aussi, 18 % des personnes qui avaient un emploi avaient manqué des journées de travail en raison d'un trouble chronique, par rapport à 5 % des travailleurs sans SPMI.

Network Activities

Health Issues

The Network has had recent correspondence with the Minister of Health asking her for a statement of support for ME/FM patients, emphasizing the need for ME/FM research, and drawing her attention to the article on the burden of illness for ME/CFS (adding that it is likely that FM would have a similar burden of illness.) We compiled a list of "Actions to improve the situation facing Canadians with ME/CFS and FM" (see next column). These actions are needed to ensure basic services for people with ME/CFS and/or FM. On March 23rd, staff in the Minister's office met with several people from MillionsMissingCanada who also conveyed the serious situation the ME/CFS community is facing and the need for action.

The Network has been in contact with staff at the Canadian Institutes of Health Research. We appreciate the statement

made in the IMHA newsletter (featured in Quest 109) and we appreciate the catalyst grant competition that is underway (announcement expected March 30). Nevertheless we take the position that the ME/FM community needs much more than it is receiving and we want to work with CIHR to move forward. We would like to draw the Public Health Agency of Canada into the discussions around issues like surveillance and exercise, and Health Canada around issues like human resource planning and opioid use.

Actions to improve the situation facing Canadians with ME/CFS and FM compiled by National ME/FM Action Network February 28, 2017

Develop an aggressive research program in Canada. Look for causes. Look for biomarkers. Look for treatments. Initiate clinical trials into promising treatments. Investigate the relationship between ME/CFS and FM which frequently overlap.

Develop models of clinical care for ME/CFS and FM and implement them.

Ensure that all points of contact with the health care system are knowledgeable about and respectful of ME/CFS and FM. This includes emergency room staff, paramedics and specialists.

Review and revise messaging around physical activity in light of findings that exercise can be harmful for certain people. Identify people who are exertion intolerant in order to protect their health.

Consider the situation of people who have been prescribed opioids for chronic pain and whose prescriptions are being cut or canceled without adequate support or alternatives.

Examine why the ME/CFS and FM communities reports very high levels of

- unmet home care needs
- food insecurity
- social isolation
- thoughts of suicide

Propose and implement solutions.

Review disability support programs to ensure that they are accessible to people with ME/CFS and FM. Remind staff of disability support programs that depriving people of disability supports is detrimental to their health.

Conduct surveillance of ME/CFS and FM

- update the 2014 statistics package produced by the National ME/FM Action Network. (2015 data

is scheduled for release on March 22, 2017 to governments and academic institutions, but not to the National ME/FM Action Network!)

- calculate the Canadian version of the US burden of illness statistics for ME/CFS and FM
- calculate the economic cost of ME/CFS and FM to Canada
- address other statistical gaps, including longitudinal studies.

Review and revise the broader messaging around ME/CFS and FM to ensure it is informed and respectful and that it reaches public audiences.

Revise ministerial and government correspondence on the topic of ME/CFS and FM.

Opioids

There has been a lot of talk in the media about the opioid crisis and overdose deaths. Usually that is portrayed as vulnerable teenagers and street junkies, but the ME/FM community is caught up in the crisis since some people are prescribed opioids for pain.

The problem stems from over-reliance by the medical community on opioids. The medical community has now decided to cut back on opioid use. There are three groups of people to consider:

- those not currently using opioids but who are dealing with pain
- those currently using opioids where the use is in control and helpful
- those currently using opioids where the use is out of control and not helpful.

The immediate problem is with the third group. Many are being denied opioids with inadequate withdrawal support. This is leaving people desperate. Some are visiting multiple doctors while others are turning to street drugs and internet supplements, sometimes with fatal results. For people on opioids, it is important to work with doctors. They are often reluctant to prescribe opioids but are allowed to do so if it is in the patient's best interest.

It is also important for the health system to address the needs of the first two groups. Pain is a serious issue and the tools to deal with pain need to be expanded and better understood.

Special thanks to our BC Director, Sherri Todd, who has been helping people caught up in this issue!

Disability Issues

Canadians with ME/CFS and FM need medical care, but they also need disability supports. Disability supports come in a variety of forms – financial, housing, transportation, communications, employment etc. As such, they fall under a number of federal government departments and agencies. The current government appointed a Minister for disability issues, Carla Qualtrough, and mandated her to develop a Canada Disability Act. Disability would be an enormous challenge in itself, but the Minister is responsible for sports issues as well.

The Network met with the Minister in February 2016 and outlined five areas needing attention. One year later, there were NO tangible changes. Here is a report card we sent the Minister at the one-year mark:

Accessibility issues facing people disabled by ME/CFS and/or FM Raised at a meeting with the Minister responsible for persons with disabilities on February 22, 2016	Tangible changes made to increase accessibility for people disabled by ME/CFS and/or FM Feb 22, 2016 to Feb 22, 2017
Ensure that eligible CPP-Disability applications based on ME/CFS and/or FM are approved without undue effort, cost or delay	NONE
Ensure that people with ME/CFS and/or FM have fair access to the <u>Disability Tax Credit</u>	NONE
Ensure that people with ME/CFS and/or FM have fair access to <u>home care</u>	NONE
Ensure that people with ME/CFS and/or FM who are able to work have fair access to <u>workplace accommodations and supports</u>	NONE
Ensure that information on the availability of at-home voting in <u>federal elections</u> is easy to find.	NONE

Note that the report card looks at tangible changes. There are discussions ongoing with CPP-D that have the potential to be very helpful in the future. We also subsequently received news of a tangible change from Elections Canada – they posted information about

voting-from-home on their websites for each of the constituencies holding by-elections!

More broadly, public hearings took place on the Canada Disabilities Act. The Network made a submission and people attended several hearings. The discussions have now moved behind the scenes. We were stunned to discover that the Network was not included in any of the working groups which were funded in October 2016. We have notified the Minister that the ME/FM community is not represented.

Also taking place are discussions about future funding of disability organizations. It appears that funding will be targeted at established organizations working in cooperative environments on feel-good projects. ME/FM organizations don't fit that profile, and won't until basic institutional stigma issues are satisfactorily addressed.

The PACE Trial

Part of growing bio-medical research is getting rid of the idea that ME/CFS and FM can be treated through psychotherapy and exercise. This largely means reducing the influence of the UK PACE trial. It was wonderful to see an article in the New York Times on March 19th critiquing the study!

The Network has written the Lancet asking for a retraction of the PACE article. In his last reply, the publisher noted that "As a leading medical journal and a focal point for debate, the Lancet will, at times, publish work that attracts criticism and controversy. Publishing such work, while also giving those who are critical a reasonable opportunity to respond, is part of the role of the Lancet." In other words, the publisher likes the attention that the article is receiving. This is not what we want.

The Network also signed a joint letter asking for the withdrawal of a follow-up article in another journal.

Classification

Ehlers-Danlos Syndromes:

Many of the symptoms of ME/CFS and FM overlap with those of Ehlers-Danlos Syndrome including pain, sleep disturbance, fatigue and POTS. Back around 1999, Dr Peter Rowe found that about 10% of his adolescent ME/CFS patients also qualified for a diagnosis of Ehlers-Danlos Syndrome. The Canadian organization serving people with EDS is The ILC Foundation.

On March 15, 2017 the American Journal of Medical Genetics published new research on the Ehlers-Danlos syndromes making changes to the classification system.

As noted in the material released by the US Ehlers-Danlos Society —"This publication clarifies the bases for the diagnosis of and updates the descriptions of more than a dozen different types of the Ehlers-Danlos syndromes. This long-awaited review updates the diagnostic criteria for the first time in 20 years, and provides management and care guidelines. It also introduces the newly-described hypermobility spectrum disorders."

"The Ehlers-Danlos syndromes are a collection of multi-systemic, heritable connective tissue disorders affecting collagen, the most abundant protein in the body. With the exception of the hypermobile type of the Ehlers Danlos syndromes, each type is a distinct entity defined by mutations in a single or small set of genes. Common features among the types include joint hypermobility, skin fragility, chronic pain, and fatigue. More severe types, such as Vascular Ehlers-Danlos syndrome, can be life-threatening, as fragile blood vessels and internal organs can spontaneously rupture. The greatest challenge for the consortium was to bring clarity and specificity to the clinical definition of the hypermobile type of Ehlers Danlos syndrome and to assess how the core features were related to comorbidities that could cloud the path to diagnosis and treatment. This effort is highlighted by the several papers in the collection that propose constructive solutions for the present and pathways to further understanding."

ICD-11

The International Classification of Diseases is a product of the World Health Organization. It is a list of diseases used for statistical and management purposes within countries. Then, with different countries using the same list, international comparisons are possible. Ten versions of the ICD have been produced. The eleventh version is now being developed. The tentative date for release is May 2018. As of March 20, 2016, the title, description and placement of ME/CFS has still not been decided, while Fibromyalgia has been moved from the rheumatology chapter and given a new description.

Considering the amount of time required to verify and translate the material, decisions have to be finalized very soon. Once ICD-11 is released, countries will review it and plan for its implementation which would take place several years or more later.

National Strategy for Lyme

In 2012, Member of Parliament Elizabeth May introduced a private member's bill calling on the government to develop a national strategy on Lyme disease. Over 4 years later, a draft national strategy was posted for comments, with the final version scheduled for release in May. The Lyme community in Canada is extremely disappointed by the draft, describing it as a "blatant failure of the Public Health Agency of Canada to follow the law as per Bill 442." This should make anyone nervous about asking for a "national strategy" since this term is so vague.

FM Volunteer Receives Award

Waterloo Region Record

Kathryn Zador of Kitchener received a Sovereign's Medal for founding FibroMoves, an in-pool rehabilitation program to help people who suffer from fibromyalgia. She also is a supporter of the Kitchener-Waterloo Fibromyalgia Support Group and the Canadian Aquafitness Leadership Alliance.

The honours were presented by Gov.-Gen. David Johnston at a ceremony in London, Ont.

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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 Quebec 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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