NATIONAL ME/FM ACTION NETWORK

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Sep 3, 2013

Hon. Rona Ambrose
Room 163 East Block
Ottawa, ON K1A 0A6

RE: FINA Pre-budget consultations – Recommendations affecting the Health Portfolio

Ms Ambrose

The National ME/FM Action Network would like to welcome you to your new position as Minister of Health. We look forward to working with you to address some very important health issues related to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM).

Our organization is a registered Canadian charity working on behalf of Canadians with ME/CFS and FM. According to Statistics Canada's 2010 Canadian Community Health Survey, there were over 750,000 Canadians who had been diagnosed with one or both of these medical conditions. The survey also shows that these conditions are very disabling. The US CDC official who was responsible for ME/CFS stated that the level of functional impairment in people with CFS is comparable to the functional impairment in people with Multiple Sclerosis, AIDS, end-stage Renal Failure, and Chronic Pulmonary Disease.

Even though ME/CFS and FM are extremely disabling, they have not been taken seriously by the Canadian health system. Patients with these conditions were found to have the highest rates of unmet healthcare needs of any of the chronic conditions on the 2010 Statistics Canada survey. There really isn't a health care "system" at all for ME/CFS and FM. There are, instead, pockets of expertise to build upon.

The lack of a system has serious consequences for patients and their families. It also has serious consequences for the Canadian economy and society. The illnesses are not well managed by the health system, meaning that there is inefficient and ineffective use of health care resources. Because patients are not adequately supported, their ability to contribute to the economy and to participate in society is reduced. Addressing issues around ME/CFS and FM would benefit all Canadians. There are many ways that the Health Portfolio can help.

At this time, we would like to draw your attention to our submission to the pre-budget consultation process of the House of Commons Finance Committee's (FINA). A copy of our submission is attached.

Our first recommendation concerns the Canadian Institutes of Health Research (CIHR). Despite the seriousness of ME/CFS and the advances being made internationally, CIHR has not approved any new funding applications that even mention ME/CFS for several years. There has been minimal funding of FM studies. CIHR did not attend the leading international conference on ME/CFS and related diseases that was held in Ottawa in September 2011. As the new Health Minister, I am sure that you will be uncomfortable defending CIHR's record on ME/CFS and FM and that you will be looking for a way to recognize the issues. We are suggesting a new institute with designated funding. You may be interested in viewing the report we wrote almost a year ago that underpins our request. http://mefmaction.com/?option=com_content&view=article&id=448&catid=69&Itemid=287

Our second recommendation is for a task force to review government information, services and programs around ME/CFS and FM. We are reminded what the Chief Public Health Officer wrote in his first annual report:

Canada has strong social policy foundations that have helped to make it both healthier and more egalitarian. Programs like the Canada and Quebec Pension Plans, Old Age Security, Employment Insurance, publicly funded health care and universal primary and secondary education have all helped to establish a minimum standard of living. This minimum standard is a critical factor in the health of Canadians. (page 62)

While the social policy foundations may be in place, they work only if they are accessible to those who need them. Canadians who are disabled by ME/CFS and FM have inordinate difficulties qualifying for CPP-Disability and other benefits, finding healthcare services and finding accommodation in the education system. Thus, they are falling below the minimum standard that has been set for Canadians. A task force could go a long way toward correcting this situation. We suggest to the Finance committee that funding could come from Health Canada just as HC funded the same type for initiative for mental health.

As you can see, there are a number of serious issues that need to be discussed. We hope to have the opportunity to meet with you and your staff before Parliament reconvenes this autumn to discuss these two recommendations and other issues facing the ME/FM community in Canada.

Margaret Parlor
President
National ME/FM Action Network