



NATIONAL  
ME / FM  
ACTION NETWORK

Charitable tax no. (BN) 89183 3642 RR0001 ISSN 1205-786X

# Quest

COMMUNICATION # 73

WEB: [www.mefmaction.net](http://www.mefmaction.net)

WINTER 2007

## CONTENTS

Restorative Exercise Therapy.....	1
New Pediatric Case Definition.....	4
Statistics Canada Publishes Statistics On ME/CFS, FM and MCS.....	4
Medical Assessors Can Be Biased; Insurance Companies May Be Unfair – and it is not a Defamation to Say it .....	6
Advocacy – You Can Do This.....	7
Network Notes.....	9
Resources.....	10

## MEDICAL NEWS

### Restorative Exercise Therapy

By: Philipa Corning, Ph.D., B.Sc., Vice-President

As promised in the Fall edition of Quest, here is the article that explains the Restorative Exercise Therapy approach entitled “When Working Out Doesn’t Work Out”. It is preceded by a foreword written by Staci Stevens.

### Foreword

The program of activity, rest, and recovery devised by Staci Stevens for CFS/ME patients is specifically tailored to ameliorate the effects of post-exertional malaise (PEM), and should only be undertaken with the help of a professional exercise physiologist, physical therapist or other health care provider familiar with CFS/ME and the problem of PEM. Even the least functional of CFS/ME patients can find a level of physical activity that will promote rather than undermine health, though a high level of patient compliance and self surveillance is necessary to monitor progress and prevent relapse. The University of the Pacific’s Fatigue Laboratory offers testing services for disability evaluation and exercise consultations which determine CFS/ME patients’ individual anaerobic threshold, enabling them to monitor physical activity without so much guesswork. A manuscript is in progress to detail a full program of analeptic rehabilitation and will include a lengthier discussion of the physiological mechanisms of PEM, and energy systems physiology than is possible here. We have not discovered a cure for CFS/ME, but can offer the CFS/ME patient two long-awaited truths: CFS/ME has a physical basis that can be objectively verified and measured, and there are helpful tools that can substantially improve quality of life for CFS/ME sufferers.

*Staci R. Stevens, MA is currently the Executive Director for the University of the Pacific’s Fatigue Laboratory. Christopher Snell, Ph.D. and J. Mark VanNess, Ph.D. are professors in the Department of Sport Sciences at the University of the Pacific.*

**Contact info:** Pacific Fatigue Laboratory  
Department of Sport Sciences  
University of the Pacific  
3601 Pacific Avenue  
Stockton, CA 95211  
(209) 946-7649 voice  
(209) 946- 3225 fax  
[sstevens@pacific.edu](mailto:sstevens@pacific.edu)

## **When Working Out Doesn't Work Out**

This article originally appeared in the *CFIDS Chronicle*, a quarterly publication of the CFIDS Association of America. To learn more about the CFIDS Association and how to receive the *CFIDS Chronicle*, visit [www.cfids.org](http://www.cfids.org).

The idea that if you'll just exercise, eat right and take better care of yourself, your health will improve is **firmly planted in the American psyche**. After all, it works for chronic illnesses like diabetes and heart disease. It should work for CFIDS, but it doesn't. CFIDS is an **exercise enigma**. What should patients and their doctors do in the face of this enigma? Read on.

**BY DR. CHRISTOPHER R. SNELL, DR. J. MARK VANNESS and STACI R. STEVENS, GUEST CONTRIBUTORS**

It is somewhat ironic that for an illness where patients are often diagnosed as deconditioned and characterized as lazy, exercise exacerbates symptoms rather than relieving them. Well-meaning health care professionals often recommend aerobic exercise as a cure-all for the symptoms of CFIDS without fully understanding the potential consequences of their prescriptions. As anyone with CFIDS who has attempted to "get fit" using traditional approaches to exercise knows, the results can be devastating.

Improved fitness is generally achieved by progressively taxing the heart, lungs and circulatory system through increases in duration and intensity of activity, for instance, running faster and for longer periods of time. This is often called graded aerobic exercise, and it has shown some success for treatment of CFIDS. However, this success may not accurately portray the exercise experience for a vast majority of people with CFIDS (PWCs). Typically, graded exercise studies employ some form of exercise stress test as a baseline measure for assessing improvements in physical functioning. Given the trauma such tests can engender, it seems reasonable that many potential participants choose not to continue with the study after the initial exercise test. One patient, for instance, told us the exercise stress test "was as bad as the worst days I ever had in six years of illness." Therefore, positive results from graded aerobic exercise studies may only reflect outcomes for a high-functioning and relatively small percentage of the CFIDS population. Contrary to the popular mantra "no pain, no gain," the reality of exercise for many PWCs is "no gain, much pain!"

**[Physical inactivity imposed by chronic illness can exacerbate already limited physical abilities and lead to greater risk of heart disease, obesity, diabetes, osteoporosis and injury.]**

## **The oxygen debt roller coaster**

By attempting to exercise on their good days, PWCs often become trapped in a cycle of overwork and collapse. The consequences of symptom exacerbation, post exertional malaise and even collapse can ultimately lead to activity avoidance. In addition to the primary effects of their illness, patients are now trapped in a downward spiral of deconditioning, with all its attendant problems. It is a cruel irony. They cannot exercise because it makes them ill, and because they are unable to exercise they become sicker still. However, all may not be lost. The solution perhaps lies in understanding how the body uses energy.

It is painfully obvious that many PWCs don't recover well from continuous aerobic activity: "I always thought that exercise meant aerobic activity – swimming, running, biking," said one patient. "Every time I do something aerobic I pay for it." This may be because, for PWCs, the activity is not aerobic. The aerobic energy system depends on a constant supply of oxygen being delivered to active muscles. There is evidence to suggest that this process may be impaired in CFIDS, with a possible link to immune dysfunction. In the absence of an adequate supply of oxygen, energy production shifts to anaerobic (without oxygen) processes. These systems are very effective at producing high levels of energy for short periods of time, but not without a cost. That cost is oxygen debt, which is the difference between oxygen required for activity and oxygen supplied and used.

To picture what oxygen debt looks like, imagine athletes doubled over, or prostrate on the ground, unable to speak and gasping for air following a 100-meter sprint. Oxygen debt equals fatigue and before normalcy can return, it must be repaid. While this oxygen debt roller coaster is not unique to CFIDS, interest rates on the payback may be significantly higher. "I felt fatigued, like I had walked a hundred miles the day before," said one PWC following exercise. "I felt very tired and slept most of the day" is another usual response.

[Did you know? If aerobic exercise is causing you to crash and burn, it may be because the way your body processes oxygen during aerobic activity is impaired. There is evidence to suggest that people with CFIDS may not get an adequate supply of oxygen during exercise, shifting energy production from aerobic to anaerobic processing. The resulting oxygen debt could be contributing to the roller-coaster effect CFIDS patients feel following exercise. The good news is there are ways to overcome this deficit.]

### **Redefining exercise**

It is our experience that if physical activity is to become a positive in the lives of CFIDS patients, they must forget the traditional approaches to training that so

often fail. It's not how much effort you put out, but rather how well you recover from the effort that is important. Patients need to recognize that it's okay to exercise for a very short time and rest. The activity should be restorative or analeptic, serving to relieve not exacerbate symptoms. Redefining exercise in this way acknowledges that a cookie-cutter approach to exercise therapy for CFIDS will not work because one size does not fit all. To be successful any exercise program should be tailored to match individual patient functionality and symptom fluctuations. As a prelude to engaging in exercise, patients should ask themselves: What activities do I already do? How do I feel immediately after and the following day? Do I experience post-activity relapse? What are my exercise goals?

### **Analeptic exercise**

It should be noted that we are not recommending exercise as a cure for CFIDS. Analeptic exercise is intended to restore functionality lost through inactivity, give patients a sense of control over their illness and, hopefully, improve the quality of their lives. Some patients also report symptom relief, in particular a reduction in muscle and joint soreness and improved cognitive functioning. One patient told us: "I really see exercise as a plus for reducing muscle and joint pain. I feel like I am getting blood circulation. I feel I can think better."

To this end, activities are designed to train the short-term, or anaerobic, energy system to increase range of motion and improve functional strength – the strength necessary to successfully and comfortably perform normal activities of daily living. Two key elements are matching program and function by setting activity levels at appropriate intensities and for reasonable durations.

To find an appropriate baseline for activity, we propose that initial durations should not exceed 30 seconds, about the length of a typical television commercial. As for intensity levels, it is essential that patients recover in a reasonable time. To this end, rest is a critical component of analeptic exercise therapy. We suggest that rest periods be at least three times, and up to six times, longer than exercise bouts. It's also likely that patients will need to reschedule or discontinue another daily activity to make time for exercise.

### **When exercise does work out**

1. A typical analeptic exercise program progresses through four stages. Patients should begin with stretching and strengthening exercises. These might include focused breathing exercises, step-ups, wall push-ups, modified chair dips and

toe raises. Stretching can be done between strengthening exercises. An exercise progression goal would be increasing from one set of four repetitions to two sets of eight.

2. For stage two, as strength improves, resistance in the form of therabands or light weights can be added to the workout. Over time patients should, as one expressed it, "feel stronger, more flexible and able to get around better."
3. Stage three of the program comprises dose-controlled interval training – exercising large muscle groups for a specific length of time interspersed with periods of rest. This could involve walking up and down stairs with a chair situated on the landing to permit resting between intervals. Success of this stage is dependent on patients learning to monitor heart rate so they avoid pushing too hard and triggering relapse. A functional goal would be for the patient to engage in activities of daily living without precipitating postexertional malaise.
4. Finally comes the maintenance stage. To ensure patients transition from chronic fatigue to chronic exercise it's important that they perceive improvements in functionality. Setting realistic, functional goals and keeping an activity diary can provide motivation. Positive feedback and support from family, friends and care providers is essential to success. Exercise *can* work out and the enigma *can* be resolved when PWCs are empowered to get off the roller coaster and off the couch, take control of their illness and experience enhanced quality of life. As one PWC recently shared, "It gives me a feeling of being empowered because it's something that I'm doing. I'm not sitting in a chair feeling victimized."

### **References**

- Fulle, S., Mecocci, P., Fano, G., Vecchiet, I., Vecchini, A., Racciotti, D., et al. Specific oxidative alterations in vastus lateralis muscle of patients with the diagnosis of chronic fatigue syndrome. *Free Radical Biology in Medicine*, 2000; 29(12), 1252-1259.
- Shephard, R.J. Chronic fatigue syndrome, an update. *Sports Medicine*, 2001; 31(3), 167-194.
- Snell, C.R., J.M. VanNess, D.R. Strayer, and S.R. Stevens. Physical performance and prediction of 2-5A Synthetase/RNase L antiviral pathway activity in

patients with chronic fatigue syndrome. *International Journal of In Vivo Research*, 2002: 16(3), 107-110.

VanNess, J.M., Snell, C.R., Strayer, D.L. and Stevens, S.R. Subclassifying chronic fatigue syndrome through exercise testing. *Medicine and Science in Sports and Exercise*, 2003: 35(6), 908-913.

### **Authors Snell, Stevens and VanNess**

*Christopher Snell, Ph.D., and J. Mark VanNess, Ph.D., are professors in the Sport Sciences Department at the University of the Pacific. They have been involved in CFIDS research for the past six years and have published widely on CFIDS-related topics. Staci Stevens, M.A., is an exercise physiologist and PWC who has designed rehabilitation programs for CFIDS patients for the last 15 years. She is the chair of the Workwell Foundation, which is dedicated to research and improving quality of life for PWCs. Staci is presently serving as a member of the CFS Advisory Committee.*

## **New Pediatric Case Definition**

**By: Margaret Parlor – Director – Youth Issues**

A pediatric case definition for ME/CFS, with accompanying questionnaires and scoring guide, has just been published by Haworth Press and is available on our website.

These tools were developed by a group of respected doctors and researchers from the U.S., Belgium, Australia and Japan.

The impetus behind their development was two-fold:  
- to better identify individual cases of pediatric ME/CFS and  
- to better support research into pediatric ME/CFS.

The authors confront the question whether it is in the best interests of a young person to receive a diagnosis of ME/CFS. The authors defend their decision to publish a case definition, pointing out that the lack of a diagnosis can lead to false assumptions about the child and family and can delay appropriate treatment.

The new pediatric case definition is closely aligned with the Canadian criteria for ME/CFS which covers both adults and children. Both definitions require chronic fatigue, post-exertional symptoms, sleep problems, pain, neurocognitive symptoms, and some autonomic, neuroendocrine and immune manifestations. Like the Canadian definition, the new definition adopts a 3-month rule for young people.

One difficult in diagnosing pediatric cases is judging whether activity levels are reduced. For adult onset

cases, there is a "before" to which an individual can compare activity levels. For pediatric onset cases, many of which are insidious, the "before" is not well established.

Therefore, there is more need to look at the young person's level of functioning in comparison to what would be expected.

Considerable thought and discussion go into the what conditions would be considered exclusionary and what would not. For instance, depression that explains the symptoms would be exclusionary, but depression brought on by the frustration and disappointment that comes with ME/CFS would not. Active Lyme disease would be considered exclusionary, but adequately treated Lyme disease would not.

The two questionnaires are very helpful. One is for the young person who can complete the information alone, while the other is for young people who need parental help in completing the form. A lot of the information is contextual: age, education, school attendance, etc. The meat of the questionnaire is the section on the symptoms in the case definition. The questions are age appropriate. For instance, instead of asking if a young person has orthostatic intolerance, the questionnaire asks question like do you "feel unsteady on your feet, like you might fall", For each question, the respondent answers yes or no, estimates when the problem started, and rates the frequency and severity on scales of 1 to 7. Having the 7-point scales communicates much more information than a simple yes/no.

The report concludes that the new tools will help not only in establishing homogeneous groups for research, but in recognizing and accommodating individual cases and monitoring changes.

We would like to remind you of the Teach-ME Sourcebook for Teachers of Students with ME/CFS and FMS. Chapter 1, which can be viewed on our website, was based on the Canadian clinical definition. Because the new pediatric guidelines are so closely aligned, the chapter makes an excellent companion document.

## **Statistics Canada Publishes Statistics on CFS, FM and MCS**

**By: Margaret Parlor, Director**

In January 2007, Statistics Canada published statistics on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia, as well as Multiple Chemical Sensitivities. The information was obtained through interviews with a large number of individual Canadians in 2002 and 2003.

Statistics tell stories. Sometimes the stories support our understanding of a topic. Sometimes they add new insights. Sometimes they go against what we understand, in which case we have to look for explanations to reconcile the differences. Throughout, we need to consider the implications of the findings.

Overall, the report confirms what the ME/CFS and FM communities have been saying all along - that these illnesses are widespread, that they carry a high degree of disability, and that they pose a major challenge to Canada's health system.

The total numbers were a surprise, much higher than expected for ME/CFS and much lower than expected for FM.

The number of Canadians reporting a diagnosis of ME/CFS was 341,000, or 1.3% of Canadians over the age of 12. This is several times higher than U.S. studies would suggest. Definitional and methodological factors might explain some of the difference, but it is very difficult to believe that they could explain the whole difference. Is there a higher rate of ME/CFS in Canada than in the U.S.? If so, why and what can be done about it? Alternately, are doctors diagnosing Canadians with ME/CFS when they have a different illness? If so, what are the health implications of the mis-diagnosis?

The number of Canadians reporting a diagnosis of FM was 393,000, or 1.5% of Canadians over age 12. The literature suggests the rate of FM is 2% to 10% of the Canadian population. This suggests that many Canadians with FM are not being diagnosed. What are the implications of this?

The statistics show a low degree of overlap between the three illnesses, ME/CFS, FM and MCS. Only 14% of Canadians said they had been diagnosed with more than one of the three illnesses. This suggests that health professionals tend to limit the number of diagnoses, even if the patient meets the criteria for more. Does this have an impact on treatment or outcomes?

The figures around gender distribution (around 70% female) and the age distribution (predominant between age 45 and 64) coincide with figures from other studies.

The finding that Canadians with these illnesses live disproportionately in lower income households makes sense when one considers the impact these illnesses have on employment. The findings that Canadians with these illnesses fall disproportionately in the marital category "divorced, separated or widowed" makes sense if one assumes that this reflects divorced and separated and one considers the impact these illnesses have on relationships.

The finding that Canadians with ME/CFS and FMS are significantly less likely than other Canadians to have completed high school is perplexing. Why would these illnesses affect those with less education? Could there be something in the work or living situation that makes lower-educated Canadians more vulnerable? Could there be a bias whereby health professionals are more inclined to diagnose lower-educated Canadians with ME/CFS or FM? Could it be that many people with ME/CFS and FMS had health issues during their younger years that interfered with their education?

Statistics Canada bravely ventured into the very sensitive area of the overlap of these illnesses with psychiatric disorders (major depressive disorder, bipolar I disorder, panic disorder, social anxiety disorder and agoraphobia). The report found that about a third of Canadians with ME/CFS and a quarter of Canadians with FM had been found to have one or more of the psychiatric disorders in the past year. (That means that around two-thirds of Canadians with ME/CFS and three-quarters of Canadians with FM did not have a psychiatric diagnosis, showing clearly that they do not have to go hand-in-hand.) The statistics also showed that a substantial number of people with ME/CFS and FM had negative perceptions of their physical and mental health and were dissatisfied with their lives. These figures should be of great concern to our health system and could be significantly improved with appropriate strategies.

The study tested degree of disability using two criteria. Firstly, did individuals need help with activities of daily living such as preparing meals, doing everyday housework, getting to appointments and running errands. Secondly, did individuals need assistance with personal activities like bathing, dressing, eating, taking medication and moving within the house. On both tests, people with ME/CFS and FM showed much higher needs than those without these illnesses. Community care planners must consider the needs of people with these illnesses.

The study also looked at how often Canadians with these illnesses consulted with health professionals, a family doctor, a specialist or an alternative practitioner. The results show a high number of visits for all three. Are the consultations contributing to better health outcomes? This should be of interest to health administrators.

In Canada, responsibility for delivery of health care is the responsibility of the provinces. At the federal level, Health Canada states that its objective is to strive to:

- \* Prevent and reduce risks to individual health and the overall environment;
- \* Promote healthier lifestyles;
- \* Ensure high quality health services that are efficient and accessible;

\* Integrate renewal of the health care system with longer term plans in the areas of prevention, health promotion and protection;

\* Reduce health inequalities in Canadian society; and

\* Provide health information to help Canadians make informed decisions.

Within these parameters, we can see plenty of opportunity for the federal government to act for the benefit of people with ME/CFS and FM.

We contacted the Minister of Health and the health critics for the three opposition parties and asked for a response to the Statistics Canada report. We got no replies. Obviously, a lot more work is required to convince decision makers that these issues are real and deserve more attention than they are currently receiving. In the meantime, we should be thankful to Statistics Canada for drawing attention to the data.

The information and the issues the information raises are now out in the open and won't go away.

## LEGAL NEWS & VIEWS

### **Medical assessors can be biased; insurance companies may be unfair – and it is not a defamation to say it!**

*AssessMed Inc. v. Canadian Broadcasting Corp.*  
(2006) 39 C.C.L.T. (3d) 201 (OCA)

By: **Hugh R. Scher**  
**Monika Curyk**

In November, 1998 the Canadian Broadcasting Corporation transmitted a short T.V. program focusing on the unfair treatment of accident victims by insurance companies. The program focused on the insurance industry and featured a claimant, whose accident benefits were withheld after a medical assessment performed by AssessMed stated that she was not disabled. In response to this program, AssessMed, its chief medical officer and psychologist sued the CBC for defamation arising from the complainant's allegations of bias which were broadcasted on the CBC.

After a lengthy trial before the Ontario Superior Court of Justice, Rivard J dismissed the claim and held that the criteria for a defence of fair comment had been met.

The trial judge reviewed the content of the program as well as the available facts and concluded that the selective approach maintained by the assessors was result driven and could be viewed as biased.

The Court held that this conclusion was supported by a quote from an article by Dr. Richman, who was interviewed during the broadcast. Dr. Richman's article stated that only 3% of 3000 claimants evaluated by his company were in need of long-term disability benefits. The trial judge reviewed the article and concluded that:

This article manifested an intellectual tendency on the part of Dr. Richman to treat claimants with suspicion and to question the validity of the opinions expressed by their treating health care workers. It was an attractive approach for those insurers who questioned the extent of their insured's disability, but left doubt as to whether the approach resulting from this ideology was objective or impartial.

While Dr. Richman's opinions find some support in medical literature, they are considered too skeptical by others. Dr. Richman's research in this area was based on discussions with assessors at AssessMed but not on any empirical or validated study. In my view, it reflected a tendentious approach to assessments, which subjected AssessMed to being viewed as partial to insurers.<sup>1</sup>

Such statistics were viewed with skepticism by many medical practitioners, even though the thesis that many claimants who are not objectively disabled, honestly believe they are disabled, finds some support in the literature.

Dr. Rathbone, who had been the claimant's treating neurologist for over four years and was also named as a defendant in the defamation law suit, was firmly of the opinion that the claimant was permanently impaired. At trial, Rivard J accepted Dr. Rathbone's conclusions as legitimate and preferable to those reached by AssessMed.

After carefully reviewing the facts, the trial judge agreed that the plain meaning of the broadcast implied that AssessMed and the insurance company wrongfully denied benefits to an incapacitated accident victim and thus, it was capable of being understood as defamatory. Moreover, Rivard J found that the broadcast was understood in its defamatory sense.

Having established the likely defamatory meaning of the program, the trial judge ruled that the defence of fair comment was made out as the defamatory words were comments based on facts rather than bare, unsupported facts. These comments concerned a matter of public interest; were reasonable; were balanced by expression of an opposing view; were held

<sup>1</sup> *AssessMed Inc. v. Canadian Broadcasting Corp.* (2006) 39 C.C.L.T. (3d) 201 (OCA) para. 78 & 79

without malice; and were based on facts that were essentially true.

Rivard J disagreed that the program implied that all accident victims were treated as liars and fakers by medical assessors and that AssessMed employed dishonest practitioners in the pockets of insurers.

AssessMed appealed the decision attacking the judgment on the basis of errors in applying the defence of fair comment and unduly narrowing the defamatory meaning of the broadcast.

The Court of Appeal upheld the trial judgment and refused to believe that the reasonable viewer understood the program to mean that the assessor's assessment was performed improperly and incompetently. The Ontario Court of Appeal thus agreed with the trial judge and described the trial findings as careful, detailed and based on the evidence.

The appeal was dismissed and the CBC was awarded their costs.

**Author:** *Hugh Scher is a Toronto lawyer who practices civil litigation, labour, employment and human rights law with a focus on the rights of persons with disabilities. He serves as counsel to the National ME/FM Action Network, ME Ontario and the Fibromyalgia Society of Ontario and has represented dozens of individuals with Fibromyalgia and Chronic Fatigue Syndrome in disputes with long-term disability insurers, the Canada Pension Plan, employers and Revenue Canada.*

*Author: Monika Curyk – Student at Law*

*Scher & De Angelis Professional Corporation  
Barristers & Solicitors  
Suite 210, 69 Bloor Street East  
Toronto, Ontario, Canada, M4W 1A9  
Telephone (416) 515-9686  
Facsimile (416) 969-1815  
Email: hugh@sdlaw.ca*

## Advocacy – You Can Do This

**By: Ryan Clarke, LL.B.**

Most charitable organizations that work in the health care field do not have a good grounding in advocacy. While this is not unusual, it is ironic. It is ironic because many patient groups are quick to claim that they 'represent' people with a specific disease or condition, and yet they know very little about how to actually make their collective voice heard to decision-makers in government. The good news is that any organization, or indeed any individual, can learn how to advocate and do it well, thereby building on all of the other strengths

that they bring to the table as not-for-profit professionals and volunteers. In other words, you can do this.

Before examining what advocacy is, let me be clear about what it is not. Advocacy is not chaining oneself to a tree to prevent it from being cut down, or scaling a building to unfurl a gigantic banner. While these activities may serve a useful purpose in the eyes of the participants, they are examples of activism, not advocacy.

Advocacy is grounded in reasonable, rational thought, with sound proof or evidence that what you are asserting is true. It is telling your story to a decision-maker, through various means, with the express purpose of compelling that person to do (or not do) something. It is a process that normally takes time to realize tangible results and there is no one way to go about advocating. And it is personal to your own style and comfort level, grounded in the establishment and fostering of good relationships with those who have the ability to affect change.

For those who are hesitant to engage in advocacy or don't know much about it, I am often asked: Why is advocacy important? Well, quite simply, the squeaky wheel gets the grease. Officials in government react to those credible groups or individuals who can most effectively bring their issues to the forefront of the public agenda, and the truth is if you don't engage, somebody else will and you'll miss the opportunity. It's also important because governments will do what they want (or they'll do nothing) unless people intervene in the process. So from the outset, it should be clear; choose not to advocate for what you think is important, and I guarantee the result – nothing will happen. But take a chance and engage, and you just might be successful.

So, let's get started. What I am going to outline below is practical enough that you will be able to start creating an actual advocacy strategy that you can then implement in support of your issues. All it requires from your group is time, commitment and a willingness to start and stick with it.

Trust forms the foundation of all good relationships, and those you need to build with people in government are no different. With trust, you are able to establish transparency and credibility, and in turn, create mutually-beneficial partnerships. If all of this sounds far-fetched in the world of government relations, it's not. You don't need to always agree with the politicians and bureaucrats you interact with in order to have trustworthy relationships. You just need to be willing to invest the time it takes to be viewed as a respected advocate, and you do that by having a well-organized plan.

There are four components to creating an effective advocacy strategy.

1. **You must identify those issues affecting your organization in which government can play a role in resolving.** The more focused your issues are, and the fewer of them you have, the more likely you are to be successful. You may need to make some choices about which matters to concentrate on, but that is preferable to having too many issues covering a broad cross-section of concerns.

You also need to be able to demonstrate that you know your issues and core facts in order to establish credibility. It is surprising, for example, how many patient organizations are uncertain about the number of people affected by the disease they represent. This is a basic fact that you need to know in order to be taken seriously. Being able to discuss your issues in the context of a story, by using examples of real people who are being impacted, is important too. That's what makes the personal story one of the absolute keys to successful advocacy.

As well, it can be beneficial to your efforts to find out what matters to the people you represent. Although it may seem obvious, many groups in Canada don't truly know their members priorities because they've never asked them. Things like surveys, round table discussions, informal discussions, focus groups and public opinion polls can all provide your advocacy efforts with enhanced legitimacy.

2. **Develop your key messages next.** Politicians as a group tend to know a little about a number of things (that's the nature of their job), so this requires taking an array of information and distilling it down to its simplest form. I recommend three key messages that explain the salient points of your issues in easy to understand language. Each of those key messages should consist of 25 words or less and be written in a clear, compelling and consistent manner. They represent the essence of what you want a decision-maker to remember and respond to around the issues presented to them. Don't forget, this person is hearing from your organization and many others all the time, so your words need to stand out.

Ideally, your three key messages should not be drafted in isolation, but rather should support other key messages that you may be delivering in furtherance of your public relations/media efforts, your fundraising efforts and even your internal communications.

It's usually at this stage that people tell me that in their organization, they have many very important things they want to say and couldn't possibly limit themselves to just three statements. Well, developing your key messages is about making choices and I'd suggest you're better off picking an initial few and getting started, then being paralyzed by internal indecision and not get any messages out to government.

To get started, your first key message should contain who you are (the name of your organization), what you do and who you represent. With that basic content established, you can then go on to develop two subsequent messages that suit which ever issues you want to highlight.

Also at this point, you need to start to think about to whom to advocate. In some cases you may have existing relationships with those you're seeking to influence, while at other times you may not.

When building on existing relationships:

- Cast the net widely – someone you know, may know someone who knows the decision-maker you need to get to
- Talk to former politicians – they can often be good sounding boards for your key messages
- Create a contact plan based on portfolios, responsibilities, caucuses, cabinet committees and legislative committees

When you have no relationships:

- Make an appointment to visit your local elected representatives and introduce yourself and your organization ie. on constituency days (Fridays)
- Invite local politicians to your events
- Communicate with them constantly about what you are doing ie. by sending a copy of your newsletter or directing them to your web site
- Offer to support them in their work by building opportunities for them to get their messages out to constituents ie. by hosting a town hall meeting
- Offer to provide them with information or other resources that may be of assistance
- Ask your local representatives to provide your group with key introductions to others in government
- Go to local events where you know policy influencers will be in attendance

3. **You will need to decide the means by which your key messages will be delivered to decision-makers.** I call these communication tools and they represent the core of any effective advocacy strategy. Anything your group uses to communicate with employees, members, volunteers, supporters or people outside the organization is a potential tool. Examples include web sites, newsletters, in person meetings with decision-makers, petitions, letters, fact sheets, news releases and e-advocacy initiatives.

I noted earlier that advocacy is a process and as such, three steps must be followed regardless of the communication tool being utilized:

- a. **Educate** – you must educate the person you are communicating with about your issues by delivering your key messages and any other relevant facts they need to know ie. how many people your group represents.
  - b. **Demonstrate** – you must demonstrate why your issues and the key messages supporting them should matter to the decision-maker you're seeking to influence. Many people in the not-for-profit sector spend their time trying to convince government officials of the importance of their issues to the organization itself. That's a given. A sophisticated advocate will focus on explaining why supporting your ideas will also benefit those in power.
  - c. **Advocate** – it's at this stage that you're ready to ask the person you're targeting to actually do something on your behalf
4. **Which brings us to the final element; presenting your one 'ask'.** This is the goal of the advocacy strategy, to be able to ask a decision-maker for the one thing you need them to do, not a list of what you want from them. It's here that most people engaged in advocacy fail to be specific enough in articulating what exactly they need the government to do for them. Instead, they present a

wish list of all of the things they want and ignore the reality of governing, which dictates that politicians and bureaucrats make choices about which policies to adopt and groups to support. It may sound contrary to what most of us believe, but in advocacy, the less you ask for and the more specific you are, the more likely you are to succeed.

Your 'ask' needs to be tangible, something that can be measured. For example, if your ask is to have a piece of legislation amended to replace the word 'shall' with the word 'may', and the government makes that change, you have been successful. But if your ask is to have your local MP support your organization in its efforts to bring about an unspecified amendment to that same piece of legislation, you haven't really asked that person to do anything. I remind organizations that asking someone for their 'support' or 'help' is akin to an empty promise; it won't ever amount to much unless you outline what exactly you need them to do to demonstrate their support for your cause or issues.

It is my hope that by adopting the components outlined above, you will be able to develop an effective advocacy strategy on behalf of your organization and the people you represent. In my work teaching and training people to be good advocates, I've come to realize that the most difficult part of the process for many groups is just getting started and believing that they can make a difference. But you can, by simply deciding that you can do advocacy.

***Ryan Clarke is founder of Advocacy Solutions, a business committed to providing a voice to organizations through the development and implementation of impactful advocacy strategies. He can be contacted at***

***[ryan@advocacysolutions.ca](mailto:ryan@advocacysolutions.ca)***

## NETWORKS NOTES

### IME/FAE Registry Submission

The **National ME/FM Action Network** continues to urge those who have attended an **Independent Medical Examination (IME)**, **Functional Abilities Evaluation (FAE)** or any other form of assessment at the request of an insurance company, Canada Pension Plan (CPP) or Workplace Safety & Insurance Board (WSIB) to fill out our 7-question, confidential, **Independent Medical Examination Registry Submission Form** so that the names of the doctors and healthcare professionals who evaluated you can be put on record. Patients, doctors, lawyers, advocates, support groups wishing to receive a copy or copies of the Form, or to inquire about specific IME doctors, please contact: **National ME/FM Action Network** – Or download the Form from our website at [www.mefmaction.net](http://www.mefmaction.net)

MEMBERSHIP: \$25.00 per year, which includes quarterly newsletters  
Payment can be made by CHEQUE, VISA or MASTERCARD.  
Do not email credit card information.  
NATIONAL ME/FM ACTION NETWORK  
3836 Carling Ave., Nepean, ON K2K 2Y6, Canada  
Tel/Fax: (613) 829-6667 E-mail: [ag922@ncf.ca](mailto:ag922@ncf.ca)  
Web: <http://www.mefmaction.net>

## RESOURCES

### Consensus Documents

#### Complete Original Consensus Documents :

**FMS Consensus Document US\$24.95**  
"The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners". Haworth Press, 2004.  
(soft cover book) ISBN: 0-7890-2574-4  
Phone: 800-429-6784 Fax: 607-771-0012  
Email: [orders@haworthpressinc.com](mailto:orders@haworthpressinc.com)  
Online: <http://www.haworthpress.com/store/product.asp?sku=5342>

**ME/CFS Consensus Document US\$14.95**  
"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

Phone: 800-429-6784 Fax: 607-771-0012  
Email: [orders@haworthpressinc.com](mailto:orders@haworthpressinc.com) Online:  
<http://www.haworthpress.com/store/product.asp?sku=4958> CFS46

#### Overviews of the Consensus Documents:

Fibromyalgia Syndrome, 24 pp, 2006  
Chronic Fatigue Syndrome, 20 pp, 2006

can be ordered from Marjorie Van de Sande at  
151 Arbour Ridge Circle NW, Calgary AB T3G 3V9.

## New ME/CFS DVD Resources

Prices include shipping & handling

- **Dr. Kenny De Meirleir - Physicians' full day workshop \$80.00. This includes 4 DVDs and a CD**

Canadian Consensus Guidelines for Diagnosis, Assessment and Treatment of

ME/CFS -What they are and how to use them.

- Research Update
  - Diagnostic Work Up and Treatment Algorithm
  - Case Examples and Discussion
  - CD of Slides
- **Dr. Kenny De Meirleir : Patients' lecture \$25.00**
  - **Dr. Pierre Flor- Henry's lecture: \$20.00** qEEG studies (current density source) & psychophysiological studies (very technical)
  - **Dr. David Bell's lecture: \$25.00** (emphasis on chronic orthostatic intolerance)

**Payment:** must be by **cheque** or **money order** payable to **Marjorie van de Sande**  
Mail it to her at **151 Arbour Ridge Circle NW, Calgary AB T3G 3V9.**

## Network Resources

***The following resources can be ordered from the National ME/FM Action Network. Prices include shipping and handling. Cheques should be made payable to the National ME/FM Action Network or you may pay by VISA or MasterCard.***

### Quest Collections

By popular request, the **National ME/FM Action Network** has published two collections of important articles which have appeared in 'QUEST' newsletters. The articles in each five-year collection have been grouped into sections according to their focus.

### **Quest Collection II (1999 – 2003): \$38.00**

**TEACH-ME: A Sourcebook for Teachers (Second Edition): \$22.00** *Discount on bulk orders*  
*With Dr. D. S. Bell, Dr. B. M. Carruthers and the TEACH-ME Task Force (teachers with ME/CFS and/or FMS)*

This educational resource book will enhance teachers' and parents' understanding of ME/CFS and FMS in young people, and assist educators in developing educational modifications and programs.

### **The Canada Pension Plan Disability Benefits Guidelines: \$7.00.**

New up-dated guidelines have been designed to assist those disabled by ME/CFS and/or FMS applying for Canada Pension Plan Disability Benefits. It will help you understand the criteria, important items to include and walks you through the various steps of the process.

### **Legal Disability Manual: \$60.00**

Approx. 400 pages *Editor: M. van de Sande*

The Legal Disability Manual includes sections on: FMS and ME/CFS Overview; The Medical Report and Expert Witnesses; Independent Medical Examinations; CPP Disability Benefits, Disability Insurance and Other Legal Articles; Case Law; Psychological Factors, Tests, and Treatments; and Research Abstracts. Many of the articles have been written specifically for the **National ME/FM Action Network** by lawyers and doctors. Our new Canada Pension Plan Disability Benefits Guidelines are also included in the Legal Disability Manual. This manual is a must for those in litigation.

**COPYRIGHT NOTICE:** The National ME/FM Action Network newsletter "QUEST" is published quarterly. Its contents are © 2004, 2005, 2006 by the National ME/FM Action Network, EXCEPT where authors of articles are indicated. These items are copyrighted by the authors and written permission must be obtained from the author in order to reprint them. Other articles may be reproduced in their entirety without alteration by other non-profit publications as long as copyright notices are included and items are clearly attributed to the NATIONAL ME/FM ACTION NETWORK, citing its name, address, telephone number and website.

**DISCLAIMER:** The NATIONAL ME/FM ACTION NETWORK serves as a clearing house for information on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia. Some of the information contained herein is intended to help patients and their physicians make informed decisions about their health. However, the NATIONAL ME/FM ACTION NETWORK does not dispense medical advice or endorse any specific medical hypothesis or product and assumes no responsibility for any treatment or action undertaken by its readers. Discuss medical treatments with your personal physician.