FIBROMYALGIA SOCIETY of EDMONTON and AREA
Support Advocacy Education Awareness
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Canadian Rheumatology Association
12-16715 Yonge Street, Suite 244
Newmarket, Ontario
L3X 1X4

The Canadian Pain Society
1143 Wentworth Street W., Suite 202
Oshawa, ON. L1J 8P7

Dear Sir/Madam,

The Fibromyalgia Society of Edmonton and Area has existed under various names for more than thirty years, providing support and guidance to persons with Fibromyalgia Syndrome and related conditions. The document, 2012 Canadian Guidelines for the diagnosis and management of fibromyalgia syndrome has been reviewed and discussed at a general meeting of our Society. This letter has been drafted to reflect the substance of our discussions. The letter was approved at the Annual General Meeting of the Fibromyalgia Society of Edmonton and Area on Saturday, June 15, 2013. We should add that, although our society is affiliated with the National ME/FM Action Network, this letter has been prepared on our own initiative and reflects our own independent opinions.

We should first make it clear that we strongly support any and all initiatives which have as their objective the improvement of the medical professions' and our understanding and treatment of Fibromyalgia. Our reservations, outlined below, should be considered in the overall context of this endorsement of the advancement of "patient-centred care" and research.

The freedom to undertake research, either as individuals or as members of a group, is an absolute right. This is not in dispute. However, it does not necessarily follow that the results of research have either merit or utility, and they must be validated before any qualitative claims are made - preferably through unrestricted peer review and consultation with other stakeholders. As far as we are aware, you have undertaken neither of these validation steps. *Ex cathedra* pronouncements are accepted only rarely from religious leaders and never from academic researchers. We estimate that there may be as many as two dozen national organizations and agencies in Canada which have an actual or potential interest in the diagnosis and treatment of Fibromyalgia Syndrome. Their opinions should not be ignored. We are very disappointed and concerned by your decision to not include them (and thus us) in your work in developing and, subsequently, distributing the Guidelines. We are also deeply concerned that "the patient voice" is missing. We do not believe that the involvement of one patient, no matter how knowledgeable and capable she may be, can come close to being accepted as adequate patient involvement in these 2012 Guidelines.

We are puzzled that there is no reference in your Guidelines to the 2004 document Fibromyalgia Syndrome: Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols–A Consensus Document (Journal of Musculoskeletal Pain Volume 11, Number 4, 2004, pp 3 - 108). We and many of our treating physicians have relied on this document for most of the past ten years, and it is our understanding that it has received wide approval, both nationally and internationally. Given the breadth of your initial consultation with "139 healthcare professionals", it is simply not possible that your committee was unaware of this document's existence, and there must therefore have been a conscious decision to exclude it from your review. We understand that a literature search which selected for patient treatment trials would not include a paper developed by clinicians and researchers at a workshop (i.e. the Consensus Document), but this is surely no reason not to acknowledge its existence. Perhaps there is another reason of which we are not aware; we shall be grateful if you would clarify this issue for us. In any event, we feel we must point out that the development of both your Guidelines and the 2004 Consensus Document have identical starting points and objectives, and the decision to exclude even a mention of the earlier document strikes us as absurd and disturbing.

In an article in the Calgary Herald on May 6, 2013, one of your Guidelines' co-authors, Dr. John Pereira, is quoted as saying, " [These] guidelines are the **first national set in the English-speaking western world.**" *(emphasis added)*. This statement is simply not true; a correction was sent to the newspaper but has not, to date, been published. If a university faculty member with a self-proclaimed interest in the treatment of fibromyalgia and chronic pain is either unaware of the 2004 Consensus Document or chooses to ignore its existence, there has been a serious breach of academic standards which could reflect poorly on the work of your committee.

We are disturbed by your comment about the distribution of these 2012 Guidelines as being of value to family physicians and only to patients "to a lesser degree". When patients meeting with their family physicians to find adequate treatment for Fibromyalgia Syndrome (and other diseases or co-morbidities) are not included in the distribution of the latest guidelines related to their diagnosis and treatment how do they have a proper discussion of their diagnosis and treatment with their medical caregivers? This raises a major concern about informed consent regarding medications and other treatments.

We also have to question the basic premise of the 2012 Guidelines that family physicians are competent to diagnose and treat patients with Fibromyalgia Syndrome without referral to a specialist. This presupposes that family physicians are also competent to distinguish between Fibromyalgia and other conditions, and also that this competence will be recognized by disability insurers and the courts. The reality is that many family physicians have limited knowledge about Fibromyalgia, and have a very limited timeline for appointments with their patients. You are now suggesting that they make lesser use of the resources which could help them work with patients who have a very complex disease and often other health issues. Too many of our members are already finding it very difficult to access the medical care they need and we feel strongly that these new 2012 Guidelines will only exacerbate this situation and have not provided the clinical physicians with the knowledge and support they need to care for Fibromyalgia patients.

In our view, a constructive next step would be to undertake a comparison of your Guidelines and the 2004 Consensus Document (having due regard for the age of the latter), to identify the differences between the two and discuss the reasons for them. We see a need to reconcile the two documents, to prevent confusion among patients and their treating physicians, and to protect patients from insurers and lawyers who insist on reports from specialists and certain tests/treatments in order to process disability claims. Their insistence on referrals from specialists to access rehabilitation and educational programs is also in jeopardy if physicians follow your 2012 Guidelines.

We trust that you will listen carefully to our concerns as we represent many Fibromyalgia patients who want their voices to be heard. It is crucial that there be a process put in place for a proper dialogue between those who have developed these 2012 Guidelines and the patients and primary care physicians who are affected by them. As we share a common concern for patient care for people with Fibromyalgia Syndrome it is very important that we find ways to work together.

Yours truly,

Christine Swaren

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John Wodak

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Disability Advocate

cc: National ME/FM Action Network
Canadian Medical Association Journal
Alberta Medical Association