NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

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mefminfo@mefmaction.com

ME and FM – The International Situation

This newsletter is based primarily on two international conferences held this summer, one for ME and the other for FM. Both conferences drew together top researchers, healthcare providers and patient advocates from around the world. The conferences were very well organized. The presentations were very professional.

As someone who has been working on ME and FM issues for two decades, I came away from both conferences with deep admiration for the participants. I also came away from the conferences with deep frustration that the research, healthcare and support systems have done so little to incorporate ME and FM into their systems. This is true not only in Canada but all around the world. This newsletter will explore what is going on.

This issue of Quest is doing double duty. It is part of the regular series published quarterly by the National ME/FM Action Network of Canada. This explains its Canadian slant. This issue will also appear on the IACFS/ME website along with other reports of the conference.

References are made to earlier issues of Quest. These can be found under resources-newsletters on the National ME/FM Action Network website.

Margaret

Margaret Parlor, President
National ME/FM Action Network

The 3rd International
Virtual Congress on
Controversies in Fibromyalgia

24-25 June 2021

2021 IACFS/ME Virtual Conference :

August 19 - 21, 2021

International Association for
IACFS/ME
Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis

A lot happened during the summer of 2021:

The Controversies in Fibromyalgia online conference – June 24-25

Publication of a study about FM and mice - July 1

Cancellation of the scheduled release of revised NICE guidelines for ME - August 17

The IACFS/ME online conference - August 19-21

Publication of new US ME/CFS diagnostic and management guidelines - August 25

The US Open Tennis Tournament - August 30 to September 12

Contents

Why bring up the US Open Tennis Tournament? Part is some Canadian bragging, but part is because it is instructive.

The men’s single side went just about as predicted, with the top two ranked players meeting in the finals. The slight surprise was that the second ranked player won. The women’s single side was a complete surprise. The final was between two teenagers, one (Canadian) ranked 73rd in the world and the other (playing for Britain but born in Canada) ranked 150th. The 150th ranked player won.

Overall, Canada did very well at the tournament. Besides the player in the women’s finals, two other Canadian players reached the semi-finals (men’s singles and women’s doubles) and two more reached the third round (men’s and women’s singles). This Canadian show of force was not too surprising. Instead of assuming that champions would magically appear, Tennis Canada established an aggressive developmental program a decade or two ago to grow Canadian tennis talent.

The events at the tournament provide two important lessons that can be applied to ME and FM:

- Rankings/assumptions are not always right.
- Developmental programs can work.

The research, healthcare and support systems in Canada and world-wide need to question their assumptions - they have ranked ME and FM far too low - and they have to recognize that aggressive developmental programs are called for.

Conferences

Controversies in Fibromyalgia

website: *https://fibromyalgia2021.com/*

The third annual conference on the topic of FM was held on-line on June 24 and 25. About 160 people were registered from about three dozen countries. The number of countries shows that the topic of FM is international but the relatively small number of registrants from each country shows that interest in the various countries is thin. There was little US participation. The conference co-chairs were from Israel and Italy. The conference was held on European time, early in the morning for us in the Americas. Fortunately, all the sessions were recorded so they could be watched at our convenience.

The conference started with a discussion of foundational issues - FM diagnostic criteria, the placement of FM in the disease classification system (primary widespread pain), and the central sensitization model to explain ME. The FM conference then had a series of presentations of individual studies, mostly focused on pain. That was followed by presentations on clinical issues. One speaker noted that FM was often missed in his country. Other speakers talked about overlapping conditions. In the final section of the conference, the Italian and Israeli patient associations spoke about their front line work and the European Network of Fibromyalgia Associations (ENFA) spoke about its frustrating attempts to draw more attention to FM issues at the political level. There were a number of posters, primarily describing research studies. The conference wound up with a round table discussion on what participants could do to expand services. They agreed that they need to continue the strategies already underway and they noted that messaging should be consistently positive and constructive.

Canadian content: Dr Maryanne Fitzcharles from McGill gave a presentation urging great caution in using opioids for chronic FM pain.

The next Controversies in Fibromyalgia conference is expected to take place around June 2022, hopefully in person and probably in Israel or Italy.

IACFS/ME Conference

website: *https://www.iacfsme.org/2021-iacfsme-virtual-conference/*

This conference was held from August 19 to 21. Over 350 people registered for this conference. It was held on Eastern time, which was great for those of us in eastern Canada. It wasn't great for those on the other side of the world. Fortunately, all the sessions were recorded so could be watched later.

On the first day, the conference offered separate sessions for researchers, clinicians and patients. I attended the research session which included presentations by two program officers at the US National Institutes of Health (NIH) describing the funding process, two officials at a data sharing centre for ME data, and two leading researchers. The next two days of the conference consisted of lectures on clinical and research issues. Topics covered included COVID, post-exertional malaise, biomarkers, neurology, immunology, epidemiology and clinical examples. The US advocacy group SolveME gave a presentation talking about their efforts to reach out to the US government. There were also over 50 poster presentations.

Canadian content: Dr Moreau's lab in Montreal was very active with two oral presenters and three posters. Dr Nacul from the BC Complex Chronic Diseases Program (CCDP) coordinated the final day's sessions and also spoke on the status of the UK NICE guidelines revisions. The ME/FM Society of BC and the CCDP had three posters between them, two based on the study featured in Quest 129 and one on program statistics. Dr Eleanor Stein talked to the patient conference on pacing. Canadian ex-pats Dr Alison Bested, Dr Peter Rowe and Dr James Baraniuk were also speakers.

The IACFS/ME is hoping to hold its next conference in person at Stony Brook University, New York, June 15-18, 2022.

Posters From the IACFS/ME Conference

What are posters? At in-person conferences, there would be oral presentations in the main hall and posters set up in the lobby or hallway. During breaks, people could view the posters and have discussions with the authors or with other individuals passing by. It was a great way of sharing ideas. With virtual conferences, the posters are displayed on-line. During the conference lunch-hour, we could click on a button to be connected with the poster's author. I used the opportunity to talk to people in Norway (where it was evening), Australia (where it was the wee hours of the morning), the US and Canada.

Course of Illness (Norway)

The Norwegian ME Association conducted an on-line patient survey in early 2019. The purpose was to investigate the typical courses of illness and the factors that contribute positively or negatively to the health of patients.

The survey was conducted in Norwegian only, so respondents would be predominantly from Norway. Almost 6,000 responses were received. While this is a very large number, the authors advise caution when analysing the results. For example, the authors suspect that people with mild cases would be less likely to complete the survey and hence mild cases may be under-represented.

The authors drew these lessons from the survey data.

ME is a chronic disease. It can go on for a long time, often for life.

Norwegian guidelines classify ME into mild, moderate, severe and very severe. The authors note that even mild cases involve at least 50% activity reduction. At a moderate degree, the patient is largely housebound, and spends several hours a day on the couch or in bed to rest. Moderate ME is a serious illness that, for the most part excludes having paid work, severely limits social activities, and makes patients depend on assistance from family and friends for daily chores.

Very severe	1%
Severe	15%
Moderate	57%
Mild	25%
Recovered	2%

Fluctuations or deterioration are typical. The authors note that the health care system likes to describe a course of illness with initial fluctuation followed by gradual improvement. Only 12% of respondents reported that pattern. Much more common were fluctuations all the time or initial fluctuations followed by gradual deterioration. Only 2% of respondents said that they had recovered. People who recover might not complete the survey, so the true figure could be a bit higher. In one way these statistics are discouraging - one always hopes for improvement or recovery. In another way, the statistics are validating - if improvement doesn't happen, one is not alone.

Fluctuations - continuing	29%
Fluctuations then gradual deterioration	25%
Fluctuations then becoming stable	13%
Fluctuations then gradual improvement	12%
Relative stability	10%
Gradual deterioration	9%
Recovery	2%

The survey asked respondents for the year of onset. The graph showed a bit of a spike in 2009, which is a year swine flu was prevalent in Norway. Flu is not generally considered a trigger for ME, but this data suggests that it might be one.

More that half the respondents who reported severe or very severe symptoms said that their illness started before the age of 20. This suggests that pediatric cases have to be taken very seriously.

Respondents were asked what benefited or hurt them. Overwhelmingly, they said that managing activity (pacing) was helpful (3,124) and that over-activity was harmful (2,769). Some people found the health system helpful (944) but for every two people who found the health system helpful, three people found the health system to be harmful (1,472). The authors note that "[i]t would be difficult to find another patient group where patients consider the healthcare service to have contributed more to the continuation or deterioration of the illness than to the improvements or recovery". A few respondents said that the Norwegian employment/welfare system was helpful (249), but many more said that it made matters worse (881).

The authors' summary is worth quoting:

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With better support, treatment and understanding, a good ME life is possible.

There are several distressing findings in this study: far more ME patients experience a deterioration rather than an improvement over time, and the healthcare service and the welfare administration greatly contribute to a worsening of the course of the illness for an already seriously ill group of patients.

The good news is that the factors that contribute positively or negatively to the processes can be changed, and do not require breakthroughs in medical research. This requires, however, that health and welfare authorities use the knowledge that we already have about the ME patients' health situation and experiences, as documented in research and broad patients surveys such as this one. A great deal can be done to create a better course of the illness for ME patients, with a lower symptom burden and better health and quality of life.

We summarize these measures in five points.

1. *Activity management from day 1*
2. *Believe in the patient*
3. *Symptom treatment from the healthcare service*
4. *Changes in Nav's rules and practices* [Nav is the Norwegian employment/welfare system]
5. *Facilitation and practical help in everyday life*

**

The English summary of the report can be found here: *https://www.me-foreningen.no/wp-content/uploads/2021/03/Norwegian-ME-Association-2021-Report-on-the-course-of-illness-English-summary.pdf*

Nutritional Issues

Two Australian posters discussed the high prevalence of gastrointestinal symptoms, dietary modification and food intolerance among ME patients. A poster from Florida's Nova Southeastern University discussed a study that used a screening tool to identify people with ME who would benefit from nutritional intervention. The study found that 85% of their patient cohort was at nutritional risk and that they benefited from nutritional education. The tool, which was developed some years ago for US seniors, is shown on page 6. The Canadian Community Health Survey has consistently shown that food insecurity is an issue for people with ME or FM in Canada.

"VANE" (Australia)

"VANE" stands for violence, abuse, neglect and exploitation. Those are stronger words than we use in Canada (Canada being a polite and understated country), so I wanted to know the background for this poster. It turns out that Australia recently set up a "Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability". The royal commission is compiling information and holding hearings, with a scheduled report date of September 2023.

It seems that there is a much stronger disability community in Australia than there is in Canada. In addition to this royal commission, a National Disability Insurance Scheme has been endorsed in a public referendum and established through their parliament. The Australians presenting this poster informed me, however, that there are still problems having people with ME recognized as disabled.

The study described in the poster involved interviews with 19 ME patients. The study found that ME often led to cutting back or ceasing work or education and becoming financially dependent on institutions – "medical, health, legal, corporations, welfare, family, government, and insurers". People were called upon to justify, report and evidence impairment and disability and meet other requirements. They often experienced loss of privacy and confidentiality.

Other posters

Another poster from Australia stressed the importance of considering the visual images used in material about ME, observing that the wrong images have the power to reinforce bias and stigma.

A poster from Australia and a poster from Norway looked at adolescent/school issues. One poster from the UK described a survey of partners and family members of people with ME, finding out that their quality of life is affected. It was great to see young people and family members recognized.

Many of us thought that the idea of ongoing infections in ME had been put to bed – that the virus was gone but the immune system did not turn off. One poster suggests that the studies that failed to find enteroviruses were flawed. This means that ME might still be related to ongoing infection.

DETERMINE YOUR NUTRITIONAL HEALTH

The Warning Signs of poor nutritional health are often overlooked. Use this Checklist to find out if you or someone you know is at nutritional risk.

Read the statements below. Circle the number in the "yes" column for those that apply to you or someone you know. For each "yes" answer, score the number in the box. Total your nutritional score.

	YES
I have an illness or condition that made me change the kind and/or amount of food I eat.	2
I eat fewer than 2 meals per day.	3
I eat few fruits or vegetables or milk products.	2
I have 3 or more drinks of beer, liquor or wine almost every day.	2
I have tooth or mouth problems that make it hard for me to eat.	2
I don't always have enough money to buy the food I need.	4
I eat alone most of the time.	1
I take 3 or more different prescribed or over-the-counter drugs a day.	1
Without wanting to, I have lost or gained 10 pounds in the last 6 months.	2
I am not always physically able to shop, cook and/or feed myself.	2
TOTAL	

Total Your Nutritional Score. If it's –

0-2	Good! Recheck your nutritional score in 6 months.
3-5	You are at moderate nutritional risk. See what can be done to improve your eating habits and lifestyle. Your office on aging, senior nutrition program, senior citizens center or health department can help. Recheck your nutritional score in 3 months.
6 or more	You are at high nutritional risk. Bring this Checklist the next time you see your doctor, dietitian or other qualified health or social service professional. Talk with them about any problems you may have. Ask for help to improve your nutritional health.

Remember that Warning Signs suggest risk, but do not represent a diagnosis of any condition.

These materials are developed and distributed by the Nutrition Screening Initiative, a project of:

AMERICAN ACADEMY OF FAMILY PHYSICIANS
THE AMERICAN DIETETIC ASSOCIATION
THE NATIONAL COUNCIL ON THE AGING, INC.

The Nutrition Screening Initiative • 1010 Wisconsin Avenue, NW • Suite 800 • Washington, DC 20007
The Nutrition Screening Initiative is funded in part by a grant from Ross Products Division of Abbott Laboratories, Inc.

Research From Montreal

Dr Alain Moreau is a senior Canadian scientist based in Montreal who started researching ME about six years ago. Members of his research team gave two oral presentations and three poster presentations at the IACFS/ME conference. The focus of Dr Moreau's research program on ME is to understand the causes of ME by different complementary approaches from genetics to epigenetics.

Genetics refers to modification often called variants, which result in changes of a short alphabet of four letters A, C, G or T. If two people have slight differences in the same gene, it could result in a slightly different protein to do the same job. The difference could have a negligible health effect or it could have an important health effect.

Gene differences are not the only issue that molecular geneticists investigate. Epigenetics can affect production of proteins, resulting in too many or too few of various proteins. For instance, the DNA might be tightly packed, making it harder for the genetic code to be accessed, which could slow down protein manufacture. This is referred to as DNA methylation. If DNA is loosely packed (acetylation) it is easier to access the information. Another epigenetic situation is where noncoding RNAs like microRNAs are floating around in the cell and interfere with protein production.

Molecular geneticists try to identify how genetics and epigenetics are affecting the body's functioning. Using biosamples, such as blood, urine or saliva, they look for unusual patterns of genes, proteins or microRNA. This involves processing the biosamples and then sifting through the data to identify areas for further investigation. Further investigation could involve looking for the effect in larger populations or recreating the genetic differences in animals to see the consequences. The goal is to determine whether the genetic finding is important and, if so, explain how the finding affects the body. This can lead to the identification of biomarkers for the diagnosis of ME and a better stratification of persons affected by ME to whom a specific treatment could be recommended.

The five studies that the Montreal lab presented at the conference all dealt with the identification of possible problems, along with recommendations on the next stage of investigation.

Presenters from Montreal:

Lynda Chalder

Poster Presentation

DNA methylation profiling of myalgic encephalomyelitis

Evguenia Nepotchatykh

Oral Presentation

Distinguishing Myalgic Encephalomyelitis from Fibromyalgia

Corinne Leveau

Poster Presentation

The impact of genetic polymorphisms on IDO1, IDO2 and THVS on thrombospondin-1 levels and disease severity

Dr Wesam Elremaly

Oral Presentation

Circulating irisin levels in myalgic encephalomyelitis are associated with disease severity

Dr Bita Rostami-Afshari

Poster Presentation

Role of sphingomyelin acid 3B in the pathophysiology of myalgic encephalomyelitis

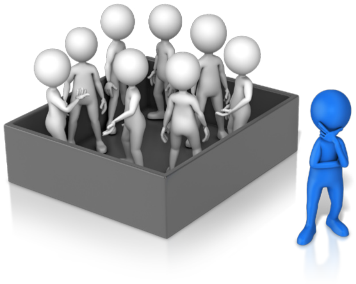
ME and FM – What Exists vs What Should Be

We have a good measure of the importance of ME as a health issue. The US NIH calculated US disease burden for about 70 health conditions combining mortality (premature deaths) and morbidity (reduced quality of life) figures. The NIH did not calculate disease burden for ME or FM. However, ME experts calculated the appropriate figure for ME using the same methodology. Their work shows that the burden of illness for ME is substantial, similar to the levels for Multiple Sclerosis, Autism or HIV/AIDS. See Quest 110 (2017). There is reason to believe that the FM burden of illness would be in the same league.

There are huge gaps between the research, healthcare and support services that would be appropriate for ME and FM's burden of illness and what is currently being offered. Lack of appropriate services has led to unnecessary suffering over many years for people with ME and with FM. These illnesses affect people's ability to contribute to their families, to the economy and to society. Everyone is harmed by inaction. The failure to address ME and FM appropriately has also left the world unprepared to deal with a new generation of disabled citizens – those dealing with the long-term effects of COVID.

The National ME/FM Action Network has heard many reasons for inaction.

- *From the research funding system, we hear that ME and FM are not ready yet for a fulsome research program and that, when officials receive good applications, the applications will be funded.*
- *From the healthcare system, we hear that there is disagreement on how to diagnose and treat ME and FM so it is premature to incorporate them into the system.*
- *From the support services system, we hear that programs are in place and people just have to apply.*
- *Overall, we hear that the problem could not be as big as we are suggesting because otherwise it would have been addressed already.*



What are these officials really telling us? To address the question, it is helpful to look at this clip-art. Imagine the people in the box working for the research, healthcare or support services system following the system's policies and procedures. Imagine that the person just outside the box is part of the system but has responsibility to keep in touch with the public. The person outside the box has responsibility for explaining to the public what the system does. The person should be listening to the public to see if there are problems or gaps in the services being offered by the people inside the box and adjusting operations accordingly. The person outside the box also has responsibility for ensuring that the system is not distracted, overloaded or discredited so that it can continue to operate. That would be a protecting role.

When the systems provide reasons for inaction, they are taking on a protecting role like a dragon guarding a castle. They could be telling us that

- they do not consider our requests to be valid,
- they are not sure how to implement our requests,
- they don't have the skills, authority or resources to fulfill our request,
- they think that implementing our requests will be disruptive to ongoing operations,
- they think that implementing our requests will not be well received, which could be by their bosses, by other clients or by the public,
- they are not sure how to implement our requests or they want someone else to go first , or
- they are busy with Covid.

Part of ME and FM advocacy is listening to the officials, showing them why services are needed, understanding their concerns, and working with them to find solutions. It is also identifying vulnerabilities in the community's requests that officials could latch onto to justify inaction.

Growing Research

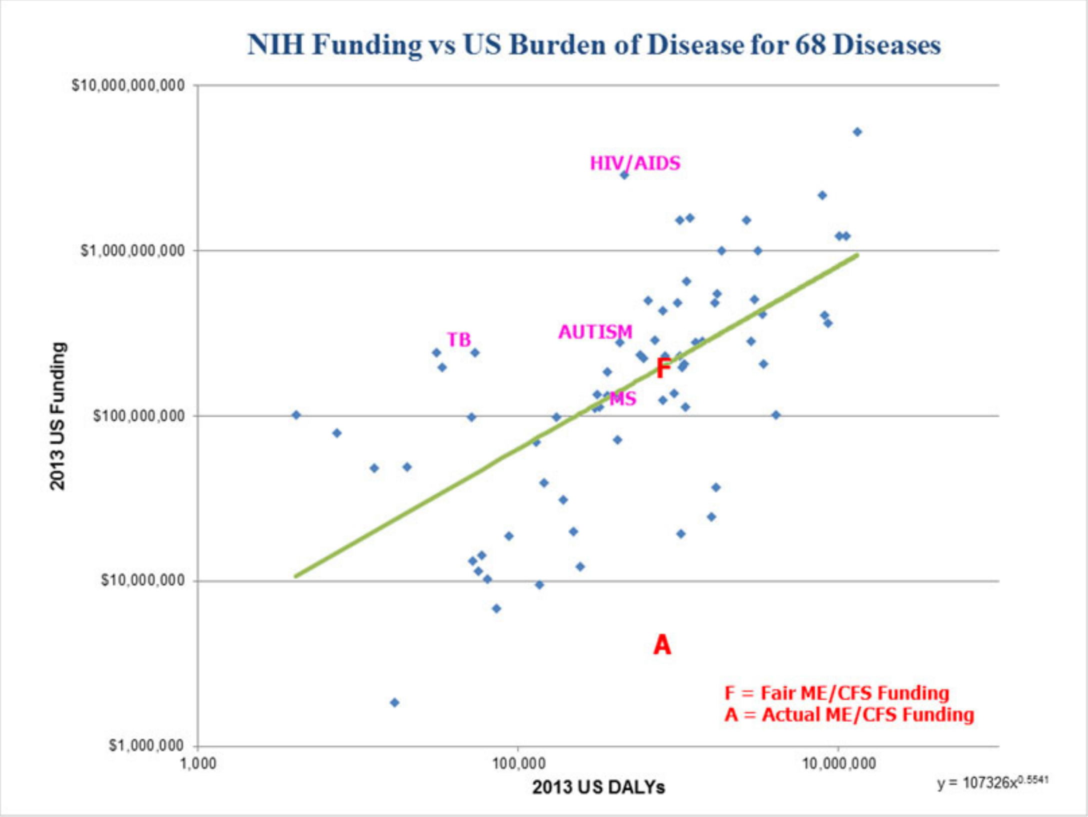
Excuse for inaction: ME and FM are not ready yet for a fulsome research program. When officials receive good applications, the applications will be funded.

The burden of illness work, mentioned above, did not stop at calculating burden of illness. It aligned the figures for each health condition with its NIH funding, then calculated a regression line which showed what funding would be for each condition if NIH funding were based entirely on burden of illness. The work showed that ME was the most underfunded health condition on the list, receiving about 7% of fair funding. Why is funding so low? Gender and stigma were found to be factors. See Quest 127 (2021) page 5-6. Again, it is important to mention that FM was not part of the studies, but appears to be in a similar situation.

Besides gender and stigma, we suggest that research funding seems to be self-perpetuating. Conditions that have sophisticated research in place are seen as deserving research, while conditions that don't are seen as not deserving research. It is also easier to write applications with existing infrastructure. Plus, giving funding to new areas can be perceived as diverting money from areas that need it. New areas are at a big disadvantage and this is a reason to introduce developmental programs for under-funded research topics.

It is the position of the National ME/FM Action Network that Canada's health research funding agency CIHR is allocating public money and should be allocating it in the public interest. A decade ago, we estimated fair funding for ME and FM at $10M each annually. We also argued that it was important to commit to long-term funding since people would not enter this research area without some assurance of stability.

After years of false starts, CIHR decided that Canada needed a research network. The concept is excellent. Unfortunately, CIHR seemed to think that they were dealing with inexperienced people, failing to recognize that very senior people have discovered this field. The government entrusted the network with $280,000 per



year for five years, 3% of ME target funding. We intend to do our best with these funds, but feel limited by the small amount and wonder what message it sends about the seriousness of ME.

Now let us look at research vulnerabilities. The presentations at both the ME and the FM conferences were interesting and professional. Research officials viewing them could be impressed with the quality of the science. They could, however, choose to find excuses for not getting involved. A vulnerable area is underlying theory. Another is diagnostic criteria, which is discussed in the healthcare section.

At the FM conference, there was discussion of how to classify pain. In the past, pain was considered to be either nociceptive or neuropathic. Nociceptive pain is the body's reaction to painful stimuli like being hit on the thumb by a hammer. Neuropathic pain is caused by inflammation, irritation or neural tissue compression. Now, a third category of pain has been added. Nociplastic pain is pain that is caused by dysfunctional pain modulation. This makes the nociplastic pain a disease in it own right (primary), while nociceptive and neuropathic pain are symptoms of something else (secondary). FM has been placed under nociplastic pain.

The FM conference also discussed the mechanisms behind FM. The leading theory is "central sensitization". The nervous system receives sensory input, processes this information, and sends back instructions to muscles, organs and glands. Central refers to the central nervous system (CNS), the brain and the spinal cord. The CNS connects to the peripheral nervous system which consists of nerves and ganglia. For FM, it is proposed that the volume control of the CNS gets turned up following previous pain experiences.

On July 1, just a week after the conference, a study was released entitled Passive transfer of fibromyalgia symptoms from patients to mice, *https://www.jci.org/articles/view/144201/pdf.* Immunoglobulin-G was extracted from people with FM and from healthy controls and was then injected into mice. The mice that received IgG from FM patients developed FM symptoms while the mice that received IgG from healthy controls did not. Further, the IgG was found in the peripheral nervous system of the FM mice but not in their central nervous system. This study puts into question both the nociplastic theory (since the FM symptoms seemed to be triggered by the immune system) and the central sensitization theory of FM (since the peripheral nervous system was implicated).

Research officials could argue that FM is not ready for major league research since its theoretical foundation is questionable. That would overlook the tone of the FM conference. The title of the conference was "controversies in fibromyalgia" which acknowledges that issues have not been settled. The speaker on central sensitization was very frank that the theory was still being tested. Science is about trying to explain things and being willing to question and adapt as new ideas come forward. The lesson officials should draw is that there is good but limited FM research underway and far more support (notably financial support) is needed to fill in the gaps in knowledge.

The ME community considers ME to be a complex multi-system disease and has a much broader causal hypothesis. There was less theoretical cohesion at the IACFS/ME conference than the FM conference. Research officials could interpret this as scatter-gun or unfocused research. Instead, they should recognize that the topic is broad and that existing researchers are spread very thin. Support (notably financial support) could help fill the gaps and help the understanding of ME move forward.

Growing Healthcare Services

Excuse for inaction: There is disagreement on how to diagnose and treat ME and FM so it is premature to incorporate them into the system.

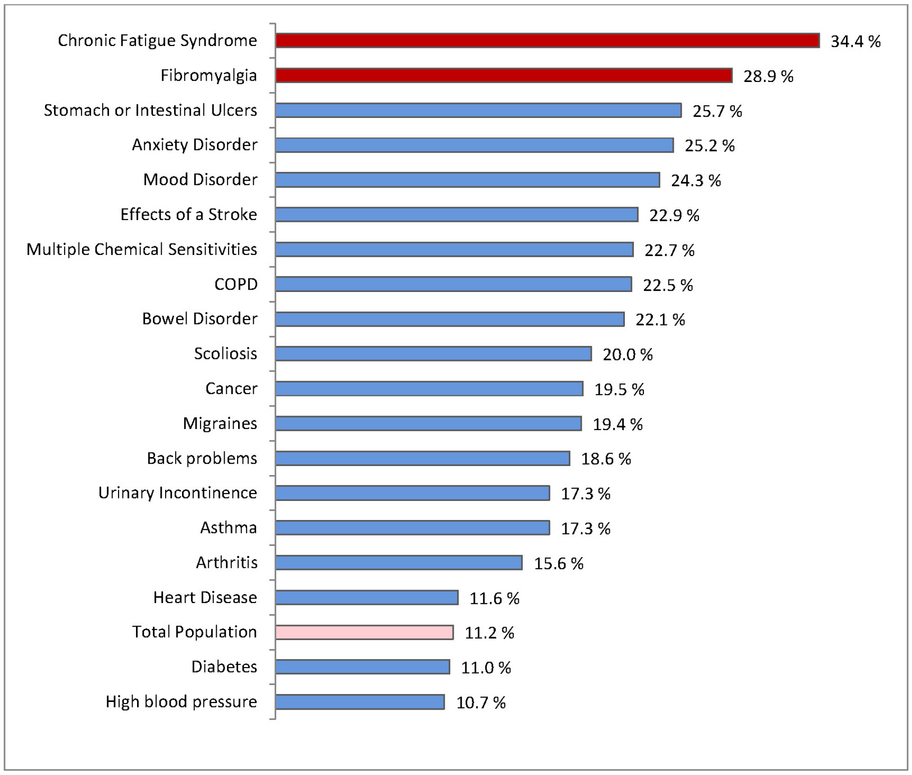
There is a great deal of evidence that healthcare services for ME and FM are inadequate. Here in Canada, we have statistics from the Canadian Community Health Survey showing high levels of unmet health care needs. (See Quest 108 (2016) for 2014 data, Quest 112 (2017) for combined 2005, 2010, 2014 data). The Norwegian survey (see page 4) also showed frustration with the healthcare system's treatment of ME and pointed out that there was a lot that could be done to improve it with the current state of knowledge.

Clinical diagnostic and treatment protocols are fundamental to healthcare services, as is the healthcare delivery model.

Outsiders looking at ME might think that there are multiple diagnostic protocols and multiple treatment guidelines. They could use this as an excuse for inaction. In fact, there is strong international consensus around ME

UNMET HEALTH CARE NEEDS

Canadians Aged 12 and Older Reporting Unmet Health Care Needs According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
Arthritis = ages 15+ , COPD = ages 35+; Urinary Incontinence = ages 25+

diagnosis and treatment, with the significant exception of the UK NICE guidelines.

The National ME/FM Action Network recognized the importance of diagnostic and treatment protocols in the 1990's. We convinced the Canadian government to establish two expert panels, one for ME and the other for FM. We facilitated the work of the two panels. Their diagnostic and treatment protocols were published in 2003. The ME diagnostic protocols are referred to as the Canadian Consensus Criteria (CCC).

The European ME Network recently looked at what criteria to use and decided on the CCC, Fukuda (as long as post-exertional malaise was required which makes it fairly consistent with the CCC) and the IOM. The IOM is a simplified version of the CCC designed to help in early diagnosis. Thus, while there are several diagnostic criteria in use, they are closely related.

When it comes to treatment criteria written for clinicians, key documents are the IACFS/ME primer, the Pediatric Primer and a review article by Drs Bested and Marshall. These documents are available in English and French on our website. All are based around the CCC. Euromene developed treatment guidelines which are consistent. A new document on diagnosis and management of ME was released in August by the US ME/CFS Clinicians Coalition. It bases itself more than the others on the US-developed IOM criteria but it provides essentially the same advice.

The outlier around treatment is the UK guidelines. The current guidelines were developed in 2007 by the UK organization NICE (the National Institute for Clinical Excellence). They recommend Graded Exercise Therapy (GET) and suggest that Cognitive Behaviour Therapy is curative. Based on research and patient experience, GET has been discredited as a treatment for ME while CBT is considered potentially supportive but not curative. In 2017, NICE began a review of those guidelines. A discussion paper was released in 2020 which removed GET and downgraded CBT. Then, the day before the scheduled release of the final guidelines in August 2021, NICE cancelled the release. It is widely believed that GET and CBT supporters objected to the new recommendations. The international ME community is mobilizing.

Before the Canadian expert panel on FM released its 2003 report, the diagnostic criteria for FM was based on pain. The Canadian panel recommended that other symptoms be considered as well. Subsequent FM criteria have moved away from an exclusive pain focus to a multi-symptom focus. While several diagnostic criteria are on the table, they continue to have the multi-symptom focus.

The treatment resources for FM are not as good as for ME. Here in Canada, we have 2012 Canadian FM treatment guidelines. While there is some good information, there are two major flaws. One is the poor recognition of ME as a possible co-morbid or alternate diagnosis. Whether or not ME is present very much affects treatment. The other is the poor recognition how serious FM can be.

There is a need to discuss how ME and FM healthcare services should be delivered. What is the responsibility of family doctors and what it the responsibility of specialists? For ME, there has never been a specialty, but our organization and the European ME Network have recommended that there be one. For FM, we in Canada saw a quiet withdrawal of rheumatologists from treating FM around a decade ago, leaving many people with FM (and their family doctors) without specialist support. The advantages and disadvantages of using the same specialists for ME and FM need to be discussed.

Growing Support Services

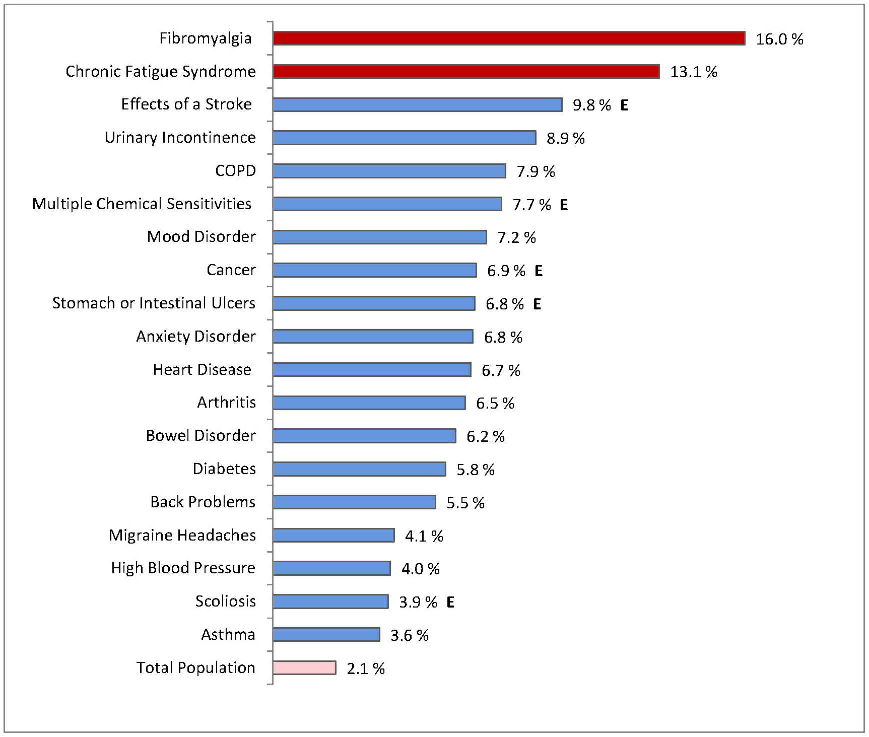
Excuse for inaction: Programs are in place. People just have to apply.

We in Canada find that people with ME and FM have a hard time qualifying for support programs. Problems we have uncovered include non-inclusive eligibility criteria, assumptions that ME and FM are not disabling, and the need for medical certification.

A decade ago, we analyzed numbers from the 2005 Canadian Community Health Survey. The data showed

UNMET HOME CARE NEEDS

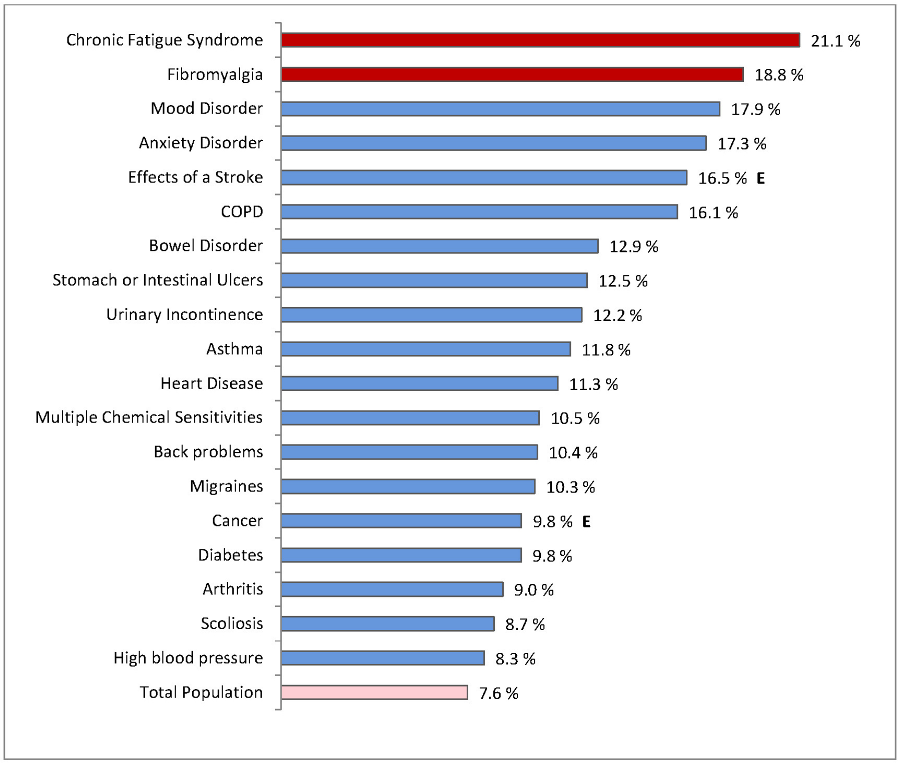
Canadians Aged 18 and Older Reporting Unmet Home Care Needs According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Master Data File
COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
COPD = ages 35+; Urinary Incontinence = ages 25+
E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)
Respondents from Ontario, Quebec, Prince Edward Island

SOCIAL IMPACT

Canadians Aged 12 and Older Reporting a Very Weak Sense of Community Belonging According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+
E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)

that people with a diagnosis of "Chronic Fatigue Syndrome" or Fibromyalgia had very high rates of unemployment, poverty, food insecurity, social isolation and unmet home care needs. The rates stayed high in the 2010 and 2014 cycles – see Quest 112 (2017). Education and housing are two issues not included in the survey; we know there are problems there too.

Some support issues did emerge at the two conferences this summer. Talking about support services internationally is challenging because there is a wide range of supports needed and because the support systems are different in every jurisdiction. There are two extremely useful international frameworks which can help bring future discussions together, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the World Health Organization International Classification of Functioning Disability and Health (ICF). The CRPD and ICF are discussed in Quest 106 (2016).

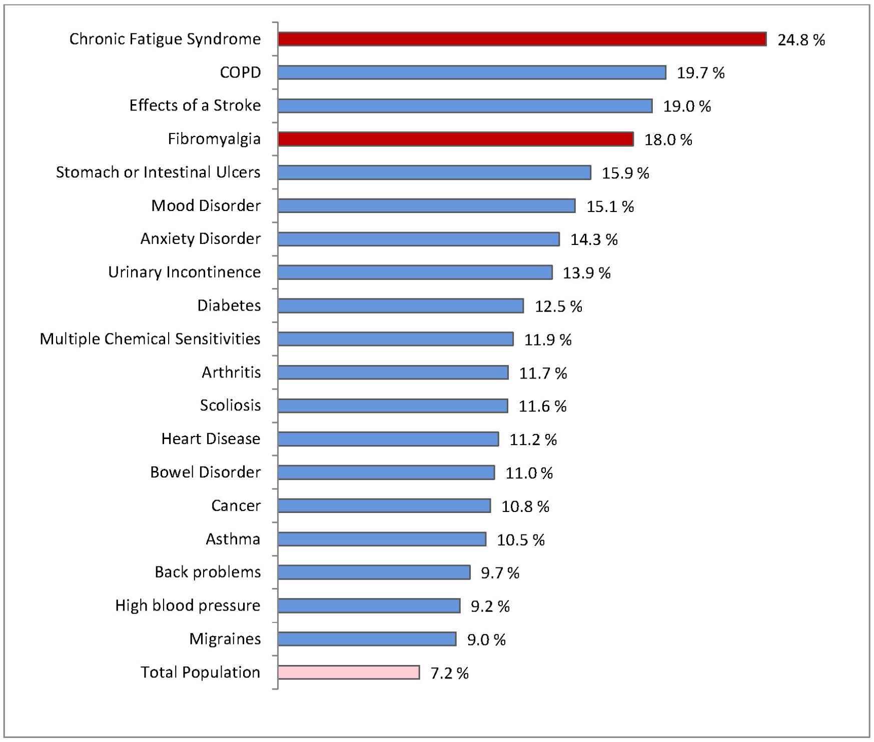
The ICF is a companion of the ICD (International Classification of Diseases). The ICF theorizes that diseases can map to impairments which can map to activity limitations which can map to participation restrictions, and the effects are influenced by personal or environmental factors. The theory is easy to implement for some disabling conditions, but it is difficult to implement for ME and FM where the causality is not understood, where people have choices in what activities they limit, and where the impairment can fluctuate.

Why do people with ME and FM have high home care needs? We discovered that some provinces use a screening tool developed by the international organization interRAI. We think that there are subtle biases against ME and FM in the tool. We would like to hear from other countries where this tool is used.

You can find the CCHS summary report on our website at *http://mefmaction.com/docs/CCHS_Stats_2014.pdf*.

HOUSEHOLD INCOME

Canadians Aged 12 and Older Reporting Household Income Less Than $20,000 Per Year According tc their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
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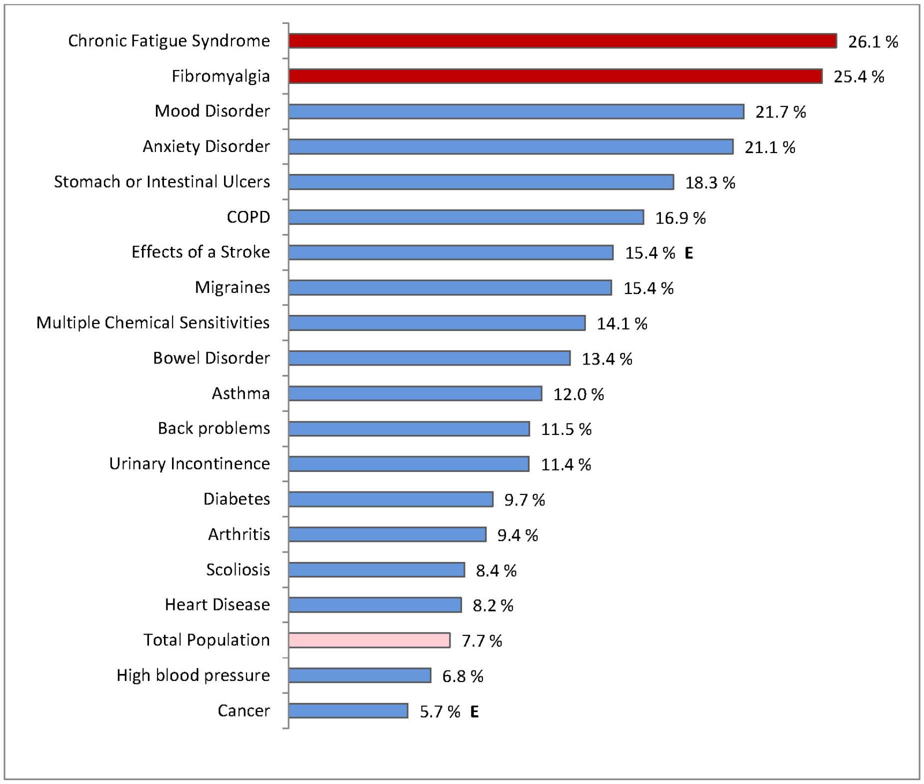
FOOD INSECURITY

Canadians Aged 12 and Older Reporting Moderate or Severe Household Food Insecurity According to their Chronic Health Condition, 2014



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COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+
E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)
Respondents from Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island

Moving Forward

The fact that research, healthcare and support services for people with ME and FM are lacking around the world tells us that there are international issues to be resolved, not just national and local issues.

We would like to acknowledge international initiatives, such as journals, websites, newsletters and organizations that bring various ME and FM communities together. We would like to extend special thanks to the organizers of and participants at the two conferences held this summer.

It is extremely important to keep our eye on the ball – better services. It is extremely important to create and maintain a positive and constructive culture that is supportive of the dedicated and skilful researchers, healthcare providers, support services providers and advocates who are working on behalf of the ME and FM communities at the local, national and international levels.

We also call on the research, healthcare and support systems at all levels to work with us. ME and FM are severely under-served. New services may magically appear, but, as Tennis Canada has demonstrated, they are much more likely to appear with pro-active intervention.

http://mefmaction.com

http://www.facebook.com/MEFMActionNetwork

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