CONNECTING THE DOTS……..

RE: GOVERNMENT

NATIONAL ME/FM ACTION NETWORK

The following are the communications that have occurred between the National ME/FM Action Network and specific government departments, federally and provincially, so that whoever contacts a specific government department will be in a position to be aware what has transpired in past communications.

It will also be of assistance to those in governments who communicate with the National ME/FM Action Network as to what has transpired from the founding of this Network on June 18, 1993 to the present.

NOTE: As the information was posted in the Network's quarterly newsletter *QUEST*, reference is made to the newsletter in which the report appeared and can be found on the Network's website under "RESOURCES" Quest Newsletters for more details.

INDEX PAGES

Employment and Social Development Canada

CANADA PENSION PLAN – DISABILITY (CPP-D)

- **QUEST 117 Winter 2018**

New CPP-D Application Processes

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For anyone in the process of applying using the new form, we suggest that you read chapter 4 of our CPP- D Application Guide very carefully and include any information that you think will help explain your disability, whether or not the information is directly requested on the application form. This could include the worksheets in the Guide, written descriptions of the problems you are encountering, and statements from family and colleagues.

Here is a letter sent to the Minister:

To: The Honourable Jean-Yves Duclos,
Minister of Families, Children and Social Development

The new CPP-Disability Application processes incorporate many improvements, but there are still problems for Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and/or Fibromyalgia.

The National ME/FM Action Network is a registered charity working on behalf of Canadians with ME/CFS and/or FM since 1993. Nearly a million Canadians have a diagnosis of ME/CFS, FM or both. These illnesses have high prevalence among people of working age and can be very disabling. Many people with ME/CFS and/or FM find themselves in the position of applying for CPP- Disability.

People with these illnesses should not be at a disadvantage in qualifying for CPP-D. The new CPP-D adjudication framework specifically identifies the adjudication of FM and ME/CFS cases as challenging, signalling that they are indeed at a disadvantage. We are recommending that a special meeting be held this winter to discuss the challenges.

Chronic Pain Syndrome is also identified as challenging. Chronic pain is a common symptom of these illnesses, but chronic pain can arise from other sources. We are copying the Chronic Pain Association of Canada and we would welcome their participation at this meeting.

The National ME/FM Action Network believes that the CPP-D income should be available to every Canadian who has contributed to the plan and who meets the eligibility criteria. CPP-D payments are an important component of medical support. Many people have told us that they cannot concentrate on their health until their financial issues are resolved.

We also believe that CPP-D should be available to all eligible Canadians on an equal basis. It should not be slower, harder or more burdensome for people with ME/ CFS and/or FM to qualify for CPP-D than it is for people with other types of impairment.

ME/CFS and FM have been seriously overlooked by the health services and health research systems. In the absence of validated diagnostic tests, diagnosis is currently based on clinical observation. Unfortunately, many health professionals are unfamiliar or even skeptical of these illnesses. However “It is the capacity to work and not the diagnosis or the disease description that determines the severity of the disability under the CPP.” Klabouch v. Canada (Minister of Social Development) 2008 FCA 33, so medical opinion should not be determinative.

The CPP-D program released a new application form, a new medical form, and a new adjudication framework in August 2018. There are many good points about the new material. Our concerns relate to the information collected to determine whether the disability is severe and prolonged

The adjudication framework specifically identifies “Fibromyalgia, Chronic Pain Syndrome and Chronic Fatigue Syndrome” as problems.

... some conditions, such as Fibromyalgia, Chronic Pain Syndrome and Chronic Fatigue Syndrome will not have the traditional objective tests available to determine whether the person meets or continues to meet the “severe and prolonged” criteria. The adjudication of these cases can be a challenge.

This challenge can discourage applicants from applying and health care professionals from completing their form. It can also discourage adjudicators from approving applications, leaving applicants the choice of appealing or dropping their claim. FM, CPS and ME/CFS applications are at an immediate disadvantage.

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In these conditions, evidence can be obtained from other sources, such as a vocational rehabilitation consultant, an occupational therapist, a physiotherapist, an employer, etc.

The people most familiar with the situation could be family, friends, former co-workers or supervisors, community members or homecare workers. Nowhere does the application form invite applicants to list names of people who are familiar with their experience and nowhere does it invite statements from these people.

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While we appreciate the specific mention of fibromyalgia and fatigue in the textual examples, the examples do not fully link to work. Reading novels, washing hair and driving kids to sports activities are generally not work activities, though organizing thoughts, finding words and seeing clients certainly can be.

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We believe that these issues need discussion. Our suggestion is that a meeting be organized this winter consisting of patients, advocates and medical professionals familiar with ME/FM issues along with CPP-D staff. The goal would be to suggest fair, non-burdensome strategies for collecting the information needed to determine CPP- D eligibility. The discussions would be of benefit to both applicants and adjudicators. We can suggest the names of participants. You may wish to consider including the Chronic Pain Society of Canada as well.

On a different note: When reassessing eligibility, we understand that the onus is on the medical adjudicator to show that the recipient has improved and no longer meets the eligibility criteria. The adjudication framework suggests that the test is whether the person would qualify if this were a new application.

Margaret Parlor
President
National ME/FM Action Network

- **QUEST #60 July 2003**

PARLIAMENTARY SUB-COMMITTEE REVIEWS CPP(D)

John Wodak, MA, PhD, CPP(D) Advisor & Advocate for the National ME/FM Action Network

John Wodak sent a submission on behalf of the National ME/FM Action Network to the Sub-Committee and is a participation at the Sub-Committee's Round Table Discussions when they are held.

See QUEST #60 July/August 2002 for details of submission.

- **QUEST #106 Spring 2016**

Canada Pension Plan-Disability

This letter was sent to a senior public servant in the CPP-D program:

February 3, 2016

Thank you for the opportunity to meet on Tuesday January 19, 2016. The focus of discussion was the first- stage adjudication of CPP-Disability cases involving Myalgia Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia.

Here are some key points:

- ME/CFS and Fibromyalgia bring with them a high degree of disability. Both qualitative and quantitative research support this statement.
- People with ME/CFS and Fibromyalgia report very high rates of unmet health care needs. There has never been an official medical specialty for ME/CFS and that there is no longer a specialty for Fibromyalgia since rheumatologist are abandoning the field. These are complex conditions for primary care physicians to be handling, especially as medical schools have provided little or no training in the area.
- Lack of information and misinformation in the medical community are huge problems. One myth is that Graded Exercise Therapy is curative for ME/ CFS. In fact, studies show that over-exertion can

cause damage to patients, leading to the conclusion that patients should not push their limits.

-
- “Chronic fatigue syndrome” was a poor choice of names. ME/CFS is a multi-system illness and is about much more than chronic fatigue. Likewise, Fibromyalgia is about much more than chronic pain.
-
- Too many people with ME/CFS and Fibromyalgia are having their application turned down at the first stage. This has enormous human cost. People tell us that they cannot focus on their health until their financial situation is stabilized.
-
- The CPP-D adjudication framework identifies ME/ CFS and Fibromyalgia as challenging to adjudicate.

The National ME/FM Action Network was pleased to hear that CPP-D has asked medical staff to review the policy and procedures concerning ME/CFS and Fibromyalgia. A key goal should be to ensure that people with ME/CFS and Fibromyalgia who meet the eligibility requirements, having sufficient contributions and being regularly incapable of pursuing any substantial gainful occupation, are approved in the first round. These illnesses are prolonged.

We have a number of recommendations on how to improve the current situation:

- Since these conditions are considered a challenge, CPP-D should assign experienced well-trained adjudicators to these applications and CPP-D should ensure that these adjudicators are kept up-to-date in this quickly evolving area.
-
- CPP-D should articulate what it wants to see in the medical submission. The medical documentation should include:
-
    - the Clinical Diagnostic Worksheet found in the Canadian Consensus Criteria for ME/CFS or the Clinical Diagnostic Worksheet found in the Canadian Consensus Criteria for Fibromyagia, or both worksheets,
    -

  - Activity Logs and an assessment of them using the Functional Capacity Scale, and
  -
  - The RAND questionnaire.
  -
- These submission requirements need to be communicated to health professionals across the country.
-
- CPP-D should remember that ME/CFS and Fibromyalgia patients are not well served by the health care system. Applications should not be denied on the basis of an incomplete medical file that is not the applicant's fault. If medical information is missing, the adjudicator could contact the health professional or the applicant for additional information or to request specific medical documentation as outlined above, commission an independent assessment, or base the decision on the non-medical evidence.
-
- CPP-D should recognize that there are often conflicting medical opinions on file. Some health professionals are not familiar with ME/CFS and Fibromyalgia while a few even deny their existence. Applicants should be adjudicated on the basis of their disability and no application should be denied on the basis of an uninformed or biased medical opinion.
-
- A rejection of an application for non-compliance with treatment requires an understanding of the benefits of the treatment and an understanding of the challenges that patients face. Generally, treatments for ME/CFS and Fibromyalgia have at best slow, incremental benefits while patients face large challenges (financial constraints, limited stamina, limited concentration, side effects of treatments, etc) Therefore, a rejection on the basis of non-compliance or even for failing to pursue a particular treatment option should be a rare event.

- Payment to health professionals should reflect the effort that goes into providing the necessary information. This payment may be higher for ME/CFS and Fibromyalgia than for other standard conditions since more time is needed to collect and document the complexity of these illnesses.
-

- Statistics should be kept on decisions (approval rates, time taken, reasons for refusal, etc.) by type of application. Patterns and trends should identified and corrective action taken when problems are noted. Statistics should be published on a regular basis to ensure that there is system transparency.

  We note the Auditor-General's report on CPP-D released yesterday and believe that our recommendations are very consistent with their recommendations dealing with the initial application/adjudication stage.

  We are willing to discuss any of these points with you and your staff.

  Thank you again for the opportunity to put these issues on the table to ensure that Canadians with ME/CFS and Fibromyalgia have equitable access to CPP-D benefits.

- **QUEST #110 Spring 2017**

CPP Retirement Benefits to Expand

but less for people on CPP-D or taking time out for childrearing

The federal government and the provinces have agreed to expand CPP retirement benefits in the future. Legislation has already passed the House of Commons.

Amazingly, legislation does not include “the drop- out” provisions that are in the existing CPP retirement program. Drop-out provisions means that the years people spend on CPP-D or on childrearing are not included in the calculation of income. Let’s say you spent 10 years working at $40k/year and 10 years on CPP-D with no income. With drop out provisions, your average salary would be $40k (because the CPP-D years are dropped out). With no dropout provisions, your average salary would be $20k (because all 20 years are considered). As the legislation is written now, future CPP retirement benefits would be based on $40k for the base portion and on $20k for the expanded portion, meaning that people on CPP-D or taking time out for child rearing will not get the full benefit of the increase in retirement payments. The House of Commons Committee was told about the problem. They felt they could not recommend changes to the legislation because this is what came out of the federal-provincial discussions. Hopefully, this problem will be fixed before the program is implemented.

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- **QUEST 116 Fall 2018**

Important Announcement on Canada Pension Plan – Disability (CPP-D)

Dear friends

On August 27, 2018 (the Government of Canada introduced a new application form and a new medical report form for CPP-D.

[For the time being, an application may be submitted on either the old or the new forms though there may be some difficulty finding the old forms on-line.]

The National ME/FM Action Network has NOT had the opportunity to look at the new forms in detail or to update our CPP-D Applications and Appeals Guide.

Nevertheless, our Guide will still be highly relevant to people applying for CPP-D. It recommends that people think about:

1) their symptoms,

2) the effect that their symptoms have on their activities, and

3) the impact that their activity limitations have on their ability to work.

This is very much the underlying model of the new application form.

We would be interested in hearing your comments on or experiences with the new form.

Our Guide can be found here:

http://www.mefmaction.com/index.php?option=com_content&view=article&id=425&Itemid=364

The new forms can be found here:

https://catalogue.servicecanada.gc.ca/apps/EForms/ pdf/en/ISP-1151.pdf

Sincerely,
NATIONAL ME/FM ACTION NETWORK

Margaret Parlor, President

GOVERNMENT OF CANADA

- **QUEST 117 Winter 2018**

Pre-budget Submission

Every autumn, the Government of Canada asks Canadians what they would like to see in the next federal budget.

We are sure that everyone in the ME/FM community would like to see investment in ME/FM research.

As we were writing up a submission around research funding, it quickly became clear that research cannot proceed without clinical services or awareness. So we expanded the submission to include all three.

The work of the National ME/FM Action Network would be a lot simpler if we dealt with only ME or only FM. However, we believe that the two are closely related despite their different histories. We struggled with how to balance ME and FM in the submission. We chose to focus on ME because it is more ready-to-go, especially with international initiative getting underway. We have not forgotten FM, and we will not forget FM as we move forward. In the same way that research can't go far without clinical services and awareness, the work around ME will not be able to go far without examining and addressing the related illnesses.

We are attaching the pre-budget submission in English and French. We have asked you to take copies of the submission, write a note on the back, sign the note with your name and address and forward it to the Minister of Health, the Minister of Finance and your local member of Parliament.

Snail mail is more effective than email, but email was more effective than not sending anything.

A signed letter is more effective than an anonymous letter but if you are not ready to go public, then an anonymous letter is better than no letter at all.

We are also attaching letters already sent by two of our supporters. They gave us permission to use their names, but asked that we remove their address. You can use these letters as models. Please don't feel that you have to write as much or as eloquently as they did or even cover the same content. What is important is that you write from your heart.

The sooner the better, but please send this by mid-January because the budget decisions are finalized then.

Address for the Minister of Health

Hon. Ginette Petitpas Taylor House of Commons
Ottawa, Ontario
K1A 0A6

Email:Ginette.PetitpasTaylor@parl.gc.ca

Address for the Minister of Finance

Hon. Bill Morneau House of Commons Ottawa, Ontario K1A 0A6

Email:Bill.Morneau@parl.gc.ca

Address the envelope to your MP as follows:

[Your local MP] House of Commons Ottawa, Ontario K1A 0A6

You can look up your MP’s name here https://www.ourcommons.ca/Parliamentarians/en/members

Enter your postal code on the right side of the page just above the first row of photos.

For digital copies of the submission in English and French go to our website at :

http://mefmaction.com/index.php?option=com_content&view=article&id=549

Please let us know what you hear back from the Ministers and your MP. Thank you!

November 8, 2018

Hon. Ginette Petitpas Taylor Minister of Health
House of Commons
Ottawa, ON K1A 0A6

Re: Pre-Budget 2019/20 Consultation Input

Dear Minister:

I want to draw your attention to a pre-budget consultation proposal by the National ME/FM Action Network (attached) and request that you include some amount of new funding in this area during the 2019/20 budget cycle.

The proposal highlights the need to commit long-term funding to research on Myalgic Encephalomyelitis (ME) and Fibromyalgia (FM), address the unmet health care needs of people living with these diseases, and to raise awareness and reduce stigma associated with these diseases.

This proposal is vitally important to me as a person living with FM and many like me. I also have Parkinson’s Disease and can equivocally say that FM is misunderstood and the available support pales in comparison to that available for people living with Parkinson’s. There is still significant stigma associated with the disease which has been considered trivial and “all in the head” of the patient – just like Multiple Sclerosis and Autism were considered in the past. FM experts know better now and must ensure health providers make good treatment recommendations, just as patients need the hope that comes from research toward a cure! The announcement of dedicated funding would fill a significant need and perhaps reduce the burden of this illness on the healthcare system.

While I have already forwarded a similar letter to the Minister of Finance and my local M.P., I would ask that if possible you encourage your Deputy Minister and policy staff to include dedicated ME/FM funding in the upcoming budget.

Thank you in advance for your consideration. Sincerely,

Dorothy Mercer

November 8, 2018

Hon. Ginette Petitpas Taylor Minister of Health Confederation Building 356 House of Commons

Ottawa, ON K1A 0A6

Since the annual federal budget will be considered soon, you are in a position to help an estimated 1 million fellow Canadians who suffer as I do from ME/FM (commonly known as Chronic Fatigue Syndrome – CFS - or Myalegia Encephalomyeletis) and Fibro Myalgia) by supporting research and health services.

This is not an airy-fairy disease, a figment of our imaginations as some medical professionals and politicians used to believe. It has a panoply of painful and debilitating symptoms that incapacitate us from supporting ourselves as contributing citizens not to mention destroying the quality of life for ourselves and our families.

I attended a national conference on ME/FM in New York City and learned a great deal about the global outlook on this illness. While interest has grown during the 25+ years that I have suffered from ME/FM, we Canadians are not even close to achieving a level of acceptable care and knowledge.

Funding research is important because:

1. Research on ME is at a potential breakthrough point regarding causes and treatments
2. Research on FM is in its infancy but shows promise to be as treatable as other inflammatory nerve conditions such as rheumatoid arthritis
3. Several European nations especially Sweden are learning apace so research information needs to be better developed here and better shared

Funding health services is important because:

- • The lack of appropriate care here compared to New York City, where I recently moved from, is considerable. It took me 17 months of living here (as a Canadian citizen) to find even the minimum of necessary care to prevent my total relapse.

-
- • Apart from me personally, about 5% of the Canadian population has already been diagnosed with this illness – and untold thousands as yet remain undiagnosed.
-
- • Research on people with disabilities shows that about half of all people diagnosed with ME/FM are too disabled to look after themselves. There is unnecessary cost to patients, their families and to society when they lack proper medical treatment.

Funding to promote awareness is important because:

- • Social support providers need to be better informed so as to provide appropriate support that is more efficient and ultimately can reduce costs
-
- • Medical professionals need to become more aware how to treat patients, as I unfortunately found out – delays in my treatment have caused unnecessary costs to address my symptoms separately instead of getting at the root causes
-
- • Patients like me suffer from social stigma even from our own families, which reduces the emotional support that we need to recover and thrive.

I would appreciate being informed on budget hearings and/or receiving relevant information on progress being made on these issues.

Thank you! Merci!

Sincerely,

Carolyn J. Curran

New Accessibility Legislation

The federal government introduced Bill-81, new accessibility legislation, this autumn and it is winding its way through Parliament.

We often talk about access to health care or access to education. When talking about disability issues, the word “access” or “accessibility” is often given a narrow interpretation. As a friend explained, if a hospital offers a service but you can’t get in the door because there is no ramp for your wheelchair or you cannot communicate with the doctor because you are deaf and there is no sign language interpretation, that is an access issue. If the hospital does not offer a particular service, that is a health care issue, not an access issue.

When you look at the Bill-81, the proposed Accessibility Act, you will see that its provisions are about access to buildings or websites or television or workplaces. You will not see provisions about modifying the Disability Tax Credit, adding health services, dealing with poverty, or increasing awareness which are changes to the services themselves, not access issues. You also will also not see provisions that are the responsibility of provinces or the private sector. The legislation is limited to matters within federal jurisdiction.

The National ME/FM Action Network wrote the House of Commons committee looking at the legislation expressing appreciation for what was included in the legislation and disappointment around what was not included.

Statistics Canada

Statistics Canada has advised us that the Canadian Community Health Survey for 2019 and 2020 will ask respondents if they have been diagnosed with Chronic Fatigue Syndrome and if they have been diagnosed with Fibromyalgia. It will not ask about Multiple Chemical Sensitivities.

The Canadian Community Health Survey has been an incredibly helpful source of information for us. It has provided evidence that people with a diagnosis of CFS and FM are dealing with serious disability, disadvantage and unmet needs. We therefore ask that, if you are contacted to participate in the survey, please do so.

We are well aware that many people would prefer that Statistics Canada use the term Myalgic Encephalomyelitis rather than Chronic Fatigue Syndrome. The problem is that not many Canadians use this term so ME would be dropped from the survey and we would be left without statistics. It is far preferable to have CFS statistics, then call for studies to determine how the diagnosis is made and what it means.

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Margaret Parlor, President
National ME/FM Action Network

MINISTER OF SPORT AND PERSONS WITH DISABILITIES

- **QUEST #97 Winter 2014**

Federal funding of National Disability Charities

The National ME/FM Action Network was sent a questionnaire about the "Social Development Partnership Program – Disability Component" (SDPP-D), a program of the Office of Disability Issues (ODI) which is part of the federal department Employment and Social Development Canada (ESDC). The SDPP-D gives out money for disability issues.

This federal department is proposing an application- based, project-based, medium-level funding program for national disability charities. The project basis would not provide our organization with stability. The medium financing would be insufficient to deal with the major needs of the ME/FM community. The application-basis would favour groups with fun projects. While we don't want to miss opportunities for funding, it just didn't seem that this proposal aligns with our needs. We responded to the questionnaire by asking for direct discussions.

- **QUEST #104 Fall 2015**

The Honourable Carla Qualtrough
Minister of Sport and Persons with Disabilities

Dear Ms Qualtrough:

Moving forward on behalf of Canadians with ME/CFS and FM

The National ME/FM Action Network would like to congratulate you on your election to Parliament and on your appointment as Minister of Sport and Persons with Disabilities.

We are a registered charity that has been supporting Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and/or Fibromyalgia for over 20 years. These diseases are far from rare. The Canadian Community Health Survey, conducted by Statistics Canada, estimated that there were over 800,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia or both in 2014.

ME/CFS and FM can involve a high degree of disability. The disability shows up primarily as reduced physical and mental stamina. This affects people's ability to participate in school, work, family, social and recreational activities. Patients may be housebound or even bedbound for years.

Here is a statistic from the 2010 Canadian Community Health Survey that gives a perspective on the extent of the problem: 20% of working age Canadians who were permanently unable to work had a diagnosis of CFS, FM or both.

People with ME/CFS or FM often have difficulty accessing programs intended for people with disabilities. Barriers to access include:

- many disability programs were designed without ME/ CFS or FM in mind
- the seriousness of the disability is under-appreciated
- disability around ME/CFS and FM can be hard to describe, measure and prove
- many people with ME/CFS or FM have difficulty finding a health professional to complete application forms.

We have identified a number of programs that need review to ensure equitable access for persons with ME/CFS and FM. These include CPP-Disability, the Disability Tax Credit, home care, and work accommodation initiatives. Even Elections Canada was not forthcoming about the option of voting from home. Fixing these programs would have a very positive impact on the lives of many Canadians.

Your mandate letter sets an overall goal of ensuring greater accessibility and opportunities for Canadians with disabilities. The letter identifies just one activity in relation to disability issues - development of a Canadians with Disabilities Act. Our specific issues are not mentioned but the mandate letter gives you the authority to add priorities to your agenda.

The ME/FM community would like to be included in discussions around the new Canadians with Disabilities Act. The community would also like your assurance that ME/FM issues, while not specified in your mandate letter, will be added your agenda.

I would welcome the opportunity to sit down with you to discuss how we can work together for the benefit of Canadians with ME/CFS and FM. Let me mention that we are in the process of preparing our winter newsletter and would like to be able to bring news of progress to our readers.

Yours truly,

Margaret Parlor
President
National ME/FM Action Network

- **QUEST #106 Spring 2016**

February 25, 2016

The Honourable Carla Qualtrough
Minister of Sport and Persons with Disabilities

Dear Minister Qualtrough,

RE Follow-up from February 22, 2016 meeting

Thank you for our meeting on Monday, February 22, 2016 to discuss issues faced by Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM). Also in attendance were James Van Raalte, Director-General of the Office of Disability Issues and Jude Welch, your Director of Parliamentary Affairs.

Statistics Canada’s Canadian Community Health Survey estimates that there are 800,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia, or both. (This figure goes up to 1.4 million if you include Multiple Chemical Sensitivities, a condition that often overlaps.) The survey data shows that these Canadians have a high degree of disability, disadvantage, and unmet needs.

While ME/CFS and FM are most prevalent among people of working age, they can affect seniors and young people as well. Our organization, the National ME/FM Action Network, prepared and published a Sourcebook for Teachers discussing issues affecting young people. It is available for free in English and French on our website.

My first ME/FM advocacy work fifteen years ago involved asking the Ontario education system to address the needs of students who, for health reasons, could not attend school full time. Frustratingly, the issues have never been satisfactorily addressed, leaving students who need part-time or home-bound schooling poorly served and in some cases unserved. No explanation was ever provided for the inaction, but obviously the system calculated that these students were not deserving enough to warrant a change to the status quo.

This is one illustration of the resistance and lack of cooperation that the ME/FM community has encountered. Dr James Coyne, a professor of psychology with over 350 publications, has just published a blog touching on the topic. He recently became interested in the controversy about the "PACE" study which supposedly justifies the use of behavioural therapy and exercise in treating ME/CFS. Patients have criticized the study on many grounds including poor participant selection criteria, the change of success criteria in the middle of the study, and the failure to declare competing interests. Dr. Coyne asked the study authors for anonymized individual data in order to test their findings. He was rebuffed. Here are his observations.

"Peter White and the PACE investigators' crude, personal, and unprofessional response to my request for data was reflexive. They are accustomed to receiving those requests from patients in a culture where patients should be seen and not heard. They were responding as if I was somehow below them in the hierarchy in which their views should be uncritically accepted with all the deference that colonialists are due. How vexatious of me to challenge the interpretations of their data that they were putting forth...

"Once I was cast among the patients, I was subject to the usual smearing and collective punishment for real and imaginary hostile actions of a few patients in a

familiar narrative crafted by Simon Wessely's Science Media Centre. Although I have a stronger publication record than any of the PACE investigators, concerns were raised about releasing data to those who are incapable of analyzing it.

“Over time, I’ve gotten to know some of the individuals who have previously requested data, although I have never met them. They impress me as amply qualified to analyze data, and they often analyze data that I report in my blogs, with them asking for no credit. Many of them have been academics or have had other professional achievements. Others were progressing well along in their educational pathways before they were struck by their illness. Still others become citizen- scientists with the capacity to publish peer reviewed letters to the editor as a result of struggling to deal with their misunderstood medical condition.

“There is something ugly, pernicious going on here, more fundamental than the question of data sharing. Being a patient with chronic fatigue syndrome/ myalgic encephalomyelitis is what sociologists like Erving Goffman would call a spoiled identity. Being a patient means being stripped of all other significant social identities and being reduced to a common denominator, stigmatized role.”

The talent and goodwill that exists in the ME/FM community needs to be recognized while the uncooperative and disrespectful way the ME/FM community is treated needs to be addressed.

Meanwhile, in our first letter to you, our organization identified five federal disability programs that need to be examined from a ME/FM perspective.

Attached are descriptions of the six projects that flow from our meeting – the five disability programs plus building a healthy relationship with the community. Our organization will work with the public service through the Office of Disability Issues to move forward in these six areas. I indicated my intention of updating this report every few months and you indicated a real interest in receiving these updates. That is very appreciated.

Thank you again for the opportunity to describe to you the situation facing Canadians with ME/CFS and FM.

Yours truly,

Margaret Parlor
President
National ME/FM Action Network

QUEST #108 Fall 2016

Participating in Disability Consultations

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

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

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

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

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

- *ME/CFS and FM are chronic disabling illnesses that impact many Canadians.*

- *The ME/FM community brings a important perspective to disability discussions – having a disability that is not well-established.*

- *The CRPD [United Nations Convention on the Rights of Persons with Disabilities] provides a definition of disability, but putting too little emphasis on participation restrictions and too much emphasis on impairments can be exclusionary.*

- *The discussion paper uses other disability legislation as the main models for moving forward. Much can be learned from experiences around building inclusion for other excluded groups.*

- *The discussion paper seems to be defining accessibility in a very narrow sense, the way it is used in article 9 of the CRPD. All rights within the*

CRPD need to be considered, including health education and income adequecy.

• Our experience is that federal government employees know little about disability issues. A key priority of the new legislation should be building federal competency.

• The federal government should be taking leadership on disability issues as there are many stakeholders.

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- *The federal government needs to understand the value of disability organizations like ours.*
- *Amendments to the Disability Tax Credit provisions should be included in the new legislation.*
- *Statistics and evaluation are extremely important.*
- **Disability Issues**
- Canadians with ME/CFS and FM need medical care, but they also need disability supports. Disability supports come in a variety of forms – financial, housing, transportation, communications, employment etc. As such, they fall under a number of federal government departments and agencies. The current government appointed a Minister for disability issues, Carla Qualtrough, and mandated her to develop a Canada Disability Act. Disability would be an enormous challenge in itself, but the Minister is responsible for sports issues as well.
- The Network met with the Minister in February 2016 and outlined five areas needing attention. One year later, there were NO tangible changes. Here is a report card we sent the Minister at the one-year mark:

Accessibility issues facing people disabled by ME/CFS and/or FM **Raised at a meeting with the Min- ister responsible for persons with disabilities on February 22, 2016**	**Tangible changes made to increase accessibility for people disabled by ME/CFS and/or FM** **Feb 22, 2016 to Feb 22, 2017**
Ensure that eligible CPP- Disability applications based on ME/CFS and/or FM are approved without undue effort, cost or delay	NONE
Ensure that people with ME/CFS and/or FM have fair access to the Disability Tax Credit	NONE
Ensure that people with ME/CFS and/or FM have fair access to home care	NONE
Ensure that people with ME/CFS and/or FM who are able to work have fair access to workplace accommodations and	NONE

supports	
Ensure that information on the availability of at-home voting in federal elections is easy to find.	NONE

- 12
- Note that the report card looks at tangible changes. There are discussions ongoing with CPP-D that have the potential to be very helpful in the future. We also subsequently received news of a tangible change from Elections Canada – they posted information aboutvoting-from-home on their websites for each of the constituencies holding by-elections!
- More broadly, public hearings took place on the Canada Disabilities Act. The Network made a submission and people attended several hearings. The discussions have now moved behind the scenes. We were stunned to discover that the Network was not included in any of the working groups which were funded in October 2016. We have notified the Minister that the ME/FM community is not represented.
- Also taking place are discussions about future funding of disability organizations. It appears that funding will be targeted at established organizations working in cooperative environments on feel-good projects. ME/FM organizations don’t fit that profile, and won’t until basic institutional stigma issues are satisfactorily addressed.

- **QUEST #111, Summer 2017**

  Accessibility Report Released

- In their election platform, the Liberals talked about a new Canada Disability Act but did not describe what would be included. Responsibility for developing the act was passed to the Minister responsible for Persons with Disabilities, Carla Qualtrough, and the Minister of Families, Children and Social Development, Jean-Yves Duclos. Minister Qualtrough has taken the lead.

- Public consultations were held over the winter. A report summarizing the discussions has just been released.

- Traditional federal government actions include encouraging employment of disabled Canadians, regulating transportation services, setting building standards and setting telecommunications standards. This report focuses on these traditional activities. This suggests that the new legislation will focus on traditional issues.

These issues are important, but it is also important to break new ground.
- The legislation is some months away. Perhaps between now and then there will develop a more aggressive vision of what federal legislation can do to help Canadians with disabilities.

- **QUEST 117 Winter 2018**

  New Accessibility Legislation

- The federal government introduced Bill-81, new accessibility legislation, this autumn and it is winding its way through Parliament.

- We often talk about access to health care or access to education. When talking about disability issues, the word “access” or “accessibility” is often given a narrow interpretation. As a friend explained, if a hospital offers a service but you can’t get in the door because there is no ramp for your wheelchair or you cannot communicate with the doctor because you are deaf and there is no sign language interpretation, that is an access issue. If the hospital does not offer a particular service, that is a health care issue, not an access issue.

- When you look at the Bill-81, the proposed Accessibility Act, you will see that its provisions are about access to buildings or websites or television or workplaces. You will not see provisions about modifying the Disability Tax Credit, adding health services, dealing with poverty, or increasing awareness which are changes to the services themselves, not access issues. You also will also not see provisions that are the responsibility of provinces or the private sector. The legislation is limited to matters within federal jurisdiction.

- The National ME/FM Action Network wrote the House of Commons committee looking at the legislation expressing appreciation for what was included in the legislation and disappointment around what was not included.

Prime Minister of Canada

- **QUEST #97 Winter 2014**

Contacting the Prime Minister

You may have considered writing or phoning the Prime Minister. You may have already done so. Many people have. Here are some statistics taken from a story in the Ottawa Citizen by Jason Fekete, November 15, 2013.

In 2012-13, Prime Minister Stephen Harper received more than

1.4 million pieces of electronic mail, 320,000 pieces of paper mail, and 13,000 telephone calls.

Of the paper mail correspondence,
28,775 pieces were considered general mail; 12,408 were considered priority mail,
232,187 were considered "write-in campaigns, junk mail, copies",
39,049 were considered greetings; and
8,035 were classified as others

The Prime Minister's Office sent 54,581 pieces of correspondence in reply to those messages. The government says the difference between the correspondence received and the number of items sent is because things such as petitions, thank you letters and some other messages don't require a response.

The bottom line is that many of the messages sent to the Prime Minister do NOT receive replies. Your chances of receiving a reply improve if you state that it is a personal letter and not a copy or campaign and if you ask the Prime Minister for specific information. A letter saying that FM is a terrible condition might be ignored. A letter asking the Prime Minister what the government proposes to do to deal with FM is more likely to receive a reply.

- **QUEST #111, Summer 2017**

Network Writes Prime Minister

Thursday, April 6, 2017
Fax #613-947-0310
Email: Justin.trudeau@parl.gc.ca

The Right Honourable Justin Trudeau House of Commons
Ottawa, Ontario Canada K1A 0A6

Dear Mr. Trudeau:

Imagine coming to work one day and catching a nasty virus that goes on for days, then weeks and then months. You see your physician who orders many tests, all of which come back negative. You may or may not get a diagnosis of chronic fatigue syndrome or fibromyalgia, but either way, your physician sends you to a psychiatrist because your doctor somehow thinks that you can will your way out of your illnesses. Your family doesn't know what to do. Your applications for disability benefits are questioned or turned down. You continue to feel sick, perhaps unable to go out of the house or even to get out of bed. You feel abandoned by the health system, by the social system, and even by family and friends.

That is the fate of many Canadians with Myalgic Encephalomyelits, often called Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM). Many have been ill for over 30 years. Many were ill as children or teenagers and never had a normal childhood. Imagine how you would feel if this happened to your child.

If you were to be ill with ME/CFS and/or FM today, your prognosis for recovery would be slim if not hopeless. You would be much better off if the illnesses were diagnosed promptly and treatment started early.

The sad part of this story is that information has been available for physicians to diagnose and treat ME/CFS and FM since 2003. Our organization, the National ME/FM Action Network, a Canadian registered charity, worked with Health Canada and 24 experienced and renowned ME/CFS and FM experts chosen by their peers, from Canada and around the world to develop diagnostic and treatment protocols. The protocols have sparked international interest. Overviews have been translated into

English, French, Spanish and Italian, with the ME/CFS overview available in German and Dutch as well. I received the Meritorious Service Award from the Canadian Governor General for my role in their development.

The problem is that the protocols have not been endorsed or publicized here in Canada. The only dissemination is what our Network could afford to send out. The Canadian government has made no effort to educate government departments dealing with health issues and has shown no leadership in encouraging their use or their inclusion in medical education. In fact, the Canadian government has been ambiguous whether it even thinks that ME/CFS and FM are real and serious.

Statistics show that over 800,000 Canadians have a diagnosis of CFS, FM or both. The statistics go on to show that Canadians with CFS and FM have very high levels of health system usage coupled with very high levels of unmet health care needs, demonstrating ineffective use of our health resources. Canadians with CFS and FM show very high levels of disability, poverty, food insecurity and social exclusion. And this is not a small problem. Fully 20% of working aged Canadians who said that they were "permanently unable to work" reported a diagnosis of CFS, FM or both.

Research funding is desperately needed. While we have an open dialogue with CIHR, funding is still abysmal. Canada is way behind other countries in the race to understand ME/CFS and FM, to find biomarkers, and to find effective treatments. Canada is not even in a position to follow developments in other countries and bring that knowledge to patients. We need dialogue with the Minister of Health on research and other issues but that dialogue is not happening. We are also encountering difficulties opening dialogue around disability issues.

Canadians with ME/CFS and FM are getting a raw deal that needs to be corrected. Mr. Trudeau, I know you are a busy man but I think you need to meet with our Network's President, Margaret Parlor, and me to discuss how we can correct this miscarriage of justice for those ill with these debilitating illnesses.

We need your leadership, Mr. Trudeau, and your help. This is an opportunity to improve the lives of many Canadians.

Sincerely,

NATIONAL ME/FM ACTION NETWORK

Lydia E. Neilson, MSM
CEO, Founder

Prime Minister Responds

Dear Ms. Neilson:

On behalf of the Right Honourable Justin Trudeau, Prime Minister of Canada, I would like to acknowledge receipt of your correspondence.

Please be assured that your comments have been carefully reviewed. In your correspondence, you raise an issue that falls within the portfolio of the Honourable Jane Philpott, Minister of Health. I have therefore taken the liberty of forwarding your email to Minister Philpott for her information and consideration.

In your correspondence, you express an interest in meeting with the Prime Minister. I regret that the Prime Minister will not be able to meet with you to discuss this situation.

Thank you for taking the time to write.

P. Monteith
Executive Correspondence Officer for the Prime Minister’s Office Agent de correspondance
de la haute direction
pour le Cabinet du premier minister

Superintendent of Insurance of Financial Institutions

- **Quest #3 December 1993**

DISABILITY INSURANCE - FEDERAL: In reply to our letter of October 12th to the Office of the Superintendent of Financial Institutions Canada, they advised in their October 18th the following:

"I sympathize with the concerns raised in your letter. Under the division of powers set out in the Constitution Act, the federal government's authority in insurance matters is limited to ensuring, to the extent possible, that federally registered companies remain in a financial position to be able to meet their contractual obligations to policy holders. The Office has no jurisdiction over provincial Superintendents of Insurance.

The regulation of provincial insurance companies, matters of contract, general business practices and underwriting criteria of all insurance companies fall exclusively within provincial jurisdiction.........

The Office's role in dealing with consumer complaints is limited to that of mediator. We contact financial institutions to ask for comments or explanations in the hope that we can contribute to resolving disputes. Although we do not have the power or mandate to settle disputes, we hope that our intervention assists in bringing both parties together so that differences can be worked out. If this does not work, consumers can choose whatever other course of action they deem appropriate." Signed: Michel Beaudry, Acting Director, Communications and Public Affairs, Office of the Superintendent of Financial Institutions Canada, 255 Albert St., 13th Floor, Ottawa, Ottawa, ON K1A 0H2 - PHONE: 1-800-387-0700

Re: BC Teachers ill with ME/FM reply from Deputy Superintendent of Insurance

Mr. Larry A.W. Neilsen, Deputy Superintenden, Insurance and International Financial Business, Province of BC, states as follows: "Part 5 of the Insurance Act of British Columbia does not provicde for an alternate dispute resolution method other than the commencement of a civil action. Participation in any other dispute resolution method, such as binding arbitration or mediation, would have to be reflected in the provisions of the policy or agreed upon at a later date by both the insurance company and the insured...."

In reply to whether an insurance company has the responsibility to send the claimant to a doctor who is knowedgeable on the disease the claimant suffers from or is claiming under, Mr. Neilsen states: "Part 5 of the Insurance Act does not address this issue. An insured should consult the terms of his or her disability insurance policy or insurance certificate for further information with respect to this issue.

As well, you may wish to consult with your local office of the Insurance Bureau of Canada and with CLHIA [Canadian Life & Health Insurance Association, Inc.] to determine what, if any, industry practices there are with respect to the insurer's responsibility to choose a physician that is qualified to diagnose the disease at the claimant alleges he or she has." Signed Larry A.W. Neilsen, Deputy Superintendent,Insurance and International Financial Business, Province of BC, 1900, 1050 West Pender Street, Vancouver, BC V6E 3S7 - Tel. (604) 660-2947 - Fax (604) 660-3170.

HEALTH MINISTER

CANADA

- **Quest #4 – February 1994**

- The National ME/FM Action Network wrote all provincial and federal health ministers etc. to request recognition of **May 12th International ME/FM Awareness Day; and**

- **Walk on Parliament Hill** - Aidan Walsh of Montreal coordinated this event and hundreds of ME/FM information bulletins were distributed to members of Parliament. Aidan also was able to hand over his written request for research to the National Minister of Health, The Hon. Diane Marleau. A copy of Aidan's letter is enclosed.

- **QUEST #5 – April 1995**

  Reply from Minister of Health on May 12 International Awareness Day

  *****The Hon. Diane Marleau, Minister of National Health & Welfare responded as follows-

  "As Minister of Health, I would like to express my support for National ME/CFS Awareness Day.

  Myalgic encephalomyelitis (ME), or chronic fatigue syndrome, can have considerable debilitating consequences. Many Canadians are affected by this disease for which there is not yet an effective treatment. I hope that ongoing research will continue to unravel this difficult and perplexing problem.

  I commend the National ME/FM Action Network, and the many volunteers in self-help and mutual aid groups across the country, for the information, advice and reassurance they provide to those afflicted by this syndrome.

Please accept my best wishes for a very successful ME/CFS Awareness Day." Signed: Diane Marleau, Minister of Health.

NOTE: Ministers of Health – By Province/Territory Listed in newsletter.

- **QUEST #36 JUNE 1999**

ME/FM CLINICAL DEFINITIONS PRESENTED TO LCDC/MINISTER OF HEALTH

Dr. Bruce Carruthers of British Columbia. and **Dr. Anil Jain** of Ontario kindly and generously donated their time and expertise to the draft of the Canadian Definitions, Diagnostic and Treatment Protocols for Myalgic Encephalomyelitis and Fibromyalgia. Our Director of Education, **Marj van de Sande** has worked diligently with these doctors on this draft and compiled the document into an 'easy to locate' format. They have worked for approximately one year on this document and the 1999/7 draft is now ready for peer-review.

At a July 21, 1999 meeting at the Laboratory Centre for Disease Control (LCDC) in Ottawa, we presented this draft definitions/protocols document to the Minister of Health's representatives. At this meeting, we were advised that there were no funds available for the peer-review as Health Canada has not allocated any funds for ME/FM. This came as a shock to us. In the Honourable Allan Rock's May 31, 1999 letter to us he stated, "The development of draft clinical definitions for ME/FM is a milestone in the fight against this complex and tragic condition."

It is essential that these definitions have the support of Health Canada/LCDC in order that these illnesses receive recognition and acceptance by the medical community. We have requested a meeting with the Honourable Allan Rock and the Director General of the LCDC for the purpose of requesting that Health Canada allocates funds for the peer-review of the 1999/7 draft definitions/protocols document for ME/FM and when completed that further funds be provided for the distribution of this booklet to all medical professionals. We will keep you posted as to the developments.

- **QUEST #37 August 1999**

ME/FM CLINICAL DEFINITIONS/PROTOCOL - UPDATE

You may recall that we informed you in our last newsletter that we had presented the draft ME/FM clinical definitions and treatment protocols to the Laboratory Center of Disease Control and were informed that no monies had been set aside for ME/FM to do the peer review and dissemination of the information. We wrote the Minister of Health and the Director General of the LCDC asking for a meeting to discuss funding. We just received a reply from the Minister of Health that he is making arrangements with the Director General of the LCDC to meet with us on his behalf.

We will keep you advised when this meeting has taken place. Please help by forwarding a letter to the Director General advising how important it is that standardized clinical definitions be established for ME/FM. Be sure to also advise him that you support our Network in its Quest to bring these definitions to fruition. Address your letter to: **Dr. Michael Shannon, Director General, Laboratory Center for Disease Control, Tunney's Pasture, Postal Locator 0602C1, Ottawa, ON K1A 0L2 - Tel. (613) 957-0315 - Fax (613) 952-8189.**

- **QUEST #38 October 1999**

ME/FM CLINICAL DEFINITIONS/PROTOCOL - UPDATE

We are pleased to advise that on Wednesday, January 5, 2000 we have a meeting with the Director General of the Laboratory Center for Disease Control, and who will also represent the Minister of Health On the agenda for this meeting is a discussion of funding for a peer-review of the ME/FM clinical definitions and treatment protocols and funding for the dissemination of the information to the Canadian doctors.

The clinical definitions and treatment protocols are necessary because, to date, there are no standardized protocols followed across Canada. The 1994 ME definition established by the U.S. Centers for Disease Control is a research definition not a clinical one. Once a clinical definition has been established, it will give doctors the knowledge necessary to diagnose and treat.

The doctor in the following article reinforces our stand about the importance of standardized ME/FM clinical definitions and treatment protocols.

The National ME/FM Action Network would like to take this opportunity to congratulate all of you on the accomplishments we have been able to achieve as the result of our partnership with you. We can all look to the new millennium with optimism and hope.

Sincerely,
Lydia E. Neilson, President CEO

- **QUEST #39 December 1999**

ME/FM CLINICAL DEFINITIONS/PROTOCOL - UPDATE - ANNOUNCEMENT

As you know, the **National ME/FM Action Network** has been working with **Dr. Anil Jain**, **Dr. Bruce Carruthers** to establish a draft standardized clinical definition for ME/FM. **Ms Marj van de Sande**, our Director of Education, has coordinated all their efforts into the draft which has taken over a year to accomplish.

This draft clinical definition was presented to the **Minister of Health** through the **Laboratory Center for Disease Control** in July 1999. Since then we have been in even closer contact with the LCDC and Health Canada in an effort to get the definitions peer-reviewed by experienced ME/FM doctors.

We are pleased to advise that there will be a **First National Conference for ME/FM and Environmental Illness (Multiple Chemical Sensitivities)** from **November 17 - 19, 2000.** This Conference will be sponsored by Health Canada/LCDC, the National ME/FM Action Network and the Environmental Illness Society of Canada.

A professional Convention Management company has been hired by Health Canada to coordinate this Convention while the planning of the conference will be performed by the Planning Committee which will be formalized at our next meeting with the LCDC/Health Canada on February 18th, 2000.

- **QUEST #94 Spring 2013**

Minister of Health (Canada) and Secretary of State for Health and Human Services (United States) Respond to Questions about ME/CFS

In the last issue of Quest, we presented a list of question that were addressed to the Minister of Health by Member of Parliament Dr. Carolyn Bennett. Dr. Bennett's questions focused around ME/CFS but also touched on FM and MCS. The topics included four area where the federal government can play an

Hon. Leona Aglukkaq (Minister of Health, Minister of the Canadian Northern Economic Development Agency and Minister for the Arctic Council, CPC):

Mr. Speaker, the government supports provincial and territorial health care delivery through fiscal transfers and targeted programs. Unlike previous governments that balanced their books on the backs of the provincial and territorial governments, we have committed to a long-term stable funding arrangement that will see health care transfers reach historic levels of $40 billion by the end of the decade. Health transfers from the federal government to provinces grew by 40 percent between 2005-2006 and 2012- 2013. Our investments in health care will help preserve Canada’s health care system so it will be there when Canadians need it.

With respect to research and awareness, in May 2008, the Public Health Agency of Canada, PHAC, and the Canadian Institutes of Health Research, CIHR, coordinated a meeting with the Myalgic Encephalomyelitis Association of Ontario and other stakeholders to explore ways to increase knowledge and awareness of myalgic encephalomyelitis/chronic fatigue syndrome, ME/CFS, and to address research needs. This meeting led to the first Canadian national scientific seminar on ME/CFS in Calgary in November 2008. This seminar was held to raise awareness, increase medical practitioners’ knowledge, and improve medical treatment for patients with ME/CFS. An article on this seminar was published by PHAC and can be found at: *http://www.phacaspc.gc.ca/publicat/cdicmcbc/293 /pdf/cdic2936eng.pdf*

CIHR has invested $28,000 since 2009-2010 in research related to ME/CFS. In addition, CIHR’s Institute of Musculoskeletal Health and

Arthritis, IMHA, has set aside a separate pool of funds in its undergraduate studentship program for myalgic encephalomyelitis and fybromyagalia. Details are available at: *http://www.researchnetrecherchenet.ca/rnr16 /vwOpprtntyDtls.do?prog=1699*

Surveillance of ME/CFS and fibromyalgia is undertaken by PHAC in looking at trends in disease prevalence in order to inform program and policy decisions. Data from the 2010 Canadian Community Health Survey, CCHS, allow PHAC to produce scientific surveillance information on ME/CFS, raise awareness and support efforts to increase understanding of the impact of these conditions.

The questions on ME/CFS, fibromyalgia, and multiple chemical sensitivities were asked of all CCHS respondents in 2010. Analysis of the 2005 and 2010 data demonstrated that there were no changes in the prevalence of these conditions in this five-year period; therefore, maintaining the data collection on these conditions every four years is appropriate.

The Public Health Agency of Canada's website is aimed at delivering information and services to users that are relevant and applicable to its mandate and that of the Government of Canada. While PHAC facilitates the sharing of clinical information via its website, it is the responsibility of health care professional associations and medical bodies to ensure that relevant clinical information is available to their members. The following documents are available at the links indicated below: Canadian Consensus Document for ME/CFS: A Clinical Case Definition and Guidelines for Medical Practitioners at: *http://www.phacaspc.gc.ca/cdmc/azindex eng.php#C* and Canadian Consensus Document for Fibromyalgia: A Clinical Case Definition and Guidelines for Medical Practitioners at: *http://www.phacaspc.gc.ca/cdmc/azindexeng.php#F*

- **QUEST #104 Fall 2015**

Nov 16, 2015

The Honourable Jane Philpott Minister of Health

Dear Dr Philpott:

Moving forward on behalf of Canadians with ME/CFS and FM

The National ME/FM Action Network would like to congratulate you on your election to Parliament and on your appointment as Minister of Health.

We are a registered charity that has been supporting Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and/or Fibromyalgia for over 20 years. These diseases are far from rare. The Canadian Community Health Survey, conducted by Statistics Canada, estimated that there were over 800,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia, or both in 2014.

There are three sets of issues challenging our community: little biomedical research, little medical system support, and difficulty accessing disability programs such as home care. This letter focuses on the first two. We have raised the accessibility issues with your colleague Ms Qualtrough.

Canadians with ME/CFS and FM have been badly served by the Canadian health system for years. Our organization knows this from our ongoing contact with patients. This neglect has been confirmed by Statistics Canada’s Canadian Community Health Survey. Chronic Fatigue Syndrome and Fibromyalgia have been on the survey five times since 2001. Each time they have had the highest and second highest rates of unmet health care needs among the chronic conditions listed.

One would think that this evidence of ongoing under- service would trigger federal government investigation and action. We have called attention to the situation and we have been supported by three Liberal MP’s who each put questions on the Order Paper. There was little meaningful action taken by the previous government. We hope that things are about to change.

Many health care providers have an unrealistic and potentially harmful approach when dealing with ME/CFS patients, telling them to change their attitude and be more active. Patients experience dismissal and invalidation of their physical symptoms – creating undue distress on already ill patients. Further, the patient may be intolerant of exertion, a point made clear in a recent report by the US Institute of Medicine.

Other health care providers are more sympathetic but have no ME/CFS or FM training, little research to refer to, and nowhere to turn for guidance. There has never been a specialty for ME/CFS and the specialty that dealt with FM (rheumatology) is abandoning the illness and, by extension, the patients.

Meanwhile, there is little biomedical research going on in Canada or internationally to understand the etiology or develop treatments. However, much is changing internationally, especially on the ME/CFS side, as leading scientists are developing a better understanding of the illnesses, are criticizing the pseudo-science that has held sway and are calling for biomedical research.

Fixing the situation here in Canada will take more than money. There needs to be a fundamental paradigm shift in attitudes, priorities, and collaboration to bring ME/CFS and FM, currently on the outside, into the research and clinical systems. This paradigm shift needs leadership to ensure effective ramp up and roll out.

This is why we are disappointed that these issues were not mentioned in the PM’s mandate letter. Your overarching goal is to strengthen the publicly-funded universal health care system and ensure that it adapts to new challenges – that is precisely what ME/CFS and FM illnesses and our community needs. The letter identifies particular priorities, yet none directly address our issues or our community. The ME/FM community fears that it will be ignored once again, just when focused attention by leadership is required.

We note the Mandate letter gives you the authority to add priorities to your agenda. We hope that the under-service of the ME/FM community is one of your additions.

We look forward to working with you to address the concerns of the community. We know how busy you are so would suggest a 15 minute get-together this month here in Ottawa to start the ball rolling. Let me also mention that our winter newsletter will be published in the next month or so and we would like to give a message of hope to our readers.

Yours truly,

Margaret Parlor
President
National ME/FM Action Network

- **QUEST #107 Summer 2016**

Meeting With Health Minister's Staff

April 14. Dr Philpott was appointed as Minister of Health six months ago. She has been given many challenges such as brining Syrian refugees to Canada, setting policy to legalize marijuana and leading the assisted dying debate. She has not found time to meet with the ME/FM community.

One person in the ME/FM community, Scott Simpson, was able to get a meeting with one of her staff members in Ottawa. He invited Dr Bested and Margaret Parlor to join him. (Dr Bested joined by phone.)

The meeting was very much an initial meeting. Health officials tend to assume that all is well within the health system. It is hard for them to grapple with the idea that there are problems, and especially problems on the scale that ME/FM is encountering. Officials either reject the message outright or leave room for further discussion. Fortunately, the staff member did leave room for more discussions. We hope to continue the dialogue soon.

CANADA RESEARCH COORDINATING COMMITTEE (CRCC)

- **QUEST 116 Fall 2018**

July 27, 2018

Canada Research Coordinating Committee launches consultation [CRCC]

The CRCC is launching a national consultation to reinvigorate Canada's support for science and to position Canada as a global leader in research excellence.

The online consultation portal was live and was focussed on 3 priorities:

1. Creating a new tri-agencyfundtosupportinternational, multidisciplinary, high-risk and rapid-response research that generates new knowledge;
2. Strengthening equity, diversity and inclusion in research; and
3. Supporting early career research.

Budget 2018 proposed to invest more than $1.7 billion over five years to support researchers through Canada's granting councils and research institutes. This includes $275 million over five years to support the new Tri-Agency Research Fund. Stakeholders are invited to provide feedback on a draft funding model that the CRCC has developed to ensure we maximize the positive impact on academic research in Canada.

Consultations were held in communities across Canada. Input from this process will inform the development of a call for proposals this fall for the tri-agency fund.

The CRCC was created to improve the coordination efforts of Canada's granting agencies - the Social Sciences and Humanities Research Council of Canada, the Natural Sciences and Engineering Research Council of Canada, and the Canadian Institutes of Health Research - as well as the Canada Foundation for Innovation.

To view entire article, please go to:

http://www.cihr-irsc.gc.ca/e/51107.html

For Canada Research Coordinating Committee Mandate & Work Plan, please see:

http://www.cihr-irsc.gc.ca/e/51107.html

Biography of Dr. Michael J. Strong

Please go to:

https://www.canada.ca/en/institutes-health-research/news/2018/06/biography-of-dr-michael-j-strong.html

Canadian Institutes of Health Research (CIHR)

[CIHR was previously called Laboratory Centre for Disease Control (Ottawa)]

Re: Government Grants

Dr.Campione-Piccardo replies in his letter of June 9, 1994 as follows:

"The main agencies granting support to researchers who may wish to contribute to a better understanding of ME/FM are the Medical Research Council and the National Health Research Development Program (NHRDP). These agencies assign grants through a peer-reviewed competitive process on the basis of perceived merit. Every Canadian with the required qualifications can apply for different types of grants to carry out research in ME/FM in different universities or other institutions."

Signed: José Campione-Piccardo, M.D., Ph.D. Chief, National Laboratory for Viral Oncology, Laboratory Centre for Disease Control, Ottawa.

- **QUEST #14 – October 1995**

LABORATORY CENTRE FOR DISEASE CONTROL - CANADA

We had written the LCDC on July 14th, 1995 requesting information as to what LCDC was going to do in Canada now that the new December 1994 definition and criteria had been published from the Centers for Disease Control in Atlanta. As no reply had been received, we followed up our request asking for a reply which we finally received via Courier on October 19th, 1995 and is quoted in its entirety:

"Thank you for your letter and information package on the above-named subject. I apologize for the delay in responding.

While I fully appreciate and share your concern about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia (ME/CFS/FM), these conditions, unfortunately, remain a very complex and intriguing group of diseases. Although many theories have been put forward to explain their causes, there still remains many unresolved issues that need further research and elucidation.

To this end, the Laboratory Centre for disease Control (LCDC) held a workshop on CFS/ME in September of 1989, to explore the diagnosis of the illness, its proper case definition and promising areas for future research. Its proceedings were published in January 1991, and are believed to have assisted the scientific community to formulate research studies to investigate the case of this disorder. LCDC also provided funds for a further workshop organized by the Nightingale Research Foundation in Vancouver in May 1991. Experts from Canada and abroad attended this workshop targeted to the need for precise research protocols and the care of patients.

In June 1992, a group of Canadian experts met to discuss the allegation of an association between hepatitis B vaccine and CFS. This working group concluded that there was no evidence to justify further research on a relationship between CFS and hepatitis B vaccine. However, postmarketing surveillance for side effects related to hepatitis B vaccine, including CFS, will continue. If surveillance data suggest a possible relationship, further work will be undertaken.

Over the years, the National Health Research and Development Program (NHRDP) of Health Canada has funded various research projects to investigate into the cause and other aspects of ME/CFS/FM, and will certainly continue to entertain research proposals on the subject. Similarly, the Medical Research Council (MRC) has always been open to considering research submissions on this issue through its peer review process.

As alluded to in the Minister's letter to you in June, because of budgetary constraints, the Laboratory Centre for Disease Control is not in a position to conduct its own research on these diseases at this point. We will, however, continue to work with NHRDP and MRC to facilitate research in this important area.

I appreciate very much your writing to me on this matter. Hopefully, with continuing government funding and dedicated research efforts of the scientific community, we will continue to make progress in resolving this important health problem." **Signed: Dr. J.Z. Losos, MD,DECH,FRCPC,FACPM, Director General, Laboratory Centre for Disease Control, Tunney's Pasture, Ottawa, Ontario K1A 0L2.**

[Editor's note: As far as we know, no follow ups were ever instituted after the original workshops in 1989 and 1991. Please put Dr. Lozos on your mailing list].

- **QUEST #15 – December 1995**

LABORATORY CENTER FOR DISEASE CONTROL (LCDC) CANADA:

In the Fall of 1995 we received a reply from Dr. J.Z. Losos, Director General of the LCDC regarding its research into ME/FM and were advised that due to budgetary constrains, the Laboratory Centre for Disease Control is not in a position to conduct its own research on ME/FM at this point but will continue to work with NHRDP and MRC to facilitate research in this important area. The National Health Research and Development Program (NHRDP) of Health Canada will continue to entertain research proposals on the subject of ME/FM and similarly that the Medical Research Council (MRC) has also always been open to considering research submissions on this issue through its peer review process.

- **QUEST #24 June 1997**

LABORATORY CENTRE FOR DISEASE CONTROL- UPDATE

We had a meeting with an official of the LCDC on July 28th, 1997 for two hours. As mentioned above, they were very impressed by the fact that we were able to get the assistance of the medical profession.

We also told them that we were trying to establish approximately how many ME/FM people there are in Canada who are ill with ME and FM through asking every support group to let us know how many people are in their group (whether or not they attend meetings or not). LCDC are very interested in those figures and we therefore again urge all groups to let us know these required figures. Remember that your individual figures will not be broadcast, just the total amounts by province.

As of September we have received replies from **41 support groups**, representing **4729 ME/FM** people. This means there are over 300 support groups who have not yet contacted us to report their

QUEST #82 Winter 2009

- **CIHR Identifies FMS and CFS Research Projects**

By: Margaret Parlor, President

The Canadian Institutes of Health Research (CIHR) is the Government of Canada's agency responsible for funding health research in Canada. CIHR was created

in 2000 under the authority of the CIHR *Act* and reports to Parliament through the Minister of Health. CIHR's budget for 2008-09 was $928.6 million.

CIHR was asked how much funding it had provided for projects researching Fibromyalgia and Chronic Fatigue Syndrome. CIHR identified projects using a modified keyword search methodology. Multiple key words were used to produce a pool from which projects were selected. CIHR listed its validated projects in a spreadsheet dated April 14, 2009 and covering the period from 2001-2 to 2013-14. The amount of the allocations past 2008-9 are not shown because they are subject to change.

To give you an idea of the types of projects on the list, we have focused on projects that were funded in the year 2008-9 (including multi-year projects which were approved in earlier years and received funding in 2008-9). According to CIHR, $715k was spent on Fibromyalgia research and $216k was spent on CFS research in that year. One study costing $35k in 2008-9 was included under both Fibromyalgia and Chronic Fatigue Syndrome.

For research projects identified by CIHR re: FM-related for 2008-9

- **QUEST #87 Spring 2011**

Virtual health library established in Canada

In conjunction with the **Canadian Institutes of Health Research (CIHR), The Canadian Health Libraries Association**, funded by CIHR, will provide all Canadian health professionals and administrators, policy and program planners, researchers and public health workers as well as clinicians, and nurses easy access to current, authoritative information and expert support from the network libraries contributing to its Canadian Virtual Health Library (CVHL). [See QUEST #87 Spring 2011 for details.

- **QUEST #93 Winter 2013**

Report on a CIHR Workshop

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

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

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

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

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

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

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

Fibromyalgia Treatment Priorities

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

- addressing uncertainties about the effects of a treatment should become accepted as a routine part of clinical practice

- patients, carers and clinicians should work together to agree which, among those uncertainties, matter most and deserve priority attention.

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

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

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

Fibromyalgia (Canada) Top 10

1. Can early targeted/personalised treatment plans based on sub-grouping and/or staging of severity improve outcome for people living with fibromyalgia?

2. What evidence is there to support the use of lifestyle interventions (i.e. nutrition, exercise, take more breaks, general lifestyle interventions) for the management of fibromyalgia symptoms?

3. What are the best ways to manage sleep problems in people living with fibromyalgia?

4. What are the effective methods for educating patients living with fibromyalgia to take an active role in their care?

5. What are the health care settings for persons with fibromyalgia that would allow for the best health care professional and optimal care pathway, and for appropriate follow-up?

6. What innovative self-management strategies, including social media and on-line tools, may be used in fibromyalgia care and do they impact outcome?

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

10. What is the most effective treatment for hypersensitivity (e.g. touch, noise, odour, light, hypervigilance) in fibromyalgia patients?

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

11. To what extent does physical environment (i.e. living/ working space) affect fibromyalgia symptoms and influence disease management?

12. By what methods can a health care professional safely and effectively wean a person with fibromyalgia off a medication?

13. How prevalent is polypharmacy (or simultaneous use of multiple medications to treat a single condition) in fibromyalgia patients and are lower doses of more drugs better than high doses of fewer drugs?

14. What are effective methods in educating health care professionals to reduce the stigma that patients living with fibromyalgia experience?

15. How does fibromyalgia impact patients’ concurrent medical conditions (e.g. diabetes, arthritis, cancer, myalgic encephalomyelitis) and vice versa? (i.e. diagnosis of new conditions, treatment of concurrent conditions, symptoms, success of treatment)

16. What workplace accommodations can be made to best allow people with fibromyalgia to continue working and manage their disease symptoms throughout the life course?

17. What factors (e.g. personality, socio-economic status, type of program, type of treatment) affect adherence to treatments for people living with fibromyalgia?

18. How effective are different medications including drugs given by novel routes of administration (injection, topical, mucosal) in fibromyalgia patients and how do they affect quality of life and ability to work?

19. What community-based resources would be effective methods of disease management for people with fibromyalgia (e.g. support groups, health literacy coaches)

20. What are effective methods in educating the public (i.e. family, friends, co-workers, employers to reduce the stigma that patients living with fibromyalgia experience?

21. Can a treatment algorithm or guidelines recommending the best treatment for symptoms be developed for people living with fibromyalgia?

22. Can the benefits of medication be maintained after the medication has been withdrawn from the patient’s treatment?

23. How can people living with fibromyalgia be screened and managed to detect risk for addictions and prevent the development of outcomes such as medication misuse.

- **QUEST 116 Fall 2018**

CIHR

[Canadian Institutes of Health Research]

News releases

June 13, 2018 – Ottawa, Ontario – CIHR

A new Collaborative Health Research Projects competition has been launched with the goal of bridging artificial intelligence, health research and, for the first time, the social sciences and humanities. The aim is to use a “fresh approach” to research funding encouraging greater collaboration across disciplines leading to new medical practices and technologies. More than $24M has been put aside, with $6 Million being reserved for investigating the ethical, legal and societal impacts associated with artificial intelligence through the health sector.

Thirty research teams from across Canada will be receiving more than $20M to address issues such as vision loss, Alzheimer’s, heart disease, and cancer. Through their collaborations, it will lead to new inventions and therapies to put into the hands of Canadian doctors and nurses who are in the front lines of treating patients.

This Collaborative Health Research Project program unites the CIHR, the Natural Sciences and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council of Canada (SSHRC) to bring cutting-edge science to the front lines of health care.

https://www.canada.ca/en/institutes-health-research/ news/2018/06/canadas-scientists-can-pitch-projects- that-bridge-artificial-intelligence-health-research.html

- **QUEST 116 Fall 2018**

June 20, 2018

The Minister of Health appointed Dr. Michael J. Strong as the new President of CIHR, commencing October 1, 2018. Dr. Strong is an internationally recognized researcher specializing in ALS (amyotrophic lateral sclerosis) known as Lou Gehrig’s disease.

Dr. Strong has served since 2010 as the Dean of the Schulich School of Medicine & Dentistry and Distinguished University Professor at Western University.

From 2000 to 2010, he served as Chief of Neurology and Co-Chair in the Department of Clinical Neurological Sciences at the London Health Sciences Centre and Western University. Dr. Strong’s re CIHR’s Budge 2018 proposed the largest increase in new funding for fundamental research and the Budget set aside dedicated funding to support researchers working across disciplines and with international collaborators.

- **QUEST 116 Fall 2018**

July 24, 2018

CIHR through an investment from the Government of Canada and a number of provincial and internationals partners and research institutions will allow scientists to test-drive new ways to treat disease and improve patient care.

Member of Parliament, Sonia Didhu, on behalf of the Minister of Health, announced that CIHR will allot $9.3 Million to St. Michael’s Hospital where three research projects will be based. Known as the Innovative Clinical Trials Initiative, additional funding of $13.3 Million from partners will also be invested. This will provide support over four years to seven projects:

- Reducing the incidence of diabetic foot issues;
-
- Reducing the number of unnecessary x-rays and pre- operative tests administered to patients;
-
- Supporting doctors to improve opioid- and antibiotic- prescribing practices;
-
- Reducing childhood obesity;
-
- Improving care and outcomes for intensive care units;
-

- Helping patients with multiple complex conditions; and
-
- Improving care and recovery for young adults with psychosis.

  For details, please go to:

  https://www.canada.ca/en/institutes-health-research/news/2018/07/health-researchers-test-drive-the- promising-new-treatments-of-the-future-with-support- from-the-government.html

search focuses on understanding the cellular biology of ALS.

Treasury Board

- **QUEST #93 Winter 2013**

Treasury Board President Responds

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

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

We received a reply from Ton Clement dated. September 1 2 201 2. We would like to thank Mr. Clement for his quick response. He quotes Sun Life Financial as saying that they follow the 2012 ICD-10- CM Medical Coding Reference Database. Sun Life adds:

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

Public Health Agency of Canada (PHAC)

- **QUEST #82 Winter 2009**

National ME/FM Action Network Request to PHAC

By: Margaret Parlor, President

The National ME/FM Action Network continues its communication with the Federal Government.

Date: Tue, 08 Dec 2009

Ms Lisa Underhill
Senior Chronic Disease Management Analyst
Public Health Agency of Canada CHRONIC DISEASE MANAGEMENT
DIV. 785 Carling Avenue
Ottawa, Ontario K1A 0K9 Canada

The October 8th announcement dealing with XMRV and CFS raises 3 very significant issues:

1) The announcement showed that a high percent of people with ME/CFS had evidence of the XMRV retrovirus. This raises the distinct possibility that XMRV is a cause of the illness, and this could lead to new diagnostic and treatment possibilities. The retrovirus concept is resonating within the ME/CFS community because it seems to reconcile with what is already known about the illness. There is a great need for follow- up research. In addition, the announcement had the effect of seriously undermining the credibility of the CDC with regards to ME/CFS. The CDC is known to have quashed retrovirus research in 1991, used research funding in unproductive ways, developed definitions that hamper rather than help our understand the illness, and generally given the illness little respect.

2) The announcement suggested that 4% of the general population carries this retrovirus. This raises the possibility that other chronic illnesses may be related to XMRV. Very preliminary testing found XMRV in people with FMS. The announcement also raises the possibility that people with XMRV who are currently healthy may develop chronic illnesses just as people with the

retrovirus HIV may develop AIDS. There is a great need for follow-up research.

3) The announcement suggests that the retrovirus is transmissible through the blood donation system and perhaps through other channels. There is a great need for follow- up research.

Since this announcement

1) CIHR has advised us that research funding will not be available until October 2010 and only through the normal funding process. That is a year away and the current funding process has been far from generous to ME/CFS research.

2) PHAC has not identified a person responsible for monitoring developments around XMRV or for liaising with our organization on this matter.

3) HC has advised us it is monitoring issues around XMRV in the blood supply though it has made no public announcement.

4) Several Canadian researchers have advised us that they would like to investigate this area but that funding is an issue.

We believe that immediate concerted action is called for.

We ask that CIHR, PHAC and HC make it a priority to develop Canadian research into the link between XMRV and ME/CFS, the scope of XMRV (notably whether XMRV is linked to FMS), and the transmissibility of XMRV. This work should begin as soon as possible - within days rather than months or years. The research strategy should take advantage of work being done in other countries, but Canada should not opt out of research by assuming that it will be done elsewhere. It should be recognized that the Canadian research infrastructure around ME/CFS and FMS is seriously lacking and that "incubation" of research into these illnesses is a necessity.

We also ask that CIHR, PHAC and HC recognize that new health care delivery models (with much greater capacity) are urgently required for ME/CFS and FMS and that planning for the new models be started right away. The objectives of the exercise would include reducing the current unacceptable level of unmet needs (seen in CCHS), ensuring that health care delivery is based on factual rather than discredited information, and ensuring that research developments can be translated into improved patient care quickly and appropriately

To get some perspective on announcement, look at some statistics.
to the end of 2005, approximately 20,000 Canadians had been diagnosed with AIDS.The Canadian Community Health Survey for 2005 showed 334,000 Canadians diagnosed with CFS, which is FIFTEEN TIMES as many. While CFS is not normally fatal, CFS patients are said to be at least as debilitated as AIDS patients.

- **QUEST #101 Winter 2014**

Research and Researchers
CIHR Research Fellowship for ME/FM

The Institute of Musculoskeletal Health and Arthritis (IMHA) of the Canadian Institutes of Health Research (CIHR) has announced designated funding for a research fellowship in the priority area of ME/CFS or FM. Fellowships provide support for highly qualified candidates at the post-PhD degree or post-health professional degree stages to add to their experience by engaging in health research. The announcement stated that

$275,000 is available to fund an application relevant to Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, and/or Fibromyalgia...The maximum amount awarded for a single award is $55,000 per annum for up to five (5) years.

Priorities that will be considered for funding are:

- *Developing a better understanding of the complex causes and clinical manifestations;*
- *Defining optimal strategies of care and management through improved models of care;*
- *Improving our understanding of the impact and consequences.*

  Applications closed on November 14 and the recipient will be announced early in the new year.

We would like to thank IMHA and CIHR for recognizing the importance of ME/FM research and making this funding available.

CIHR Workshop and Symposium

The National ME/FM Action Network was invited to a Workshop in September and a Symposium in October, both sponsored by the Institute of Musculoskeletal Health and Arthritis (IMHA) of the Canadian Institutes of Health Reseach (CIHR). CIHR is the government agency responsible for distributing the federal dollars allocated to health research, currently around $800M a year.

There are essentially two ways CIHR could hand out the money, 1) reactively - picking the best submissions from the research community and 2) proactively - choosing what research should be done. CIHR distributes most money reactively in open competition, with researchers in all areas competing against each other. Researchers apply for funding, applications are given scores by peer- review committees, and the applications with the highest scores receive funding. Proactive strategies include designated funding and the institute system. There are 13 institutes focused on different areas of health research.

The table on page 3 shows CIHR funding over the past 3 years. The table was compiled from CIHR's funded research database which gives a brief textual description of each study receiving funding. I compiled the table using keyword searches, looking for words like "fibromyalgia" in the brief descriptions. You can see that very few funded studies mentioned "fibromyalgia" or "chronic fatigue syndrome", and no funded study mentioned the phrase "multiple chemical sensitivities". I then converted the funding to annual per capita spending using prevalence figures from the Canadian Community Health Survey.

Note that the CCHS does not include all Canadians. People in care institutions are not included, meaning that the number of people with conditions like Parkinson's and Alzheimer's are underestimated, meaning that the spending per capita for these conditions is overestimated. Even taking methodological issues into account, it is obvious that research on ME/CFS, FM and MCS is seriously underfunded. There is a need for proactive measures.

This summer, the National ME/FM Action Network received invitations to two events sponsored by the Institute of Musculoskeletal Health. IMHA is just launching a 5 year strategic plan with three priorities: 1) chronic pain and fatigue, 2) inflammation and tissue repair and 3) mobility, disability and health. The first event was a workshop to discuss the Chronic Pain and Fatigue theme. The second was a larger symposium to launch the strategic plan.

To prepare for the workshop, I looked at

- work that has been done on Arthritis in Canada - page 4.
-
- statistics on chronic pain – page 8-9

• the kinds of biomedical studies that ME/FM patients would like to see – page 14-15

There were about 20 people at IMHA's September workshop on Chronic Pain and Fatigue including several ME/FM clinicians, researchers and patient advocates. At that meeting, IMHA announced that it would be funding a research network in Chronic Pain and Fatigue – about $1M per year for five years. It also announced funding of two research fellowships, with one designated for ME/FM (see page 1) and the other for chronic pain.

The Network has mixed feelings about these developments. On the positive side, we know that chronic pain and chronic fatigue deserve more attention. We see that FM patients want more chronic pain studies. On the worrisome side, we know that chronic pain and chronic fatigue are broad topics and the specific issues relating to ME/CFS and FM could get lost. Looking at pain tables 1 and 2, you can see that many people with a diagnosis of CFS or FM have severe or moderate pain. Looking at pain tables 3 and 4, you can see that most people with severe or moderate pain have other chronic conditions.

In October, IMHA held a symposium launching its strategic plan. This was piggy-backed on the a meeting organized by the Arthritis Alliance of Canada, meaning that the symposium was arthritis-heavy. Again there were mixed feelings. On the positive side, a bit of attention was paid to ME/FM. On the worrisome side, it wasn't much attention.

We will be continuing our dialogue with CIHR and will keep you posted on developments.

- **QUEST #102 Spring 2015**

CIHR Announces Priority Setting Exercise

Editor's note: Subsequent to the circulation of Lydia's statement above, the Institute of Musculoskeletal Health (IMHA) of the Canadian Institutes of Health Research (CIHR) released this public announcement on the priority-setting exercise. As you can see, the topic has been changed from "Adult fibromyalgia" to "fibromyalgia and widespread chronic pain". To reiterate Lydia's words, these are separate topics and cannot be combined.

Members of the IMHA community will be interested to hear that the Institute has begun work on a new initiative, the James Lind Alliance Priority Setting Partnerships (PSP). Priority Setting Partnerships bring patients, care givers and clinicians together to identify and prioritize treatment uncertainties in a particular area of focus. IMHA is engaging in this process to address the top 10 uncertainties or 'unanswered questions' with regards to the management of **fibromyalgia and widespread chronic pain**. Updates on this initiative will appear regularly in this newsletter.

As always, I encourage you to continue to submit any questions or comments to IMHA@cihr-irsc.gc.ca. Please also follow me on Twitter @HaniElgabalawy.

Sincerely,

Hani El-Gabalawy MD FRCPC
Scientific Director CIHR
Institute of Musculoskeletal Health and Arthritis

see http://cihr-irsc.gc.ca/e/49007.html

CIHR Fellowship

The Canadian Institutes of Health Research announced that is would give priority designation for a fellowship in the area of ME, CFS or FM. That fellowship has now been awarded to Santiago Herrera Monroy. Mr Herrera will be working under the direction of Dr Patrick McGowan at University of

Toronto (Scarborough). The topic of the study is Genotypic influences on epigenetic variability in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.

Priority Setting Partnership on Adult Fibromyalgia

The Canadian Institutes of Health Research is continuing its project to identify the top 10 treatment uncertainties around Adult-Fibromyalgia. The project supposedly follows a process developed by the James Lind Alliance (JLA) in the UK. The JLA process has been used for other medical conditions like asthma, eczema, Parkinson’s and schizophrenia.

The National ME/FM Action Network has been asked to promote the project and to distribute survey questionnaires. We will not be doing so. The project does not meet components 1-3 of the Dimmock/Lazell Fairman list – community engagement, strategy and definition (see previous article):

1. The project has not engaged the FM community in an appropriate way. It was not built as a partnership but rather as people telling the community what the community should want.
2. The project does not meet a current strategic need. The JLA process asks front-line clinicians and their patients to identify “treatment uncertainties” in order to motivate funders and researchers to pay attention to those issues. This implicitly assumes that funding, research and treatment are already in place (components 4-8 above). This is not the case for FM.
3. The scope of “Fibromyalgia” has not been specified for this project though indicators suggest that that a broad chronic pain definition is being used.

The Network has contacted the James Lind Alliance pointing out that the project was not following the proper protocols, notably the oversight by partners.

Statistics on Mobility

The issue of mobility has been identified as a priority by the Canadian Institutes of Health Research.

The Canadian Community Health Survey (CCHS) 2010 questionnaire asks about mobility using the following question:

Are you usually able to walk around the neighbourhood without difficulty and without mechanical support such as braces, a cane or crutches? Yes / No

The National ME/FM Action Network sent the following letter to the Canadian Institutes of Health Research (CIHR).

Dr. Alain Beaudet
President
Canadian Institutes of Health Research

Dr. Jane Aubin
Chief Scientific Officer and Vice-President, Research, Knowledge
Translation and Ethics Canadian Institutes of Health Research

Dear Dr. Beaudet and Dr Aubin,

Re: Research into ME/CFS and FM - US Developments

For several years, the National ME/FM Action Network has been asking CIHR to reconsider its approach to ME/ CFS and FM research. The Network has

- asked that these diseases be taken much more seriously,
- asked that appropriate funding be made available, and
- suggested that a new institute be established.

  While there has been a bit of movement, notably the designation of a fellowship, CIHR's overall response to date tells us that CIHR does not share our perspective on the seriousness of the diseases, the barriers in the funding process, and the novelty and importance of the medical issues.

The ME/CFS patient community in the United States has been asking NIH to reconsider its approach. The US discussions have now moved to a new level. Government appointed committees and serious researchers are joining the discussions and are siding with patients. We would like to ensure that you are aware of these developments.

The US Chronic Fatigue Syndrome Advisory Committee (CFSAC) makes recommendations to the US Secretary of Health and Human Services

(HHS). The committee met on August 18-19, 2015. At the meeting, CFSAC considered two recent reports on ME/CFS: the Institute of Medicine (IOM) and the Pathways to Prevention (P2P) reports. The IOM report was commissioned directly by HHS and the P2P report was commissioned through the National Institutes of Health. In the background were two additional, recent reports on ME/CFS done through two other HHS agencies: the Agency for Healthcare Research and Quality (AHRQ) and the Federal Drug Administration (FDA). **The reports consider ME/CFS to be very serious. They identify lack of research as a roadblock to their being able to answer thoroughly the questions they were assigned and they call for more research.** See Appendix 1 for some quotes from those reports

At the CFSAC meeting, a NIH official (Dr. Cheryl Kitt, Deputy Director of the Center for Scientific Review) suggested that the reason for low NH funding was poor submissions. This comment raised the hackles of patients because the community knows that proposals for some very good research has been rejected. This comment also raised hackles in the research community, including among some very prominent US researchers.

Dr. Ron Davis, a member of the National Academy of Sciences and winner of the 2011 Gruber prize in Genetics, is one of the greatest scientists in the US today. He has developed many of the technologies used for modern diagnostic testing. Dr. Davis was a member of the IOM ME/CFS panel and is the parent of a young adult with very severe ME/CFS. Dr. Davis has put together a medical team of prominent researchers and a medical advisory board that includes three Nobel Laureates to study ME/ CFS in a project they call “The End ME/CFS Project.” They submitted proposals aimed at finding biomarkers for diagnosing ME/CFS using biochemical tests. Both their submissions were rejected at the pre-proposal stage. Following Dr. Kitt’s comment, Dr. Davis released a short but powerful statement listing the reasons NIH gave for rejecting the proposals and his rebuttal to the rejections.

One reason for rejection was the lack of a hypothesis; Dr Davis responded that ME/CFS is in the observation stage which comes before the hypothesis stage. Another reason for rejection was that the proposal did not fit within the neurological institute’s mandate; Dr. Davis argued that it certainly did.

Dr. Ian Lipkin is a very respected scientist popularly known as ‘the Virus hunter’. He has, until very recently, had his ME/CFS proposals rejected. Here is a quote from Dr. Lipkin:

“I have been in competition now twice to get funded, and the people there who reviewed me gave me abysmal scores. And the critiques of my work were unfair, and one of the people who critiqued my work said, in fact, that this is a psychosomatic illness. I was floored.”

Just before the CFSAC meeting, a group of researchers released a letter stating that ME/CFS research was massively underfunded and asking for designated funding using a Request for Applications process . A Canadian researcher was one of the signatories.

An issue that came up in this letter, in the statement prepared by Dr. Davis, at the CFSAC meeting and in general discussions is the question of which institute of NIH is or should be responsible for ME/CFS. ME/CFS has been acknowledged as a multi-systemic acquired chronic condition with a hallmark symptom post- exertional malaise (also known as post-exertion collapse, post-exertional neuroimmune exhaustion or systemic exertion intolerance). The NIH grants which have been awarded to study the biological underpinnings of ME/ CFS have come from a wide range of Institutes including NINDS, NIAID, Office of the Director and the Institute of Nursing Research. Dr. Davis found his proposals in the middle of a ping-pong match between two institutes.

In a video, Dr. Davis noted that his son scores normal on usual tests, but scored an astonishing 16 standard deviations from the mean on a special test. The implication is that ME/CFS is very different from commonly-considered diseases and that new approaches are needed. Dr. Davis describes ME/CFS as perhaps the last major unexplored area of medicine. He mentions that there are other diseases like it. While he doesn’t mention FM, that is an obvious candidate. He suggests the establishment of a new institute at NIH to look into this area.

In summary, the issue of ME/CFS research is being actively discussed in the US, there is increasing recognition of the seriousness of the disease, and the pressure for change is growing.

Many of the issues raised in the discussions apply equally to Fibromyalgia as to ME/CFS. Although the IOM, P2P and AHRQ reports were commissioned to deal with ME/CFS, they did acknowledge the often co-existing condition of Fibromyalgia and its clinical overlaps with ME/CFS. There were several presentations at the P2P Workshop dealing with overlapping conditions and the need for research studies that take these conditions into account. The IOM report (footnote 1 pp. 145-147) discusses some of the issues related to distinguishing ME/CFS and FM while the AHRQ report (footnote 3 page ES-10 and 89) specifically highlights the need for diagnostic instruments that would enable the conditions to be clinically distinguished.

As always, the National ME/FM Action Network is prepared to work with CIHR to more research into ME/ CFS and FM forward.

Yours truly, *Margaret Parlo*r President

ME/CFS Catalyst Grant Offered in Canada

In an unexpected move, the Canadian Institutes of Health Research announced that it was making available $200k for each of three years to bring people together around ME/CFS research. The money would not be used to fund research, but rather to help build the ability to put forward research proposals. (A catalyst is something that stimulates action.)

The deadline was short, but a team of people came together very quickly. Dr Alain Moreau of Montreal coordinated the grant application along with his amazing administrative assistant Dominika Kozubska. The team that came together includes people from the following universities and organizations: University of Alberta, University of British Columbia, University of Calgary,Université de Montréal, University of Toronto, Association Québecoise de l'encéphalomyélite myalgique, National ME/FM Action Network

- Myalgic Encephalomyelitis/Chronic Syndrome; and
- Fibromyalgia.

People diagnosed with these types of conditions face challenges in their experiences as patients, from diagnosis to treatment to living with the long-term impacts. People also suffer from stigmatization in clinical settings, the workplace and other areas of their lives as a result of a general lack of understanding of these complex conditions.

The Ministry of Health and Long-Term Care (MOHLTC) has announced the establishment of a Task Force on Environmental Health to provide recommendations and advice to:

- inform possible guidelines and policies to support patients with conditions triggered by environmental factors;
-
- increase public and health care providers’ knowledge of health conditions triggered by environmental factors;
-
- identify gaps in evidence, knowledge transfer and care for those affected by these conditions; and
-
- identify patient-focused actions to improve health outcomes of affected patients.

  The Task Force consists of 15 members appointed by the Minister of Health and Long-Term Care, of which 1/3 are patients or caregivers. The Task Force has a term of up to three years beginning in 2016 and ending in 2019. The Task Force members are:

  • Howard Hu (Chair), Dean, Dalla Lana School of Public Health, University of Toronto

National ME/FM Action Network, Nova Scotia Health Authority, Ontario College of Family Physicians, Shepherd’s Hill Medical Clinic and Women’s College Hospital.

The application has been submitted. CIHR is expected to announce in late August whether the grant will be awarded. Work would begin almost immediately.

- **QUEST #108 Fall 2016**
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CIHR Turns Down Catalyst Grant

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

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Unfunded science: A case study

- On August 25, 2016, CIHR announced that a review committee had rejected the only application CIHR had received in its funding competition for a Canadian research network focused on ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome).
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- The review committee, made up of only a few people, assumed a psycho-social model for ME/CFS, criticized the application for focusing on physical pathology and biomarkers, and went as far as to say that the "there is no evidence that CFS is a real disease". This is reminiscent of a 2013 book by a Canadian academic referring to CFS as a quasidelusional disorder.
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- CIHR has chosen to stand behind the review committee decision. Nobody in the federal government has stated what should be obvious - that the committee's evaluation does not stand up to scientific scrutiny.
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- According to Statistics Canada's Canadian Community Health Survey, there are over 400,000 Canadians with a diagnosis of ME/CFS and over 500,000 with a diagnosis of Fibromyalgia. The data shows that these Canadians have high degrees of disability, high levels of health care utilization, high levels of unmet health and home care needs, high levels of socioeconomic disadvantage, and high levels of social isolation.
-
- According to the prestigious US Institute of Medicine in February 2015, "ME/CFS is a serious, chronic, complex, systemic disease that often can profoundly affect the lives of patients". The IOM added that "remarkably little research funding has been made available to study the cause of ME/CFS, mechanisms associated with the development and progression of the disease, or effective treatment, especially given the number of people affected" [emphasis mine].

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

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

- CIHR is mandated to develop health research in emerging areas. Patients have been asking CIHR for years for help in building research capacity for both ME/CFS and Fibromyalgia. Currently, there is only one project being funded by CIHR which even mentions ME/CFS for a total of $45k this fiscal year. There are two studies that mention Fibromyalgia for a total of $152k. We have suggested the establishment of a new institute, pointing out that an institute was the strategy used to develop aboriginal research. Failing an institute, we suggested multi-year designated funding to attract researchers. We conservatively suggested that funding should be about $10M/year for ME/CFS and the same for Fibromyalgia, not taking into account retroactive entitlement. Note that $20M/year is typical institute funding.
-
- In early March 2016, CIHR announced a competition for a catalyst grant to build a ME/CFS research network in Canada. Funding was set at $200k per year for three years. There was no commitment to any additional or ongoing funding and there was no support offered in putting together the application.
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- Despite the paltry offering, a dream team came together – Canadian researchers who have become interested in ME/CFS, public health academics, supportive clinicians, and patients representatives.
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- The major focus of the application was on the physical pathology of ME/CFS and biomarkers.
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- The ME/CFS community has suffered from decades of scientific abuse and scientific neglect as biological research was pushed aside in favour of the psycho-social approach favoured by the review

committee. With the announcement of the catalyst grant competition, the community found new hope. With the rejection of the application, the community felt abused and abandoned once again.

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- Ironically, just before this decision was announced, the psycho-social approach was seriously undermined in two separate ways, no surprise to anyone following events. Several days after this decision, a study came out of a US university that found a metabolite signature for ME/CFS and suggested that ME/CFS could represent a hypometabolic state caused by the activation of an evolutionary cell protection mechanism. While the study needs to be debated and replicated, the study provides a very promising way of looking at ME/CFS.
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- Fundamental research into ME/CFS is already happening and much more is going to happen. Europe recently established a research network and the US NIH is moving in this direction. Canada missed this opportunity to get off the ground in a coordinated fashion, though individual researchers are involved in ME/CFS research.
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- From Canada’s point of view, it cannot be a leader in all areas of science. From the patient perspective, it does not matter if discoveries are made in Australia or Norway or the US. So what is the problem?
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- The problem is that Canadian public policy is based on false science. For years, public policy has ignored evidence that ME/CFS is real, is having a major impact on Canadians, and is not being properly addressed by the health and social systems. For CIHR to reject an application because there is no evidence that CFS is a real disease sends the message that it is okay to blame patients for their misfortune and that there is no need for clinical care or social policy to change.
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- Maybe Canada cannot be a leader in all areas of science, but it must be involved in this area of science. Otherwise, patients will continue to suffer from neglect.
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- What would we like the Science Panel to do? We would like it to look carefully at the measures of success for CIHR. As far as we can see,

the current measures of success include avoiding controversy and not getting involved in stigmatized areas. We would like the measures of success to change to include resolving scientific conflicts, exploring new areas, confronting stigma, and focusing on high needs areas. More broadly, a measure of scientific success would be public policy based on a solid foundation.

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- Yours truly,
- NATIONAL ME/FM ACTION NETWORK
- *Margaret Parlor*
- President

- **QUEST #109 Winter 2017**

CIHR Supports ME/FM Research

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- The Canadian Institutes of Health Research (CIHR) / les Instituts de recherche en santé du Canada (IRSC) is the government agency responsible for funding health research. CIHR includes a number of institutes. Issues around ME/CFS and FM have been assigned to the Institute of Musculoskeletal Health and Arthritis (IMHA) / l'Institut de l'appareil locomoteur et de l'arthrite (IALA). In the Nov/Dec 2016 IMHA/IALA newsletter, IMHA issued a statment of support for research into ME/CFS and Fibromyalgia. We have reproduced the announcement on page 2 of this newsletter. The full newsletter is on the CIHR website at: *http://cihr-irsc.gc.ca/e/50100.html*
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- We would like to express great appreciation to Dr El- Gabalawy, Scientific Director of IMHA/IALA, and others at CIHR/IRSC for speaking so strongly in support of ME/FM research.
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CIHR Announces New ME/CFS Catalyst Grant Competition

- In November, CIHR announced a new funding opportunity for ME/CFS. They offered two 1-year grants of up to $100,000 each to support the development of new research projects in the area of

ME/CFS. This recognizes that researchers often need seed funding to develop proposals. The closing date for applications is January 10, 2017. The anticipated announcement date is February 28, 2017.

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- Please remember that when the applications are received, they are sent to a committee which reviews and scores the proposals. In order to receive funding, proposals must receive a passing grade. If no proposal receives a passing grade, no proposal will be funded.
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Announcement

- With regards to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), CIHR – IMHA is committed to supporting high-calibre research that will contribute to the evidence base and develop capacity in this field.
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- ME/ CFS is a chronic, complex, multisystem illness. Preliminary research has linked it with disturbances in energy metabolism, immunology, brain and nervous system functioning, cardiovascular functioning, epigenetics, and the microbiome. More research is needed to determine the underlying pathology of ME/CFS, advance understandings of its relationship with overlapping conditions such as Fibromyalgia, and establish effective treatments.
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- An estimated 800,000 Canadians are affected by ME/ CFS, Fibromyalgia, or both. The National Institutes of Health(NIH) in the United States and the Stafford Fox Medical Research Foundation in Australia are ramping up investment in biomarker discovery, diagnostic testing, and patient subgrouping for ME/CFS.
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- You will see in this newsletter that CIHR-IMHA recently launched a series of Catalyst Grants, with two dedicated to ME/CFS. These grants are intended to serve as seed money to support research activities that represent a first step towards the pursuit of more comprehensive funding opportunities.
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- We are also seeking to engage in partnerships with other funding agencies to advance the ME/CFS research agenda. This is a

fascinating area of research in which investigators from many disciplines have the potential to make groundbreaking contributions.

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CIHR Looks for Review Committee Members

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- A major lesson that everybody learned from the previous CIHR catalyst grant competition is the importance of having good people on the committee that reviews ME/ CFS and FM applications - people that are familiar with ME/FM theory, the state of ME/FM research, and the needs of the ME/FM community.
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- CIHR asked the National ME/FM Action Network: ‘‘If you know of anyone who would be interested in reviewing for this particular competition, feel free to send me their names. The competition team will be in touch with the ones they feel have the required matching expertize to review the applications that come in to provide them with more information about the timing of the reviews and when they anticipate the committee meeting to happen etc.’’
-
- There are people we would obviously suggest as reviewers – people on the previous grant application, people at the IACFS/ME conference in October, etc. We were especially looking for people that were not so obvious. We sent around a bulletin and, to our delight, several very qualified community members stepped forward. We have passed names onto CIHR.
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- At the IACFS/ME conference, Dr Lenny Jason gave a very interesting talk about how his application for a grant to conduct a survey of the Chicago population to estimate the prevalence of CFS was turned down several times before it was finally accepted. He talked about how the team learned from the comments of the various review committees. The grant was eventually approved and the study was an important success. This illustrates that review committees have an important role not only in allocating funds but in guiding the development of research.
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- Let us be fair to the reviewers who will be reviewing the applications for these catalyst grants. Their job is not to approve all the

applications, as much as we want funding. What we ask is that they review the merits of the proposals put before them in a fair and knowledgeable way and provide constructive comments. This will help good research to evolve.

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- **QUEST 115 Summer 2018**

A Fair Research Program

In discussions with CIHR on Day 1 and at the conference itself, I talked about building a fair research program.

What is fair funding for a disease area? This is not a simple question but generally it should be based on the national impact of the illness. Other that factors might be considered including how much benefit is expected from the investment, the international impact and historical factors. Unfortunately in the past, funding appears to be supply driven – going to where research is most organized. Researchers and private funders do not generally gravitate to stigmatized areas. Related to this, funding also appears to be gender driven with male dominated diseases receiving more funding than female dominated diseases.

Back in 2012, looking at per capita spending for diseases with comparable impact, I suggested that CIHR should be allocating $10M/ year to ME research, and the same to FM research. This does not include retroactive entitlement for years of underspending or other special considerations. Funding has been running at around $100k per year for ME and for FM in recent years. The US National Institutes of Health calculated the illness burden for a number of illnesses. An ME team calculated the equivalent illness burden for ME, plotted the illness burdens against NIH funding, and calculated the appropriate funding for each illness. ME should be receiving $188M/year, which compares unfavourably to the $13M/year it is currently receiving. The NIH funds more research than CIHR, leaving the $10M estimate for Canada looking extremely reasonable.

How can CIHR get ME funding from $100k per year to $10M/year?

The answer seems to be to offer small grants for meetings to build research ideas or for small studies, followed quickly by larger grants for follow-up work. The Montreal conference was funded primarily by a small

($70k) CIHR research grant and there was a recent announcement of a $355k/year for 5 year funding competition.

$355k/year is progress, but we would need 28 of these grants to get to $10M.

Interestingly, CIHR recently announced a funding opportunity for a Lyme disease network at $1M/year for 4 years. We would need only 10 of those grants to get to $10M.

The question becomes – are there multiple research opportunities in the ME area?

The answer is yes. A colleague with CIHR experience and I had no problem coming up with multiple themes or “mandates”. Several of these (notably the first an second) could be broken down into multiple grants. And the different areas would appeal to different kinds of researchers so we would minimize having the same people on all the projects.

- Cause biomarkers and subgroups
- Treatment
- Assessing prevelance
- Clinical diagnosis
- Pediatrics and youth
- Longitudinal studies/Evolution of disease
- Co-morbidities
- Exertion Intolerance/Post Exertional Malaise
- Functional capacity, employment and income security
- Care pathways
- Social isolation
- Education/Awareness

  Interestingly, we learned later that CIHR talks about 4 pillars of research which tie into the ideas we put forward – biomedical; clinical; health services; and social, cultural, environmental and population health research. We also learned that the European ME research network of 20 countries has five working groups (plus one on researcher development) that cover a similar range of topics: epidemiology; biomarkers; socio-economics; clinical research enablers and diagnostic criteria; and dissemination and exploitation. This tells us that we are on the right track.

> The key message is that we want fair funding, and there is a path to fair funding for ME within years rather than decades, and that strategy is based on building a holistic research program.
>
> And the same type of strategy is needed for FM.

Co-Morbidities

> One of the theme areas we identified for further research is the issue of co-morbidities – when people have ME or FM, what other medical conditions could they have? And what are the consequences?
>
> We have a starting point for discussion. The Canadian Community Health Survey (CCHS) asks people if they had been diagnosed with certain chronic conditions – Chronic Fatigue Syndrome, Fibromyalgia, Multiple Chemical Sensitivities, anxiety, arthritis, asthma, etc. Respondents can answer yes or no to each of these conditions.

The Network has compiled the following table based on the CCHS Public Use Microdata Files for 2010 and 2014. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network. Information about the CCHS can be found on page 12 of the insert to Quest 108.

The table has been subdivided into four sections for ease of reading. The figures show what percent of people with a diagnosis of the chronic condition in the first column have the additional diagnoses shown across the top. For example, 29.2% of people reporting a diagnosis of CFS also reported a diagnosis of FM in the 2014 survey and 22.9% of people reporting a diagnosis of FM also reported a diagnosis of CFS.

On average, people reporting a diagnosis of CFS or FM reported an additional five diagnoses from the list. The most common additional diagnoses were back problems and arthritis, but CFS and FM showed some overlap with every chronic condition on the list.

Let's look at arthritis to illustrate how the data can be used. The statistics show that 50.9% of people with a diagnosis of CFS and 64.6% of people with a diagnosis of FM also had a diagnosis of arthritis in 2014. This means that health care providers treating people with CFS and FM need to be knowledgeable about arthritis. Coming from a different direction, among people diagnosed with arthritis, 4.3% had an additional diagnosis of CFS and 6.8% had an additional diagnosis of FM. This means that health care providers treating people with arthritis need to be knowledgeable about CFS and FM.

The data show that people with a diagnosis of CFS are three times more likely than the total population to have a diagnosis of arthritis (50.9%/16.5%). People with FM are four time more likely than the total population to have a diagnosis of arthritis (64.6%/16.5%). Why this is the case needs to be explained. Is it because the conditions genuinely occur together? Is it because the definitions of CFS, FM and arthritis overlap? Is it because health providers are more likely to diagnose arthritis when somebody already has a CFS or FM diagnosis or when the symptom of pain is raised?

Having two years of data helps interpret the data. Because the CCHS is based on a sample, some variability is to be expected. Data changes may also reflect actual events. In interpreting this data, please refer to the time series analysis done in Quest 112 where we discussed changes in

HOUSE OF COMMONS

- **QUEST #11 April 1995**

MAY 12TH UPDATE - NATIONAL ME/FM AWARENESS DAY:

NATIONAL PETITION: We, the National ME/FM Action Network, in co-operation with Canadian provincial-based organizations, particularly M.E. Ontario and Northern Ontario Fibromyalgia Association, is doing a National Petition to be presented in the House of Commons. This Petition has been sent to all known Support Group Leaders/Contacts and to our members. We have asked everyone to get 25 signatures to be returned to us no later than May 31st, 1995. This closing date was chosen so that everyone could take advantage of May 12th to get additional signatures from the general public.

The Petition will be presented and read to the House of Commons by a prominent member (MP) of the Federal Government. This opportunity allows us a chance to influence the Government of Canada to officially recognize ME/FM and chemical sensitivities with regards to cause/effect and to implement research initiative. The proposed means will have the Petition read to the House, it will allow our team to be present for the reading, and give us media coverage through a press release. A successful proposal and media coverage will mean a very large step in building the necessary platform in Canada's political and medical environment. We enter this endeavour with great hopes.

This is an official Petition and was therefore pre-approved as to form and content by the Federal Minister of Health's office of Diane Marleau's office so that it can be officially presented in the House of Commons. Special thanks to Leni Johnson and Bill Leeming of M.E. Ontario for their financial support and input into our Petition and to Byron Timmermans of the Northern Ontario Fibromyalgia Association for his help in getting the Petition approved as to form, content and its French translation.

- **QUEST #12 – June 1995**

PETITION TO THE HOUSE OF COMMONS - UPDATE - WE HAVE MORE TIME

The response to our request for signatures for our Petition to the House of Commons was terrific. There was not enough time to present the Petition as they are breaking for the summer. Therefore, we will be accepting Petitions until **Friday, September 15th, 1995**. If you still have forms, feel free to photocopy them front to back so that the forms do not need to be stapled. This form is also available in French. If you have no forms, please let us know and we will send you one. Our finances do not permit us to send another mailer across Canada to all the known support groups

RESULTS - **Total signatures received to date - 13,003.**

NATIONAL HEALTH & WELFARE - HON. DIANE MARLEAU

We received the following reply from Ms Marleau in response to our question about research funds for ME/FM: Our letter was sent December 23, 1994:

".....M.E. and Fibromyalgia are extremely distressing disorders which, because of their many causes, are difficult to diagnose and treat. In my correspondence with many patient-support groups concerned with the M.E. and other related disorders, such as Fibromyalgia, I have repeatedly expressed awareness and concern for the distress and suffering experienced by patients diagnosed with these disorders. Also, my Department has acknowledged the frustrations experienced by those patients who, while in pain, see their disorder dismissed as non-valid or non-existent by the general public and, sometimes, even by their own physicians....I would encourage organizations like yours to contact researchers to persuade them to submit proposals to funding agencies. Perhaps, if advocacy and patient-support groups were successful in directly attracting the attention of researchers and academic institutions, granting agencies could benefit from a larger pool of submissions on M.E. and related diseases, and individuals would benefit from a larger output of soundly researched data....Signed: Diane Marleau, Minister of Health c.c. The Hon Allan Rock, Minister of Justice and Attorney General of Canada.

- **QUEST #14 – October 1995**

PETITION TO THE HOUSE OF COMMONS - UPDATE: National Total: 14,279

Breakdown by Province: Saskatchewan: 222; Ontario: 10,793; Quebec: 372; Manitoba: 954; Nova Scotia: 455; British Columbia: 751; Prince Edward Island: 211; New Brunswick: 220; Newfoundland: 39, Alberta: 262.

We have been working very closely with M.E. Ontario and Northern Ontario Fibromyalgia Network Inc. and as a result we have successfully secured the help of Ms. Beryl Gaffney, who is a Federal MP and is preparing a Private Members Bill to be presented to the House of Commons. We would like to encourage you to write to Ms Gaffney and thank her for her efforts, along with a note as to how ME/FM have impacted your life. It certainly would not hurt also if included with your letter or instead of a letter, proper scientific literature is sent with it. Please address your correspondence to **MS BERYL GAFFNEY, MP - HOUSE OF COMMONS, OTTAWA, ONTARIO K1A 0A6** and put her on your mailing list**.**

- **QUEST #15 – December 1995**

PETITION TO THE HOUSE OF COMMONS - UPDATE - NATIONAL TOTAL 14,391 signatures - Breakdown by Province: Alberta: 262; British Columbia: 751; Manitoba: 954; New Brunswick: 220; Newfoundland: 39; Nova Scotia: 455; Ontario: 10,848; Quebec: 372; Prince Edward Island: 211; Saskatchewan.

On Thursday, January 18th, 1996, we have a meeting with the Honourable Beryl Gaffney, MP at which time we will be officially handing over the Petitions collected. Ms Gaffney is preparing a Private Members Bill to be presented to the House of Commons. Ms Gaffney will also hand over the Petitions to the MPP [Members of Parliament Provincial] to the Province concerned so that there will be Provincial as well as Federal involvement. At this time, we do not know when the Petitions will be presented in the House but we will keep you informed. In addition, Ms Gaffney has also requested help from The Honourable Roger Simmons, P.C., MP, Chair, Standing Committee on Health and she will keep us advised on developments in that regard.

- **QUEST #16 February 1996**

PETITIONS TO THE HOUSE OF COMMONS: Final signature totals:**ALBERTA: 262; BRITISH COLUMBIA: 751; MANITOBA: 954; NEW BRUNSWICK: 220; NEWFOUNDLAND: 39; NOVA SCOTIA: 455; ONTARIO: 10,848' QUEBEC: 372; PRINCE EDWARD ISLAND: 211; AND SASKATCHEWAN: 375. Grand Total: 14,487.**

These signatures were handed over to the Hon. Beryl Gaffney, MP on January 18th, 1996. Ms Gaffney, in turn, is handing over the signatures to the Provincial MPPPs who in turn will contact their Provincial Parliaments requesting official recognition for ME/FM.

Ms Gaffney has pledged to help us in which ever way she can and has contacted the relevant government authorities regarding research funds, recognition etc.

She also is still working on the Private Member's Bill to the House of Commons and we will keep you advised on her progress.

- **QUEST #17 April 1996**

PETITIONS TO THE HOUSE OF COMMONS - MAY 10TH, 1996 -

Re:National ME/FM Awareness Day, May 12, 1996

The Honorable Beryl Gaffney MP will be presenting the Petition of the signatures we have collected from across Canada to the House of Commons

See newsletter for details of Mrs. Gaffney's speech to the House of Commons.

- **QUEST #18 June 1996**

PETITIONS TO THE HOUSE OF COMMONS - UPDATE:

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.

- **QUEST #18 June 1996**

REPLY TO OUR PETITION TO THE HOUSE OF COMMONS:

On Tuesday, September 3rd, 1996 a meeting was held in Mrs. Beryl Gaffney's office regarding the Government;s response to our Petition which

was presented to the House of Commons on Friday, May 10th, 1996 requesting official recognition of ME/FM and Multi Chemical Sensitivities (MCS) as well as requesting that monies be set aside for research purposes for these illnesses. Present at this meeting were the following people: Beryl Gaffney MP and her Legislative Assistant, Helen Burton; Kristin Brulé, Special Assistant to the Hon. David Dingwell, Minister of Health; Karl H. Benne, Senior consultant, Health Care & Issues Division - Health Canada; Dr. Felix Li, Director, Cardio-Respiratory Diseases and Diabetes, as well as ME/FM/MCS and representing Dr. Losos, Director General of the Laboratory Centers for Disease Control; Lydia Neilson and Mike Martin of our organization; Tina Harvey, Director of Medical Research and John Warren, Director of Communications of ME Canada.

Dr. Li stated that in addition to his function of representing MCS in his Department, he also was in charge of ME/FM/MCS. As far as he knew, there were no other individuals working on these important issue.

From our meeting, it became painfully obvious that as Dr. Li discussed the Conferences that were held on ME/FM/MCS, the recommendations outlined in these conferences did go no further by putting someone in charge of making sure the recommendations were carried out.

A lengthy discussion followed and it was mutually decided that a sub-committee should be set up under the umbrella of the Standing Committee on Health which would specifically address the issues of ME/FM and MCS. We therefore wrote the Hon. Roger Simmons, P.C., MP, Chair of the Standing Committee on Health, to request that he set up a sub-committee so that there will finally be one location that both doctors, researchers and the general public could access for information on ME/FM/MCS. This sub-committee would meet and have the input from the National organizations as well as the provincial groups so that this matter can be dealt with once and for all. It was pointed out that both ME Canada and our organization stand united in our quest to help to further awareness and information for ME/FM/MCS and in that way convince the governments that it is important to admit that these illnesses must be studied so that our people will be treated with respect and compassion

BERYL GAFFNEY, MP REMOVED FROM STANDING COMMITTEE

We were advised this week that due to the cabinet shuffle, Beryl Gaffney is no longer a member of the Standing Committee on Health. However, her office assures us that she is committed to keep working with us as she has in the past. We take this opportunity to thank her for all the progress we have made due to her and her staff.

- **QUEST #20 October 1996**

PETITION TO THE HOUSE OF COMMONS - UPDATE:

In our Communication #19 we reported on the meeting that took place on September 3rd, 1996 at Mrs. Beryl Gaffney, MP's office which was attended by representatives of the Minister of Health and the Laboratories Center for Disease Control, our Network and ME Canada. We have now received a copy of Mrs. Gaffney's Summary Report on this meeting. If you would like a copy of it, please send us a stamped self-addressed envelope (5 pages).

We are still awaiting a reply from the Hon. Roger Simmons, P.C., MP, Chair of the Standing Committee on Health requesting that a subcommittee be established to particularly deal with ME/FM issues. At the present time there is no particular source in the government where a physician or a private individual will get proper information on ME/FM. A follow-up to our request for a sub-committee to be established has been sent to Mr. Simmons.

- **PETITION TO THE HOUSE OF COMMONS - UPDATE:**

Now that the Laboratory Centers for Disease Control, Ottawa, has accepted the U.S. definition on CFS (see our newsletter October/November 1996), on Monday, December 2, 1996 Mrs. Beryl Gaffney, MP spoke in the House of Commons requesting Health Canada to formally announce the recognition of ME/FM, and again requested the setting up of the sub-committee under the Standing Committee on Health. She stated that:

"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."

- **QUEST #91 – Summer 2012**

May 12 Awareness Day

Once again, there was considerable activity around Awareness Day. Many thanks to people who organized events or handed out information. This all contributes to increased recognition of ME/CFS, FM and related illnesses. The following statement was made in the House ofCommons on May 31, 2012:

Hon. Carolyn Bennett (St. Paul’s, Lib.): Mr. Speaker, May is ME/CFS Awareness Month, myalgic encephalomyelitis/chronic fatigue syndrome.

Chronic fatigue syndrome refers to a severe, continued tiredness that is not relieved by rest and is not directly caused by other medical conditions. Four hundred thousand Canadians are bed-bound or house-bound with ME/CFS.

Often misdiagnosed and misunderstood, patients experience muscle aches, headaches and extreme fatigue. Although some patients completely recover after six months to a year, others never feel like they did before they developed CFS.

There is currently no cure for CFS and so far treatment is focused on relieving the symptoms. As a physician, I know just how the strain of dealing with this disease often leads to depression and other psychological disorders which make recovery that much more difficult.

Unfortunately, this condition still does not have the recognition it deserves. Increased awareness is the best way to defeat the stigma surrounding CFS.

We must also continue the fight to find a cure and give these Canadians back their lives.

- **QUEST #93 Winter 2013**

MP's Questions to the Federal Government

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

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

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

1. a) what funding has been allocated to research this illness in the last two years;
2. b) how does the government propose to encourage Canadian research into ME/CFS so that the level of research into this complex, multi-system illness is commensurate with its extent and impact;
3. c) what is the government doing to develop strategies and programs to meet the needs of Canadians with ME/CFS;
4. d) how is the government ensuring that health professionalsareawareofthefollowingdocuments,

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

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

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

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

(ii) post the French version of this document;

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

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

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

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

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

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

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

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

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

- **QUEST #96 Fall 2013**

Submission for 2014-15 federal budget

The House of Commons Finance Committee asked the public for suggestions of what might be included in next year's federal budget. The National ME/FM Action Network made two suggestions; 1. A new institute at the Canadian Institutes for Health Research with designated funding to research ME/CFS and FM issues, and 2. An interdepartmental task force to review government information about ME/CFS and FM and to look at programs and services to ensure that the ME/ FM community has equitable access. The submission is available on the News section of our website.

- **QUEST #97 Winter 2014**

House of Commons Standing

Committee on Finance - Pre-budget Consultations 2013

This brief is submitted by: National ME/FM Action Network (see www.mefmaction.com)

Recommendation 1: Topic: Health

- Create a new institute at the Canadian Institutes for Health Research to investigate health research issues around Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia. This research would support the health care system in addressing the needs of ME/FM patients.

- Provide the new institute with designated long term funding to encourage researchers to move into this field of study.

Expected cost or savings: $100 Million to $499.9 Million over 5 or more years

Federal funding: Reallocation within CIHR. CIHR has $1Billion per year for research. Almost none has been allocated to ME/FM research. Designating some of the CIHR funding for ME/FM research would allow a ME/ FM research community to develop to the point that it can eventually compete for funding on an equitable basis with established research areas.

Intended beneficiaries:

- people with ME/CFS and/or FM, their families and caregivers
- health professionals who are grappling inefficiently and ineffectively with these illnesses
- taxpayers who are paying for the inefficient and ineffective health system
- the economy which is losing valuable human resources to these illnesses
- Canada’s international reputation in health and research

General impacts:

With better understanding of these illnesses, some cases could be prevented or minimized while the quality of life of other people could be substantially improved.

Recommendation 2: Topic: Disabled Persons

Create an interdepartmental task force to address the discrimination and stigma facing Canadians with ME/ FM. The task force would:

- review government publications and websites to ensure that information is complete and correct

- review government programs and services to ensure that they are inclusive and that deserving applicants are approved without undue effort or delay

- implement a public awareness campaign to ensure that Canadians are informed about these illnesses and resulting disabilities

- identify additional initiatives needed to ensure justice and equality for Canadians with ME/FM.

Expected cost or savings: $5Million-$9.9Million over 2 years

Federal funding: Health Canada funds the Mental Health Commission to undertake an anti-stigma anti- discrimination strategy in the area of mental health, a parallel exercise. Other funding could come from participating departments and agencies.

Intended beneficiaries:

- \- people with ME/FM, their families and caregivers
-
- \- officials who want to provide optimal, inclusive programs and services
-
- \- members of the public who encounter people with ME/ FM such as employers, co-workers, teachers, fellow students, neighbours and friends
-
- \- taxpayers who are paying for an inefficient, ineffective and unfair social system
-
- \- the economy which is losing valuable human resources to these illnesses Canada's international reputation for justice and equity
-
- General impacts: This recommendation will go a long way toward addressing the social disadvantage experienced by the vulnerable ME/FM community. With better public understanding of the illnesses, there will be less sense of isolation. With better programs and services, there will be less economic and social distress.

Recommendation #1

ME/CFS and FM are complex multi-system illnesses with abnormalities in the neurological, immune, endocrine and metabolic systems.

Research is needed to support prevention, diagnosis and treatment of these illnesses

Canada has almost no ME/FM research activity. There has been almost zero funding from CIHR over the past decade.

The mandate of CIHR includes developing research capacity in emerging areas. Current strategies haven't worked for this emerging area. CIHR needs a new strategy

Our recommendation asks for the creation of a new institute at CIHR with long term designated funding to attract research to this neglected area of study and to prove the health system with a solid foundation for diagnosing, treating and preventing ME/CFS and FM.

Recommendation #2

ME/CFS and FM have been plagued by lack of information and misinformation. The seriousness of the illnesses and resulting disability have been grossly underestimated. It is hard enough dealing with the illnesses without having to deal with misinformation and stigma as well. We are asking for an interdepartmental team to fix the problems right away so that people with ME/FM do not have to deal with this additional burden.

These two initiatives are needed for patients and their families. These initiatives will also benefit all Canadians who value an efficient, effective health care system and a fair and inclusive society.

- **QUEST #98 Spring 2014**

Comments on the Order Paper

Questions about ME/CFS were placed on the House of Commons Order Paper in 2009, 2012 and 2014 by Members of Parliament Rob Oliphant, Carolyn Bennett and Hedy Fry. The government's response to the 2014 questions was tabled in the House of Commons on March 24, 2014.

Thank you to Dr Fry (and to Dr Bennett and Mr Oliphant) for putting the questions on the order paper. The replies are very helpful in understanding what government is thinking and in opening doors to future discussions.

Thank you to the six Ministers who responded for your honest, respectful answers.

To the Minster responsible for Employment and Social Development Canada (ESDC), thank you for the open invitation to meet with your staff. The ME/FM community would like to talk about the concept of disability.

Many people and programs think of disability in a narrow sense that does not include the type of disability that people with ME/CFS and FM experience or that underestimates the impact. There are also practical access issues in applying for disability benefits. We need further discussions with staff at the Office for Disability Issues and the CPP-Disability program. Because of your comment that the National ME/ FM Action Network did not participate in a particular ESDC consultation process, we have posted the correspondence on our website. The National ME/FM Action Network does not have resources to spend on activities that will have little benefit to the ME/FM community.

To the Minister of Health, thank you for the steps forward that have occurred. Canada has an amazing health care system; nevertheless, aggressive action is required to meet the health care needs of the ME/FM community in Canada. Statistics show that Canadians with these illnesses make multiple visits to health professionals and yet they still have unmet healthcare needs. The health system is not working well for ME/CFS or FM patients, their family and friends, employers, health professionals, or taxpayers. Concerted, coordinated federal leadership would help in the areas of knowledge transfer, healthcare delivery, surveillance and health research. The sentence in your response about XMRV suggests that the advice you are receiving on ME/CFS is behind the times. Research on ME/FM will be of value to an understanding of many diseases and disorders. Support for research on ME/FM directly or indirectly benefits research on, for example, cancer, sleep disturbances, chronic pain, fatigue, neurological disorders, autoimmune diseases, and infectious diseases. We appreciate very much that two representatives from CIHR were at the IACFS/ME biennial conference. They held a meeting with research, clinical and patient representatives, and they agreed to host a research workshop in 2014. We have high hopes for this workshop.

To the Minster responsible for Statistics Canada, we very much appreciate the support we have received from the organization and are very appreciative that the questions on ME/CFS, FM and MCS are slated for inclusion on the Canadian Community Health Survey in four of the next eight years. The CCHS statistics have been extremely useful in describing the scope of the issues. We are interested in the Survey on Disability and hope to have input into it.

To the Minister responsible for the Canada Revenue Agency, thank you for considering the issues facing Canadians with ME/CFS. We would question whether the ME/FM community has equitable access to the Disability Tax Credit and the various programs that are based on it.

To the President of the Treasury Board, please consider how well federal employees who become disabled through ME/CFS or FM are accommodated or supported.

To the Minister of Justice, your response was a surprise. We were expecting you to refer us to the group responsible for human rights, but instead you referred us to the group responsible for ethics, conflict resolution and wellness. We are interested in learning more about this group. We are also looking forward to be invited to participate in future consultations at the Department of Justice.

Overall, the responses show that ME/CFS is starting to gain traction, but that there is a lot of work to be done. Very importantly, the response opens doors for dialogue.

A special mention goes to the individual who worked with Dr Fry to have the questions placed on the order paper. People ask why FM wasn't included. Remember that this was a private initiative. FM patients have the opportunity to ask a Member of Parliament to submit questions about FM.

Special mention also goes to the people who contacted their Members of Parliament to say that they were interested in receiving the government response. This would have encouraged the government to put extra effort into their answers.

Please feel free to talk to your Member of Parliament about your reaction to the order paper questions and response and about what you wish to see happen at the federal level.

NATIONAL ME/FM ACTION NETWORK

Margaret Parlor, President

House of Commons Order Paper

Questions:

Q-2442 - January 28, 2014 - Ms. Fry (Vancouver Centre) - With regard to Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS):

(a) how much money has the Canadian Institute for Health Research (CIHR) invested or allocated into researching ME/CFS in 2012-2013 and 2013-2014, specifically into: (i) the etiology, (ii) diagnostic markers, (iii) pathophysiology, (iv) treatment of ME/CFS;

(b) how much research has CIHR funded into treating ME/CFS with (i) Rituximab, (ii) other autoimmune medications, (iii) anti- viral medications, (iv) other medications;

(c) what strategies has CIHR designed and implemented to ensure that ME/CFS research is fairly funded;

(d) what strategies has CIHR designed and implemented to (i) develop a ME/CFS scientific research community in Canada, (ii) ensure that the ME/CFS research community is multidisciplinary bringing together immunologists, neurologists, cardiologists, endocrinologists, system biologists, geneticists, etc.;

(e) has CIHR considered creating a new institute to focus on this emerging area;

(f) has CIHR outlined areas of ME/CFS research as priorities for funding, and designating a specific amount of money for ME/ CFS research and, if so, how much;

(g) will CIHR amend the grant application process to remove the barriers for new and stigmatized conditions to ensure that ME/ CFS as an emerging area of research has a fair chance of being funded;

(h) how has the government, including (i) Health Canada (HC), (ii) CIHR, (iii) Public Health Agency of Canada (PHAC), (iv) Employment and Social Development Canada (ESDC), (v) Statistics Canada (StatCan), (vi) Department of Justice Canada (JUS), (vii) Treasury Board of Canada

Secretariat (TBS) and (viii) Canada Revenue Agency (CRA) educated itself on ME/CFS;

(i) did representatives from (i) HC, (ii) CIHR, (iii) PHAC attend or will they be attending (1) the Invest in ME International Conferences, (2) the Biennial International Association for CFS/ ME Conference in Ottawa in 2011, (3) 2014 Stanford University ME/CFS Symposium on March 19, 2014, (4) the Biennial International Association for CFS/ME Conference co-hosted by Stanford University from March 20-23, 2014;

(j) to what extent has the government, including (i) HC, (ii) CIHR, (iii) PHAC, (iv) ESDC, (v) StatCan, (vi) JUS, (vii) TBS, (viii) CRA, fulfilled its obligation under the UN Convention on Rights of Persons with Disabilities (article 4.3) to closely consult with and actively involve people with ME/CFS through their representative organizations, notably the National ME/FM Action Network;

(k) when will (i) the Minister of Health, (ii) Health Canada (iii) CIHR, (iv) PHAC, (v) ESDC, (vi) StatCan, (vii) JUS, (viii) TBS, (ix) CRA next meet with the National ME/FM Action Network;

(l) when will foundational documents, notably (i) CFS/ME: A Primer for Clinical Practitioners, (ii) Profile and Impact of 23 Chronic Conditions in the 2005 Canadian Community Health Survey, be posted on government information websites in English and French;

(m) how is the government working with the provinces, territories, professional organizations, educational institutions and other stakeholders to meet the needs of Canadians with ME/CFS;

(n) what steps has the government taken to ensure that ME/CFS patients in its jurisdiction have access to appropriate medical care;

(o) how many medical professionals in Canada including (i) doctors, (ii) nurses currently specialize in ME/CFS and how is the Health Human Resources Strategy ensuring that there will be an adequate supply of health providers specializing in ME/ CFS in Canada in the future;

(p) how is the Health Care Policy Contribution Program being used to improve health care for ME/CFS patients;

(q) how is the government working with stakeholders to deal with other needs of Canadians with ME/CFS shown by the 2005 and 2010 Canadian Community Health Survey (CCHS) including (i) reducing the levels of unmet home care needs, (ii) reducing the levels of food insecurity, (iii) increasing the sense of community belonging experienced by Canadians with this condition;

(r) why has the CCHS decided to monitor the extent and impact of ME/CFS, only every four years;

(s) will the government review disability programs and services to ensure that they cover the full spectrum of disabilities so that people with ME/CFS have fair and equitable access and will the government review the information and documents it disseminates to ensure that ME/CFS issues are presented adequately and fairly;

(t) when will the Canada Pension Plan-Disability Adjudication Tool that guides adjudicators in their assessment of ME/CFS, Fibromyalgia, Multiple Chemical Sensitivities and Chronic Pain cases be reviewed in conjunction with the stakeholder communities to ensure that people with the conditions have fair and equal access to Canada Pension Plan-Disability; and

(u) when will the Canada Pension Plan-Disability Adjudication Tool that guides adjudicators in their assessment of ME/CFS, Fibromyalgia, Multiple Chemical Sensitivities and Chronic Pain cases be posted on government websites?

Answers to Order Paper Questions from Ministries:

Note: The government's response was provided on scanned hardcopy, and converted to electronic form by an optical character reader. Small typographic errors may have been introduced in the process.

Minister of National Revenue (CRA) - Honourable Kerry-Lynn Findlay

With respect to the above-noted question, what follows is the response from the Canada Revenue Agency (CRA). The CRA has been asked to answer to Parts (h)(viii), (})(viii) and (k)(ix).

Part (h)(viii): The CRA administers the Disability Tax Credit (DTC) based on the criteria set in the Income Tax Act (ITA). The DTC is a nonrefundable credit that may reduce the amount of income tax that either a person with a disability or their supporting person has to pay. To qualify, an individual must have a severe and prolonged impairment in physical or mental functions, as defined in the ITA and as certified by a qualified practitioner. The ITA is very clear in that the medical condition itself is not a considering factor in determining an individual's eligibility for the DTC, but rather the effects that the impairment has on the person's ability ta perform one of the basic activities of daily living (e.g., walking, dressing, speaking, etc.).

Individuals diagnosed with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) may be eligible for the DTC if they are markedly restricted in performing at least one of their basic activities of daily living, all or substantially all of the time.

Part (/)(viii): Though the UN Convention on Rights of Persons with Disabilities does not specifically require the CRA to consult with ME/CFS, the CRA will continue to consult and communicate with persons with disabilities, the general public,

other government departments, qualified practitioners, disability associations, and medical associations concerning the eligibility criteria for the DTC, how to apply for the credit and ways to improve the processing of applications.

Part (k)(ix): With respect to when the CRA will next meet the National ME/FM Action Network, the CRA does not have any plans to meet with the National ME/FM Action Network at this time.

Minister of Employment and Social Development Canada- Honourable Jason Kenney

(h) how has the government, including (iv) Employment and Social Development Canada (ESDC), educated itself on ME/ CFS.

• Representatives of the National Myalgic Encephalomyelitis and Fibromyalgia (ME/FM) Action Network met with officials of Employment and Social Development Canada's (ESDC) Office for Disability Issues (ODI}. During the meeting, both organizations exchanged information on their mandate and program objectives. The Network also expressed an interest to work more closely with government officials to improve the lives of people suffering from ME/FM.

- ODI invited the National ME/FM Action Network to participate in a consultative process, as part of its efforts to consult with stakeholders on the eligibility requirements for the creation of a national funding stream. The National ME/ FM Action Network declined to participate in this process.

(j) to what extent has the government, including (iv) ESDC, fulfilled its obligation under the UN Convention on Rights of Persons with Disabilities (article 4.3) to closely consult with and actively involve people with ME/CFS through their representative organizations, notably the National ME/ FMAction Network.

- ESDC. has fulfilled its obligation with respect to Article 4.3 of the UN Convention on Rights of Persons with Disabilities.

(k) when will (v) ESDC, next meet with the National ME/FM Action Network.

- ESDC has informed the National ME/FM Action Network that they would like to keep an ongoing dialogue and are available to meet whenever the ME/FM Action Network is available.

Minister Of Health - Honorable Rona Ambrose

The Government of Canada is committed to a publicly funded, universally accessible healthcare system that provides

healthcare for all Canadians, according to the criteria and conditions of the Canada Health Act. While the provinces and territories have primary responsibility for the design, delivery and management of healthcare in their jurisdictions, federal actions and investments make an important contribution. Federal funding through the Canada Health Transfer will reach a record high of $30.3 billion this year and continue to grow to more than $40 billion by the end of the decade. These investments will help ensure that Canada's healthcare system continues to be sustainable over the long-run, and provides the provinces and territories with both the certainty they need to plan a head and the flexibility to invest where they see fit.

The management and treatment of Myalgie Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) is not unique to a specific medical or nursing specialty in Canada. As such, reliable data on the number of healthcare professionals practicing in this field is presently unavailable. While provincial and territorial governments plan for and manage their health workforces, the federal government acts within its jurisdiction to help them and health system stakeholders create and maintain a health workforce that meets the needs of all Canadians. Health Canada's Health Care Policy Contribution Program (HCPCP), which includes the Health Human Resources Strategy, is a national program designed to promote policy research and analysis, evidence-based projects and evaluations on current and emerging healthcare system priorities. The HCPCP has not provided funding specific to the healthcare needs of patients with ME/CFS, however, it has made investments to support key areas such as: health human resources, the integration of internationally educated ·health professionals, access and wait times, primary healthcare, chronic disease management, home and continuing care, quality care, patient safety, and palliative and end-of-life care.

Federal investments to support the health human resources needs of Canadians include: $39.5 million, over six years, to support the training of up to 100 family physicians in rural and remote communities across Canada; $9 million per year in Canada Student Loan relief for new family physicians, medical residents, nurse practitioners and nurses who choose to practice in rural and underserved communities; $18 million per year to support the integration of internationally trained health professionals and advancement of the Pan- Canadian Framework for the Assessment and Recognition of Foreign Qualifications; $6.5 million for a research project at McMaster University to evaluate team-based approaches to healthcare delivery; and, nearly $4 million in support of a multi-stakeholder project on the Future of Medical Education in Canada, including the implementation of recommendations that will help align medical education with population health needs.

Consistent with its public health surveillance mandate, the Public Health Agency of Canada (PHAC) monitors the prevalence of ME/CFS using data from Statistics Canada's Canadian Community Health Survey (CCHS), a national health survey that asks Canadians about their health and well-being, the factors that affect their health, and their use of health care services. Data from the 2010 CCHS are available online at www.infobase.phac-aspc.gc.ca.

PHAC develops and provides surveillance information to ME/CFS stakeholders, including the National ME/FM Action Network. PHAC has worked with the National ME/FM Action Network for several years in analyzing surveillance findings on ME/CFS for the development and publication of scientific papers. PHAC officials meet with the National ME/FM Action Network as necessary pertaining to the analysis of surveillance data. Meetings were held in June 2012 and January 2013 to discuss the needs and

challenges of ME/CFS patients, developments in surveillance, collaborate on scientific papers, and facilitate the Network's access to federal data.

PHAC currently provides document links for CFS/ME: A Primer for Clinical Practitioners on its website (www.phac-aspc.gc.ca/ dpg-eng.php#cfs). PHAC ·officials also attended the Biennial International Association for ME/CFS Conference in Ottawa in 2011.

Since 2006/07, the Government of Canada, through the Canadian Institutes of Health Research (CIHR), has invested over $231K in research related to Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), including more than $198K in 2012/13 alone. The 2012/13 projects included an operating grant entitled "Structure function analysis of the dual protein kinase-RNase signalling proteins and the elF2a protein kinases", which is aimed at determining the structure function of protein kinases; including RNaseL, whose function has been found to be perturbed in patients with chronic-fatigue syndrome (CFS). Another CIHR-funded new investigator award, "Characterization of a glycoprotein entry complex from a novel human retrovirus", aims to understand the viral life cycle of, and how xenotropic murine leukemia virus-related virus (XMRV) enters the human host. XMRV was recently detected in a large proportion of CFS patients and understanding its function may help provide a template for novel entry inhibitors and therapeutics.

CIHR's Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA)is deeply engaged in understanding the research agenda for ME/CFS through attendance at scientific meetings. Also, CIHR-IMHA aims to raise awareness about ME/CFS and other health issues through, newsletters to its research community. This past May, CIHR-IMHA highlighted that May 12 is Fibromyalgia and Chronic Fatigue Syndrome National Awareness Day.

CIHR-IMHA is also focused on fostering international discussion and understanding of MEICFS. As such, it will be sending two representatives, Dr. Hani El-Gabalawy, Scientific Director of IMHA and Liz Stirling, Assistant Director of IMHA, to the Biennial International Association for CFS/ME Conference co-hosted by Stanford University from March 20-23, 2014.

CIHR has good ties with the research community in this field and many of our staff have an understanding of the impact, complexities and challenges the conditions pose on so many Canadians. Our team is always open to discussing opportunities and concerns with our research community and relevant stakeholders. Additionally, since ME/CFS falls under the mandate of numerous CIHR Institutes, the research community is encouraged to contact the Assistant Directors of the Institutes as well as to monitor CIHR’s ongoing funding opportunities.

Minister Of Industry - Honourable James Moore

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

(h) Statistics Canada (STC) consults extensively with its federal, provincial and territorial stakeholders on the need to collect information on chronic conditions and diseases and relies on their expertise in this area to guide the content determination process of its surveys.

(j) STC has worked very closely with the Persons with Disabilities Technical Advisory Committee (TAG) in the development of the Canadian Survey on Disability. Regular consultations occur through face-to- face meetings, teleconference calls and emails between disability experts and members from the disability community.

In addition, the Canadian Community Health Survey (CCHS) team at STC has ongoing contact with the President of the ME/ FM Action Network and has built a relationship around open dialogue. The President has contacted the CCHS team with questions and has also provided answers to questions from STC on the ME/CFS.

(k) STC routinely consults the President of the ME/FM Action Network as needed during content consultation and development processes for the CCHS.

(r) According to the CCHS content plan for 2015-2022 that was approved by the Canadian Population Health Survey Program (CPHSP), questions about ME/CFS will be included in CCHS for 2015, 2016, 2019 and 2020. To ensure an acceptable leve! of response burden for the CCHS, modules must be rotated in and out of the survey on a regular basis to manage the competing demands for increased information across a number of health dimensions. This process strikes a balance between the information needs of people interested in ME/CFS versus those interested in other health related topics such as functions health and food security.

Minister Of Justice And Attorney General Of Canada - Honourable Peter MacKay

(h) (vi) The Centre for Ethics, Conflict Management and Wellness of the Department of Justice does not offer services and tools specific to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Activities by the Centre focus on preventative measures that can be implemented to maximize overall personal well-being.

(j) (vi) Article 4.3 of the UN Convention on Rights of Persons with Disabilities (Convention) requires states to closely consult with and actively involve persons with disabilities in developing and implementing legislation and policies to implement the Convention. This obligation allows for a broad range of ways in which the government can engage persons with disabilities and their representative organizations. Pursuant to Article 4.3 of the Convention, the Department of Justice consults with persons with disabilities and their intermediary organizations in the development, design and evaluation of public policies, programs, legislation and services. This includes informal discussions and exchanges between officials from the Department of Justice and persons with disabilities. As a recent example, in-person and public consultations were held in the summer and fall of 2013 with disability organizations, professionals, and individuals with disabilities in developing the proposed Canadian Victims Bill of Rights.

(k) (vii) There are no current plans to meet with the National ME/FM Action Network.

President Of The Treasury Board - Honourable Tony Clement

The Treasury Board of Canada Secretariat is responsible for responding to parts (h){vii), O)(vii) and (k)(viii).

(h) how has the government, including (vii) Treasury Board of Canada Secretariat (TBS), educated itself on ME/CFS; ... (j) to what extent has the government, including (vii) TBS, fulfilled its obligation under the UN Convention on Rights of Persons with Disabilities (article 4.3) to closely consult with and actively involve people with ME/CFS through their representative organizations, notably the National ME/FM Action Network; ... {k) when will {vii) TBS next meet with the National ME/FM Action Network.

With regard to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, the activities noted in the question are not part of the mandate of the Treasury Board of Canada Secretariat.

- **QUEST #99 Summer 2014**

Private Members Bill

OTTAWA – Elizabeth May’s Private Members Bill, C- 442,An Act respecting a Federal Framework on Lyme Disease, has passed through 3rd reading with the unanimous consent of the House of Commons. Bill C-442 will now be referred to the Senate, where it will be sponsored by Senator Janis Johnson and taken up in the fall.

3. The Minister must, no later than 12 months after the day on which this Act comes into force, convene a conference with the provincial and territorial ministers and stakeholders, including representatives of the medical community and patients’ groups, for the purpose of developing a comprehensive federal framework that includes

(*a*) the establishment of a national medical surveillance program to use data collected by the Agency to properly track incidence rates and the associated economic costs of Lyme disease;

(*b*) the establishment of guidelines regarding the prevention, identification, treatment and management of Lyme disease, and the sharing of best practices throughout Canada; and

(c) the creation and distribution of standardized educational materials related to Lyme disease, for use by any public health care provider within Canada, designed to increase national awareness about the disease and enhance its prevention, identification, treatment and management.

4. The Minister must prepare a report that sets out the federal framework and publish the report on the Agency’s website within one year after the federal framework referred to in section 3 is developed.

## *	QUEST #104 Fall 2015

Statements by Political Parties

Early this summer, the House of Commons Finance Committee asked Canadians to submit ideas for the next federal budget. The Network put together a submission, just as we have done for the last two years. This year, the committee asked that the submissions focus on themes like productivity and infrastructure. In our 2015 submission, we noted that ME/CFS and FM cause a remarkable loss of productivity to the Canadian economy and we suggested that the federal government rethink the ME/FM infrastructures for health research, for healthcare delivery and for social services.

By the time we sent in the submission, the election had been called and the committee no longer officially existed, so our submission was returned to us.

What we did instead was send the submission to each of the 5 main political parties on August 13 and invite them to provide us with a statement for our website and newsletter. We set a deadline of August 31. We sent a reminder on August 27.

We received one response by the deadline. The four other parties did not respond.

Recommendations From Network Submission

1. Our recommendationistocreateanewinstituteatCIHR with long term designated funding. A new institute is needed because this is a large and complex area of study but also because a fresh start is needed to dispel faulty information about these illnesses. Designated funding is needed to attract new researchers to this neglected area of study. The research will provide the healthcare system with a new and solid foundation for diagnosing, treating and preventing ME/CFS and FM.

2. Our recommendation is to create a task force to address healthcare delivery to Canadians with ME/ CFS and FM. The task force would consult with patients, provinces, territories and other stakeholder and be mandated to:

    - develop a model of healthcare delivery for ME/CFS and FM in Canada
    -
    - estimate the health human resources needed to implement the model
    -
    - develop a strategy to getting the resources in place as quickly a possible
    -

3. Our recommendation is to create an interdepartmental task force to address the discrimination and stigma facing Canadians with ME/CFS and/or FM. Working with the patient community and other stakeholders, the task force would:

• review government publications and websites to ensure that information is complete and correct

• review government programs and services to ensure that they are inclusive and that deserving applicants are approved without undue effort or delay

• implement a public awareness campaign to ensure that Canadians are informed about these illnesses and resulting disabilities

• identify additional initiatives needed to ensure justice and equality for Canadians with ME/ CFS and/or FM.

Reponse From the Green Party of Canada

Dear Ms. Parlor,

Thank you very much for writing to the Green Party of Canada with your recommendations for improving the quality of life for people living with

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/ CFS) and Fibromyalgia (FM).

In a prosperous country like ours, no Canadian's disability should ever preclude them from meaningful engagement with their communities. However, the unfortunate reality is that Canadians with disabilities are disproportionately vulnerable to poverty and excluded from full participation in our society. In particular, Canadians living with ME/ CFS or FM are stigmatized and left without the social and economic support they need to meet their unique needs.

ME/CFS and FM are frequently misunderstood, as are those living with these illnesses. The contributions of hardworking Canadians with ME/CFS and FM are invaluable. We must make inclusion a priority, and take action to promote better understanding of ME/CFS and FM. Canadians with ME/CFS and FM should be fully supported in their workplaces and in our communities. Indeed, as you mentioned, all Canadians would benefit from a greater awareness of and respect for the realities of ME/CFS and FM.

The Green Party supports your call for stronger research, health, and social infrastructure to support Canadians living with ME/CFS and FM. The fact that ME/CFS is poorly understood contributes to a lack of treatment and care options for those living with the illnesses. Moreover, a general lack of public awareness has contributed to the unfair stigma associated with these conditions, which, in turn, makes it more difficult for people living with ME/ CFS to access the accommodation they are entitled to.

For these reasons, we agree that improved funding and research, health care delivery, and public awareness that respects the realities and needs of Canadians living with ME/CFS and FM is needed.

The Green Party strongly believes that every Canadian deserves access to high quality, patient centred care, that extends beyond the clinic. The federal government must work with the provinces and the medical community to ensure that general practitioners are properly equipped, and that there are enough specialists to provide appropriate treatment to Canadians with ME/CFS and FM.

With stronger support for improved research, health, and social outcomes, the federal government can ensure that Canadians living with ME/CFS and FM are treated with understanding, justice and equity.

Sincerely,

Emily McMillan, Executive Director Green Party of Canada

- **QUEST #104 Fall 2015**

Letter From the Liberal Party of Canada / Parti libéral du Canada

Prior to the election we sent letters to each of the federal parties asking for a response to our submission to the House of Commons Finance Committee. We received the following letter from the Liberal Party of Canada, too late for our fall Newsletter but before the election date.

October 14, 2015

Lydia E. Neilson
Founder and Chief Executive Officer National ME/FM Action Network 512-
33 Banner Road
Nepean, ON K2H 8V7

Dear Ms. Neilson,

Thank you for your submission regarding you budget priorities for sufferers of ME/CFS and FM. The Liberal Party of Canada recognizes that these are complex illnesses that negatively affect the lives of thousands of Canadians.

A Liberal government will ensure the federal government rebuilds its capacity to deliver on evidence-based decision-making. Without evidence, government makes arbitrary decisions that have the potential to negatively affect the daily lives of Canadians. We need reliable economic indicators and data for sound economic policy, and to provide other governments, businesses, and civil society with the tools to enrich our national life. This commitment to scientifically driven, evidenced-based policy will help to restore Canada to the forefront of health research. Sound science, not ideology, will drive our funding and programming in health research.

We are deeply concerned about cuts this government has made to scientific research, such as the CIHR. Stable, predictable funding is necessary for the CIHR to perform its work, and address complex, multifaceted health issues such as ME/CFS and FM.

A Liberal government believes that a collaborative approach is required to deliver health care in Canada.

The federal government must collaborate with the provinces, territories, stakeholders and experts on a real plan to improve research into these diseases, as well as the services and supports for those who live with these conditions and their caregivers. As an immediate commitment, a Liberal government will invest $3 billion over the next four years to prioritize additional and improved home care services for all Canadians.

Our commitment is nothing less than ensuring an integrated primary care system in Canada that is multidisciplinary, patient-centered, and committed to managing chronic disease within community, home, and long-term care settings. We will work with the provinces and territories to ensure all Canadians have access to high-quality in-home caregivers, financial supports for family care, and, when necessary, palliative care. As already announced, as part of a Liberal government's commitment to a new, ten-year investment of nearly $20 billion in social infrastructure, including long-term care facilities. We will also expand access to the Employment Insurance Compassionate Care Benefit, so that it is available for more than only end-of-life care.

Further, the Liberal Party knows we must do a better job supporting caregivers in the important work they do. Caring for each other is an essential part of what it means to be Canadian. Nearly every Canadian family is confronted at some point with the important responsibility of caregiving. Under our current framework, many of those providing care for loved ones do not qualify for benefits, nor do they have job security while they are providing care. The result is that people are too often forced to leave their jobs and drain their personal savings to provide essential care. This is not only unfair, but it hurts our economy and our middle class.

That is why a Liberal government will introduce a more flexible and accessible Employment Insurance Compassionate Care Benefit, available to any Canadian who provides care to a seriously ill family member. Though applicants will still be expected to submit a medical certificate in order to qualify, the benefit will have more inclusive eligibility requirements. Canadians who are caring for a seriously ill adult family member who needs significant care over and above what can be provided during evenings and weekends - or a seriously ill child who cannot attend school for an extended period of time - will no longer be excluded from the benefit.

We look forward to working in partnership with organizations like yours moving forward and value your interest in the Liberal Party of Canada’s policies as they relate to these critical issues.

Yours sincerely,

Anna Gainey, President Liberal Party of Canada

- **QUEST #114 Spring 2018**

Government Response Misses the Mark

Sent to a member of parliament

When we met on Friday, we touched on the House of Commons e-petition #734 which asked the federal government to commit to a concerted effort to address the needs of Canadians with Myalgic Encephalomyelits/ Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities.

https://petitions.ourcommons.ca/en/Petition/ Details?Petition=e-734

Let me paraphrase the document that the government submitted in response to the e-petition:

- *We have funded one ME/CFS research project (for a total of $100k) and we put a statement in a newsletter to researchers saying that more research is needed.*
- *We set up a group to talk about what Fibromyalgia research would be nice. (The response neglected to mention two studies being funded for total of about $150k that year).*
- *We don't have anything to report about Multiple Chemical Sensitivities.*

  Now assume that the same petition was about Autism, Multiple Sclerosis and HIV/AIDS rather than ME/CFS, FM and MCS. Substitute Autism, Multiple Sclerosis and HIV/AIDs in place of ME/CFS, Fibromyalgia and Multiple Chemical Sensitivities in the three statements above. Between them, they receive around $40M in funding per year. Would they be impressed?

> We chose Autism, Multiple Sclerosis and HIV/AIDS because research has found that each of these illnesses has a disease burden that is roughly the same as (actually a bit less than) the disease burden of ME/CFS.
>
> *http://www.oatext.com/Estimating-the-disease-burden- of-MECFS-in-the-United-States-and-its-relation-to- research-funding.php*

We are not aware of any studies estimating the burden of illness for Fibromyalgia or Multiple Chemical Sensitivities. However, considering their prevalence, age distribution and degree of disability (information available from the Canadian Community Health Survey), their disease burden would be roughly the same as for ME/CFS and therefore MS, Autism and HIV/AIDS as well.

Here is a preferable response to the e-petition:

“We know there are major problems with services to the ME/FM/MCS community and we have made fixing the problems a government priority. Because we want to see more research in these areas, we have established a project team (or new institute) to encourage research and we have committed long term funding (in the 10’s of millions a year) knowing that researchers will follow the money. Meanwhile, we have asked the Public Health Agency of Canada to increase surveillance (statistical activities). We have also asked PHAC to look at messaging around activity and exercise – it has promoted exercise but this message must be nuanced so that Canadians understand that exercise can be harmful to people who are exertion intolerant. We have asked the health human resources team at Health Canada to look at what is required to build ME/CFS, FM and MCS into the health care system as quickly as possible. We are also asking staff who are working in the areas of chronic pain, opioid use, food security and home care to consider ME/FM/MCS issues. We know that the disability area of government is looking at disability issues affecting the ME/FM/MCS community. Meanwhile, recognizing the importance of good communication and the expertise that exists outside government, we are appointing an advisory committee to report jointly to the Minister of health and the Minster responsible for persons with disabilities. The committee secretariat will have an important role in coordinating activities in government to address these issues.”

Standing Committee on Health

- **QUEST #18 June 1996**

The Standing Committee on Health, of which **Mrs. Beryl Gaffney, MP** is a member, held a session with the Health Protection Branch on April 23, 1996.

Dr. Lozos, **Director General of the Laboratories for Disease Control** (LCDC} stated that

"We have mobilized two separate national consensus meetings, one on chronic fatigue syndrome and one on environmental sensitivities, at which we brought all of the experts together to try to come up with a position on what the next steps might be. On chronic fatigue syndrome, we actually also subsequently brought a group of experts together to try to come up with research proposals that they could submit to the national health research and development program of Health Canada and to the Medical Research Council to try to break the ground. That's the first step necessary to try to measure how much there is, and what it is in the population." He further stated "........**The ball has been put directly in the court of the basic science researchers to come up with some objective measure or case definition that we in public health can then pick up to take the next publish health steps."** [bold printing done by ed [Ed. note: 1) We have written a letter to Dr. Lozos stating that we are aware of the workshop they held in February 1989 which was published in 1991 and the workshop organized by The Nightingale Research Foundation, partially funded by Health and Welfare Canada in May 1991;

- **QUEST #20 October 1996**

STANDING COMMITTEE ON HEALTH - UPDATE

We have not heard directly from the Standing Committee on Health with regard to our proposal of a sub- Committee under the Standing Committee which would specifically deal with ME and FM issues. As mentioned in previous issues, there is no one place the medical profession or the public can turn to get the latest of information on ME and FM.

Mrs. Beryl Gaffney, in her letter to us dated November 28, 1996 advised us that she has been informed by the Clerk of the Committee that the subject of ME/FM was added to a list of items which may be studied, in the future, by the Standing Committee.

- **QUEST #28 February 1998**

BRIEF PRESENTED TO THE STANDING COMMITTEE ON HEALTH

On Tuesday, February 17th, 1998 at 9:00 A.M, the Fibromyalgia Society of Ontario (FSO) and our Network jointly presented a brief to the Standing Committee of Health regarding food supplements, and non-drug medication. We thank the FSO for being the one to instigate this effort and for making all the arrangements for us to attend this important panel discussion. We pointed out to the Committee that it was essential that the following recommendations are addressed:

- ▪ establish methods of licensing and regulating for all complementary medical health care professionals;
- ▪ establish a board of professionals with extensive knowledge of herbs and other natural substances to ensure quality control of natural nutrient supplements and herbs;
- ▪ ensure that all products sold in health food stores or through other modes of marketing as nutrient supplements and herbs should be properly tested and their packages labeled, including warnings of possible side effects;
- ▪ establish a body that can regulate network marketing and address any grievances from consumers against network marketers; and
- ▪ insist that any claims regarding cures, made by health care professionals or companies selling herbs or nutrient supplements, are backed up with scientific fact.

  By having regulatory bodies to which unsatisfied consumers can lodge complaints, it will go a long way to rectifying the present confusion and uncertainty in the field of complementary medicine, and the market of natural nutrient supplements and herbs.

- **QUEST #35 April 1999**

HEALTH COMMITTEE FOR AN IN-DEPT STUDY

By: Judy Spence, RN - President

In 1995 the **National ME/FM Action Network** began moving CFS-MCS-FM onto the National Agenda. Since October 1998, the **Environmental Illness Society of Canada (E.I.S.C.)** has co-ordinated the effort to gain recognition of MCS, CFS and FM by asking Parliament to vote affirmatively on **Motion, M-468**, which reads: **"That, in the opinion of this House, the government should recognize: (a) multiple chemical sensitivity, chronic fatigue syndrome, and fibromyalgia as illnesses that have the capacity to cause disability; and (b) those suffering the disabling aspects of these diseases require protection and a strong moral commitment to their well-being."** Many, many individuals and affiliate organizations took part, with cards, letters, faxes and calls making their voices heard.

On **International ME Awareness Day '99 [May 12**] the motion went before the Private Members Motions sub-committee where it was decided the motion would not be 'votable' but that it would be debated. On June 2, 1999 during the debates on the motion, **MPs Mac Harb and Marlene Catterall** and **Defence Minister, the Honourable Art Eggleton** spoke eloquently and, at great length, to the issues concerning people suffering from our illnesses. **MP Blaikie (NDP), MP Casey (PC) and MP Hardy (NDP)** spoke about the illnesses and about their own constituents who were sick with these conditions. At the end of the debates all five political parties unanimously adopted a motion referring the whole matter of CFS-MCS-FM matter to the standing Health Committee for an in-dept study.

Health Canada

- **QUEST #40 February 2000**

First National Symposium on Multiple Chemical Sensitivity, Chronic Fatigue Syndrome, and Fibromyalgia: Environmentally-Triggered and Emerging illnesses

Health Canada, the Environmental Illness Society of Canada and the National ME/FM Action Network, with the support of the University of Calgary and the College of Family Physicians of Canada, are pleased to announce the **First National Symposium on *Multiple Chemical Sensitivity, Chronic Fatigue Syndrome and Fibromyalgia:* Environmentally Triggered and Emerging Illnesses.** The symposium will be held at the Château Cartier Resort in Aylmer, Québec from **November 17 - 19, 2000**.

This Symposium is designed to raise awareness of these illnesses, share information on the state of the science and to begin a preliminary review by medical experts of draft clinical case definitions. The program will include plenary sessions, workshops, round table discussions and displays, and will be of particular interest to those in government, the medical community, research, advocacy groups and industry stakeholders.

- **QUEST #42 June 2000**

OFFICIAL ANNOUNCEMENT: FIRST NATIONAL SYMPOSIUM ON MCS, ME AND FM POSTPONED

The "First National Symposium on Multiple Chemical Sensitivities (MCS), Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FM)" was originally scheduled for November 17-19, 2000. There are seven partners on the Planning Committee which include: **Health Canada, National ME/FM Action Network, Environmental Illness Society of Canada (EISC), , Canadian Public Health Association, College of Family Physicians of Canada, Canadian Society of Environmental Medicine, and the University of Calgary.** The partners have been actively seeking resources to fund the event.

On June 27, 2000, in a special meeting of the Planning Committee, it was decided that the Symposium was unable to secure sufficient resources in time for the November date and so the Symposium has been delayed until **March 30th - April 1, 2001**. It will still be held in Aylmer, Quebec (near Ottawa).

Currently, the Planning Committee continues to work on fundraising. An Expert Panel Selection Sub- committee continues to develop the science and methodology for the Canadian clinical case definitions for MCS, CFS and FM.

It is hoped that with the dedicated efforts of the scientific and public community, progress in resolving important issues concerning MCS, CFS and FM will continue to be made.

Please continue to do whatever you can to raise funds for this most-important Symposium. Presently, 25% of the funds needed has been raised. We still have a long way to go and have until October 30th, 2000 to raise most of the funds needed to cover immediate expenses which are on a time schedule.

Our **National ME/FM Action Network** is also responsible for the funding necessary to bring the ME/FM experienced doctors to the Symposium to peer-review the draft clinical definitions for ME and FM which were drafted by **Dr. Anil Jain** and **Dr. Bruce Carruthers**, who both have extensive experience in ME/FM.
Please forward whatever amount you can afford to the **National ME/FM Action Network, 3836 Carling Avenue, Nepean, Ontario K2K 2Y6 Canada**. A tax receipt will be issued for all donations. No amount of money is too small to make a meaningful difference. The Symposium must be a success. Each one of us deserves a proper diagnosis and appropriate medical treatment.

- **QUEST #44 October 2000**

SYMPOSIUM OFF BUT PEER REVIEW OF ME/FM CLINICAL DEFINITIONS ON SCHEDULE

The **Canadian ME/FM Clinical Definitions and Treatment Protocols** are scheduled to be peer-reviewed on **March 30th to April 1, 2001**. Once a consensus has been reached, preparations will take place to have the results published in a Canadian medical journal.

Our Board of Directors has always preferred that we hold a Symposium after the ME/FM Clinical Definitions and Treatment Protocols are peer reviewed and published so that doctors across Canada can gather together and share the information. However, when Health Canada invited us to participate in the planning of a Symposium, we took the opportunity to do so. Our main goal has always been the peer review of the ME/FM clinical definitions and treatment protocols.

On November 28th, 2000 after serious consideration, the Planning Committee for the First National Symposium on Multiple Chemical Sensitivities (MCS), Chronic Fatigue Syndrome (CFS) and Fibromyalgia (FM) reached the decision to cancel the Symposium based on a number of considerations, including lack of secured funding. Although the Symposium will not take place in March, the peer-review of the ME/FM Clinical Definitions and Treatment Protocols will take place.

Thank you for the generous response to our fundraising request. Please continue to send in your donations earmarked for the peer-review of the ME/FM clinical definitions amd treatment protocols and seek out individuals and companies looking for tax- deductible receipts. We have made good progress towards the funds necessary for the peer-review and we will be contacting those who gave donations towards the Symposium to ask permission to transfer these donations towards the peer-review. We urgently need your continued help to realize our goal. All of us, doctors, lawyers, patients, relatives and friends of those who are ill, will all gain by having standardized clinical definitions and treatment protocols in place. **Let's ensure that all patients will receive a timely diagnosis and appropriate treatment. Let's ensure that the illness will have the credibility and respect it deserves from the medical and insurance communities.**

- **QUEST #91 Summer 2012**

Meeting With Federal Officials

On June 6, 2012, Maureen MacQuarrie and Margaret Parlor had a short meeting with a senior staff member in the office of the federal Minister of Health. Also in attendance were a senior manager from the Public Health Agency of Canada and a senior manager from the Canadian Institutes of Health Research. There was acknowledgment from these officials that a number of issues need to be addressed, in particular support for research, information on health websites, and disease surveillance. Follow-up activities are now being organized.

PROVINCIAL GOVERNMENTS

ALBERTA

- **QUEST #62 November 2003**

National ME/FM Action Network Responds to Alberta's New Legislation

Letter sent to Honourable Greg Melchin , #29, 735 Ranchlands Blvd. N.W.,Calgary, AB T3G 3A9 - December 12, 2003

Pursuant to our telephone conversation, I am writing you on behalf of the National ME/FM Action Network, which is a Canadian, registered, non-profit 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. Our bimonthly newsletter "QUEST" goes out to individuals including doctors and lawyers experienced in ME/CFS and FMS, as well as over 450 support groups across Canada.

Our organization has serious concerns regarding the new regulations being established in Alberta for motor vehicle accident claims, including the $4,000 limit for pain and suffering for "minor" injury, the criteria for establishing what will be included in "minor injuries", appropriate protocols, and the use of independent medical examinations.

It is my understanding that the original time period recommended for the limit for pain and suffering for "minor" injuries was four months, which is reasonable. However, it has since been reported in the news that the government is considering extending this time period beyond 18 months. How can pain and suffering that last 18 months or more, be considered minor? In cases where insurance companies dispute the accident claim of up to the ceiling of $4,000.00 for "minor injuries", the accident victim will be discouraged from pursuing the matter in court because the prohibitive legal costs would never be recovered.

A major concern is how "minor" injuries will be determined. To set criteria to establish what will be considered a "minor" injury is domed to failure. Dr. Thomas Romano, Diplomate and President of the Board of Directors of the American Academy of Pain Management, cites Dr. Stephen Gould, a famed biologist and geologist, who maintains “that if one wishes to describe a complex biological system using measures of tendency such as averages or means, he or she will be wrong”.(1) The human body is a complex biophysiological system, so there is no typical patient and no typical injury. It is impossible to determine how an individual will react to trauma as identical injury site loads affect individuals differently depending on their structural elements and weakest site.(2,3) An erroneous global statement sometimes presented by the insurance industry is that if a patient is not sent to hospital, s/he could not have received substantial injuries. Soft tissue injuries, neck and back pain, headaches and many other symptoms may be delayed by weeks, or many months.(3) Another erroneous global statement often promoted by the insurance industry is that whiplash and soft tissue injuries heal within a couple of weeks to six months (a “minor injury”). Nothing could be further from the truth. Ligaments that are stretched past their capacity and injured are very difficult to heal as they have limited blood supply, particularly where they attach to the bone. Lax ligaments do not hold the joints in place properly so there is abnormal joint movement. Muscles around the joint tend to react by contracting in order to help stabilize the joint and prevent further damage. Muscles that are shortened from spasm are dysfunctional and chronically fatigued.(4) Common causes of chronic pain following whiplash injury are the development of myofascial pain syndrome (MPS) and/or fibromyalgia syndrome (FMS),(4,5,6,7,8) which take several months to develop. There is no known cure for fibromyalgia syndrome. Degenerative disease of the cervical spine also often develops.

To suggest that whiplash and soft tissue injuries are “minor” injuries is not only erroneous, but it discriminates against females. Females generally have a more flexible and delicate skeleton, longer necks, and thinner, less massive muscles than males. This gender difference in physiology makes females more prone to whiplash injuries as they are likely to experience a greater degree of extension and flexion of the neck. A study of the spinal canal diameter of whiplash injury patients revealed that the cervical spinal canal was significantly smaller in patients with prolonged symptoms, and the cervical canal was smaller in females.(9) The sacroiliac and pubic joints of females have had their ligaments stretched during pregnancy and childbirth, making them less stable and more prone to low back injury. Females have less tolerance for pain than males, as females produce more of some brain chemicals that increase pain signals and less of some other brain chemicals that decrease pain signals.(4)

Thus, injuries should not be classified as “minor” by their diagnosis. If there must be a classification, it should be on the severity of the symptoms and the patient’s functional abilities/limitations.

The Alberta Government website indicates that the “best practice guidelines would ensure injured victims receive the proper and prompt diagnosis and treatment for their injuries” and “pre-approved protocols would be developed to help health care practitioners provide appropriate and consistent treatment.” There is a great need for better education about FMS and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) among health care practitioners. I am pleased to advise you that consensus documents, with the first clinical case definitions, diagnostic and treatment protocols for fibromyalgia syndrome(4) and myalgic encephalomyelitis/chronic fatigue syndrome(10) have been completed. The consensus documents also have research sections as well as a number of helpful appendices. Health Canada selected the expert consensus panels and established the “Terms of Reference”. I am attaching a brief article entitled “Clinical Milestones for the Diagnosis and Treatment of Fibromyalgia Syndrome and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome” that explains how these consensus documents came into being. The ME/CFS consensus document was published in February, 2003. The FMS consensus document is in press and will be in the next issue of the Journal of Musculoskeletal Pain. We strongly suggest that these expert consensus documents be used as the guidelines for the diagnosis and treatment of FMS and ME/CFS patients.

Another major concern of our Network is regarding who will be responsible for deciding the eligibility for injury compensation. Our organization has been hearing from an alarming number of disabled patients all over Canada, including Alberta, who have had compensation or benefits denied based on an “independent medical examiner’s” report in spite of the reports by the patients’ treating physicians and specialists confirming their injuries and/or disabilities.

The so called “Independent Medical Examinations” have been a dismal failure because insurance companies choose doctors whom they can rely upon to produce reports which will benefit the insurance companies. Frequently patients, who have no psychiatric history, are sent to psychiatrists who allege that the injuries or symptoms are all in “the patient’s head”.

The Alberta Legislature now has the serious responsibility and opportunity to set up a fair and just independent medical examination process. I am enclosing the article, “Making ‘Independent Medical Exams’ Independent” by G.V. Rossie and R. D. Gretzinger, which was in our newsletter “Quest” #32, Oct/Nov. 1998. This article explains the most successful independent medical evaluation system that was legislated in Colorado for MVA.

We would also like to suggest: This fair IME program should be run by an independent body outside of the insurance industry.

I am also enclosing a copy of our position paper, “INDEPENDENT MEDICAL EXAMINATIONS IN CANADA: THE NEED FOR REFORM”, which we hope the members of the group assigned to establishing guidelines, as well as the Members of the Legislature of Alberta, will read and consider while deliberating this serious issue. Although a number of examples refer to Chronic Fatigue Syndrome, they also apply to whiplash injuries, myofascial pain syndrome, fibromyalgia syndrome, and other soft tissue injuries. Ms. Noel, a member of our organization, has a Ph.D. in History, has lectured extensively and written dozens of articles on the problem of human rights. Her book on the subject won the Governor General’s Award (in French) in 1989 and the updated translation in English, published in 1994 by McGill-

Queens University Press, received the American Gustavus Myers Center Award for The Study of Human Rights in North America.

Those injured in motor vehicle accidents are entitled to fair, unbiased evaluations by doctors whose expertise is in the area of the injuries. It is paramount that the human rights of injured individuals be safeguarded. Every individual deserves a fair evaluation and to be treated with respect and dignity.

The Alberta Government website states that “the definition of minor injury will be developed in consultation with organizations representing injured people, insurers, lawyers and health care providers”. As Director of Education for the National ME/FM Action Network and Consensus Coordinator for both the Clinical Consensus Documents for Fibromyalgia Syndrome(4) and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome,(10) I would be pleased to participate in this group.

Would you kindly send a copy of this information to the appropriate people.

Thank you for considering our concerns and for your assistance in this matter. I look forward to a reply at your earliest convenience.

Sincerely,
Marjorie van de Sande, B. Ed., Grad. Dip. Ed,
Director of Education, National ME/FM Action Network

Queen's Jubilee Medal Awarded to Network adviser

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

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

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

BRITISH COLUMBIA

- **QUEST #8 October 1994**

Replies to Network's letters from:

BRITISH COLUMBIA - INSURERS' MISCONDUCT:"If the Superintendent considers that the conduct of a financial institution is misleading, deceptive or unconscionable, he may institute proceedings with a view to protecting the rights of an insured. However, in this situation it is difficult to conclude that the actions of the insurance companies are misleading, deceptive or unconscionable, given the divergence of medical opinions on

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and/or Fibromyalgia and given that the doctors who express such opinions have their own professional standards of independence to which they must adhere." [Signed] Robert J. Hobart, Superintendent and Chief Executive Officer, Financial Institutions Commission, Province of BC, 1900, 1050 West Pender Street, Vancouver, BC V6E 3S7 - Tel. (604) 660- 2947 - Fax (604) 660-3170.

- **QUEST #87 Spring 2011**

BRITISH COLUMBIA

BC Ministry of Health approves $2 million clinical and research study for variety of complex chronic diseases, such as chronic lyme disease, fibromyalgia, and chronic fatigue syndrome, with screening, diagnosis and treatment.

- **QUEST #94 Spring 2013**
- **QUEST #97 Winter 2014**

BC Government Consults on Disabilities

The BC government has established a consultation process to explore ways to improve services for people with disabilities. They invite people to submit ideas to their website before March 11, 2014, *http://engage.gov.*

bc.ca/disabilitywhitepaper, to attend one of the public meetings being held in January and February, or to mail, tweet or phone in comments.

The consultation process has not won unanimous sup- port. Here is what one commentator wrote (*http://beaconnews.ca/blog/2013/12/disabled-needs- secret-bc-government/*):

The BC Government is not ignorant of what disabled people need. It knows how badly it has treated disabled people since the nineteenth century. But the Government's priority is how to dodge having to act on the facts.

Experience has taught the Government that many disabled people and their families are suckers for what Public Relation fraudsters call "stakeholder engagement." Stakeholder engagement is a magic show intended to create an illusion of democracy. And like all magic shows, stakeholder engagement only works if the audience wants to be fooled.

To which someone replied "I'm a bit of a sucker because

I will participate in this process if only to tell them that they should already know what to do."

With that background, we suggest that people do take the opportunity to submit their thoughts and ideas. They may be heard!

MANITOBA

- **QUEST #23 April 1997**

A/SUPERINTENDENT OF INSURANCE OFFERS ASSISTANCE WITH CLAIMS

Ms Lucy M. Couture, A/Superintendent of Insurance in a letter to our organization dated May 13, 1997 advised that the office of the Superintendent of Insurance for, if contacted in writing by consumers, will approach insurance companies outlining the concerns of which they are made aware. The Superintendent's office in Manitoba will mediate disputes between consumers and their insurance companies.

The Insurance Act however does not empower the Superintendent to compel insurance companies to pay claims nor to determine how much a claim is worth. If the parties are unable to negotiate a settlement then the matter as a civil matter, may be taken to the courts.

NEW BRUNSWICK

- **QUEST #18 June 1996**

"There is no definition on this matter in the New Brunswick Insurance Act, nor haveprovided any guidelines to the industry. In my experience, these situations are usually resolved through a mutual understanding of all parties as to who is acceptable in providing an independent medical report. It is usually the interpretation of the medical reports that creates disharmony,e matter may need to be resolved in a court of law.....New Brunswick does not maintain records on specific losses or claims...."Signed R.W. Richard, Superintendent of Insurance, P.O. Box 6000, Fredericton, NB E3B 5H1 - Tel. (506) 453-2512 - Fax (506) 453-2613

- **QUEST #40 February 2000**

NEW BRUNSWICK

Andy Scott, MP awards Lydia Neilson

On February 21, 2000, at his office on Parliament Hill in Ottawa, the Hon. Andy Scott MP, Fredericton, presented Lydia Neilson, President CEO of the National ME/FM Action Network with a National Award. Written on the certificate is: "This is to certify that Lydia Neilson is awarded the National Award by The New Brunswick ME/CFS Association for her outstanding commitment to those with Myalgic Encephalomyelitis and Fibromyalgia." It is signed by President/Founder Brenda Duffy.

"In your lifetime you may be lucky enough to meet the one person who inspires you," states Brenda Duffy. "For me, it is Lydia. She has integrity, knowledge of people and a steadfast determination to help sufferers and their families gain awareness, respect and understanding from governments, the medical community and the general public. In spite of her own ill health, she is a model of dedication."

ONTARIO

- **QUEST #14 – October 1995**

ONTARIO

We have had written and verbal discussions with the present Harris Government re: Insurance Legislation and will be meeting with them in the next few weeks and once we have met with them, we will be in a better position to advise what kind of assistance we may require. Although we are presently dealing with the Ontario Government, the same will be done for each Province and Territory.

- **QUEST #15 – December 1995**

Ontario - BILL 26 - If approved would give health-fraud investigators widely expanded powers to collect medical information, including patient records. We have written The Clerk of the Standing Committee on General Government advising them of our alarm with this particular Bill as it seems the only people who could possibly want this type of information would be the insurance industry. Right now, a signed Release must be obtained from the patient before any kind of medical information can be obtained. We have asked for clarification on this most important issue.

- **QUEST #18 June 1996**

Women's College Hospital Receives three-year Grant from Ontario Ministry of Health

We received a letter from the Dr. Frank J. Foley, Medical Director of the Environmental Health Clinic at Women's College Hospital. They advised that they have received a three-year grant from the Ontario Ministry of Health to do the following:

1. Provide a consultation and assessment service for people with multiple chemical sensitivities;

2. Collaborate with the University of Toronto's Research Unit on Environmental Hypersensitivities to improve the management of these disorders; and

3. Develop a provincial network of physicians who are more knowledgeable about multiple chemical sensitivities.

In their follow-up letter to us of August 28, 1996 as we asked them how that would help ME/FM patients, they replied that they do not offer specific treatments since they are only funded as an assessment and research clinic. They stated that they do assessments and consultations for persons with Chronic Fatigue Syndrome and fibromyalgia. They have, however, submitted a proposal to the Ministry of Health in Ontario for a treatment clinic, and the Ministry is reviewing the proposal at this time.

ONTARIO

Blair Tully states in his letter of Oct 12/94 "To the extent there may be doctors who are not prepared to accept ME as a genuine medical condition, I would suggest this is a matter more appropriately considered by the Ontario College of Physicians and Surgeons. Similarly, if there is evidence to suggest that a physician is deliberately alteg his or her findings and opinions, that might be a matter that warrants reporting to the Ontario College of Physicians and Surgeons." Siged Blair Tully, Commissioner, Ontario Insurance Commission, 5160 Yonge St., Box 85-15th Flr, North York, ON M2N 6L9 - Tel. (416) 590-7000 - Fax (416) 590-7078.

- **QUEST #27 December 1997**

ONTARIO

ONTARIO HUMAN RIGHTS COMMISSION TAKES A STAND ON ME/FM

In the past, people with Chronic Fatigue Syndrome and/or Fibromyalgia had difficulty getting the Human Rights Commissions to take these illnesses seriously. Usually, people were told to see a psychiatrist for help or were advised that they could not help them, without any explanation..

We have been working with the **Fibromyalgia Society of Ontario in Sudbury** (formerly the Northern Ontario Fibromyalgia Network) to get this matter addressed in Ontario. We feel that by having one Human Rights Commission take a favorable position on ME/FM, the rest may follow.

The Chief Commissioner, **Mr. Keith C. Norton,** Q.C., B.A., LL.B. advised us that he had reviewed our concerns about ME/FM people with his senior staff at the Ontario Human Rights Commission to identify possible solutions. He assured us that under the Human Rights Code, "persons with ME/FM have the same rights and protections as any other person in Ontario." If a person claims to have a handicap resulting from ME/FM, then the Commission will deal with the matter as it would in any disability complaint. He pointed out that section 17 of the Code makes it clear that persons with handicaps are to be accommodated in accordance with their individual needs.

Mr. Norton also pointed out that the education component extends to the Commission's own staff and advised us that the Corporate Services Branch will be developing a staff training session to address the needs of persons with disabilities. These sessions are planned for the next fiscal year. [1998].

[Ed.note: **1)** We will be contacting all other Human Rights Commissions in all provinces and territories to get the same commitment from them as we have from the Ontario Chief Commissioner. If you would like to get in touch with **Mr. Norton** about any human rights problems you have experienced and to offer your support, Mr. Norton can be reached at **180 Dundas Street West, Toronto, ON M7A 2R9 - Tel. (416) 314-4541; and**

2) You only have **six months to file a complaint** with the Humans Rights Commission i.e. six months from the date when the incident occurred**]**

* QUEST #33 – December 1998

ONTARIO

MP SURVEYED DOCTORS IN PEEL REGION RE: ME/FM - 25% Responded

Ms Colleen Beaumier, MP of Brampton West-Mississauga due to contacts by her constituents, did a survey of General Practitioners' in the Peel Region. - (Ms Beaumier uses " Fibromyalgia / chronic fatigue syndrome" which we have condensed to ME/FM).

1. Would you describe ME/FM as a curable psychological illness? Yes: 12% No: 79%

2. Would you describe ME/FM as an organic illness? Yes: 50% No: 38% Uncertain: 6%

3. Have you ever diagnosed ME/FM in a patient? Yes: 79% No: 10% Uncertain: 6%

4. Have you ever been requested by an insurance company to provide a secondary opinion as to **any** illness or injury?

Yes: 35% No: 50%

5. In your practice during the past 5 years, how many ME/FM cases have you or are you currently treating? 0: 2% 1-10: 73% 11-20: 6% >20: 13%

6. In your experience do most ME/FM patients become Cured? 0%
Get Better? 29% Get Worse? 10% Stay the same? 62%
7. Are you familiar with the use of tender point identification as a method of diagnosis?

Yes: 94%
8. Are you able to identify the locations of the tender points? Yes: 85% No: 12%

9. Which fibromyalgia symptoms do fibromyalgia patients indicate most impacts their ability to function?

Widespread Pain: 81% Headaches: 25% Chronic Fatigue: 70% Impaired Memory: 17%

Sleep Problems: 67% Stiffness: 29% Balance Problems: 6% Cold Extremities: 5%

Irritable bowel: 15% Irritability: 25% Depression/anxiety: 40% Cognitive Problems:17%

10. Which fibromyalgia symptoms are most easily treated? Widespread Pain: 13% Headaches: 9%

Chronic Fatigue: - Impaired Memory2% Sleep Problems: 29% Stiffness: 21% Balance Problems: 2%

Cold Extremities:- Irritable Bowel: 7% Irritability: - Depression/anxiety: 29% Cognitive Problems: 2%

11. What seems to work best in treating fibromyalgia? Antidepressants: 73% Aerobic exercise: 50% Chiropractic: 4% Massage: 21% Narcotics: - Painkilling drugs: 6% Physical Therapy:23% Psychiatric: 13%

Relaxation: 15% Rest: 17% Steroid Injections: - Support Groups: 40%
Tranquilizers: - Anti-Inflammatory drugs: 6% No Treatment works: 4% Do Not know:2%

12. Does Fibromyalgia cause sufficient disability to prevent people from regular/unadjusted working or

performing normally? Yes: 69% No: 12% Uncertain: 6%

13. Have you ever supported a fibromyalgia patient in a claim for either Long Term Disability or Canada

Pension Plan? Yes: 63% No: 29%

14. Would you agree that your profession would benefit from a standardized criteria used to diagnose FM? Yes 75%

No: 6% Criteria already exists: 13%

15. If such a criteria were to be developed, which of the following groups should be asked to provide opinions on the definition?

Very Important Some Importance No Importance

General Practitioners? 73% 12% -

Insurance Companies? 15% 13% 38%

Chiropractors? 12% 46% 15%

Mental Illness Specialists? 38% 38% 6%

Rheumatologists? 79% 4% 2%

Others: 15%

16. How many tender points, in your opinion, would warrant a diagnosis of fibromyalgia?

1-3: - 4 - 7: 17% 8-10: 21% 11-15: 21% >15: 6% Don't Know: 9% Don't believe to be a significant method: 8%

- **QUEST #33 – December 1998**

ONTARIO

WHAT YOU NEED TO KNOW ABOUT CPD AND FIBROMYALGIA: By: Carmela DiMondo, Constituency Advisor for Colleen Beaumier, MP Brampton West-Mississauga

As many of the readers are aware, Fibromyalgia is an illness that is subjective; there is no clear-cut medical evidence to prove an individual has fibromyalgia. Thus, the task of proving that an individual with Fibromyalgia warrants a Canada Pension Disability benefit can become a difficult one. The office of Colleen Beaumier, M.P. Brampton West-Mississauga acknowledges this fact and has taken great interest in the frame work of Canada Pension Disability, particularly with the length of time in case processing. This does not only pertain to individuals with fibromyalgia, but also involves individuals with different illnesses.

Due to the backlogs that currently exist in the system, it is prevalent that applicants at the time of their initial application, submit all medicals indicating that their condition is severe and prolonged in the context of CPP legislation. Doctors' notes must clearly state that the condition is severe and prolonged, meaning a disability which is long term and prevents an individual from doing any type of paid work on a regular basis. Thus, no gainful employment can be obtained. Doctors' notes must be accurate, as unclear wording will result in delays and denials.

As Fibromyalgia is subjective, it is difficult to assess the severity of an individual case. Diagnosis is not the primary focus of an assessment. When assessing a CPD application, it is prevalent the assessor determine how and to what extent, the illness has impacted or will impact, upon an individual. This is determined through medical assessments, which sometimes will include a psychiatric evaluation. While some cases may require a psychiatric evaluation, this is not to suggest CPD doubts that the individual has fibromyalgia. There are varying degrees of this illness, therefore evidence supporting the applicant's efforts to cope with the pain and receive treatment is imperative.

Our office takes issues pertaining to Canada Pension seriously and that is why we have taken case processing issues as well as the criteria for Fibromyalgia, to Ottawa. Our response was favourable. We are continuing to insure that measures are taken to alleviate the backlogs that are currently in the system. In our discussions with Minister Pettigrew and his staff, we have been given an Adjudication Tool to aid those applying for disability that have fibromyalgia and Chronic Fatigue Syndrome. Currently pilot projects are underway to alleviate confusions pertaining to denial letters. In Ontario, clients are being called at the initial denial sage, before the letter is processed, to explain why they have been denied. Similar steps are taking place across Canada; the information from these pilots will be collected and evaluated to help determine a more informative and efficient means of relaying denials. Moreover, additional staff has been hired to deal with the backlogs in the system and thus, case processing time periods have decreased from previous years.

[Ed. Note: To obtain a copy of Presentation of Ms Di Mondo to House of Common and Diagnostic Tool, please send cheque for $4.00 to cover postage and photocopying costs]

Office has facilitated all means necessary to address CPD concerns. It is sufficient to say that we do not take matters pertaining to CPD delays lightly and thus we are doing our best to clarify and alleviate our constituents' concerns. I hope this information will be of assistance to those applying for Canada Pension Disability Benefits. To obtain the Adjudication Tool or further information regarding CPD, Fibromyalgia and Chronic Fatigue Syndrome, please contact this Network.

- **QUEST #39 December 1999**

ONTARIO

COMMISSIONED BY ONTARIO MINISTRY OF HEALTH AND LONG-TERM CARE

HAVE YOU MADE A COMPLAINT TO THE COLLEGE OF PHYSICIANS AND SURGEONS OF ONTARIO? OR

ARE YOU A PHYSICIAN WHO HAS BEEN THROUGH THE COMPLAINTS PROCESS?

We want to hear from both patients and physicians who have had direct experience with the complaints and discipline process.

Your input will remain confidential. **KPMG Consulting LP** has been commissioned by the **Ontario Ministry of Health and Long-Term Care** to conduct an

independent review of the complaints and discipline process of the **College of Physicians and Surgeons of Ontario**.

- **QUEST #62 November 2003**

ONTARIO

The Guidelines Advisory Committee of the Advisory Committee of the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care Reviews the ME/CFS Consensus Document

Alison Bested, MD, FRCP(C), who was a member of the Expert Consensus Panel for the ME/CFS Consensus Document; and a representative of The Myalgic Encephalomyelitis Association of Ontario, met with Dr. David McCutcheon, Assistant Deputy Minister, Health Services Division, Ministry of Health and Long-Term Care for Ontario to discuss whether the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care would review the ME/CFS Consensus Document. Dr. McCutcheon agreed to have the Guidelines Advisory Committee of the Ontario Medical Association and Ontario Ministry of Health and Long Term Care evaluate the ME/CFS Consensus Document.

We are pleased to report that the Guidelines Advisory Committee of the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care gave “Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols”, Journal of Chronic Fatigue Syndrome 11(1):7-116, 2003 a three out of four-apple rating. In a letter from the Guidelines Advisory Committee, the chairman reported, “Three apples denote a very good guideline”. Dr. Davis continued, “three-apple guidelines are well produced and useful for practicing clinicians". The chairman added, "We hope that this information proves useful as you deliberate on how to ensure the early diagnosis and medical care of patients with chronic fatigue syndrome."

The Myalgic Encephalomyelitis Association of Ontario sent their congratulations to the National ME/FM Action Network, in particular, to Lydia Neilson for initiating this project, and to Marjorie van de Sande for her hard work coordinating the project and compiling the document. Both Myalgic Encephalomyelitis Association of Ontario and the National ME/FM Action Network would like to extend a special thank you to Dr. Bruce Carruthers and Dr. Anil Jain, who wrote the original draft document, and to all the physicians and researchers who were members of the Expert Consensus Panel for the ME/CFS Consensus Document, for generously donating their time and expertise to establishing the first clinical definition and guidelines for ME/CFS.

Please note that when you are discussing the ME/CFS Consensus Document with your physician, it is important to tell your physician that the Guidelines Advisory Committee of the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care favourably reviewed the consensus document, “Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols”. Journal of Chronic Fatigue Syndrome, 11(1):7-116, 2003.

- **QUEST #67 Winter 2004**

ONTARIO

Canadian Underwriter - Liberals offer up new DAC replacement scheme in Ontario 12/6/2004

According to documents from the Financial Services Commission of Ontario (FSCO) obtained by Canadian Underwriter, a new system to replace Ontario's "Designated Assessment Centers" (DACs) has been established.

The new "post-DAC" system would allow claimants to receive assessments within the Statutory Accident Benefit Schedule (SABS) from their health care provider, and allow insurers to request their own assessment if the initial assessment is in question. However, the DAC stage is eliminated and a disputed SABS claim will go directly to FSCO's dispute resolution process or to the courts following mediation. The goal is to eliminate DACs, which were found to be a costly and duplicative service by the new Ontario Liberal government. The first stab at reform, the "expert assessor network" was not well received by stakeholders, including insurers, sending the government back to the drawing table.

The new system, which will require amendments to the SABS regulations, will create a new category of examinations in addition to existing "section 24"

Provincial Ministries of Health in Canada will follow?

It has taken many years to get to this point of lobbying, meetings, etc. With the publication of the Canadian Definition, which was initiated by the **National ME/FM Action Network**, this made this possible. Over the last several years, **The Myalgic Encephalomyelitis Association of Ontario** has been in meetings with the Ontario Ministry of Health to lobby for a Diagnostic Code and we are so pleased that we now finally have one. **Dr. Alison Bested** did a fantastic presentation to the Ontario Medical Association. **What does it mean to have a (CFS) code"?** It means that:

1. NO physician can ever say again that our illness does not exist;
2. All physicians in Ontario will receive a notice from **OHIP** of our new **CFS Diagnostic Code 795** as a **Neurological Ilness**;

3. The fact that the Ontario Medical Association gave CFS a Diagnostic Code as a Neurological Illness will cause concern to Insurance companies;
4. It will help individuals applying for Ontario Disability Support Program and the Canada Pension Disability Plan;

5. It now makes it possible to collect Statistics in Ontario; and
6. It will hopefully give incentive to the other provinces to follow.

NOTE: The CFS Diagnostic Code is given to someone who is being diagnosed with CFS for the first time. The code is not a time-based fee code. Follow up appointments for any illness (heart disease, MS, CFS, etc. at the present time is usually billed as Supportive Therapy if you take more time than a normal appointment.

- **QUEST #68 Spring 2005**

ONTARIO

Ontario Human Rights Commission Releases Guidelines on Accessible Education

Myalgic Encephalomyelitis Association of Ontario

The Ontario Human Rights Commission has just published a report on educational rights for students with disabilities that should be very helpful to students with ME/CFS in Ontario. Because it does an excellent job of articulating principles of accessible education, people from other jurisdictions may find it helpful as well.

When consulting the disabled community in 2002, the Commission found that, despite some positive aspects of the Ontario education system, “a significant number of students with disabilities continue to face obstacles in their attempts to access educational services in Ontario”. One obstacle they identified was a lack of understanding of Commission policy and

the rights and responsibilities of all parties under the Ontario Human Rights Code. This report, entitled “Guidelines to Accessible Education” sets out to describe rights and responsibilities of students, of education providers, and of third parties (unions etc.).

The report describes disability broadly and specifically mentions chronic fatigue syndrome. It puts a responsibility on the disabled student (or the parent/guardian) to work with education providers to develop and monitor accommodations. It puts a heavy onus on education providers to create a welcoming environment, to accommodate appropriately, and to respect confidentiality principles. While education providers are generally responsible for accommodating only those disabilities of which they have been made aware, the report suggests that they should educate themselves about nonevident disabilities and, where a student appears to have a disability, they should offer assistance and accommodation.

More generally, the Commission takes a dim view of harassment of disabled students and of delays and inefficiencies that work against a student’s needs.

Two examples in the report are very relevant for ME/CFS students. One questions scholarships that are offered to full time students only, and the other questions a requirement that a student attend a course for a fixed number of hours in order to pass. [Myalgic Encephalomyelitis Association of Ontario: contact P.O. Box 84522, 2336 Bloor Street West, Toronto, ON M6S 4Z7, 4162228820 or 1877632 6682 (outside GTA area), www.meao-cfs.on.ca]

- **QUEST #71 Spring/Summer 2006**

ONTARIO

By: Audrey MacKenzie, R.N. ,

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO

is pleased to inform you that ‘**fibromyalgia/Chronic Fatigue Syndrome care' has now the OHIP time- based billing Code number K037.**

In the past, many physicians have refused to accept ME/CFS/FMS patients because "they took too long". However, with this new code, physicians will be paid for the time they spend with patients who have these complex illnesses.

OHIP has notified all of Ontario's Physicians of this new Code.

In addition, the new Diagnostic Code for CFS, number 795, picked up the newly diagnosed patient, but with the new K037 Code, patients who were previously diagnosed will be able to be recorded by OHIP, thus allowing future statistics to be collected on these illnesses in the Province of Ontario.

(We do recognize that there are areas in Ontario where there is such a severe shortage of physicians that ME/CFS and FMS patients still may not be able to have all the time they need in one visit.)

Many thanks to all who have helped this come about: **Dr. Alison Bested** for her excellent presentation to the **Ontario Medical Association**; the **National ME/FM Action Network** for initiating the Canadian ME/CFS and Fibromyalgia Definitions, Diagnostic and Treatment Protocols; the **Board of Directors of The Myalgic Encephalomyelitis Association of Ontario** for their meetings and advocacy with the **Ontario Ministry of Health** and our **Members who have written, called their MPPs and written to the Ministry of Health;** the Ontario Support Group Leaders and their Members and individuals throughout the province who have advocated on behalf of CFS.

If I may borrow a phrase "it takes a village".

Thanks everyone for all your hard work and efforts in having CFS and FM accepted and recognized for the complex illnesses that they are by the Ontario Medical Association!!

Awareness Day, May 12th: This year, Senator Wilbert Keon read a May 12th Proclamation in the Federal Senate, forever marking the day in

- **QUEST #93 Winter 2013**

ONTARIO

Future of Social Assistance in Ontario

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

This is the opening paragraph of a the report of the Social Assistance Review Commission released in October 201 2. The report is 1 81 pages long and makes 1 08 recommendations.

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

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

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

- **QUEST #99 Summer 2014**

ONTARIO

Ontario Ministry of Health announces 2 new fellowships

The Ontario Ministry of Health has announced that it will fund 2 new fellowships in Environmental Health at the University of Toronto.

The funding will support education on environmentally linked illness like environmental sensitivities, myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia and other chronic, complex disorders.

The province is providing nearly $560,000 to support two new annual fellowships over three years for a total of six new fellowships. They will allow family medicine graduates to complete an extra year of focused training in environmental health, and will help primary care providers like family doctors offer the right care to assess, diagnose and treat environmentally-linked health issues.

The new fellowships will be offered by the University of Toronto's Department of Family and Community Medicine and the Dalla Lana School of Public Health, in collaboration with physicians at the Environmental Health Clinic at Women's College Hospital.

- **QUEST #107 Summer 2016**

ONTARIO

Ontario Announces Task Force on Environmental Health

The following announcement was posted on the Ontario Ministry of Health website on May26th:

http://www.health.gov.on.ca/en/public/programs/ environmentalhealth

Many Ontarians live with conditions triggered by environmental factors that are difficult to diagnose and treat.

These conditions may include:

• Environmental Sensitivities/Multiple Chemical Sensitivity;

• Neil Stuart (Vice-Chair), Health Care Consultant

• Bill Manson, Senior Director, Performance Management, Toronto Central Local Health Integration Network

• Cornelia Baines, Professor Emerita, Dalla Lana Faculty of Public Health, University of Toronto

• Denise Magi, Vice-President, Myalgic Encephalomyelitis Association of Ontario

• Dona Bowers, Physician, Somerset West Community Health Centre

• Izzat Jiwani, person with lived experience

• Joanne Plaxton, Director, Health Equity Branch, Ontario Ministry of Health and Long-Term Care

• John Molot, Staff Physician and Medical/Legal Liaison, Environmental Health Clinic, Women's College Hospital

• Julie Schroeder, Standards Development Branch, Ontario Ministry of the Environment and Climate Change

• Maureen MacQuarrie, person with lived experience

• Mike Ford, person with lived experience

• Nancy Sikich, Director, Health Technology Assessment, Health Quality Ontario

• Sharron Ellis, person with lived experience • Varda Burstyn, person with lived experience

- **QUEST #111, Summer 2017**

ONTARIO

The work of the Minister's Task Force on Environmental Health is proceeding, focusing on the topics of research, care and education. This is year one of a three year endeavor. An interim report is being prepared for submission to Ontario's Minister of Health.

MEAO's Awareness Day Event at Queen's Park was held on May 9th. Members of the Provincial Parliament from the three parties attended.

Mayor John Tory proclaimed May 12th as International Awareness Day for Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, Fibromyalgia and Environmental Sensitivities/Multiple Chemical Sensitivity in the City of Toronto. Thanks to the City of Toronto for their long standing support!

- **QUEST 115 Summer 2018**

ONTARIO

Feedback on Ontario Task Force Report

For our workshop in Montreal, we invited people to comment on the Ontario Task Force Report. We received two dozen replies. These were packaged and presented to the Task Force Chair. You can read the full comments online. This is a quick overview.

There was general consensus that the current health care system is dysfunctional and that the report identified very important actions for change.

The importance of dealing with stigma was raised over and over. People emphasized that this is a real illness, that acceptance is needed, and that stigma is a burden to individuals.

The importance of professional training was raised over and over. Also raised was the need for information to patients, caregivers and the public.

It was questioned whether “environmental illnesses” is an appropriate umbrella term. It was also questioned whether the three illnesses, ME/CFS, FM and ES/MCS could indeed be lumped together.

When it came to diagnostic protocols, there was strong reaction. The task force was advised not to repeat work already done or to take undue time seeking the prefect product. There was also emphasis that this is a national issue and Ontario should not go it alone.

There were many suggestions of areas that need more thought, including the availability of testing, the availability of aggressive treatments, poverty, housing, isolation, home care, the consequences of post-exertional malaise (“exercise can kill you”), use of the media, quiet areas in hospitals, telemedicine to avoid having to travel and the role of support groups.

It was suggested that a human rights specialist be added to the task force.

It was suggested that a processes are needed to ensure patients are not treated poorly or refused diagnosis, testing or treatment, and that a process is needed to correct incorrect medical records.

Very importantly, the issue of money came up. How should doctors be paid? But also it was also pointed out that a business case can be made for implementing changes since money is currently being wasted on ineffective appointments and testing with the societal cost of the illnesses are staggering.

PRINCE EDWARD ISLAND

- **QUEST 115 Summer 2018**

May 12th Awareness

Into the Light - An ME/FM Awareness Event with the P.E.I Lieutenant Governor

P.E.I. Lieutenant Governor, Madame Antoinette Perry, hosted an information and awareness session on May 16, 2018 at Government House. Entitled Into the Light, the event shone light onto ME and FM , two of the most prevalent illnesses in the world yet largely unknown.

Dolores Griffin, Her Honour Antoinette Perry, Dr. Jonathan Fox

Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS) is a debilitating illnesses characterized by persistent post exertional malaise and numerous other symptoms related to cognitive, immune and autonomous dysfunction which cannot be explained by any other medical condition. Fibromayalgia (FM) is characterized by chronic widespread pain of the muscles, ligaments and tendons and accompanied by other symptoms affecting various systems within the body.

There are nearly a million Canadians and approximately 4500 Islanders diagnosed with ME/CFS and FM for which there is no treatment or cure. These illnesses are more common than breast cancer, Parkinsons and MS combined.

It was special event with Dr. Jonathan Fox, MD from the Integrated Chronic Care Service in Fall River, NS as key note speaker. He is a specialist in the treatment and care of patients with ME/CFS and FM and multiple chemical sensitivities. The Center at which he works is the only one of its kind in the Maritime region and accepts referrals from other provinces.

The Center adopts a holistic approach to treatment and care and has a wide range of health care professionals on staff to meet the varied needs of its patients.

The event was also special in another way, in that the Kay Larkin, Janice Coady and Dolores Griffin followed Dr. Fox’s presentation by providing a perspective on the impact ME/CFS and FM has had on their lives. This was followed by a poem entitled Do You See Who I Am written and read by Rita Stanley who lives with the daily struggles of FM and the many other health issues that come with it.

There were over 60 people in attendance which included health care professionals, and organizations, government officials, politicians and policy makers, university staff and students and patients and their family and friends. Following the presentations, guests were treated to an afternoon tea hosted by Her Honour, Madame Perry.

The event was organized by Dolores Griffin, a local volunteer member of the ME/FM Acton Network, which is a national non-profit organization dedicated to supporting ME and FM patient through advocacy, information, research and education. Support for the event was also provided by Confederation Center of the Arts, Murphy's Pharmacies and the Dundee Arms Inn.

The event was also followed up by an interview with Dr. Fox by PEI's evening TV program Compass.

SENATOR STATEMENT

Remarks of the Honourable Diane F. Griffin Senator for Prince Edward Island
May 24, 2018

Honourable Senators,

May 12 was International Awareness Day for myalgic encephalomyelitis - also known as Chronic Fatigue Syndrome - and Fibromyalgia.

This date was chosen as it was the birthdate of Florence Nightingale, the British Army nurse who became chronically ill with what is thought to have been Chronic Fatigue Syndrome and was housebound and often bedridden for most of her life.

Symptoms include fatigue, inappropriate loss of physical and mental stamina after exertion, sleep dysfunction and pain. It also affects the neurological, endocrine and immune systems.

My own family has been impacted with two sisters-in- law, one with Chronic Fatigue Syndrome and the other with Fibromyalgia. These formerly very active women find it difficult to plan their lives as they don’t know how they will feel when the day of an event arrives. For instance, will they have the energy and feel well enough to participate in a family reunion and enjoy it? Another instance, a cousin had to retire early as a high school art teacher even though she loved teaching art to appreciative students.

There are not yet tests to identify Chronic Fatigue Syndrome or Fibromyalgia, so all other illnesses with overlapping symptoms must be ruled out before these diagnoses are considered.

Because we don’t have good diagnostic tools, it is hard for sufferers to get proper care.

There is much that can be done to help these Canadians including supporting research, raising awareness, combating stereotypes and ensuring programs are inclusive.

QUEBEC

QUEBEC

- **QUEST #94 Spring 2013**

Positive News from Quebec

As is probably the case in every Canadian province, Quebec has a problem with the recognition of ME/CFS. ME/CFS is a medical condition that is not well known in medical circles and the majority of people with it encounter serious difficulties in getting diagnosed and treated.

In 2010, AETMIS (the Quebec agency responsible for evaluating health technologies and interventions) now known as INESSS (the Quebec institute for excellence in health and social services), issued a report to the Minister of Health and Social Services describing the lack of resources and support for people with ME/CFS as well as the lack of knowledge among doctors about this health issue. AETMIS recommended better support for patients, the establishment of centers of expertise, strengthened initial and continuing medical education, and the encouragement of research around ME/CFS.

With this background, INESSS produced a brochure about ME/CFS aimed at the general public and the Quebec Ministry has started to set up a center of expertise in care and health services for people with ME/CFS. We are currently a long way from completion, but important stepping stones are being put in place. Responsibility has been given to the Constance Lethbridge Rehabilitation Centre which is affiliated with the "RUIS McGill", the health care network coordinated by McGill University. [There are four health care networks in Quebec based on the four faculties of medicine. Each network is responsible for health services to a section of the province.] The project involves developing the infrastructure to serve people with ME/CFS, to provide initial and on-going medical training about ME/CFS and to promote research into ME/CFS.

As you can tell, the challenge is immense, especially when you take into account that there is no infrastructure in place at the moment.

Representatives of AQEM (the Quebec Association for ME) met late last summer with Mme Lefebvre who was, at the time, the director of rehabilitation programs and Mme Bouvrette-LeBlanc, the project manager at Constance Lethbridge Rehabilitation Center, to discuss the scope of the work. Initially, this program will be developped for the area of Quebec served by the McGill health network. When the McGill program is up and found to be working, it could then be incorporated into the other university networks for Quebec to serve the whole province.

The meeting was very positive and, as a bonus, one or more representatives of AQEM will likely be invited to sit on the program development committee for ME/CFS services. That doesn't mean that we will have treating doctors tomorrow morning, but one thing is certain – our cause is moving forward and we can look to the future with optimism.

Claudine Prud'homme, Vice-president, Quebec Association for Myalgic Encephalomyelitis

REVENUE CANADA

1995

- **QUEST #14 – October 1995**

DISABILITY TAX CREDIT - Form T2201

As many ME/FM people have been denied this Credit, we instituted talks with Revenue Canada. We pointed out to them that this Credit was virtually impossible to obtain due to its stipulated wording. From our conversations, it was suggested that if you are denied this Credit 1) Appeal; 2) If Appeal denied, advise Revenue Canada that you wish to take your case to Tax Court. There is no costs involved in doing so. This will delay any payback for up to one year. This can be done easily without legal help. In the meantime are discussing with a Tax lawyer challenging this legislation in Court in order to address the unfairness of the legislation. Please remember to contact me if you are experiencing difficulties. **MIKE MARTIN, 31A Kadeer Way, Nepean, Ontario K2J 1J6 - Tel. (613) 825-2019.**

- **QUEST #15 – December 1995**

DISABILITY TAX CREDIT - Form T2201

We are in touch with The Hon. Paul Martin, P.C., MP, Minister of National Revenue, from whom we are awaiting a reply regarding the unfairness of this Credit to people who suffer from ME/FM.

Revenue Canada has indicated that it is willing to discuss the situation affecting persons with unique physical afflictions, and Mr. Siegel [lawyer] strongly suggests that this door be left wide open.

DISABILITY TAX CREDIT UPDATE: We have heard from a few people who advised us that they appealed to Revenue Canada regarding its refusal to allow the Credit. When they wrote their letter of Appeal, they received the response that their request was reconsidered and their Tax Credit was now allowed.

We also have been contacted by a person who went through a Tribunal review and she also was approved for a Tax credit.

We also received a reply from the Deputy Minister, Pierre Gravelle Q.C., who in his letter to us of February 13th, 1996 advises that should an individual have a balance outstanding, he would invite them to contact the Assistant Director of Revenue Collections at their local tax services office, in order that a review of their current financial situation may be completed and an arrangement concluded. He also stated that interest relief may also be considered in instances where an individual is experiencing financial hardship and has no ability to pay the liability in full, interest relief could be a possiblity.

We have written Mr. Gravelle again on February 26th in which we itemized ME/FM symptoms in accordance with their criteria list for a Tax Credit and how we felt it applies to ME/FM people. We will keep you advised of developments.

- **QUEST #16 February 1996**

DISABILITY TAX CREDIT UPDATE: We have heard from a few people who advised us that they appealed to Revenue Canada regarding its refusal to allow the Credit. When they wrote their letter of Appeal, they received the response that their request was reconsidered and their Tax Credit was now allowed.

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We have written Mr. Gravelle again on February 26th in which we itemized ME/FM symptoms in accordance with their criteria list for a Tax Credit and how we felt it applies to ME/FM people. We will keep you advised of developments.

- **QUEST #18 June 1996**

DISABILITY TAX CREDIT - UPDATE:

We had written a letter to Mr. Pierre Gravelle, Q.C., the Deputy Minister of Revenue Canada regarding the unfairness of the Disability Tax Credit Form T2201 and people who suffer from ME/FM and we asked for a chance to meet and discuss it.

As a result of this, we met with Mr. K.M. Burpee, Assistant Deputy Minister and Ms Edie Pastuch, Senior Programs Officer - Processing Division on April 16th. They pointed out that it is their job to enforce the *Income Tax Act* and that they have no authority to change it. They stated that the disability tax credit "recognizes that people with severe and prolonged disabilities have higher costs of living and working. The *Act* spells out the rules for claiming the Credit. The law is intended to define as severe any mental or physical impairment that is equivalent in its effect to being blind[or deaf] or confined to a bed or a wheelchair."

He also stated that "when establishing eligibility for the credit a physician has to consider whether the patient's ability to perform the basic activities of daily living is restricted all or substantially all the time (90%), and whether the use of aids or assistive devices reduces or alleviates the restriction. Two people with the same medical condition who have different levels of functional impairment may not both qualify for the credit."

As we were about ready to leave, Mr. Burpee mentioned that in the recent budget the government announced that it would look at measures for people with disabilities and advised us whom to contact about changes to the *ACT.* We therefore sent a letter on May 27th to the Honourable Paul Martin, Minister of Finance, House of Commons, Ottawa, Ontario K1A 0A6 outlining the difficulties ME/FM people are faced with regard to this Credit and we asked for a chance to meet with him with a view of considering making changes for ME/FM people, in the same way as exceptions have been made for people who are deaf or blind.

- **QUEST #18 June 1996**

DISABILITY TAX CREDIT - UPDATE:

We received a letter from Ms Jane Stewart, P.C., MP of the Minister of National Revenue's office dated July 12th, 1996. In this letter she stated that there have been many issues raised surrounding this tax credit and Revenue Canada has undertaken an extensive review of this disability tax credit program and concluded that many individuals did not understand the eligibility requirements for the credit. In order to improve this situation, Revenue Canada, in consultation with the Canadian Medical Association, stated that they have substantially revised Form T2201 to make it easier to complete and to provide more information about the eligibility requirements.

Ms Stewart stated that she has initiated a number of changes to the administration of the Credit within Revenue Canada to ensure each case is handled with compassion and that uncertainty is removed for those who apply for the credit. She cited as an example, that "new applications for the disability tax credit will now be reviewed **at the time of initial assessment to ensure that the eligibility requirements are met.**" She stated that this will significantly reduce the possibility of individuals claiming the credit only to find at a later date that they were not eligible. This means that a person will not be approved one year, only to find out later that he/she owes the tax department a lot of money due to the credit being denied at a later date when audited, resulting in other years being reviewed and disallowed.

Ms Stewart has asked our organization for its input of the draft 1995 version of the Disability Tax Credit Certificate and we therefore in turn sent a copy of the draft to some of the ME/FM specialists, Provincial Support Groups and our own Board of Directors. We were given a deadline of August 16th, 1996 so our time was limited but are pleased that they felt that we should be consulted due to our constant intervention of private individuals and the ME/FM people as a whole who are having this Certificate denied to them and owing sums of money that they can ill afford to pay. They assured us that our comments and suggestions will be given serious consideration.

We are pleased to say that about 3 people that we know of have been successful in reversing the decision of Revenue Canada and we are awaiting replies on others. If there is anyone who needs our help, please send us details of your problems with the tax department and enclose a Direction signed and dated authorizing us to intervene on your behalf. One of our members has volunteered to help us with this task. He has successfully challenged Revenue Canada.

We also received a copy of a letter from a member who had received it from the Hon. Paul Martin, PC, MP., Minister of Finance, dated August 9, 1994 in which Mr Martin stated "......I would like to explain the policy rationale that underlies the measure. The disability tax credit is intended to recognize the effect of a severe and prolonged disability on an individual's ability to pay tax."

We have therefore filed an ACCESS TO INFORMATION APPLICATION on July 26, 1996 under the Access to Information/Privacy Act requesting such things as the original intent of Section 118.4 of the Income Tax Act. We had contacted people in Revenue Canada asking them what the original intent of the Disability Credit was and they were unable to tell us that. They advised and the Finance Minister confirms that Revenue Canada only "administers and interprets the Income Tax Act." Somehow with all the changes in the past the intent has been buried. We therefore felt it was important to file the above Application to continue our intervention.

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- **QUEST #23 April 1997**

FORM T2201 DISABILITY TAX CREDIT - UPDATE

In the past couple of months, a new questionnaire (3 pages) has surfaced from Revenue Canada. This questionnaire is sent directly to the patient's doctor and seems to be a follow-up to the doctor's completion of Part B of Form T2201.

We have written a letter of complaint to Ms Jane Stewart, Minister of Revenue, as the questionnaire gets into so much detail that it will make it even more difficult to get this Tax Credit.

- **QUEST #26 October 1997**

DISABILITY TAX CREDIT - FORM T2201

In our ongoing negotiations with Revenue Canada, the Minister of Revenue, the Hon. Herb Dhaliwal, P.C., MP advised us in his letter of September 3rd, 1997 that tax credits made on 1994 returns, 84,000 were reviewed. During this review process, 67,200 claims were found to be eligible and were allowed.

Mr. Dhaliwal also advised that for the 1995 and 1996 taxation years, all new claims for the disability tax credit were reviewed prior to being allowed to individuals. This process significantly reduced the possibility of individuals claiming the disability tax credit only to later find out that they were not eligible. He reminded everyone that new claimants are required to file the Tax certificate for the first year in which the disability tax credit is claimed but that in subsequent years they can claim the disability tax credit without filing another certificate, provided they continue to qualify.

We are continuing with our negotiations with Revenue Canada because although it is an improvement that you are either allowed or denied the credit at the time of request for a tax credit, it leaves a lot to be desired for people who suffer from ME/FM. We will keep you advised.

- **QUEST #56 November 2002**

PROPOSED AMENDMENTS TO DISABILITY TAX CREDIT (FORM T2201) WITHDRAWN

In August 2002 the Federal Department of Finance announced that it was considering amendments to the Income Tax Act which would further limit who would qualify for the Disability Tax Credit. Due to the outpouring of the disability community, the controversial proposal was withdrawn and new consultations have taken place for a revised proposal. The deadline for these submissions was January 17, 2003. We await to see whether the new proposals will help or hinder applying for this Tax Credit.

Statistics Canada

- **QUEST #88 Summer 2011**

An in-depth look at the figures & findings of the 2010 Canadian Community Health Survey

- **QUEST #96 Fall 2013**

2012 Statistics Canada Data

You will remember that FM, CFS and MCS were included on the first three cycles of the Canadian Community Health Survey (CCHS) in 2001, 2003 and 2005. The sample size of these surveys was over 130k Canadians. When the CCHS moved to an annual basis in 2007, the sample size was reduced to about 60k per year and the questions on FM, CFS and MCS were dropped. After pressure from the community, survey officials agreed to include the questions on the CCHS in the years 2010 and 2014.

It turns out that, in addition to the regular CCHS for 2012, a special CCHS was run that year. The survey was restricted to the provinces (not territories) and to Canadians aged 15 and up (rather than 12 and up in the regular CCHS). The sample size was a much smaller 25k. The theme was mental health, but the survey included many of the chronic conditions on the regular CCHS, including diabetes, heart disease, high blood pressure, CFS and MCS. Two of the questions were “arthritis excluding fibromyalgia” and “back problems excluding fibromyalgia and arthritis”, but shockingly fibromyalgia itself wasn’t asked.

This survey was officially released on September 18, 2013. To protect the confidentiality of the respondents, the detailed data was not released. Instead, two articles and several tables were released to the public, and a “share file” was made available to government agencies and academic institutions but not the Network. The Network won’t have direct access to details until the “public use microdata file” is released until next spring. That puts us at a big disadvantage in talking to government officials who have access to the share file.

Through some begging, we were able to get the Canada totals for CFS (373k) and MCS (753k). The numbers were lower than in 2010, more than would be explained by removing the territories and the 12-14 year olds.

The drops might be due to sampling variability – 25k is a small sample - or it might be because people with MCS and CFS disproportionately opted out of the survey. It could also be a signal that the 2010 estimates were slight overestimates. For the time being, we don't know why the figures dropped a little, but we are sticking with the 2010 figures which are based on a larger sample size, include fibromyalgia, and are more accessible.

- **QUEST #97 Winter 2014**

Statistics Canada Canadian

Community Health Survey 2014

Statistics Canada will be asking about Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities on the Canadian Community Health Survey questionnaire throughout the year 2014. The questionnaire goes to about 1 in every 500 Canadians. Some readers of this newsletter could be asked to complete the survey.

If you are asked, we do encourage you to participate. The information provided in past surveys have been very useful to us.

One particular issue is Statistics Canada's use of the term "chronic fatigue syndrome". Many people prefer the term "myalgic encephalomyelitis". This has been drawn to Statistics Canada's attention, but it was too late to make a change to the 2014 survey. If you are surveyed and asked about "chronic fatigue syndrome", you can ask the interviewer to note that you prefer the term "ME" but please accept "chronic fatigue syndrome" for now. Otherwise, your experiences with ME won't be recorded.

- **QUEST #110 Spring 2017**

2015 CCHS Statistics

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

	Number, 2015	**% of target population**
Fibromyalgia		
Total	493,600	1.6%

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

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

- **QUEST #112, Fall 2017**

Special Issue

Under-Served and in Great Need

What the Canadian Community Health Survey
2005, 2010, 2014 tells us about
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia

Commentary

by Margaret Parlor

Under-Served and in Great Need

Statistics from the 2005 Canadian Community Health Survey (CCHS) showed that health and social systems in Canada were doing a very poor job of serving people with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM). One of the declared purposes of the survey is to provide information to government organizations to plan, implement and evaluate health and social programs. Despite the alarming statistics from 2005, there was little response from government organizations. Statistics for 2010 and 2014 show that

Canadians with ME/CFS and FM continued to be under-served and in great need.

While Quest has published statistics from the 2005, 2010, and 2014 surveys separately, this issue of Quest focuses on patterns over time. We look at characteristics of the ME/CFS and FM communities (age, gender and disability) and at health care utilization, but the primary focus of our analysis is on key variables that show how well health and social systems are supporting the ME/ CFS and FM communities.

There are some variables which should be of paramount concern to government departments and agencies at the

federal, provincial, territorial and local levels because they provide important information on how well the health and social systems are responding to the needs of a group. These key variables include:

- unmet health care needs,
- one’s sense of community belonging,
- income (poverty),
- food insecurity, and
- unmet home care needs.

While the provincial and federal governments have had access to information from the CCHS since the first cycle data was released in May 2002, the National ME/FM Action Network only became aware of the information following the release of two articles. The first was published in the Public Health Agency of Canada journal in 2006 using the 2001 data. The article focused on describing the group of Canadians with FM – prevalence, age, gender, etc. The second was published by Statistics Canada in 2007 using 2003 data and entitled “Medically Unexplained Physical Symptoms” to refer to ME/CFS, FM and Multiple Chemical Sensitivities. Like the first article, this article focused on group characteristics and not on an evaluation of the services (or lack thereof) offered by health and social systems.

In 2009, the National ME/FM Action Network jumped in with analysis from the 2005 survey. Our analysis found that people with ME/CFS and/or FM fared badly in terms of these key variables. The 2005 data sent clear signals that health and social systems were not working well for people with ME/CFS or FM. The statistics from 2010 and 2014 show no improvement.

What was happening (or not happening) during this period? And what do officials need to understand when they do step forward to help?

CCHS Basics:

The Canadian Community Health Survey (CCHS) is based on interviews with a random selection of Canadians aged 12 or older. It was originally a biannual survey that ran in 2001, 2003 and 2005. Respondents were asked if they were diagnosed with various chronic conditions. CFS, FM, and Multiple Chemical Sensitivities (MCS) were on the list.

In 2006, the survey became an annual survey. The number of respondents each year was half the number that had been in each of the first three cycles. The questions on CFS, FM and MCS were dropped from the questionnaire. The Network led a campaign to have these three conditions reintroduced, and officials agreed to include these chronic conditions in the years 2010 and 2014.

The survey was redesigned for the period 2015-2022. The sampling methodology was changed, as were the questionnaire and the instructions to interviewers. Because of these changes, Statistics Canada cautions against comparing data from 2015 onward with pre-2015 data. It was decided to include CFS, FM and MCS on the questionnaire in four of the eight years (2015, 2016, 2019 and 2020).

Data from the CCHS is personal and sensitive. Therefore, access to the data is carefully managed. Basic information from the survey is released free of charge. The Network relies primarily on the “Public Use Microdata File” which is provided free of charge and allows us to explore data in some depth. Unfortunately, this file is not released for months after the initial release. We will be asking Statistics Canada to make the tables referenced in this report available when each cycle of data is released.

Note that the CCHS questionnaire asks about “Chronic Fatigue Syndrome”. In 2015, an instruction to interviewers was added instructing them to accept the answer “Myalgic Encephalomelitis”. In this report, we use the term ME/CFS interchangeably with CFS.

The survey description, written when the survey was first developed, included the following sentence: "*Federal and provincial departments of health and human resources, social service agencies, and other types of government agencies use the information collected from respondents to plan, implement and evaluate programs to improve health and the efficiency of health services.*"

- **QUEST 117 Winter 2018**

Statistics Canada

Statistics Canada has advised us that the Canadian Community Health Survey for 2019 and 2020 will ask respondents if they have been diagnosed with Chronic Fatigue Syndrome and if they have been diagnosed with Fibromyalgia. It will not ask about Multiple Chemical Sensitivities.

The Canadian Community Health Survey has been an incredibly helpful source of information for us. It has provided evidence that people with a diagnosis of CFS and FM are dealing with serious disability, disadvantage and unmet needs. We therefore ask that, if you are contacted to participate in the survey, please do so.

We are well aware that many people would prefer that Statistics Canada use the term Myalgic Encephalomyelitis rather than Chronic Fatigue Syndrome. The problem is that not many Canadians use this term so ME would be dropped from the survey and we would be left without statistics. It is far preferable to have CFS statistics, then call for studies to determine how the diagnosis is made and what it means.

UNITED NATIONS

- **QUEST #95 Summer 2013**

United Nations Convention on the Rights of Persons with Disabilities

Canada ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) on March 11, 2010. The CRPD is based on the social model of disability and places obligations on governments to ensure that the human rights of persons with disabilities are respected. There is a reporting and review process to monitor whether governments are meeting their obligations. This article

- describes the social model of disability,
- lists some of the rights enumerated in the CRPD,
- looks at some of the ways government is called upon to support people with disabilities, and
- looks at the reporting and review process.

  The story in a nutshell? The CRPD could have been the springboard for the government to tackle a myriad of disability issues in Canada. Instead, the Canadian government has chosen a minimalist approach. (In contrast, Australia and New Zealand have taken proactive approaches.) On the positive side, the CRPD has been ratified by Canada and is another tool that Canadians can use to insist on basic human rights.