NATIONAL ME/FM ACTION NETWORK

● Phone 613-829-6667 ● Fax 888-522-8006
● 512-33 Banner Road
●Ottawa, ON K2H 8V7 Canada
●mefminfo@mefmaction.com
● (BN) 89183 3642 RR0001

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Canadian Pain Society
1143 Wentworth Street West
Suite 202
Oshawa ON L1J 8P7

Re: 2012 Canadian Guidelines for the diagnosis and management of fibromyalgia syndrome

Dear Dr Watt-Watson

The National ME/FM Action Network is a registered charity founded in 1993 to work on behalf of Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM). Our accomplishments are many, including

- Providing information on ME/CFS and FM through our website, newsletter and email bulletins.
- Providing individual support to many people with ME/CFS and FM.
- Spearheading the development of Canadian Clinical Working Case Definitions, Diagnostic and Treatment Protocols for both ME/CFS (2003) and FM (2004).
- Preparing educational material, such as a sourcebook for teachers of students with ME/CFS and FM and a guide for patients who are applying for disability benefits.
- Analyzing data from the Canadian Community Health Survey.
- Hosting the 2011 IACFS/ME biennial international conference on ME/CFS, FM and related diseases.

Canadians with FM reported the highest level of unmet healthcare needs of the 18 chronic conditions surveyed in the 2010 Canadian Community Health Survey. The current healthcare system is obviously not working well for FM patients.

We welcome initiatives that aim to improve healthcare for Canadians with FM. We therefore read with great interest the “2012 Canadian Guidelines for the diagnosis and management of fibromyalgia syndrome”. We recognize how valuable clinical practice guidelines could be and how ambitious it is to try to develop a set of guidelines for FM.

The stated objective of the exercise was “[t]o develop evidence-based guidelines for the evaluation, diagnosis and management of persons with FM in Canada taking into account new

advances in the understanding of the pathogenesis of FM and new diagnostic criteria, and to identify and assess the evidence supporting these recommendations." Evidence in this context means peer-reviewed articles.

The resulting document is very comprehensive. However, the conclusion we draw from it is that there are very few studies around FM in peer-reviewed journals that are stronger than opinion evidence. This is consistent with a topic that is in the relatively early stages of understanding. Of the 46 recommendations, 33 were given, in whole or in part, a level D or consensus rating meaning that the recommendations are based on opinion or on inconsistent or inconclusive studies. It is obvious that more research into FM is needed. The National ME/FM Action Network has already asked the federal Minister of Health to look at the lack of FM research in Canada. This document will be very helpful in demonstrating the state of knowledge.

Despite the weak level of evidence and the lack of involvement of patient organizations in developing the guidelines, they have been endorsed by the Canadian Pain Society and the Canadian Rheumatology Association and implementation activities are underway.

Our review of the guidelines tells us that they will have unintended unfavourable consequences. We can see these Guidelines leading to confusion, further deterioration in service for FM patients, and an increase in stigma. For example, we can foresee people being cut off disability benefits because of the definition change, people being pressured to return to work who really cannot cope, and people needing specialist services when none are available.

We are therefore requesting that the Canadian Pain Society and the Canadian Rheumatology Association suspend their endorsement of the current document and postpone implementation until the implications of the document have been discussed and resolved.

We know that it is possible to develop guidelines that could have a very positive impact on Canadians with FM. We hope you will agree to work with us to find ways to create clarity, improve service and reduce stigma for these Canadians.

Yours truly

Margaret Parlor
President