NATIONAL ME/FM ACTION NETWORK

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A Step Backwards for Fibromyalgia

A major focus of this issue is on a document entitled "2012 Canadian Guidelines for the diagnosis and management of fibromyalgia syndrome". These guidelines have been endorsed by the Canadian Pain Society and the Canadian Rheumatology Association and are being shared with health professionals across the country. The National ME/FM Action Network was not involved in any way in the development of the 2012 guidelines.

While the National ME/FM Action Network welcomes initiatives aiming to improve the diagnosis and treatment of patients with FM, we have serious concerns about the 2012 guidelines. ***Our analysis suggests that the 2012 guidelines will lead to confusion, further deterioration in service for FM patients, and an increase in stigma.***

The National ME/FM Action Network has contacted the Canadian Pain Society and the Canadian Rheumatology Association asking them to suspend their endorsement of the 2012 Guidelines and to postpone implementation until the implications of the document have been discussed and resolved. We will also be talking to the federal government about the implications of the document.

In this issue, we also hear about recent developments around ME/CFS. Valerie Free of Alberta points out a number of positive events that have taken place in the last few months in the US and Canada. She sees a theme developing - creating a solution. Thank you Valerie for your analysis!

Margaret Parlor
President

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The 2012 FM Guidelines:

Why have Clinical Guidelines for FM?

In the 2010 Canadian Community Health Survey, Canadians were asked if they had been diagnosed with certain chronic health conditions. They were also asked if they had unmet healthcare needs over the past year. Here is a table showing the percentages of people with the various chronic health conditions who reported unmet healthcare needs.

Chronic Condition	% with unmet health care needs
Fibromyalgia	31%
Chronic fatigue syndrome	29%
Anxiety disorder	27%
Multiple chemical sensitivities	25%
Mood disorder	25%
Stomach or intestinal ulcers	22%
Chronic bronchitis/emphysema/COPD	22%
Bowel disorder/Crohn's disease/colitis	22%
Effects of a stroke	21%
Migraine headaches	20%
Back problems	20%
Asthma	17%
Arthritis	17%
Cancer	16%
Alzheimer's disease or other dementia	14%
Heart disease	13%
Diabetes	12%
High blood pressure	11%
Total population	11%

Table 1: Population Aged 12 and Over Suffering from Selected Chronic Conditions who have Unmet Health Care Needs, Canadaian Comunity Health Survey 2010 (Statistics Canada)

There are two key messages from the table.

The first message is that FM had the highest rate of unmet healthcare needs of any of the chronic conditions listed, with Chronic Fatigue Syndrome a close second.

The second message is that the rate of unmet healthcare needs for FM does not have to be nearly that high. There are other chronic conditions that are complex and disabling that have much lower rates of unmet healthcare needs.

The rate of unmet healthcare needs for FM could be brought to a much lower level if appropriate measures were taken. Measures include ensuring that there are trained health care professionals available and that health care professionals diagnose and treat the condition in appropriate ways. Clinical guidelines define the condition, describe the presentation and course of the illness, and set forth the desired outcome of treatment. In a nutshell, they advise healthcare professionals how to diagnose and treat patients. Guidelines also provide the framework for training programs and are referenced by social programs. Good clinical guidelines are very important for good health care and social support.

How were the 2012 FM Guidelines developed?

A document entitled “2012 Canadian Guidelines for the diagnosis and management of fibromyalgia syndrome” has just been released on the websites of the Canadian Pain Society and the Canadian Rheumatology Association. The full document is 44 pages with an additional 8 pages of appendices. A French translation of the Guidelines is also available.

English:
http://www.canadianpainsociety.ca/pdf/Fibromyalgia_Guidelines_2012.pdf

French:
http://www.canadianpainsociety.ca/pdf/Fibromyalgia_Guidelines_2012_fr.pdf

The 2012 guidelines were developed at the request of the Canadian Pain Society by the “Canadian Fibromyalgia Guidelines Committee (CFGC)” which is described as “a multidisciplinary team representing healthcare professionals from relevant fields managing FM patients, a patient representative, an external international expert, and a research coordinator”.

Canadian Fibromyalgia Guidelines Committee (CFGC)

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The authors of the 2012 guidelines wanted to develop "evidence-based guidelines" with evidence limited to articles in peer-reviewed journals. They identified, summarized, and graded 336 articles. Their work shows that there are very few articles about 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.

In contrast, the Canadian Consensus Document for FMS (2004) was developed by an expert panel selected by Health Canada. The panel included a representative of the National ME/FM Action Network. The panel looked at peer-reviewed material but considered clinical and patient experience as well. The 2004 document captures the chronicity and complexity of FM in ways that the 2012 guidelines do not. The 2012 guidelines do not even mention the 2004 document.

The 2012 guidelines were developed according to these steps:

1. Using input from 139 Canadian healthcare professionals, the committee developed a set of 18 questions that health professionals would like answered, such as (1) how should FM be diagnosed and (7) how should patients with FM contribute to their management.

2. These questions were used to guide a literature review from the following databases: EMBASE, MEDLINE, PSYCHINFO, PUBMED and the Cochrane Library covering the period 1990 to July 2010. Only literature on those data bases was considered to be valid evidence. Important literature like the 2004 Canadian Consensus Document, Dr Bested's book "Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia" and the analysis from the 2005 Canadian Community Health Survey were not included in the valid evidence.

3. Relevant articles were assessed from Level 1 (strongest evidence to support the article's conclusion) to Level 5 (opinion evidence).

4. Recommendations were developed by the committee. They were sent by internet to 35 members of an "advisory board" and approved if 80% of board members voted yes. The recommendations were graded from Grade A (strong evidence to support) to Grade D (based on opinions or inconsistent/inconclusive studies). Grade D recommendations were upgraded to "consensus" if all the members of the committee agreed to the recommendation.

Of the 46 recommendations, 33 were assessed in whole or in part at level D or consensus, meaning that the evidence that was found was weak or non-existent. Nevertheless, the Canadian Pain Society and the Canadian Rheumatology Association endorsed the recommendations.

The next planned step is "implementation", with committee members making the document and recommendations much more widely known among health care professionals. This is already underway, so FM patients may encounter these recommendations when dealing with health professionals anytime in the future.

What do the 2012 recommendations say (or don't say)?

We are including the 2012 recommendations in this newsletter so that you have them for reference. Here are some of the issues that we have identified.

The 2012 guidelines recommend using the 2010 ACR alternate definition and dropping the tender point test.

In 1990, the American College of Rheumatology (ACR) defined FM based on wide-spread pain and the existence of tender points. In 2004, the Canadian expert panel accepted that definition but went on to note that Fibromyalgia is often associated with other symptoms that contribute to the burden of illness. In 2010, the ACR suggested a new definition incorporating other symptoms while dropping the requirement for tender points.

The 2010 ACR definition had two parts. Part 1 looks at joint/body pain. Crucially, there is no requirement for tender points. Part 2 looks at other symptoms under 4 categories: fatigue, waking unrefreshed, cognitive symptoms and somatic symptoms. Forty-one somatic symptoms are listed.

In 2011, a modification to the 2010 definition was proposed in a journal article. The list of somatic symptoms is reduced from 41 items to three (pain or cramps in the lower abdomen, depression and headaches).

The 2012 guidelines committee recommends that the health care system use the 2010 version of the alternate definition. This drops the 1990 definition and its requirement for tender points. However, Appendix D uses the 2011 modification. Do the 2012 guidelines

recommend the 2010 definition or the 2011 variation? It is not clear.

An editorial published along with the 2011 modification identified 4 undesirable consequences that could come with using the 2010 or 2011 definition rather than the 1990 definition:

- the inclusion of milder cases changes prognosis
- the various definitions identify different patient groups
- the 2010/11 criteria fail to discriminate symptoms of FM from other rheumatic diseases.
- the 2010/11 criteria reduce the ability to recognize FM concurrent with other diseases.

Definitions are very important for diagnosis, but they are also very important for research as we have seen with ME/CFS. Studies based on one definition may not be applicable to patients diagnosed under another definition. There is also a problem with definitions that describe heterogeneous cohorts. Some patients may respond to treatments while others don't, but the study's findings may be said to apply to everyone.

There are practical implications to changing definitions. Patients who qualified under the 1990 definition may not qualify under the 2010 definition and vice versa. If insurance companies and social agencies adopt the 2010 definition, a diagnosis based on the 1990 definition may or may not be accepted when patients apply for disability benefits. Patients who previously qualified for benefits using the 1990 guidelines may be called upon to re-qualify.

The strengths and weaknesses of the various FM definitions need to be studied and documented. Changing definitions should not be taken lightly.

The 2012 guidelines recommend diagnostic criteria which includes depression as a featured symptom.

In the 2010 definition, depression is one of 41 somatic symptoms listed. In the 2011 modification, it is one of three symptoms that are each worth one point in making a diagnosis.

Anyone contracting a life-altering chronic illness might experience feelings of frustration or depression, but depression is not a diagnostic criteria for other illnesses. It is very important to keep FM and depression separate. Dealing with illness and dealing with the emotional aspects of an illness are both important, but they should not be blended. FM patients often feel that too much emphasis is being put on the emotional component and not enough on the illness itself.

We often use a test when checking a statement for fairness and reasonableness. We ask if the same statement would be made for another illness such as diabetes. Can people with diabetes be depressed? Some may be. Can people with diabetes benefit from psychiatric or psychological help? Some may benefit. Is depression a diagnostic criterion for diabetes? No. The focus is on the pathophysiology of diabetes.

Here are some observations from the Canadian Community Health Survey:

- About a quarter of Canadians reporting a diagnosis of FM also reported a diagnosis of mood disorders (and the other three quarters did not report a diagnosis of a mood disorder).
- About a third of Canadians reporting a diagnosis of FM also reported a diagnosis of mood disorders and/or anxiety disorders (and the other two-thirds did not report a diagnosis of either a mood disorder or an anxiety disorder).
- Over half of Canadians with FM reported a co-diagnosis of Arthritis.

Making depression a diagnostic criteria sends the message that depression is an integral part of FM. Healthcare professionals and the broader public will be more likely to assume that FM and depression go hand in hand.

The 2012 guidelines put the responsibility for diagnosis and continuing care on family doctors and discourage referrals to specialists.

This recommendation needs to be considered in conjunction with two published articles.

The first article was an editorial written in 2009 by two members of the Canadian Fibromyalgia Guidelines Committee (Shir and Fitzcharles) entitled “Should Rheumatologists Retain Ownership of Fibromyalgia?” In the editorial, they say

“The time is ripe for rheumatologists to consider abrogating care of [FM] patients for these reasons:

- the pathogenesis of FM is now firmly centered in the nervous system, and FM is not a musculoskeletal complaint

- Optimal patient management requires attention to the many symptom components of FM in addition to pain management
- Patients with FM will also require prolonged care with continued tailoring of treatments, as symptoms are likely to change over time
- Finally, as 2% to 4% of the population suffers from FM, it would be unrealistic to require that all or most of these patients be evaluated or followed by rheumatologists."

The editorial also states that:

"We propose that primary care physicians are today the most appropriate and best qualified physicians to manage these patients. Other healthcare professionals such as neurologists, psychiatrists, or psychologists may be equally capable of managing patients with FM, but again, resources are limited and would likely preclude continued care and followup."

This was followed by a survey of Ontario rheumatologists published in 2012. Here is the abstract:

"Fibromyalgia is a controversial widespread chronic pain disorder that includes a wide constellation of somatic and emotional symptoms. This study surveyed the opinion of Ontario rheumatologists with respect to their beliefs about the nature and management of fibromyalgia. A key objective was to ascertain if rheumatologists should continue to be the main care providers for these patients. A survey comprising 13 questions was sent electronically to all 150 Ontario rheumatologists. The questionnaire was designed to obtain demographic data as well as opinions regarding different aspects of fibromyalgia. Data were analyzed descriptively, and comparisons were made using chi-square tests. A total of 80 respondents completed our survey for a completion rate of 53 %. The majority had completed their training in Canada (85 %) and had been practising for more than 15 years (50 %). Key findings were: (1) 71 % believe that rheumatologists should not retain ownership of fibromyalgia, (2) 55 % believe that fibromyalgia is primarily a psychosomatic illness as opposed to a physical illness, (3) 89 % believe that the family physician should be the main care provider for these patients, and (4) rheumatologists who consider fibromyalgia to be a physical illness were also significantly more likely to believe that rheumatologists should retain ownership of this disease (p=0.023) and were more likely to continue managing these patients in their practice (p=0.011). The majority of Ontario rheumatologists do not wish to retain ownership of fibromyalgia. However, most of them continue to manage these patients, even though they believe that the family physician should be the main care provider for patients with fibromyalgia. Rheumatologists may be providing care to these patients primarily because this care is not available to them from their primary care physicians."

Note that there are rheumatologists who believe that FM is a physical illness and want to continue providing services. If you are seeing a rheumatologist who is being supportive, be sure to thank him or her.

There is no doubt that family doctors can and do play a role in FM care. Whether they should have as large a role as is proposed needs to be debated. And even if the family doctors have a larger role, there needs to be a specialty to support the family doctors, to handle difficult cases, and to lead research.

Patients seeing specialists may be sent back to their family doctors. Patients may find it more difficult to get referrals to specialists. If rheumatologists do not retain ownership of FM, where will there be center of expertise for diagnosis, treatment and research?

The 2012 guidelines set no expectation or requirement that the physician assess the patient's total illness and determine the burden on the patient's life.

The recommendations fail to validate the patient's suffering by failing to acknowledge or discuss the extent of the burden the illness may bring.

The 2004 Canadian Consensus Document, on the other hand, provide the following guideline: "Assess the Patient's Total Illness: The clinical status of FMS is arrived at by consideration of the total burden of illness on the patient's life. This requires an assessment of all of the patient's symptoms, as well as a working knowledge of the demands associated with the patient's lifestyle, occupation, etc."

The 2004 Document goes on to instruct the clinician that: "the [therapeutic] program must reflect the patient's total illness burden. The patient's impairments, their interactions and any aggravating or extenuating circumstances, must be assessed and reflected in the program."

Without assessing the illness burden, the health care provider may not fully understand, recognize or document the severity of the impact of FM on the

patient, leaving the patient feeling misunderstood, invalidated and potentially exposed to attitudes and decisions (by disability insurers, social agencies, employers, family and friends, etc.) which fail to acknowledge the extent of disability.

The 2012 guidelines fail to recognize the dynamic nature of the illness and that patients must respect the limitations imposed by their illness in order to manage its impact.

"The biopsychosocial model is a general model or approach that posits that biological, psychological (which entails thoughts, emotions, and behaviors), and social factors, all play a significant role in human functioning in the context of disease or illness. Indeed, health is best understood in terms of a combination of biological, psychological, and social factors rather than purely in biological terms." (J.W. Santrock).

While the 2012 guidelines recognize that FM is biologically real, there is not a consistent recognition that the biological aspects of the illness can actually affects the functioning of patients. Thus, for instance, patients are invited "to pursue as normal a life pattern as possible" when, for many patients, life is nowhere near normal. Vocabulary used in the discussion includes "self-efficacy" and "locus of control". The implication is that the illness has little impact and that patients have a fair amount of psychological control over the health outcome.

The 2012 guidelines note parenthetically that FM is a "condition that can wax and wane over time" but they fail to provide any discussion or validate the experience of the FM patient that "the more I do, the worse I get." This rebound response to activity will be confused with the simplistic view that the condition is simply fluctuating, rather than recognizing that the severity of the illness burden can increase to and remain at incapacitating levels with excessive levels of activity.

The 2012 guidelines state that "…fear of pain and activity is reported by almost 40% of FM patients and…fear avoidance should be addressed to maintain adherence to exercise recommendations." The guidelines go on to state, "Education and active participation with reassurance regarding "no harm" caused by physical activity should be the focal point of treatment, especially if a patient is passive regarding health and lifestyle practices."

In contrast, the 2004 Canadian Consensus Document notes:

"The Pathophysiology of FMS must be respected and reflected in the program.

- The complexities and interactive nature of the varied dysfunctions of FMS are a physiological reality of the illness and must be accommodated.
- The symptoms and activity boundaries of FMS patients fluctuate on a day to day and even hour to hour basis.
- Avoid exacerbating the patient's symptoms."

The consequence of the 2012 guidelines is that the patient may be instructed to push beyond the physiological limits imposed by their illness thereby increasing the risk of rebound symptoms and even relapse and the patient may be characterized as passive or afraid of physical activity or non-compliant if their symptoms legitimately restrict their activity. By missing the illness burden and interactions, the healthcare provider may be prolonging suffering and impeding potential for recovery.

The 2012 guidelines discourage healthcare professionals from ordering any but very basic medical tests.

The 2004 Canadian Consensus Document also notes that few laboratory and investigative tests are useful to diagnose FM. It advises clinicians to carefully evaluate the cost-benefit ratio of additional tests and to avoid unnecessary duplication. However, the 2004 Document is more encouraging of additional testing to understand the illness and to rule out other conditions.

The 2012 guidelines recommend graduated exercise programs.

The literature is more nuanced than Recommendation 21 would suggest. Here is a quote from the Cochrane review on "Exercise for treating fibromyalgia syndrome", a key document in giving this recommendation a grade of A.

"[T]he exercise programs that were studied were safe for most. The intensity of aerobic exercise training should be increased slowly aiming for a moderate level. If exercisers experience increased symptoms, they should cut back until symptoms improve. If in doubt

about adverse effects, they should check with a health care professional.

The 2004 Canadian Consensus Document spends several pages on exercise, with the theme that as much care must be taken in prescribing exercise as prescribing medication, and that the exercise program must be specific for the physiological pathology of FM and must be adapted to the patient's abilities and limitations.

The 2012 guidelines say that there is currently insufficient evidence for healthcare providers to recommend complementary and alternative treatments.

Examples of complementary and alternative treatments include supplements, dietary interventions, spiritual interventions, acupuncture, massage, etc. It is important to remember that the committee only considered information from peer-reviewed sources. The lack of information from these sources does not necessarily mean that the treatments have no benefits. If the healthcare profession is going to require peer-reviewed evidence, they should be organizing peer-reviewed research. In the absence of this research, they could be listening to the experience and wisdom of patients.

Patients may not get much support from their health care providers for complementary and alternative therapies. Social and insurance programs may use these recommendations to deny financial assistance for these therapies.

The 2012 guidelines recommend a multi-pharmacological approach for symptom relief, but focus primarily on pain.

The 2012 guidelines focus on the pain relieving qualities of the medications reviewed and their ancillary benefits on other symptoms, but do not fully recognize the interactivity of symptoms with the potential for alleviating the total burden of the illness. For example, there is very little discussion of the very prevalent problem of sleep dysfunction which, if treated, can have the very beneficial outcome of pain relief. Interestingly, the guidelines neglect to provide any guidance whatsoever on the importance of sleep hygiene in the education and self-management protocols.

Likewise, there is little discussion on other debilitating symptoms. Potential targeted pharmacological remedies for fatigue, restless leg syndrome, IBS, bladder dysfunctions, vertigo, dizziness and cognitive impairments are lacking.

The 2004 Canadian Consensus Document takes a different approach in presenting pharmacological treatments by prevalent symptom, rather than just by the pain relieving effects of the medication. This allows for detailed reference to each medication, recommendations for dosing for the specific FM symptom, and the common side effects for each medication. For the most part, the medications referenced by both documents is similar but the 2012 guidelines lack detailed information on dosing and side effects and lack detailed recommendations by prevalent symptom even though they recommend a 'symptom-based' approach. For the treating physician looking for guidance, the 2004 Canadian Consensus Document is more comprehensive and likely easier to follow.

The 2012 guidelines do not emphasize the pharmacological sensitivity of FM patients and the need for individualization.

The 2012 guidelines do acknowledge the need to start patients at low doses of medications and titrate upwards cautiously, but they fail to acknowledge the extreme sensitivity of FM patients to even the lowest possible doses, nor advise physicians that optimum dosing for beneficial effect is often typically well below traditional therapeutic levels and it may take several weeks/months before the benefit is evident at such low doses. Again, careful dosing with close and frequent monitoring is essential for appropriate care of this patient group.

The 2004 Canadian Consensus Document provides the following observation for physicians regarding pharmacological treatments;

"Target Therapy of FMS. It is anticipated that the optimal therapy for FMS in the near future will be established using a limited cocktail of low dose medications, with each target a specific receptor known to be involved in the pathogenesis of FMS. By keeping the dosing below the usual toxicity level for each and choosing agents with different kinds of toxicity, it may be possible to achieve clinical benefit while avoiding toxicity."

While the 2012 guidelines note that there is very little evidence for any of the remedies reviewed in the treatment of FM, the guidelines fail to note that no

remedy has been shown to help all patients in clinical practice. The pharmacological (and indeed overall treatment program) must therefore be highly individualized and the physician must use a pharmaceutical approach of trial and error, carefully adding or subtracting remedies one at a time while watching for deleterious side effects and providing ample time for the medications to show any beneficial effect which is typically longer than usual. Likewise, there is little discussion or specific guidance on the need for frequent and thorough follow-up to determine the efficacy of the pharmaceutical approach.

The 2012 guidelines describe the symptoms of FM as 'bothersome' rather than 'serious'; and say that adverse medication effects are rarely serious or life-threatening.

This again reflects the lack of understanding or acknowledgment of the total illness burden.

The 2012 Guidelines are non-specific around desired outcomes.

There is a saying that you can't improve what you don't measure. Nevertheless, the Guidelines suggest that progress can be assessed simply by a narrative report from patients.

What's Next?

The National ME/FM Action Network has written the Canadian Pain Society and the Canadian Rheumatology Association pointing out that they have endorsed recommendations that are not, for the most part, evidence based and that the consultation process did not include the FM patient community. We have asked that they suspend their endorsement of the recommendations and open up a consultation process. We invite individuals, groups and organizations to contact them as well.

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The National ME/FM Action network will also be talking to federal government officials about the situation since the recommendations raise important issues about health care in Canada.

Meanwhile, however, the Guidelines are in circulation and may be acted upon by the healthcare and social service providers you meet. We are suggesting that you familiarize yourself with the recommendations and the attitudes expressed in the document so that you are not taken by surprise if you encounter them. Forewarned is forearmed.

Thank you to Susan MacLean, President of the ME/FM Society of BC, Maureen MacQuarrie, and Anne Marie MacIsaac for their valuable insights into the 2012 guidelines.

The 2012 Recommendations

*Note to assist you when reading the recommendations: Level 5 [1,2], Grade D (example taken from Recommendation 3) means that the evidence, which is in the articles cited in footnotes 1and 2 of the full document, was assessed at level 5 (opinion) and the recommendation is assessed at Grade D (which means that it was based on opinion evidence or on inconsistent or inconclusive studies)

Section 1: The diagnosis

The clinical evaluation	1. Fibromyalgia, a condition than can wax and wane over time, should be diagnosed in an individual with diffuse body pain that has been present for at least 3 months, and who may also have symptoms of fatigue, sleep disturbance, cognitive changes, mood disorder, and other somatic symptoms to variable degree, and when symptoms cannot be explained by some other illness [Level 5 [2, 12, 45, 46], Grade D]. 2. All patients with a symptom complaint suggesting a diagnosis of fibromyalgia should undergo a physical examination which should be within normal limits except for tenderness on pressure of soft tissues (ie. hyperalgesia which is increased pain following a painful stimulus) [Level 4 [2, 3, 66], Grade D]. 3. Examination of soft tissues for generalized tenderness should be done by manual palpation with the understanding that the specific tender point examination according to the 1990 ACR diagnostic criteria is not required to confirm a clinical diagnosis of fibromyalgia [Level 5 [1, 2], Grade D].

Testing & confirming the diagnosis	4. Fibromyalgia should be diagnosed as a clinical construct, without any confirmatory laboratory test, and with testing limited to simple blood testing including a full blood count, erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), creatine kinase, and thyroid stimulating hormone (TSH). Any additional laboratory or radiographic testing should depend on the clinical evaluation in an individual patient that may suggest some other medical condition [Level 5 [75, 76], Grade D]. 5. The primary care physician should establish a diagnosis of fibromyalgia as early as possible, without need for confirmation by a specialist, and communicate this diagnosis to the patient. Repeated investigations after diagnosis should be avoided unless driven by the onset of new symptoms, or signs on physical examination [Level 5[6, 77, 82, 83], Grade D]. 6. The ACR 2010 diagnostic criteria for fibromyalgia can be used at initial assessment to validate a clinical diagnosis of fibromyalgia with the understanding that symptoms vary over time [Level 3 [1, 2, 58], Grade B].

Differential diagnosis & coexisting conditions	7. Healthcare professionals should be aware that some medical or psychological conditions may present with body pain similar to fibromyalgia, and patients with other medical illnesses may have an associated fibromyalgia [Level 5 [76, 86, 87, 90, 91], Grade D].

The healthcare team	8. Management of persons with fibromyalgia should be centered in the primary care setting with knowledgeable healthcare professionals, and ideally, where possible, this care may be augmented by access to a multidisciplinary team [Level 1 [96, 97], Grade A] or team member to provide support and reassurance [Level 3 [101, 102], Grade C]. 9. Specialist consultation, including referral to a sleep specialist or psychologist may be required for selected subjects, but continued care by a specialist is not recommended and should be reserved for those patients who have failed management in primary care or have more complex co morbidities [Level 5 [77], Grade D].

Education & knowledge	10. In caring for persons with fibromyalgia, healthcare professionals should be educated regarding the pathogenesis of fibromyalgia [Level 5, Consensus], empathetic, open, honest, should not demonstrate negative attitudes, and should practice shared decision-making [Level 3 [106, 107, 110], Grade D]. 11. Healthcare professionals should be knowledgeable that objective neurophysiologic abnormalities have been identified in patients with fibromyalgia in the research setting, but are not available in clinical practice for either the diagnosis or care of persons with fibromyalgia [Level 5 [111, 117], Grade D]. 12. Patients and healthcare professionals should acknowledge that genetic factors as well as previous adverse events may have contributed to the development of fibromyalgia, but focusing excessively on a triggering event could compromise patient care and should therefore be discouraged [Level 5 [123, 126, 130], Grade D].

Section 2: Management

Treatment overview	13. A treatment strategy for patients with fibromyalgia should incorporate principles of selfmanagement using a multimodal approach [Level 1 [131, 132], Grade A]. It is recommended that attention should be paid to individual symptoms in a patient tailored approach, with close monitoring and regular follow-up, particularly in the early stages of management [Level 5 [131] Grade D]. 14. Patients should be encouraged to identify specific goals regarding health status and quality of life at the initiation of treatment, with re-evaluation of goals during the follow-up [Level 5 [102], Grade D].

Non pharmacologic overview	15. Non pharmacologic strategies with active patient participation should be an integral component of the therapeutic plan for the management of fibromyalgia [Level 1 [132, 137], Grade A]. Encouraging selfefficacy and social support will facilitate the practice of health promoting lifestyles [Level 3 [141, 142], Grade D]. 16. Persons with fibromyalgia should be encouraged to pursue as normal a life pattern as possible, using pacing and/or graded incremental activity to maintain or improve function [Level 4 [143, 144], Grade D].

Psychological interventions	17. The attainment of effective coping skills and promotion of self-management can be facilitated by multicomponent therapy [Level 5 [137], Grade D]. 18. Interventions that improve self-efficacy should be encouraged to help patients cope with symptoms of fibromyalgia [Level 1 [168], Grade A]. 19. Psychological evaluation and/or counselling may be helpful for persons with fibromyalgia in view of the associated psychological distress [Level 5, Consensus], and patients should be encouraged to acknowledge this distress when present and be informed about the negative impact this may have on wellbeing [Level 3 [149], Grade D]. 20. CBT even for a short time is useful and can help reduce fear of pain and fear of activity [Level 1 [150, 151], Grade A].

Physical activity	21. Persons with fibromyalgia should participate in a graduated exercise program of their choosing to obtain global health benefits and probable effects on fibromyalgia symptoms [Level 1 [174-178, 184, 185], Grade A].

Complementary and Alternative Medicine	22. Patients should be informed that there is currently insufficient evidence to support the recommendation of complementary and alternative medicine (CAM) treatments for the management of fibromyalgia symptoms, as they have mostly not been adequately evaluated regarding benefit [Level 1 [194, 195, 200], Grade A]. 23. Patients should be encouraged to disclose use of CAMs to the healthcare professional who should be understanding and tolerant of this disclosure and should provide information on current evidence-based understanding of efficacy and risks where available [Level 5, Consensus].

Pharmacologic overview	24. Physicians should identify the most bothersome symptom(s) in order to help direct pharmacologic treatments according to a symptom-based approach. An ideal pharmacologic choice may address multiple symptoms simultaneously and may require a combination of medications, in which case attention must be paid to drug interactions [Level 5 [111, 131], Grade D]. 25. Pharmacologic treatments should be initiated in low doses with gradual and cautious upward titration to reduce medication intolerance [Level 5 [131], Grade D] with regular evaluation regarding continued efficacy and side effect profile, with the knowledge that drug side-effects may appear similar to symptoms of fibromyalgia [Level 5, Consensus]. 26. Physicians prescribing medications for fibromyalgia should be open-minded and aware of the broader spectrum of agents available to treat symptoms, and should not confine treatments to a single category of medications [Level 5, Consensus].

Traditional pain relieving therapies	27. In line with the World Health Organisation step-up analgesic ladder, acetaminophen may be useful in some patients, but with attention to safe dosing [Level 5, Consensus]. 28. In the event that NSAID's are prescribed, particularly for associated conditions such as osteoarthritis, they should be used in the lowest dose and for the shortest period of time in view of possible serious adverse events [Level 5 [218, 219], Grade D]. 29. A trial of opioids, beginning with a weak opioid such as tramadol, should be reserved for treatment of patients with moderate to severe pain that is unresponsive to other treatment modalities [Level 2 [208, 224], Grade D]. 30. Strong opioid use is discouraged, and patients who continue to use opioids should show improved pain and function. Healthcare professionals must monitor for continued efficacy, side effects or evidence of aberrant drug behaviours [Level 5 [233], Grade D].

Non-traditional pain relieving therapies	31. A trial of a prescribed pharmacologic cannabinoid may be considered in a patient with fibromyalgia, particularly in the setting of important sleep disturbance [Level 3 [236, 238, 239], Grade C]. 32. The pain-modulating effects of antidepressant medications should be explained to patients with fibromyalgia in order to dispel the concept of a primarily psychological complaint [Level 5 [249], Grade D]. 33. All categories of antidepressant medications including TCAs, SSRIs and SNRIs may be used for treatment of pain and other symptoms in patients with fibromyalgia [Level 1 [243, 248], Grade A], with choice driven by available evidence for efficacy, physician knowledge, patient characteristics, and attention to side effect profile [Level 5, Consensus]. 34. Anticonvulsant medication use should be explained as having pain-modulating properties and treatment should begin with the lowest possible dose followed by up titration, with attention to adverse events [Level 1 [259, 261, 262], Grade A].

	35. Physicians should be aware that only pregabalin and duloxetine have Health Canada approval for management of fibromyalgia symptoms and all other pharmacologic treatments constitute “off label use” [Level 5, Consensus].

Section 3: The outcome

Patient follow up	36. Clinical follow up should be dependent on the judgement of the physician or healthcare team with likely more frequent visits during the initial phase of management or until symptoms are stabilized [Level 5, Consensus]. 37. In the continued care of a patient with fibromyalgia, the development of a new symptom requires clinical evaluation to ensure that symptoms are not due to some other medical illness [Level 5, Consensus]. 38. Patients should be informed that the outcome in many individuals is favourable even if symptoms of fibromyalgia tend to wax and wane over time [Level 3 [297-299], Grade B]. 39. Patients who have experienced previous adverse lifetime events that have impacted on psychological wellbeing and have not been effectively addressed should be offered appropriate support to facilitate attaining health-related outcome goals [Level 5, Consensus]. 40. Physicians should be alert that factors such as passivity, poor internal locus of control and prominent mood disorder may have a negative influence on outcome [Level 5, Consensus].

Outcome tools	41. Outcome can be measured by narrative report of symptom status or patient global impression of change (PGIC), without need for more complex questionnaires [Level 3 [305, 306], Grade C]. 42. Patient goals and their levels of achievement should be recorded as a useful strategy to follow outcome [Level 5, Consensus]. 43. Tender point examination should not be used as an outcome measure [Level 3 [58], Grade C].

Work recommendations and health cost containment	44. Physicians should encourage patients to remain in the workforce, and if necessary may provide recommendations that could help maintain optimal productivity, as outcome is generally more favourable for those who are employed [Level 3 [321], Grade C]. 45. Patients with fibromyalgia on a prolonged sick leave should be encouraged to participate in an appropriate rehabilitation program with focus on improving function, including return to work if possible [Level 5 [326], Grade D]. 46. In persons with fibromyalgia, other co morbid conditions including depression should be recognized and addressed in order to reduce healthcare costs [Level 3 [335, 336], Grade C].

Les Recommandations de 2012

*Note afin de faciliter la lecture des recommandations: Niveau 5 [1,2], Grade D (exemple tiré de la recommandation 3) signifie que l'évidence, qui se trouve dans les articles cités dans les notes 1 et 2 de bas de page dans le document complet, a été évaluée selon le Niveau 5 (opinion) et la recommandation selon le Grade D (ce qui signifie que l'évaluation était basée sur une opinion que l'on avait de l'évidence ou sur des études inconsistantes ou non concluantes.)

Section 1: diagnostic

Évaluation clinique	1. La fibromyalgie, syndrome caractérisé par un cycle d'exacerbation et de latence des symptômes, devrait être diagnostiquée suite à la présence depuis au moins trois mois, de douleurs corporelles diffuses chez un individu qui peut aussi manifester des symptômes de fatigue, des troubles du sommeil, des changements de nature neurocognitive, des troubles de l'humeur ainsi que d'autres manifestations somatiques d'intensité variable, et lorsque les symptômes ne peuvent pas être expliqués par une autre maladie [Niveau 5 [2, 12, 45, 46], Grade D]. 2. Tous les patients dont les symptômes sont compatibles avec un diagnostic de fibromyalgie, devraient être soumis à un examen physique répondant aux normes, à l'exception de la sensibilité à la pression des tissus mous (c.-à-d. hyperalgie, douleur accrue suite à un stimulus douloureux) [Niveau 4 [2, 3, 66], Grade D]. 3. L'examen des tissus mous visant à évaluer la sensibilité générale devrait être exécuté par palpation manuelle, tout en considérant que l'examen de points sensibles douloureux précis, tel qu'énoncé dans les critères de 1990 de l'ACR, n'est plus nécessaire à la confirmation d'un diagnostic clinique de fibromyalgie [Niveau 5 [1, 2], Grade D].
Épreuves, examens et confirmation du diagnostic	4. Le diagnostic de la fibromyalgie devrait reposer sur une évaluation clinique globale, sans épreuves de laboratoire de confirmation, ainsi que le recours à des analyses de laboratoire simples comme l'hémogramme, la vitesse de sédimentation (VS) de même que le dosage de la protéine C-réactive (C.R.P.), de la créatine kinase et de la thyréostimuline (TSH). Tout autre examen de laboratoire ou radiographique devrait résulter de l'évaluation clinique d'un patient donné si l'on soupçonne la présence d'une autre anomalie [Niveau 5 [75, 76], Grade D]. 5. Le médecin de premier recours devrait poser le diagnostic de FM aussi tôt que possible, sans solliciter la confirmation d'un médecin spécialiste, et communiquer le diagnostic au patient. Suite au diagnostic, il faut s'abstenir de faire des examens à répétition sauf, en cas d'apparition de nouveaux symptômes ou signes lors de l'examen physique [Niveau 5[6, 77, 82, 83], Grade D]. 6. Les critères 2010 de l'ACR pour le diagnostic de la fibromyalgie peuvent servir à l'évaluation initiale, en vue de confirmer un diagnostic clinique de fibromyalgie tout en sachant que les symptômes fluctuent au fil du temps [Niveau 3 [1, 2, 58], Grade B].
Diagnostics différentiels et affections concomitantes	7. Les professionnels de la santé devraient savoir qu'une douleur corporelle s'apparentant à celle de la fibromyalgie peut aussi faire partie des manifestations de certaines autres affections médicales ou psychologiques. En outre, les patients chez qui on a diagnostiqué d'autres maladies peuvent également présenter une fibromyalgie concomitante [Niveau 5 [76, 86, 87, 90, 91], Grade D].
Équipe de soins de santé	8. On devrait concentrer la prise en charge des personnes souffrant de FM dans un contexte de soins de premier recours, constitués de professionnels de la santé bien informés et, idéalement, lorsque possible, accompagnés de l'accès à une équipe multidisciplinaire [Niveau 1 [96, 97], Grade A] ou à des membres d'équipe en mesure de leur fournir du soutien et de les rassurer [Niveau 3 [101, 102], Grade C]. 9. Les consultations auprès de spécialistes, y compris les spécialistes du sommeil et les sychologues, peuvent être indiquées pour certains patients ciblés, mais des soins suivis prodigués par un spécialiste, ne sont pas recommandés et devraient être limités aux patients, pour qui la prise en charge en contexte de soins de premier recours a échoué ou, qui présentent des comorbidités plus complexes [Niveau 5 [77], Grade D].

Enseignement et connaissance	10. Dans le cadre des soins de santé aux personnes aux prises avec la fibromyalgie, les professionnels de la santé devraient connaître la pathogenèse de la fibromyalgie [Niveau 5, Consensus], faire preuve d'empathie, d'ouverture et d'honnêteté, ne pas afficher d'attitudes négatives et intégrer le patient au processus décisionnel [Niveau 3 [106, 107, 110], Grade D]. 11. Les professionnels de la santé devraient savoir, que dans le cadre d'études de recherche, des qu'elles ne peuvent servir dans un cadre clinique au diagnostic ou aux soins des personnes atteintes de fibromyalgie [Niveau 5 [111, 117], Grade D]. 12. Les patients et les professionnels de la santé, devraient reconnaître que des facteurs génétiques, de même que des événements traumatiques antérieurs, peuvent être en cause dans l'apparition de la fibromyalgie, mais, qu'il est déconseillé d'accorder une attention exagérée à un événement déclencheur, car cela peut compromettre les soins au patient [Niveau 5 [123, 126, 130], Grade D].

Section 2 : prise en charge

Approches thérapeutiques	13. L'approche thérapeutique visant les patients souffrant de fibromyalgie devrait intégrer des principes de prise en charge autonome, dans un cadre multi facettes [Niveau 1 [131, 132], Grade A]. Il est recommandé de porter attention à chacun des symptômes dans le contexte d'une approche personnalisée, tout en assurant une surveillance étroite et un suivi constant, principalement au début de la prise en charge [Niveau 5 [131] Grade D]. 14. À l'instauration du traitement, on devrait encourager les patients à cibler des objectifs précis, relatifs à l'état de santé et la qualité de vie, ainsi que procéder à la réévaluation des objectifs tout au long du uivi [Niveau 5 [102], Grade D].

Thérapie non pharmacologique	15. Les approches non pharmacologiques comprenant la participation active du patient, devraient faire partie intégrale du plan thérapeutique de la prise en charge de la fibromyalgie [Niveau 1 [132, 137], Grade A]. La promotion de l'auto-efficacité et le soutien social favoriseront la pratique de modes de vie sains [Niveau 3 [141, 142], Grade D]. 16. Dans la mesure du possible, on devrait encourager les personnes atteintes de fibromyalgie à mener une vie normale, par la répartition ou l'augmentation progressive des activités, en vue de conserver ou d'améliorer la capacité fonctionnelle [Niveau 4 [143, 144], Grade D].

Intervention psychologique	17. L'acquisition de capacités d'adaptation efficaces et la promotion de la prise en charge autonome sont favorisées par une approche thérapeutique à composantes multiples [Niveau 5 [137], Grade D]. 18. On devrait faire la promotion des interventions visant à améliorer l'auto-efficacité afin d'aider les patients à composer avec les symptômes de fibromyalgie [Niveau 1 [168], Grade A]. 19. En regard de la détresse psychologique présente dans les cas de fibromyalgie, l'évaluation psychologique ou la consultation pourraient s'avérer bénéfiques pour cette clientèle [Niveau 5, Consensus]. De plus, on devrait sensibiliser les patients à reconnaître la présence de cette détresse et les informer de ses conséquences sur le bien-être [Niveau 3 [149], Grade D]. 20. La TCC, même sur une courte période, est utile pour aider à atténuer la crainte inspirée par la douleur et l'activité physique [Niveau 1 [150, 151], Grade A].

Activité physique	21. Les personnes qui souffrent de fibromyalgie devraient participer à un programme d'activité physique adapté de leur choix, afin de retirer les bienfaits globaux pour la santé et les répercussions possibles sur les symptômes de fibromyalgie [Niveau 1 [174-178, 184, 185], Grade A]

Médecines douces et parallèles	22. Les patients devraient être informés du fait que pour le moment, nous ne disposons pas de données probantes pour appuyer le recours aux médecines douces et parallèles (MDP) pour la prise en charge des symptômes de fibromyalgie, les bienfaits probables n'ayant pas été évalués adéquatement [Niveau 1 [194, 195, 200], Grade A]. 23. Les patients devraient être incités à divulguer leur usage de MDP au professionnel de la santé qui doit faire preuve de compréhension et de tolérance envers cet aveu et fournir l'information disponible fondée sur la recherche relative à l'efficacité et aux risques [Niveau 5, Consensus]
Thérapie pharmacologique	24. Les médecins devraient identifier les symptômes les plus nuisibles afin d'orienter le traitement pharmacologique en fonction d'une approche ciblant les symptômes. Le choix pharmacologique idéal ciblera simultanément plusieurs symptômes et pourrait être constitué d'une combinaison de médicaments, auquel cas, il faudra tenir compte des interactions médicamenteuses [Niveau 5 [111, 131], Grade D]. 25. Les traitements pharmacologiques devraient être amorcés par de faibles doses suivies de hausses progressives et prudentes, en vue d'éviter les intolérances aux médicaments [Niveau 5 [131], Grade D], et suivis d'évaluations constantes en ce qui a trait à l'efficacité et à l'apparition des effets indésirables, tout en étant conscients que les effets indésirables attribuables aux médicaments peuvent présenter des similitudes avec les symptômes de fibromyalgie [Niveau 5, Consensus]. 26. Les médecins qui recommandent les médicaments pour la fibromyalgie, devraient avoir l'esprit ouvert et être conscients du grand éventail de produits offerts pour soigner ces symptômes, et ne devraient pas restreindre le traitement à une seule classe de médicaments [Niveau 5, Consensus].
Traitements classiques de la douleur	27. Conformément à la hiérarchie par paliers des antalgiques de l'Organisation mondiale de la santé, l'acétaminophène peut convenir à certains patients tout en s'assurant de s'en tenir à un dosage sécuritaire [Niveau 5, Consensus]. 28. Dans le cas où un AINS est recommandé, surtout en présence de maladies concomitantes comme l'arthrose, il devrait être utilisé à la plus faible dose et pendant la durée la plus courte possible, afin d'éviter l'apparition d'effets indésirables graves [Niveau 5 [218, 219], Grade D]. 29. Une tentative avec les opioïdes, en débutant par un produit à faible dose comme le tramadol,devrait être réservée aux patients qui présentent des douleurs d'intensité modérée à forte, et qui n'ont pas été soulagés par le biais des autres approches thérapeutiques [Niveau 2 [208, 224], Grade D]. 30. L'usage d'opioïdes puissants est déconseillé et, de plus, les patients qui persistent à utiliser les opioïdes devraient démontrer une amélioration de la douleur et de la capacité fonctionnelle. Les professionnels de la santé doivent exercer une surveillance ontinue du maintien de l'efficacité, des effets indésirables et des comportements aberrants à l'égard des médicaments [Niveau 5 [233], Grade D].
Traitements non classiques de la douleur	31. L'essai d'un traitement pharmacologique de cannabinoïdes sous ordonnance pourrait être envisagé pour un patient aux prises avec la fibromyalgie, particulièrement en situation de perturbations appréciables du sommeil [Niveau 3 [236, 238, 239], Grade C]. 32. On devrait expliquer aux patients qui souffrent de fibromyalgie, les effets modulateurs de la douleur attribuables aux antidépresseurs, afin de dissiper la notion voulant qu'il s'agisse d'un symptôme d'origine psychologique [Niveau 5 [249], Grade D]. 33. Toutes les classes de médicaments antidépresseurs, y compris les ATC, les inhibiteurs sélectifs du recaptage de la sérotonine ainsi que les inhibiteurs du recaptage de la sérotonine-noradrénaline, peuvent servir au traitement de la douleur et autres symptômes chez les patients atteints de fibromyalgie [Niveau 1 [243, 248], Grade A], le choix étant déterminé par la présence de données appuyant l'efficacité, la connaissance du médecin, les caractéristiques relatives au patient ainsi que l'attention portée au profil d'effets indésirables [Niveau 5, Consensus].

	34. L'effet modulateur de la douleur relié à l'usage des médicaments anticonvulsivants, devrait être expliqué et le traitement devrait être entrepris à la plus faible dose possible, suivie d'un ajustement à la hausse, tout en surveillant l'apparition d'effets indésirables [Niveau 1 [259, 261, 262], Grade A]. 35. Les médecins devraient savoir, que seules la prégabaline et la duloxétine, sont approuvées par Santé Canada pour la prise en charge des symptômes de la fibromyalgie, et que toutes les autres thérapies pharmacologiques représentent des produits dont l'emploi est non conforme [Niveau 5, Consensus].

Section 3: évolution de l'état de santé

Suivi du patient	36. Le suivi clinique devra reposer sur le jugement du médecin ou de l'équipe soignante et comportera généralement des visites plus rapprochées au début de la prise en charge, et ce jusqu'à la stabilisation des symptômes. [Niveau 5, Consensus]. 37. Dans le contexte du suivi continu d'un patient atteint de fibromyalgie, toute nouvelle manifestation symptomatique devrait faire l'objet d'une évaluation clinique afin d'éliminer la possibilité que ce symptôme soit attribuable à une autre maladie [Niveau 5, Consensus]. 38. Les patients devraient être informés que l'évolution de l'état de santé chez plusieurs personnes est favorable, même si au fil du temps les symptômes de fibromyalgie sont modulés par un cycle d'exacerbation et de latence [Niveau 3 [297-299], Grade B]. 39. On devrait offrir aux patients qui ont subi au cours de leur vie des traumatismes qui ont altéré leur bien-être psychologique, et qui n'ont pas été pris en charge efficacement, un soutien approprié en vue de favoriser l'atteinte des objectifs en matière d'évolution de l'état de santé [Niveau 5, Consensus]. 40. Les médecins devraient être à l'affût de facteurs tels que la passivité, le faible locus de contrôle interne et la présence d'un trouble de l'humeur, car ces derniers nuisent à une bonne évolution de l'état de santé [Niveau 5, Consensus].

Critères d'évaluation de l'évolution de l'état de santé	41. Il est possible de mesurer l'évolution de l'état de santé par une approche de médecine narrative ou àl'aide du PGIC (patient global impression of change) sans avoir recours à des questionnaires plus complexes [Niveau 3 [305, 306], Grade C]. 42. Les objectifs du patient ainsi que leurs niveaux d'atteinte devraient être documentés et servir d'approche de suivi de l'évolution de l'état de santé [Niveau 5, Consensus]. 43. L'examen des points sensibles douloureux ne devrait pas servir de critère d'évaluation [Niveau 3 [58], Grade C].

Recommandations en matière d'emploi et maîtrise des coûts de santé	44. L'évolution de l'état de santé étant généralement moins favorable chez les gens sans emploi, les médecins devraient inciter les patients à demeurer en emploi et, lorsque nécessaire, faire des recommandations visant la conservation d'un niveau de productivité optimal [Niveau 3 [321], Grade C]. 45. Les patients aux prises avec la fibromyalgie, qui sont en congé de maladie depuis longtemps,devraient être encouragés à participer à un programme de réhabilitation adapté, visant l'amélioration de la capacité fonctionnelle et, si possible, le retour en emploi [Niveau 5 [326], Grade D]. 46. Chez les personnes qui souffrent de fibromyalgie, il est essentiel de reconnaître les autres maladies concomitantes comme la dépression, et d'en assurer la prise en charge en vue d'abaisser les coûts de soins de santé [Niveau 3 [335, 336], Grade C].

Update on ME/CFS

by Valerie Free

This is my layperson's view of the progress in the ME/CFS world in the last 2 months or so - BIG TIME ACTION. It is not all that is going on - and I may not have relayed it perfectly - but it is what personally impacted me the most and I hope it will impact others too.

There is a shift in the tide and a continued change of view toward ME/CFS and the people suffering from it. The theme of that change would be: creating a solution.

LOOK WHAT LEADERSHIP, ADVOCACY, CO-OPERATION AND TIMING CAN DO.

In the US:

President Obama has ordered urgency and priority to be placed on ME/CFS in response to an advocate family's request for him to get informed and involved.

The US Centers for Disease Control and Prevention (CDC) had a teleconference in August with patients and advocates disclosing their serious commitment to helping this group. They made clear what had to be done in order to accomplish that – including an evidence-based definition - despite the lack of government funding foreseeable in the future.

They have also started changes in medical education by including two CME courses for doctors on their website. The public also has access to them.

As well, on educational material, The IACFS/ME professional group in the US has released "The Primer," available in download or book format, for physicians to understand, diagnose, and give appropriate symptomatic treatment for ME/CFS. Further, the Primer has been accepted for posting on the National Guideline Clearinghouse.

The IACFS/ME held its last international conference in Ottawa in September 2011. They announced that their next conference will be held in March 2014 in the San Francisco area and will be co-sponsored by Stanford University!

The US Federal Drug Administration (FDA) held a teleconference with patients and advocates in September. They reassured us of their commitment to, and serious view of, ME/CFS. Dr. Sandra Kweder said: "We consider your condition to be in the category of **serious or life threatening** diseases." Drugs for ME/CFS are reviewed by the Division of Pulmonary, Allergy and Rheumatology Products division. They are aware that drugs, and drug trials, are needed for this illness and that there is no FDA-approved treatment.

Although the FDA's role is to review and regulate the drugs brought forward to them (not to create or market them) they are encouraging advocacy in this regard. They will be holding a webinar in November called *Excellency in Advocacy* on how to **come together and develop common themes to further mutual goals**. They work with many illness groups in this way, and that is how most illnesses get the changes they need in government, eg HIV/AIDS and Autism.

http://www.prohealth.com/library/showarticle.cfm?libid=17222

Ian Lipkin, a world renowned viral researcher, gave a news conference, along with his colleagues, on September 17. The XMRV retroviruses, thought to be linked to some cancers and CFS, were not validated and were found to be, indeed, lab contamination of some sort. That took 3 years and millions of dollars. It seems discouraging at first.

Although this last piece brought disappointment to many over the last year when the word was that XMRV was not going to be "it", this has inspired and motivated many experts into the field such as Ian Lipkin who have joined forces with other researchers around the globe to understand and solve ME/CFS.

Lipkin also was very clear that the way to change the status of these diseases is through **aggressive political pressure applied by loved ones, friends, and anyone interested, as well as advocates and patients** (which is often impossible while so ill or struggling). The squeaky wheel thing, right?

Everybody needs to hear him on this point, especially now that the ball is rolling.....PUSH. At some point the ball will be rolling downhill but it isn't there yet.

Two organizations in the US just won a Chase Community Giving contest worth thousands of dollars to each: Phoenix Rising and NIDA (Neuro-Immune Disease Alliance). This will help them to continue their good works to support the community in different ways. This was done by Facebook vote so that really shows a lot of patient and advocate support.

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I participated in all of these events when possible by phone and laptop, and they often brought tears to my eyes and grief to my heart (weird, right?). Although I am so happy to see all of this move forward, many still suffer, and for so many people, decades of health and much more have been lost. And, unfortunately, it doesn't bring us into health today and put us all back into normal lives. That just doesn't seem to come fast enough for most. It seems we have been pleading for so long. As well, it will still take some years to really see the results of this new movement.

However, as my sister reminds me, ***The best time for action was 25 years ago, but the next best time is today****.*

I do want to be clear that the action I mean is by political and medical arenas and not advocacy because people have been advocating for this and related illnesses since they showed up many years ago. Their actions have made a difference but there was little to no appropriate response from the powers that be. So onward and upward.

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As for Canada, I have some things to report. We have our first provincial petition (Alberta) in circulation for policy change and attention for the illness addressed to the Health Minister, Finance Minister, and Human Services Minister, as well as the MLAs of our province.

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The **MEAO** of Ontario has received a meaningful grant to look at patient needs and healthcare delivery models.

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In British Columbia, the first **centre dedicated to Neuro-Immune disease** (including chronic Lyme, ME/CFS and Fibro) has started. A Canadian doctor with years of experience in this field, Dr. Bested, is its medical director, so that province is lucky.

Alberta's Dr. Ellie Stein has just released a **manual for patients** and/or doctors: Strategies for Living with ME/CFS, Fibro, and MCS.

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As well, our **National ME/FM Action Network** has applied for federal funding for public awareness and community development and has asked for patient and advocate support by contacting Members of Parliament (MPs) in Canada.

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I personally am getting a chance to do a radio interview about ME/CFS in January on an internet station about chronic illness and pain and I am plugging away at a book about the illness written for the general public as audience.

I sent my first letter to **60 Minutes**. I felt that with all the new goings-on under our belt, it might be time for some influential reporting for the public to further change the worldview of ME/CFS. When the public gets on board, the fuel for the fire will grow immensely as it has for cancer, MS, Parkinson's, etc. The other day Michael J Fox was on Ellen and reported that he had helped to raise 300 million dollars for research for Parkinson's through the organization he works with. I am sorry to report we are working with numbers too small to mention for ME/CFS. We also would really appreciate a champion for our cause like Michael J.

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So as you can see, timing, effort, better leadership in politics, and advocacy do make a difference. It is only a beginning; but the ball is beginning to roll in the right direction thanks to those who have worked so hard in the past and those who are speaking up, acting out, writing about, or signing everything they can sign and forwarding it to someone who may be able to help today.

Keep up the great work and thank you to those who have paved the way for this new direction. Every voice and signature really does matter now it seems. For those who would like to get on board but don't know how, any of the organizations mentioned above will guide you or receive donations for help.

Anyway.....(As Ellen would end her show)

Signing off for now,

Valerie Free

Chronic Fatigue Syndrom Is Not Linked to Suspect Viruses XMRV or pMLV

Press Release - Sep 2012, Center for Infection and Immunity, Mailman School of Public Health, Columbia University

Multi-site blinded study puts to rest the notion that these viruses cause the mysterious ailment.

The causes of chronic fatigue syndrome (CFS) have long eluded scientists. In 2009, a paper in the journal Science linked the syndrome—sometimes called myalgic encephalomyelitis (ME)—to infection with a mouse retrovirus called XMRV (xenotropic murine leukemia virus (MLV)-related virus). Given that affected patients often have symptoms consistent with a chronic infection, this viral connection seemed plausible, and the findings were celebrated as a major achievement for a complex disease that afflicts nearly 1 million in the U.S. Another study in early 2010 published in Proceedings of the National Academy of Sciences detected murine retrovirus-like sequences (designated pMLV: polytropic MLV) in CFS/ME patients, which provided further support for a viral theory.

Follow-up investigations by several laboratories were unable to detect XMRV or pMLV in CFS patients. However, none of them examined a sufficiently large population of well-characterized CFS/ME patients to rigorously test the validity of those findings. In the absence of a definitive study, many in the general public may have retained the opinion that XMRV and/or pMLV are responsible for the disease, and some clinicians continue the "off-label" prescription of antiretroviral drugs.

To definitively resolve this issue, the National Institute of Allergy and Infectious Diseases, part of the National Institutes of Health (NIH), commissioned a study under the auspices of the Center for Infection and Immunity at Columbia University's Mailman School of Public Health, in partnership with the Centers for Disease Control and Prevention, the Food and Drug Administration, and the NIH's National Cancer Institute and Warren G. Magnuson Clinical Center.

The research is published in mBio.
http://mbio.asm.org/content/3/5/e00266-12

A total of 293 subjects, 147 with CFS/ME and 146 matched controls, were recruited from six sites across the United States following extensive clinical assessments and laboratory screening. Clinical sites included Brigham and Women's Hospital (Boston, MA), the Simmaron Research Institute (Incline Village, NV), Miami Veterans Affairs Medical Center (Miami, FL), the Infectious Disease Clinic at Stanford University (Palo Alto, CA), the Levine Clinic (New York, NY), and the Fatigue Consultation Clinic (Salt Lake City, UT).

All CFS/ME patients chosen for the study: **1)** were between the ages of 18 and 70; **2)** had never suffered from another neurologic or psychiatric illness; **3)** met both the "Fukuda" and "Canadian Consensus" criteria for CFS/ME; **4)** were suffering from symptoms of a viral infection prior to CFS onset; **5)** had reduced scores on the RAND36 quality-of-life survey (vitality subscale <35, social functioning subscale <62.5, role-physical subscale <50) and the Karnofsky Performance Scale (<70%); **6)** were not pregnant, lactating, or less than 3 months postpartum to prevent maternity-related fatigue from being confused for CFS/ME.

Control subjects were recruited to match age, sex/gender distribution, race/ethnicity, and geographic location. Controls had no previous contact with individuals with CFS/ME. All potential subjects were then tested for evidence of any metabolic, endocrine, or infectious disease that might cause fatigue. Blood from CFS/ME and control subjects who met this selection criteria was collected for blinded XMRV and/or pMLV analysis using molecular, culture and serological methods, which were previously established in the individual laboratories where evidence of XMRV or pMLV had been reported or ruled out.

None of the laboratories found evidence of XMRV or pMLV in samples from the recruited CFS/ME or control subjects. For quality assurance of the molecular tests, separate positive controls (blood samples intentionally spiked with XMRV/pMLV) and negative controls (blood samples prescreened and lacking the retroviruses) were used and confirmed that the diagnostic assays were functioning properly.

Nine control and nine CFS/ME blood samples were positive for XMRV/pMLV-reactive antibodies. The accuracy of this assay cannot be determined because

there are no positive controls in the general population with XMRV serology. Nonetheless, there was no correlation of antibody reactivity in blood from CFS/ME and controls.

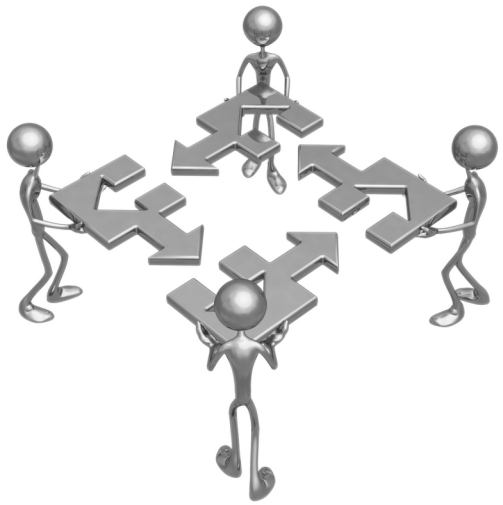
Statement from Dr. Mikovits, the author of the Science paper wherein XMRV was first linked to CFS: “I greatly appreciated the opportunity to fully participate in this unprecedented study. Unprecedented because of the level of collaboration, the integrity of the investigators, and the commitment of the NIH to provide its considerable resources to the CFS community for this important study. Although I am disappointed that we found no association of XMRV/pMLV to CFS, the silver lining is that our 2009 Science report resulted in global awareness of this crippling disease and has sparked new interest in CFS research. I am dedicated to continuing to work with leaders in the field of pathogen discovery in the effort to determine the etiologic agent for CFS."

“Although the once promising XMRV and pMLV hypotheses have been excluded, the consequences of the early reports linking these viruses to disease are that new resources and investigators have been recruited to address the challenge of the CFS/ME”, said W. Ian Lipkin, MD, director of the multi-site study and John Snow Professor of Epidemiology in the Mailman School of Public Health of Columbia University. “We are confident that these investments will yield insights into the causes, prevention and treatment of CFS/ME.”

This study was funded by National Institutes of Health award AI1057158 (NBC-Lipkin).

Collaborating Research Groups

- Department of Transfusion Medicine, Warren G. Magnuson Clinical Center, National Institutes of Health, Bethesda, MD.
- Mikovits Consulting, Oxnard, CA.
- Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, GA.
- Cancer and Inflammation Program, Frederick National Laboratory for Cancer Research, Frederick, MD.
- Tissue Safety Laboratory, Office of Cellular, Tissue and Gene Therapies, Center for Biologics Evaluation and Research, Food and Drug Administration, Bethesda, MD.
- Nova Southeastern University, Fort Lauderdale FL.
- Miami Veterans Affairs Medical Center, Miami, FL.
- Brigham and Women’s Hospital, Boston, MA.
- Infectious Disease Clinic, Stanford University, Palo Alto, CA.
- Fatigue Consultation Clinic, Salt Lake City, UT.
- Levine Clinic, New York, NY.
- Simmaron Research Institute, Incline Village, NV.
- Department of Biostatistics, Columbia University, New York, NY.
- Department of Molecular Biology and Genetics, Cornell University, Ithaca, NY.
- Center for Infection and Immunity, Columbia University, New York, NY.
- Department of Molecular Biology and Microbiology, Tufts University, Boston, MA.



Complex Chronic Disease Clinic Appoints Medical Director

*Press release - July 10, 2012, Provincial Health Services Authority, British C*olumbia

Vancouver – A new clinic focused on treating people who suffer from a group of complex chronic diseases has appointed its first Medical Director.

Dr. Alison Bested will lead the Complex Chronic Disease Clinic, which will be located at BC Women's Hospital and Health Centre in Vancouver. The clinic is the first of its kind in the province.

Dr. Bested is expected to start on October 1, 2012, giving her time to close up her current medical practice in Toronto where she treats patients with complex medical illnesses.

In March 2011 the Ministry of Health announced a $2 million investment to study cases and best practices for patients with complex chronic diseases.

The clinic will focus on diseases such as Lyme disease, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome. Clinic staff will work with patients and doctors from across the province not only to provide care for people but to also learn more about these complex diseases.

Bested is a medical specialist who has worked with complex medical illnesses for the past 21 years. She is the Medical Specialist Liaison at the Environmental Health Clinic at Women's College Hospital in Toronto. She is also a lecturer in the Department of Family and Community Medicine at the University of Toronto.

Quotes:

Dr. Alison Bested, MD, FRCPC

"I'm looking forward to continuing my work in the field of complex chronic diseases in British Columbia," said Bested. "This clinic will be an excellent way for us to focus our resources and energy on patients dealing with very complex medical illnesses that require specialized treatments."

Alain Gagnon, Senior Medical Director, BC Women's Hospital

"We are thrilled to have recruited one of Canada's premiere physicians in this field, said Alain Gagnon. "Her passion for knowledge translation as well as her dedication to patients will advance the care for people all across British Columbia."

Dr. Alison Bested's Biography

Dr. Alison Bested is a Haematological Pathologist. For the past 21 years she has a medical practice in Toronto that treats patients with complex medical illnesses including: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivities.

Dr. Bested is the Medical Specialist Liaison at the Environmental Health Clinic at Women's College Hospital in Toronto. She is a lecturer in the Department of Family and Community Medicine at the University of Toronto.

Dr. Bested uses Telemedicine to outreach individual patients in Ontario and also with her Education and Support Group.

Dr. Bested was one of the authors of the Canadian ME/CFS consensus definition that was published in the Journal of Chronic Fatigue Syndrome in 2003.

The second edition of her book "Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia" was published by Sourcebooks House in 2008.

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If you would like to receive our free informative pamphlets on ME/CFS and/or FM, please contact us or you can print copies off our website at www.mefmaction.net.

Consensus Documents for ME/CFS and FM

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols [Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004 ISBN:0-7890-2207 9] and The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4}] can be viewed on our website at www.mefmaction.net and is also available at Amazon.com or at Chapters.ca
Or view the Consensus Documents on our website at www.mefmaction.net

ME/CFS and FM Overviews - $2.50 each

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents entitled Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols and The Fibromyalgic Syndrome: A Clinical Case Definition for Practitioners.

Overviews can be ordered from Marjorie Van de Sande via email at mvandesande@shaw.ca or by regular mail at 151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 Canada, or from the NATIONAL ME/FM ACTION NETWORK Or may be viewed on our website at www.mefmaction.net

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