NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

www.mefmaction.com
Quest 137, Spring 2023
mefminfo@mefmaction.com

How the Network started

The National ME/FM Action Network was incorporated on June 18, 1993, which means that the Network is about to celebrate its 30th birthday. Lydia Neilson tells us how the Network came about.

In December 1985, one of the law clerks in the office where I worked became ill. She assumed she had a cold but the cold wasn't getting any better. She visited her family doctor who diagnosed her with mononucleosis. By that time, everyone in the office had become ill. Everyone recovered, except for me.

I continued working. I struggled to get through the day and would completely collapse when I got home from the office. The week-ends would be spent in bed. I would recover enough to go back to work the following week. This became my routine.

My boss' office was one floor up. The only way I could climb the stairs was to sit on my behind and slowly bump up or down. Of course I wanted to do that in secret. That technique was not an option when I was called unexpectedly.

I made numerous visits to my doctor and to specialists. Tests came back negative. It was like being on a merry-go-round. I knew I was ill. Having numerous doctors tell me it was all in my head added to my already shaken life.

On Friday, October 17, 1986, on my doctor's advice, I took a leave of absence from my job. This temporary leave turned out to be permanent.

Several years later, at one of my regular appointments, my GP told me that she knew I was ill but had no idea how to help me. However, she had received a letter from a Dr. Byron Hyde of The Nightingale Research Foundation (NRF) alerting doctors that he was seeing many patients who all had the same symptoms but no diagnosis. Dr. Hyde stated that he was willing to see anyone who was undiagnosed and displayed the symptoms he outlined in his letter as they may be suffering from Myalgic Encephalomyelitis (ME). I went to see Dr. Hyde. He ordered more tests and gave me a diagnosis of ME.

I started volunteering at NRF whenever I could. For about 3 years I was the Communications Director. During this time, Dr. Hyde was compiling a book, The Clinical and Scientific Basis of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome. It was published in 1992. This book contained important information on the scientific history and past names of ME. It contained studies by noted medical practitioners and researchers. I learned a lot working on it.

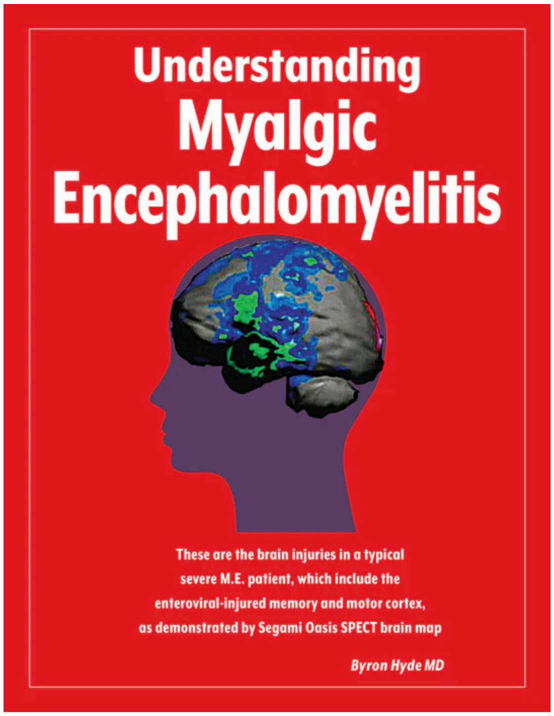
Through my position as communications director, I had the opportunity to meet and speak to many ME and FM patients who came to Dr Hyde for help. That was a real eye-opener for me. I learned that they were dealing with the same issues that I was. ***I recognized that there was a need for a Canada-wide organization to provide information to patients and to speak on behalf of patients. That is why I started the National ME/FM Action Network.***

Contents

Context

Quest Newsletters can be found on the National ME/FM Action Network website. Go to mefmaction.com. Under Resources click Quest newsletters.

Links to other Network publications can be found on the front page of the website.



Understanding Myalgic Encephalomyelitis

These are the brain injuries in a typical severe M.E. patient, which include the enteroviral-injured memory and motor cortex, as demonstrated by Segami Oasis SPECT brain map

Byron Hyde MD

Dr Hyde's 1992 book, which we refer to in this issue of Quest, can be purchased from the Nightingale Research Foundation or accessed for free at this link:

https://www.dropbox.com/s/zik0o5oyauru3rp/Chronic%20Fatigue%20Syndrome.compressed.pdf

ME and FM prior to 1993

For several centuries, muscle pains have been known as rheumatism and then as muscular rheumatism. The term fibrositis was coined by Gowers in 1904 and was not changed to fibromyalgia until 1976. The American College of Rheumatology published diagnostic criteria for FM in 1990 and rheumatologists took responsibility for FM. Thus, FM was doing fairly well in 1993 when the Network started. That would change around a decade and a half later.

In 1955, there had been an outbreak of something chronic at the Royal Free Hospital in London, England. In a 1956 article, Dr Melvin Ramsay described biomedical symptoms, tied in several previous outbreaks, and suggested the name Myalgic Encephalomyelitis. Then, about fifteen years later, two psychiatrists reviewed case files and attributed the Royal Free outbreak, as well as other outbreaks, to mass hysteria. This opened up the idea that ME might not be a biomedical illness – that it might instead be the fault of patients.

In the 1980's, there were outbreaks of ME in the US. The US Centers for Disease Control (CDC) did not link these outbreaks to Dr Ramsay's ME. Instead, the CDC developed a new definition and assigned the name "chronic fatigue syndrome" in 1988. The vagueness of the CDC definition and the choice of the name "chronic fatigue syndrome" opened the door for a psychiatric explanation. And indeed, a psychiatric explanation was proposed in a 1989 publication as follows:

SUMMARY. *Simple rehabilitative strategies are proposed to help patients with the chronic fatigue syndrome. A model is outlined of an acute illness giving way to a chronic fatigue state in which symptoms are perpetuated by a cycle of inactivity, deterioration in exercise tolerance and further symptoms. This is compounded by the depressive illness that is often part of the syndrome The result is a self-perpetuating cycle of exercise avoidance. Effective treatment depends upon an understanding of the interaction between physical and psychological factors. Cognitive behavioural therapy is suggested. Cognitive therapy helps the patient understand how genuine symptoms arise from the frequent combination of physical inactivity and depression, rather than continuing infection, while a behavioural approach enables the treatment of avoidance behaviour and a gradual return to normal physical activity.*

The psychiatric explanation does not match patient experience. Nevertheless, it has given the health research, health care and disability systems an excuse not to get involved with ME.

Basing health and social policy on the wrong model has consequences. The effect was described in a posting on a parents' on-line discussion group some years ago. A mother said she would raise a ME issue with her child's doctors and teachers and get blank stares. She would post the comment on the discussion page and get instant understanding. She said that she felt that she was living in a parallel universe.

The National ME/FM Action Network does not want people with ME/FM to live in a parallel universe. We have been working for the last 30 years to bridge the divide. The aim of the Network, as Lydia stated, is to provide information to patients and to speak on behalf of patients.

Lydia Neilson, founder and CEO of the National ME/FM Action Network

Some Network Milestones

• Newsletter Quest (1993)

The Network published its first newsletter in August 1993. The title was QUEST. The dictionary defines ‘Quest’ as a verb - to try, undertake, strive - and as a noun - the act of seeking something,

In the early years, Quest was published six times per year. Newsletters were an important way of keeping people in touch. They were printed and sent through the postal system, this being before the widespread use of the internet. Thirty years later, we are up to issue #137. (We have to confess that we mis-numbered twice - there is no Quest #89 and no Quest #135.) Even today, we provide the option of paper copies, recognizing that paper is much easier for some people than electronic material.

Excerpts from early newsletters:

Quest #1 (August 1993) stated the aims of the Network.

This is an ACTION support group...It will be actively involved in issues that are of great concern to all of us, as voiced by individuals and support groups leaders - insurance problems, government involvement, children and young adults and the school system, media misinformation, lack of proper medical testing and doctor and lawyer referrals etc.

Quest #1 also explained why the Network serves ME and FM, not just ME.

You will note from the proposed name of the organization that Fibromyalgia has been added to the name. Very few people escape the pain of Fibromyalgia when they are ill with ME nor do many FM people escape the central nervous system (CNS) problems experienced by ME individuals. It is possible that both conditions have the same origin and may actually be variations of the same illness.

The newsletters provided advice. Quest #1 made this statement which is as true today as it was 30 years ago.

WARNING: NEVER presume that a new symptom you experience is related to your ME/FM. See your doctor to have the new symptom checked out, and once other factors have been ruled out, you can then be comfortable in knowing it is related to ME/FM. There are many conditions that can be treated and some can become very serious if not taken care of immediately. Too often we have become resigned to our symptoms that we fail to remember that some may not be related at all and therefore suffer needlessly.

The newsletters shared experiences. Quest #2 (1993) introduced a delightful little section about the consequences of ME and FM.

WELCOME TO OUR WORLD:

SPACED OUT: My body is here but my brain is out to lunch.
ME. SHUFFLE: I am trying to walk slower than my heartbeat to preserve energy.
DRS (Delayed Reaction Syndrome): I can hear you but my brain needs to catch up.

The newsletters recognized the strength of the community. Quest #3 (1993) started with a statement by Lydia:

In an interview with the Montreal Gazette, I was asked why there all of a sudden was such a big interest in ME/FM and what did I think was the cause of it? I advised her that it was not all of a sudden but that a lot of hard work had been done by many people to accomplish this change of attitude and increase in awareness. I told her that the support groups and its members are mainly responsible by working together and individually and that they deserve most of the credit for all that has happened in 1993. This remark never reached the printed page but it is true nonetheless.

The rest of the credit goes to some very dedicated physicians and researchers who are overworked and under-funded but who nevertheless believe in us. With them lies our hope and because of them, we will keep going.

• Court intervention (1995)

In 1995, an Alberta court decision stated that “Fibromyalgia doesn’t exist”. The judge may have meant that the person appearing before her did not have Fibromyalgia, but it could have meant that Fibromyalgia does not exist at all. The Network mobilized, raised funds, and hired lawyers to apply to intervene. The judge hearing the application clarified that the individual in this case was found not to have Fibromyalgia but someone could certainly be found to have Fibromyalgia in other cases. (Quest #13, 1995)

In 1998, a woman who was unable to work due to Chronic Fatigue Syndrome was denied long-term disability payments. She sued. The Alberta Court of Queen's Bench held that the plaintiff's condition was not a psychoneurotic or behavioural disorder and was covered by the policy. No intervention was needed. (Quest #30, 1998)

• House of Commons petition (1996)

The Network along with provincial groups developed a petition requesting official recognition of ME/FM and Multiple Chemical Sensitivities (MCS) as well as requesting that monies be set aside for research purposes for these illnesses. A total of 14,487 people from across Canada signed. On May 10, 1996, Member of Parliament Beryl Gaffney presented the petition to the House of Commons. Quest #18 (1996) reported that:

On Friday, May 10th, 1996 Mrs Beryl Gaffney, MP presented our Petitions requesting official recognition of ME/FM and Multiple Chemical Sensitivities. Mrs. Gaffney presented the Petitions for Ontario together with a speech she had prepared to the House. The following representatives presented the Petitions for other Provinces: Mr. John Harvard (Winnipeg St. James, Lib.); presented the Petitions of Manitobans; Mr. Andy Scott (Fredericton--York---Sudbury, Lib.) presented the Petitions for New Brunswick and for Nova Scotia; Mr. Nick Discepola (Vaudreuil, Lib.) for Quebec; Ms Bonnie Brown (Oakville-Milton, Lib.) for British Columbia; Mr. Wayne Easter (Malpeque, Lib.) for Prince Edward Island; Mr. John Loney (Edmonton North, Lib.) for Alberta; and Ms Jean Augustine (Etobicoke-Lakeshore, Lib.) for Newfoundland.

It was like there was a multiple echo in the House when one member after the other stood up and asked the Government to ensure care, treatment, comfort and dignity for persons afflicted with these illnesses. This was in addition to Mrs Gaffney asking for official recognition.

Following the petition, Mrs Gaffney arranged a meeting which included several public servants. (Quest #19 1996) Soon afterwards, she made a statement in the House of Commons congratulating Health Canada for officially recognizing a case definition for chronic fatigue syndrome. (Quest #21, 1996) The case definition mentioned is the CDC's "Fukuda" definition which was published in 1994, updating the CDC's "Holmes" definition published in 1988. The Fukuda definition was still quite vague and still used the term "chronic fatigue syndrome".

Mr. Speaker, the longest journey begins with one step. I congratulate Health Canada for taking a step in the fight against myalgic encephalomyelitis and fibromyalgia.

Health Canada has recognized a revised chronic fatigue syndrome case definition for research purposes. This is thanks to the 10,000 people in Ontario and the 5,000 from other provinces who have signed petitions presented to the House in May [1996].

It is also thanks to the efforts of the ME/FM Action Network. Health Canada can now take the step to boost further awareness by formally announcing the recognition of ME/FM. Parliament should move forward by setting up a health subcommittee to study and hear witnesses on ME/FM.

These diseases affect over 100,000 Canadians. Many times healthy, vital people are reduced to an inability of coping. We can no longer afford to be robbed of so many productive citizens by a disease for which we do not know the cause and we do not know the cure.

Let us remedy this situation. We must act now to raise awareness, continue research and find a cure.

• Website (1997)

In 1993 computers were at a basic stage and online information was not widely available. Everything that was to be passed on to the public, government, the medical establishments etc. needed to be done by telephone or by Canada Post. The Network got an email address in 1996. The Network's website came on line in mid-1997. The announcement was made by "Al Neilson, Computer Geek (husband of the boss)." (Quests #24 1997) Al was generally in the background, but he was enormously supportive of the Network. We lost Al to cancer in 2008.

The internet has made a huge difference in the ability to share information with the Canadian ME/FM community and to stay in touch with what is happening internationally.

• Teach-ME Sourcebook (2001)

Quest #48 (2001) announced the release of the TEACH-ME Sourcebook for Teachers of Children with ME/CFS and/or FM.

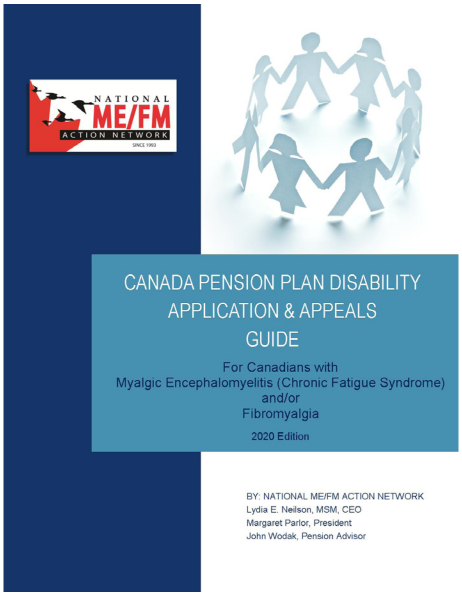
Who Wrote This Book? - The authors of this Sourcebook are Canadian teachers, disabled with ME/CFS and/or FM, who are members of the National ME/FM Action Network. We developed a unique e-mail conference, known as TEACH-ME, in which we discussed ways that children with ME/CFS and/or FM could be provided with uninterrupted, high quality education. As people with ME/CFS and/or FM ourselves, we were devastated to imagine the effects of ME/CFS and/or FM on young people. As teachers, we remained unwaveringly committed to the importance of providing ongoing and enriching education to all children, no matter how ill or disabled. Yet, as adults who were homebound by the illness, we knew this could not be an easy task - for the young person or for the classroom teacher. We wanted to use our combined expertise in teaching and experience of the illness to help these courageous youngsters.

We were very privileged to have the consultation of Dr. David S. Bell, a renowned paediatrician and the leading international researcher on ME/CFS and/or FM in children, and Mary Z. Robinson, a US educator, research assistant to Dr. Bell, co-author of "A Parent's Guide to CFS" and parent of two children with ME/CFS/FM. Our collaboration with Dr. Bell and Ms. Robinson enabled us to link our personal experience and teaching expertise with the most up-to-date and sound international research knowledge.

A second edition of the Sourcebook was released in 2005 incorporating the diagnostic criteria for ME and FM published in 2003.

Over the next few years, The Myalgic Encephalomyelitis Association of Ontario (MEAO, recently renamed CareNow Ontario) raised funds and used these funds to send Sourcebooks to schools, school boards, and children's aid societies across Ontario. MEAO repeatedly asked the provincial government to amend their policies to ensure that young people with ME/FM could access part-time and homebound instruction as a special education option from school boards all across Ontario. To this day, the Ontario government has not addressed this gap in its special education system.

• CPP-Disability Guide (2003)



NATIONAL
ME/FM
ACTION NETWORK
SINCE 1993

CANADA PENSION PLAN DISABILITY
APPLICATION & APPEALS
GUIDE
For Canadians with
Myalgic Encephalomyelitis (Chronic Fatigue Syndrome)
and/or
Fibromyalgia
2020 Edition

BY: NATIONAL ME/FM ACTION NETWORK
Lydia E. Neilson, MSM, CEO
Margaret Parlor, President
John Wodak, Pension Advisor

Quest #61 (2003) announced the availability of a Canada Pension Plan Disability Application Guide designed to assist those disabled by ME/CFS and/or FM apply for Canada Pension Plan Disability payments. It discussed the criteria, important items to include and how to proceed through the various steps of the process. While focusing on CPP-Disability, the guide can be useful when applying to other disability programs.

This document has been updated several times over the years. Special thanks to Dr John Wodak who assisted many people in applying for CPP and provincial disability payments, served for years on the government's CPP-D advisory committee and contributed enormously to Guide updates.

One of the important components of today's Guide is the Functional Capacity Scale. This was developed by Dr Alison Bested and Dr Lynn Marshall at the Environmental Health Clinic at Women's College Hospital Toronto. They would ask their patients how they were doing. Some would say they were doing better. The doctors would then suggest that they try going back to work. For many, the return to work was unsuccessful. Then the doctors realized that somebody improving to what we now call a level 8 might succeed in returning to work, but somebody else improving to a level 5 would not succeed. It was important to know functioning level!

The functional capacity scale can also be used in non-employment contexts.

• ME and FM Diagnostic and Treatment Protocols (2003)

Early on, the Network recognized how important it would be to have diagnostic and treatment protocols for clinical use. (Diagnostic criteria had been written for research purposes, not clinical purposes.) In Quest #46 (2001), Marjorie van de Sande, who was Director of Education for the Network, provided a summary of how the protocols were developed.

A few years ago we sent a questionnaire to 200 doctors who were knowledgeable about these illnesses, asking what was the most important thing that needed to be done towards recognition of these illnesses and assisting the medical community. Approximately 150 doctors replied and all voiced the opinion that clinical definitions and treatment protocols for these illnesses are of prime importance. The stage was set.

We recruited Dr. Anil Jain of Ontario and Dr. Bruce Carruthers of British Columbia, two of Canada's top experts in these illnesses, who kindly and generously donated their time and expertise to co-author the draft clinical definitions, diagnostic and treatment protocols documents. As consensus coordinator, I have had the privilege of working with these doctors for the past two and a half years.

Lydia presented the draft documents to Health Canada in July 1999. The Honourable Alan Rock, Minister of Health, responded, "The development of draft clinical definitions for ME/FM is a milestone in the fight against this complex and tragic condition". The National ME/FM Action Network worked in partnership with Health Canada on the review process for a year and a half.

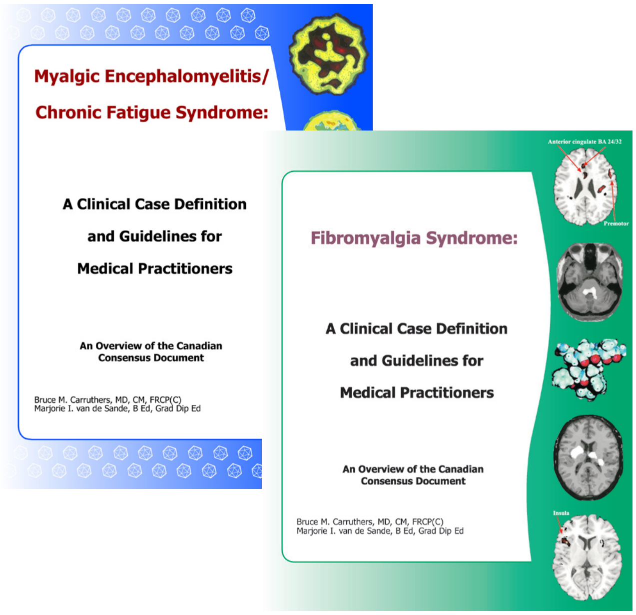
The Expert Medical Subcommittee established by Health Canada selected two Expert Medical Consensus Panels, one for ME/CFS and one for FMS. This subcommittee of Health Canada also established the "Terms of Reference" for the panels. One of the stipulations was that at least one member of each panel must be nominated by each of the five stakeholder groups of government, universities, clinicians, advocacy and industry. The twenty-five doctors who were selected received over 80 nominations representing numerous nominations from each of the stakeholder groups. Four doctors from outside Canada were allowed to sit on each panel. A wide range of expertise was represented on the panels including rheumatologists, specialists in internal medicine and infectious disease, a neurosurgeon/ neuro-researcher, a haematologist, etc. There were treating clinicians, teaching university professors and researchers including world-renowned researcher, Dr. Kenny De Meirleir of Belgium who has approximately 300 scientific publications. His research on the dysfunction of the RNase L antiviral defense pathway may lead to a clinical marker for ME/CFS.

The panels have been reviewing the documents since December 2000. The consensus meetings were held in Toronto on March 30 to April 1, 2001.

Canada makes history in ME/CFS and FM as both expert panels came to consensus on their clinical definition/ protocols document.

Both the ME and FM protocols were published in peer-reviewed journals in 2003. Ms van de Sande and Dr Carruthers wrote overviews in 2005. These overviews have been translated into several languages and are available on our website.

While the ME diagnostic criteria have withstood the test of time, there has been movement in the treatment area. A team from the IACFS/ME wrote a "primer" using the 2003 Canadian diagnostic protocols for ME and updating the treatment protocols. Dr Bested and Dr Marshall wrote an article on diagnosis and treatment that appeared in a journal. Another team wrote a pediatric primer, again based on the 2003 diagnostic criteria. The National ME/FM Action Network considered these documents to be very important and had them translated into French and posted on our website.



Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome:

A Clinical Case Definition
and Guidelines for
Medical Practitioners

An Overview of the Canadian
Consensus Document

Bruce M. Carruthers, MD, CM, FRCP(C)
Marjorie I. van de Sande, B Ed, Grad Dip Ed

Fibromyalgia Syndrome:

A Clinical Case Definition
and Guidelines for
Medical Practitioners

An Overview of the Canadian
Consensus Document

Bruce M. Carruthers, MD, CM, FRCP(C)
Marjorie I. van de Sande, B Ed, Grad Dip Ed

Chill sets in – late 1990’s

The advances made by the ME/FM community seem to have scared the health and social systems. Cooperation chilled in the late 1990’s. The government promised to organize meetings for the expert panels but the meetings kept being postponed. (This explains the year and a half gap between the submission of the draft protocols in July 1999 and the panel reviews starting in December 2000.) In the end, the Network found non-governmental funding for the expert panel meetings (ensuring that the funding would not influence the panels in any way). In blunt terms, the expert panels met thanks to the Network and without government financial support.

• Lydia Neilson awarded MSM (2004)

This is quoted from the website of the Governor-General of Canada:

Mrs. Lydia Neilson

- Nepean, Ontario, Canada
Meritorious Service Decorations - Civil Division
- Meritorious Service Medal
- Awarded on: November 25, 2004
- Invested on: May 30, 2005

Lydia Neilson, M.S.M., Ottawa, Ontario
Meritorious Service Medal (civil division)

In 1993, Lydia Neilson founded the National ME/FM Action Network, an advocacy organization dedicated to advancing the recognition and understanding of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and fibromyalgia syndrome (FMS) through education, advocacy, support and research. Actively involved in issues that affect individuals with ME/CFS and FMS, Ms. Neilson also spearheaded the publication of internationally acclaimed diagnostic and treatment protocols for these conditions, bringing much-needed information and standardization to these areas of research.

• Another court intervention (2008)

There were three Supreme Court of Canada decisions in the second decade of the Network that are worth noting.

In Nova Scotia (Workers’ Compensation Board) v Martin (2003), the Court struck down provisions within Nova Scotia’s Workers’ Compensation Act that prohibited people who were disabled by chronic pain from benefits as a violation of section 15(1) of the Canadian Charter of Rights and Freedoms. In Fidler v Sun Life (2006), the Court ruled that the insurance company had unfairly cut off payments to a person with ME and FM. In Honda v Keays (2008), the court found that Mr Keays had been wrongfully dismissed from work due to his ME. The Network had intervenor status in the Keays case.

• Canadian Community Health Survey statistics (2009)

In the late 1990’s, Statistics Canada invited representatives from the federal, provincial and territorial departments of health to co-design a new Canadian Community Health Survey. The ME, FM and MCS communities were extremely fortunate that one of the provincial representatives was familiar with these conditions and had them included on the survey questionnaire. (ME is called “chronic fatigue syndrome” on the survey). The survey was run in 2001, 2003 and 2005. It came to the Network’s attention that there was data for these conditions, and that the data was available on a “public use microdata file” which the public could access.

Margaret Parlor had recently retired from Statistics Canada where she had worked as an analyst and program manager. She started exploring the CCHS data. She was interested in descriptive statistics – how many people, their age, their education levels, etc. She was also interested in people’s experiences – how many experienced unmet needs, social isolation, food insecurity, etc. The experience figures could be used for performance measurement. For instance, one goal would be to reduce the level of unmet health care needs.

The Network published results from the 2005 survey in Quest #80 (2009) comparing the experiences of people with CFS, FM and MCS with the experiences of people with other chronic conditions and with the general population. The numbers were shocking. There were a third of a million Canadians with a diagnosis of “chronic fatigue syndrome” and slightly more with a diagnosis of FM. The CFS and FM groups showed high levels of unmet

Publications Available from the National ME/FM Action Network

Encefalomielite Mialgica/ Sindrome Della Fatica Cronica: Una Definizione Clinica del e Linee Guida per Medici Specialisti

Myalgische Encephalomyelitis Chronic Fatigue Syndrom: Klinische Falldefinition Und Leitfaden Für Ärzte

Myalgische encefalomyelitis / Chronische-vermoeidheidssyndroom: Klinische definitie en richtlijnen voor medisch personeel

Encefalomielitis Miálgica / Síndrome de Fatiga Crónica: Definición del caso c y de las pautas para médicos.

Encéphalomyélite myalgique / Syndrome de fatigue chronique : Définition clinique et lignes directrices à l'intention des médec

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners

An Overview of the Canadian Consensus Document

Bruce M. Carruthers, MD, CM, FRCP(C)
Marjorie I. van de Sande, B Ed, Grad Dip Ed

The Overview of the Canadian Consensus Definition for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome has been translated into French, Spanish, Italian, German and Dutch

Síndrome de Fibromya Definición clínica y recomendaciones para m

Syndrome de fibromyalgie Définition clinique et lignes directrices à l'intentio des médecins Abrégé du Consensus canadien

Fibromyalgia Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners

An Overview of the Canadian Consensus Document

Bruce M. Carruthers, MD, CM, FRCP(C)
Marjorie I. van de Sande, B Ed, Grad Dip Ed

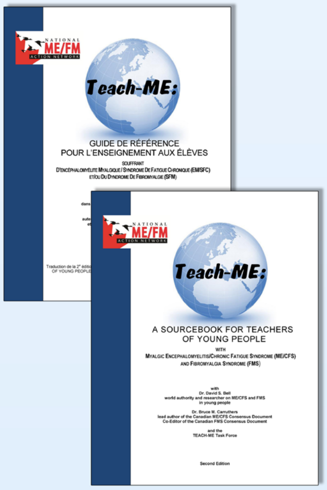
The Overview of the Canadian Consensus Definition for Fibromyalgia has been translated into French and Spanish

NATIONAL ME/FM ACTION NETWORK

National ME/FM Action Network

512-33 Banner Road
Nepean, Ontario K2H 8V7

www.mefmaction.com



Teach-ME: GUIDE DE RÉFÉRENCE POUR L'ENSEIGNEMENT AUX ÉLÈVES

Teach-ME: A SOURCEBOOK FOR TEACHERS OF YOUNG PEOPLE WITH MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME (ME/CFS) AND FIBROMYALGIA SYNDROME (FMS)

Second Edition

The Teach-ME Sourcebook for Teachers of Young People is available in English and French

Syndrome de fatigue chronique Encéphalomyélite myalgique
Petit guide pour la médecine clinique Édition Canadienne 2014

Chronic Fatigue Syndrome Myalgic Encephalomyelitis
Primer for Clinical Practitioners 2014 Canadian Edition

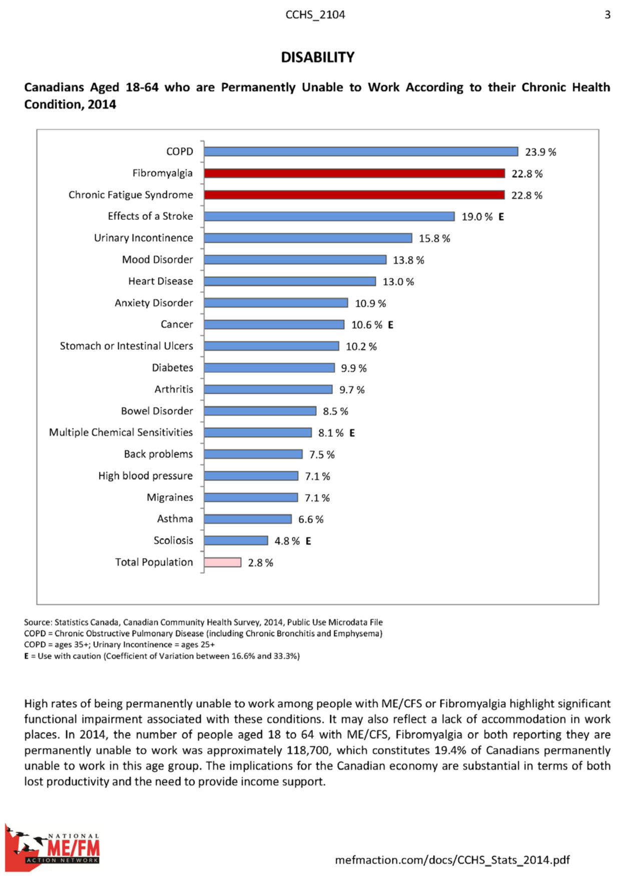
International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis IACFS/ME

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis A Primer for Clinical Practitioners was produced by the International Association for Chronic Fatigue Syndrome (IACFS) and based on the Canadian Consensus Definition. The French translation was produced by the ME/FM Action Network.

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

CANADA PENSION PLAN DISABILITY APPLICATION & APPEALS GUIDE
For Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and/or Fibromyalgia Syndrome

Canada Pension Plan Disability and Appeals Guide was prepared by the National ME/FM Action Network It is available in English and French.



CCHS_2104 3

DISABILITY

Canadians Aged 18-64 who are Permanently Unable to Work 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)
COPD = ages 35+; Urinary Incontinence = ages 25+
E = Use with caution (Coefficient of Variation between 16.6% and 33.3%)

High rates of being permanently unable to work among people with ME/CFS or Fibromyalgia highlight significant functional impairment associated with these conditions. It may also reflect a lack of accommodation in work places. In 2014, the number of people aged 18 to 64 with ME/CFS, Fibromyalgia or both reporting they are permanently unable to work was approximately 118,700, which constitutes 19.4% of Canadians permanently unable to work in this age group. The implications for the Canadian economy are substantial in terms of both lost productivity and the need to provide income support.

mefmaction.com/docs/CCHS_Stats_2014.pdf

health care needs, poverty, social isolation, needing help with tasks, and food insecurity compared with the general population and even with other chronic conditions. This reinforced what the Network was hearing anecdotally.

By this time, the survey had become annual and CFS, FM and MCS had been removed from the questionnaire. The Network contacted Statistics Canada and the questions were returned to the survey in 2010 and 2014. Another professional statistician, Erika Halipy, stepped forward. Together, she and Margaret analysed the 2010 and 2014 data. They also did a combined analysis of the 2005, 2010 and 2014 data. The 2010 analysis can be found in Quest #88, (2011) and in a report by MEAO *https://meao.ca/files/Quantitative_Data_Report.pdf.* The 2014 data can be found in Quest #108, (2016). The combined 2005, 2010, 2014 analysis can be found in Quest #112 (2017). There are special tables in other issues (eg. chronic pain in Quest #101, mobility in Quest #103, and co-diagnoses in Quest #115).

CCHS data was also collected in 2015, 2016, and 2019. Prevalence figures are available in Quest #112, (2017) and #125, (2020).

Rheumatology drops FM – early 2000's

One of the interesting findings in the 2010 data was that FM had the highest rate of unmet health care needs of any of the chronic conditions. We were surprised since new medications had recently been introduced which should have increased satisfaction, not decreased it. It was only later that we learned that rheumatologists had quietly decided not to handle FM cases and had quietly been turning away FM patients.

• IACFS/ME Conference (2011)

The International Association for CFS/ME is an organization that has consistently supported the biomedical model of ME. The organization brings together researchers, clinicians and patients.

The National ME/FM Action Network was proud to host the IACFS/ME's 2011 conference in Ottawa. The Network insisted that FM be considered as well. Two topics at the conference were long-term symptoms after SARS and the possibility that ME was caused by a retrovirus, a study having recently been published linking ME to the retrovirus XMRV.

There have been 5 IACFS/ME conferences since 2011. The Network gave a presentation on statistics at one and a workshop on international issues at another. The Network has done official reporting on the two most recent conferences (Quest #130, 2021 and #134, 2022)

• Focus on FM (2012)

In 2010, the American College of Rheumatology suggested new Fibromyalgia criteria. The 1990 guidelines were based on widespread pain and tenderpoints. The 2010 criteria incorporated additional symptoms described in the 2003 Canadian FM diagnostic and treatment protocols (without giving credit to the expert panel).

In 2012, a team produced what they called the "Canadian Fibromyalgia Guidelines" based on the 2010 criteria. The guidelines do not mention ME. This is a serious omission. Physical exercise is often recommended for FM. If the patient has co-morbid ME or has ME instead of FM, this exercise could be harmful. The guidelines also assign responsibility to family doctors with no role for rheumatology. This assumes that FM treatment is straight-forward and FM impact is quite minor, which is often not true. Quest #92 (2012) discusses these issues.

The Network also focused on FM in Quest #128, (2021) to highlight recent developments.

The Network attended and reported on the 2021 and 2022 international FM conferences. (Quest #130, 2021, #133, 2022) It might be noted that the international organization is European based and the United States had very little presence at the meetings.

• Parliamentary Breakfast (2013)

One way of getting the attention of federal politicians and their staff is to offer free breakfasts with guest speakers. The Network worked with two Members of Parliament and hosted a breakfast on May 12 Awareness Day in 2013 with Dr Gordon Broderick as guest speaker. The Network offered another in 2016 and an event for public servants in between. Special mention to Lisa Schneiderman who did much of the organizing. Lisa also organized a fundraising event at the 2017 Montreal research conference.

In addition to parliamentary breakfasts, the Network has asked members of parliament to put questions on the order paper. Such questions require an official government response. We have also met with a number of Members of Parliament.

Left to right: Margaret Parlor, Maureen MacQuarrie, Lisa Schneiderman, Dr Gordon Broderick, Christiane Garcia

• BC Clinic opens (2013)

There were three factors that led to the establishment of the British Columbia Complex Chronic Diseases Program (CCDP) which serves British Columbians with ME, FM and chronic Lyme disease. One was the CCHS statistics that show substantial prevalence and seriousness of CFS and FM. Another was a study that suggested that ME was caused by the retrovirus XMRV, leading to considerable interest in ME. The third was the activism of the Lyme community.

The Network was involved in planning the establishment of the clinic. Dr Alison Bested was hired as the first medical director. The Clinic was officially opened in 2013 (Quest #96). The Network's BC Director, Sherri Todd, has been a member of the CCDP Community Advisory Committee ever since.

The CCDP joined the clinics already existing in Toronto and Halifax. A fourth Canadian clinic has just opened in Montreal.

• Disability Submission (2016)

In 2016, the federal government announced that it would be creating new legislation on disability and invited Canadians to make submission. The Network identified a number of issues including the need to consider non-traditional disabilities, the need to revise the eligibility criteria for the Disability Tax Credit and the need to ensure public servants understand disability issues (see Quest #131, 2022). The new legislation, the Accessible Canada Act, did not incorporate those ideas. Disability discussions are now moving into a new round and the Network is prepared.

US and UK rule ME biomedical (2015, 2021)

Any history of ME has to talk about the PACE trial. This was a UK government funded study to test the effectiveness of Cognitive Behaviour Therapy and Graded Exercise Therapy. The results were first published in 2011 and showed that these strategies had positive impact.

The PACE trial has become a case study on how not to do studies. For instance, don't have conflicts of interest, don't influence study participants, and don't change methodology mid-stream.

ME advocates were highly critical of the study. One very determined ME advocate applied under freedom of information provisions for access to the raw data. This was eventually granted in 2016. Advocates then recalculated using the methodology that was originally proposed and found that CBT and GET had insignificant effect. The criticisms of the study and the recalculation very much undermined support for the psychiatric model of ME. The tide was turning.

In 2015, the US Institute of Medicine was asked by the CDC and the NIH to review ME diagnostic criteria. The IOM agreed that ME was a biomedical disease (not a psychiatric condition), agreed with the Canadian diagnostic protocols, then suggested a simplified version could be used to identify cases more quickly. The symptoms to look for are reduced activity levels, post-exertional malaise, sleep dysfunction, and cognitive difficulties or orthostatic intolerance or both.

In 2021, the UK's medical advisory body, the National Institute for Clinical Excellence or "NICE", which had previously suggested that ME could be treated with exercise, agreed that post-exertional malaise was real and that exertion could be harmful.

• Ontario Task Force report (2018)

The delivery of health services is a provincial responsibility. Credit for convincing the Ontario government to establish the Ontario Task Force on Environmental Health goes to The Myalgic Encephalomyelitis Association of Ontario (MEAO, recently renamed CareNow Ontario). MEAO has been prodding the Ontario government to improve services for ME, FM and Multiple Chemical Sensitivities. The task force released an interim report in 2017 and a final report in 2018.

The Network has played a supporting role. It helped with the business case, especially the statistical section. It led a workshop at a Montreal research conference in 2018 looking at provincial implementation issues and invited Task Force members. People from six provinces attended (see Quest #115, 2018).

In 2020, the new Minister of Health asked public servants to propose next steps. That report has been submitted but has not been released. The Network has asked the Government of Ontario for release of the information so that it can be discussed in Ontario and in other jurisdictions. (Quest #136, 2023) The Ontario government claims that the report contents are exempted under freedom of information laws.

• ME Research Network funded (2019)

The Network has been pushing the federal government for research funding for the past 30 years. The occasional study was funded, but the level of funding has been nothing like the $10M/year the Network estimated ME and FM should each be receiving from the Canadian Institutes of Health Research based on their burden of illness.

ICanCME

Dr Alain Moreau, Director of the ICanCME Network

In 2016, CIHR ran a competition for a ME research network. Under the competition process, each application is scored by a panel of peer reviewers. Funding goes to the application with the highest score, but the score must be above a certain level. In this competition, there was one application but the peer review panel did not give that application a passing score. The reviewers said that “there is no evidence that CFS is a disease”, “psychosocial factors are strongly associated with the development of CFS” and “research focus on biomarkers is likely to provide limited additional value”.

CIHR then has a decision to make. It could accept the peer review, it could override the peer review and fund the application anyway, it could throw out the first review and ask a new committee to review the application, or it could recognize the unscientific stigma ME was facing and propose a different funding process. To their shame, CIHR chose to accept the peer review.

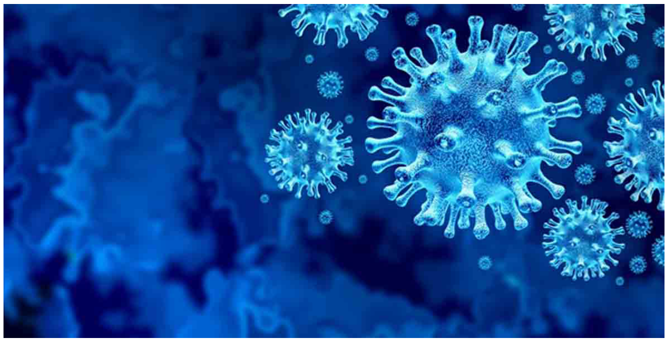
It would be three more years before an ME research network was funded. Further, the funding provided in 2019 was only 3% of what we had suggested as fair funding. For the official announcement, see Quest #120, (2019)

Back in Quest #3, Lydia referred to “very dedicated physicians and researchers who are overworked and under-funded but who nevertheless believe in us. With them lies our hope and because of them, we will keep going.”

We are very fortunate that some very dedicated physicians and researchers joined the research network. We cannot name them all, but let us recognize Dr Alain Moreau who has been a true leader of the research network and the physicians and researchers on the network’s executive committee, Dr Abdolamir Landi, Dr Luis Nacul, Dr Kathleen Kerr and Dr Walter Siqueira.

• Pandemic support (2020)

The Network has provided information to the ME/FM community from the early days of the pandemic. In our summer 2020 issue of Quest (#123) we included advice from Dr Lucinda Bateman, a leading US ME/FM clinician. We also asked ME/FM community members about their pandemic experiences and shared their stories in that issue of Quest. We followed that with a special issue (#124) outlining the special disability payment offered by the federal government. In Quest #127 (2021) we shared advice from top physicians on vaccines which has just been released. In Quest #132 and #133, we shared community experiences from later in the pandemic.



• Linking Long-Covid to ME/FM (2020)

Dr Hyde’s 1992 book on ME states “This disease has usually closely followed the patient’s contact with an environmental stimulus and usually this stimulus has been an infectious disease.” A number of infections have been associated with ME and FM.

With the arrival of the Covid pandemic, the Network anticipated that many people might develop ME and/or FM as a result of Covid. Just months into the pandemic, the Network wrote an introduction to ME/FM for long-Covid patients. (Quest #125, 2020).

The Network is watching with considerable concern as the research and health systems are treating long-Covid as something quite new and are underestimating the wisdom that has developed in the ME/FM research, clinical and patient communities over the years. Linking long-Covid with ME/FM would have big advantages for both the ME/FM and the long-Covid communities. We have drawn this issue to the attention of the Canadian Institutes of Health Research and the Chief Scientific Officer for Canada. (Quest #136, 2023) A very positive recent development is an announcement that the US National Academy of Science, Engineering and Medicine will be holding a conference in June 2023 to map out a research plan for post-infectious conditions.

• Information for Employers (2022)

As part of a project the Network was involved in, the Network noted that there was relatively little material for employers encountering an employee with ME/FM. So we wrote a fact-sheet for employers. We noted that employers are not responsible for diagnosing or treating ME or FM, but that employers can have a substantial impact on the affected worker's well-being. The fact-sheet outlines basic vocabulary and basic concepts. It is intended to improve understanding between employers and affected workers. (Quest #133, 2022)

• Pre-budget Submissions (2023)

Over the fall and winter every year, the federal government identifies what its priorities should be for the next fiscal year. It invites suggestions from the public. This is an opportunity for Canadians to make their priorities known.

The Network has made many submissions over the years. Our 2023-24 submission is shown in Quest #136 (2023). For health care, we suggested investments in ME/FM statistical surveillance, health system design, information, awareness, capacity building and research. For disability, we asked that the government conduct an examination of the disability needs of the ME/FM community and implement corrective action.

Our basic message is that ME/FM issues are not going to go away (and indeed they are going to get worse with the surge of long-Covid cases coming), and the sooner these issues are addressed the better off everyone will be.

After Thoughts

Going through the 30 year history of the National ME/FM Action Network has been a useful exercise. We can see that the Network has held to its original aims - to provide information to patients and to speak on behalf of patients. We can see that the challenges we faced – convincing the health and social systems to take ME and FM seriously - were enormous and international.

Lydia always says that a structure built on a poor foundation cannot stand. The psychiatric model for ME/FM used by the health and social system is based on the fantasy that exercise and attitude can overcome the medical issues. The biomedical model, supported by our organization, the IACFS/ME and other groups around the world, is based on decades of patient, clinical and research experience. The biomedical model has a proper foundation and will win out. Hopefully that will be sooner rather than later.

We would like to thank the many people who have supported us over the years. Thank you to our directors, to our advisors, to our members and to those who have supported us financially. Thank you to everyone who has shared their story with us. It has been a pleasure to work with you. We mentioned a few names on the way through, but there are many more people who have contributed to this work.

We would like to say a word to our new arrivals – those who develop ME/FM due to long-Covid. We consider you part of the ME/FM community and we are working for you too.

On June 18th of this year, please take a moment to remember us and the whole ME/FM community in Canada and around the world. And please consider sending us a note about how the ME/FM Action Network has affected you over the years.

Note: The Network no longer has a Fax number.

http://mefmaction.com

http://www.facebook.com/MEFMActionNetwork

NATIONAL
ME/FM
ACTION NETWORK
SINCE 1993

MEMBERSHIP APPLICATION or RENEWAL FORM

NEW MEMBERSHIP or RENEWAL fees

ANNUAL MEMBERSHIP FEE : $30.00 per year including quarterly newsletter Quest

IN ADDITION, I would like to donate *$______________ to help with the many projects of the National ME/FM Action Network.

**Tax Receipt issued for all donations*

TOTAL PAYMENT:

$________________________

PAYMENT OPTIONS

☐ Cheque

Please make Cheque Payable to the:

NATIONAL ME/FM ACTION NETWORK

☐ VISA

☐ Master Card

☐ Other ________________

Card Number:

____

Expiry Date:

month ______ year ________

CVV________ (3 digit code on back of card)

Name on Card:

____

Signature:

____

☐ **I would like to be a member. Please waive the annual fee.**

For online application and renewals go to MEFMaction.com

Date: ____________________

Name / Organization

____

Contact Name __________________________________

Address ______________________________________

____

City ______________________________________

Province/State __________Postal Code/Zip __________

Country ______________________________________

Email ______________________________________

Phone ______________________________________

Website ______________________________________

☐ Please send news updates to my email address

☐ **Do not** send news updates to my email address

____

☐ Please send an electronic version of the Quest newsletter

☐ Please send the Quest newsletter to my mailing address

MAIL FORM & PAYMENT TO:

NATIONAL ME/FM ACTION NETWORK
512-33 Banner Road
Nepean, ON K2H 8V7

THANK YOU FOR YOUR SUPPORT!

CREDIT CARD TRANSACTIONS CAN BE MADE BY PHONE

Our phone number is 613-829-6667