29th October, 2012

Dear Ms. Parlor,

Thank you for the interest that the National ME/FM Action Network has shown in the 2012 Canadian Fibromyalgia Guidelines. We appreciate your comments and would like to clarify a few points that have been raised.

The 2012 Canadian Fibromyalgia Guidelines were developed at the request of the Canadian Pain Society and followed a rigorous procedure as set down by the Oxford Centre for Evidence Based Medicine and the document was prepared in accordance the principles laid down for this process. In this context the full working group comprised health care professionals from various disciplines as well as a patient representative, who all had input into the final document as is stated in the guideline document. Of the 139 persons that participated in the needs assessment and were invited to contribute to the guidelines, 34 and the 11 members of the steering committee comprised the final working group, 2 of whom are medical advisors to the National ME/FM Action Network according to the ME/FM website. Therefore we believe that we have fairly included all stakeholders, with the exclusion of the pharmaceutical industry. We quote directly from the document as follows: **A patient representative made a significant contribution by reviewing each stage of the development of these guidelines. No representatives of pharmaceutical companies were involved in the guideline development.**

We appreciate your comments that the document is "*very comprehensive*". The intention of the guideline was as follows: **The guideline recommendations have been formulated in order to help healthcare physicians better diagnose, manage and follow patients with FM. Therefore, these guidelines are meant to be clinically useful. It is however recognized that each patient is unique and treatments should be individualized.** We would emphasize that guidelines are tools and not rules, and we have repeatedly stated throughout the document that each person should be treated as an individual.

We agree that there are many hiatuses in the understanding of fibromyalgia. There is a paucity of studies regarding diagnosis and patient trajectory that adhere to high standards in the peer review process, although there is ample literature available regarding treatments. Amongst the peer reviewed literature regarding treatments, there is also a mass of anecdotal or poorly executed studies. We believe that our process has provided some clarification on many issues of treatment that can be confusing to both the health care community and patients. Unfortunately *"weak level of evidence"* is not a justifiable reason to reject rational recommendations which were developed to facilitate care of these patients, but should provide a stimulus to further study.

In the absence of evidence in the literature, the medical community still needs direction and once again in accordance with the Oxford Centre for Evidence Based Medicine, the working group proceeded to provide response to the questions formulated by the needs assessment. Absence of evidence does not allow elimination of a question. We fully agree that more research is needed to better understand both the pathogenesis and management of fibromyalgia.

We respectfully disagree with your statements that these guidelines will have *"unintended unfavourable consequence"* or lead to *"confusion, further deterioration in service for FM patients and an increase in stigma",* or lead to *"people been cut off disability benefits because of the definition change, people been pressured to return to work who really cannot cope, and people needing specialist services when non are available".*

The goal for management of any health related condition should be towards attainment of optimum health, while taking into consideration contextual factors which include both personal and societal factors. Active patient participation in health care is vital and applies to all medical conditions. In the absence of a cure for fibromyalgia, the rational objective for Canadian persons with fibromyalgia should be to focus towards symptom alleviation where possible and retention of function.

We appreciate your interest in our endeavor and as you stated, we too hope that the 2012 Guidelines will *"be very helpful in demonstrating the state of the knowledge".*

Yours truly,

Mary-Ann Fitzcharles

On behalf of the 2012 Canadian Fibromyalgia Guideline committee