NATIONAL ME/FM ACTION NETWORK

● Phone 613-829-6667 ● Fax 613-829-8518
● 512-33 Banner Road
●Ottawa, ON K2H 8V7 Canada
●mefminfo@mefmaction.com
● (BN) 89183 3642 RR0001

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

NATIONAL
ME/FM
ACTION NETWORK

● Phone 613-829-6667 ● Fax 613-829-8518
● 512-33 Banner Road
●Ottawa, ON K2H 8V7 Canada
●mefminfo@mefmaction.com
● (BN) 89183 3642 RR0001

February 22, 2017

The Honourable Carla Qualtrough
Minister of Sport and Persons with Disabilities

Dear Minister Qualtrough,

RE: Follow-up from February 22, 2016 meeting

One year ago, we met to discuss disability issues facing Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM), or both. Statistics Canada's Canadian Community Health Survey 2014 found 800,000 Canadians with one or both diagnoses. The survey data showed that these Canadians had a high degree of disability, disadvantage, and unmet needs.

At that meeting, I identified five federal programs where people with ME/CFS and FM did not have full and fair access: CPP-Disability, the Disability Tax Credit, home care, workplace accommodations and voting in elections. We also talked generally about improving relationships between government and the ME/FM community.

In a follow-up letter to that meeting, I indicated that our organization would update you on progress every few months. I have postponed these updates until now, hoping for something positive to report. With the passage of a year, I have completed the update, inserting comments into the description and status report which was attached to that letter.

There have been a few glimmers of hope, but **there have been no tangible changes in the past year that address the accessibility issues experienced by the ME/FM community**.

MParlor

Margaret Parlor
President
National ME/FM Action Network

Disability Action Items
Description and Status Report
National ME/FM Action Network
February 25, 2016
Updated February 22, 2017

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

Update February 22, 2017: We have made submissions to the accessibility legislation consultation and the poverty reduction consultation. The poverty reduction officials invited us to meet with them to discuss our issues. The accessibility officials have not. We offered to partner with other disability groups on applications for federal funding related to the accessibility consultations but we were not approached by anyone. Our organization has been participating on a working group looking at funding of disability organizations. We see several fundamental problems. Firstly, the disabling aspects of ME/CFS and FM are not well recognized. Secondly, including ME/CFS and FM would expand the concept of disability beyond the concept traditionally used and there is no concomitant expansion of funding. This makes our presence uncomfortable. Thirdly, the funding model is based on partnerships and leveraging, while we are, at this stage, simply trying to become incorporated in existing government programs. We therefore do not fit within the model being proposed.

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.

Update February 22, 2017: CPP-D staff shared a draft adjudication guide for FM with us. We identified problems and have heard nothing since. We continue to be represented at round table meetings but no action has resulted.

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

Update February 22, 2017: Having received no response from ODI, we contacted the office of the Minister responsible for CRA who put us in touch with an official in the DTC program. The official explained that responsibility for the DTC is split between Finance (legislation) and CRA (administration). We wrote a letter to the official outlining how the ME/FM community encounters both legislative and administrative barriers to qualifying. We have not heard back from CRA on the administrative issues. We asked both CRA and ODI for a contact at Finance to pursue the legislative issues and have not been provided with one.

http://mefmaction.com/index.php?option=com_content&view=article&id=529:network-raises-issues-with-the-disability-tax-credit&Itemid=287

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

Update February 22, 2017: We learned that there is a standard questionnaire that is widely used in Canada to determine eligibility for home care and to monitor services. We purchased and reviewed the questionnaire and identified areas of bias which could help explain the unusually high level of unmet home care needs experienced by the community. We do not know where to take our findings.

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

Update February 22, 2017: No 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

Update February 22, 2017: Elections Canada replied May 2, 2016. They claimed that the information is easily accessible during general elections. They also noted that they take the information about at-home voting off the website between general elections. We think that this service should be advertised at all times. We have written Elections Canada pointing out that at-home voting should be available and advertised during by-elections as well as general elections.