Senate committee recommendations on DTC/RDSP – Please include the ME/FM community

To: Minister of National Revenue, Minister of Finance, Minister for Families, Children and Social Development and Minister for Persons with Disabilities
July 3rd, 2018

The National ME/FM Action Network is a Canadian charity working on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM), or both.

As you consider the government response to the report entitled Breaking Down Barriers by the Standing Senate Committee on Social Affairs, Science and Technology, we hope that you will recognize

- that the ME/FM community is a major disability stakeholder group and
- that significant changes are needed to the Disability Tax Credit eligibility requirements so that people with ME/CFS and/or FM have equitable access to DTC-based programs

and therefore the ME/FM community should be involved in the discussions that follow from the Senate committee's recommendations.

People with ME/CFS and FM have impairments of energy production and/or pain signalling which reduce the quantity of physical and mental activities people can undertake. People with relatively mild cases have to cut back on some of their activities, people with more severe cases are largely or completely homebound, while people with the most severe cases are bedridden. In other words, the ability of people with ME/CFS and/or FM to participate in society is reduced to some degree due to impairment. This is the essence of disability as described by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

One of our organization's key concerns has been the eligibility criteria of the Disability Tax Credit (DTC). Eligibility for the DTC is the entry point for income support programs including the Registered Disability Savings Plan (RDSP). The purpose of these programs is to recognize the additional expenses and loss of earning capability that come with disabilities. The DTC also signals to the public what the federal government means by disability.

The DTC eligibility criteria focus on specific activities. Many of our people, even some who are homebound and unable to work or study, can technically do each of the activities on the list if they need to. However, doing each activity means setting other activities aside. Further, people may experience repercussions from the effort of doing the activity. The DTC criteria, including the cumulative criteria, were written without serious consideration of this scenario. As a result, people may be very disabled and still not apply or qualify for the DTC.

The Canadian Community Health Survey (2014) showed that over 800,000 Canadians had a diagnosis of CFS, FM or both. Most people who are affected are women and of working age. People diagnosed with CFS and/or FM showed high rates of unemployment, poverty, food insecurity, and social isolation. This shows that social programs are not adequately reaching the ME/FM community You can see the statistics here:

English: http://mefmaction.com/docs/CCHS_Stats_2014.pdf

French: http://mefmaction.com/docs/CCHS Stats 2014 Fr.pdf

The CRPD describes disability as an evolving concept. We hope that the DTC criteria will evolve to recognize impairments in energy production and pain signalling so that people with reduced functional capacity will receive the social and financial support they badly need.

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