NATIONAL ME/FM ACTION NETWORK

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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.*
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> *"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,

MParlor

Margaret Parlor
President
National ME/FM Action Network

c.c. James Van Raalte
Jude Welch

Disability Action Items
Description and Status Report
National ME/FM Action Network
February 25, 2016

Building a healthy relationship

Background

The ME/FM community has encountered stigma and lack of cooperation. It has received little help in overcoming these challenges.

Action to date

Need identified

Next Step

Develop action plan in collaboration with ODI

CPP-Disability

Background

ME/CFS and FM often strike people in the workforce, robbing them of their ability to work and their financial security. The CPP-Disability program was designed for this situation. However, people with ME/CFS often have difficulty qualifying. Our organization has published a guide to help people through the process, but the problems go much deeper. We have identified a key goal "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." We should have added "without undue effort, cost, or delay."

Action to date

Met with Kris Johnson, Director-General of the program on January 19, 2016. He advised us that CPP-D medical staff would be reviewing the adjudication of ME/CFS and FM cases.

Followed up with a letter dated February 3, 2016 making a number of recommendations to improve the current situation.

The Auditor-General of Canada released an audit of the CPP-D program on February 2 which found that the application process is long and complex and also found that many of the applications sent to the Social Security Tribunal could have been approved earlier. A stakeholder meeting was held on February 17 to review broad issues. The National ME/FM Action Network was represented at that meeting.

Next step

Response from CPP-D.

Disability Tax Credit

Background

The DTC is a program which provides tax relief to qualified individuals. It has also been expanded to be the entry point into other benefits such as the Registered Disability Savings Plan. The qualification criteria are outlined in the Income Tax Act. The application form (Form 2201) is filled out by the applicant and must be signed by a designated health professional.

From our point of view, the application form does not "speak the language" of ME/FM applicants, the process in cumbersome, doctors are unsure how to complete the form, and many forms are being sent back to doctors for more information. We would like to work with the program to find solutions so that people with ME/CFS and FM who are deserving of the credit can receive it without undue effort, cost and delay.

Action to Date
February 16, 2016 - Asked ODI whom we should be contacting

Next step
Response from ODI

Home care

Background
Statistics Canada's Canadian Community Health Survey show that people with ME/CFS and FM report high levels of unmet home care needs compared to people with other chronic conditions or even to the elderly. Expanding home care is a Liberal priority. We want to ensure that people with ME/CFS and FM are not left out.

Action to date
Need identified

Next step
We are trying to figure out whom to contact

Work Accommodation Initiatives

Background
For patients with moderate or severe symptoms, employment would be contra-indicated, but for patients with stable, mild symptoms, some employment may be possible. The ME/FM community has developed a Functional Capacity Scale (which has been validated) that runs from 0 (completely bedbound) to 10 (very healthy and active). The rule of thumb is that a person has to be consistently at a level 6 before part time flexible work is even considered and consistently at level 7 before full time work is even considered. Other factors would come into play such as how strenuous the work is and how accommodating the workplace is. There is little research into ME/FM workplace issues and we are not aware of any ME/FM-specific employment support services. This is a topic that needs to be developed.

Action to date
February 16, 2016 – requested a meeting with ODI staff.

Next step
Response from ODI

Elections Canada – At-home voting

Background
Some people in the ME/FM community are home-bound and cannot cope with administration, but would still like to participate in the election process. We discovered that Elections Canada will come to private homes on request, look after the administrative matters, hand over a ballot package, and take away the completed ballot. The problem is that this service is not advertised. We are asking specifically that this service be readily apparent on the Elections Canada website.

Action to date
Contacted Elections Canada on August 6, 2015, September 9, 2015, and January 21, 2016

Next step
Response from Elections Canada