Quest #50 October 2001

CONSENSUS UPDATE:

After years of working in partnership with Health Canada, in March 2001 in Toronto, Ontario, the **National ME/FM Action Network** hosted the peer-review of the Canadian ME/CFS and FM Clinical Definitions, Diagnostic and Treatment Protocols documents drafted by **Dr. Anil Jain** of Ontario, and **Dr. Bruce Carruthers** of British Columbia. A consensus of the contents of the documents has been reached by the doctors, who are experts in diagnosing / treating / and /or researching ME/CFS and/or FM and who were chosen to participate in the peer-review by Health Canada and a panel of their peers.

The ME/CFS Canadian Clinical Definition, Diagnostic and Treatment Protocol document is presently being peer-reviewed by a medical journal, in order to be considered for publication. Meanwhile, editing continues on the FM document.

We hope to have more news for you in our next issue of QUEST.

The **NATIONAL ME/FM ACTION NETWORK** thanks you for all the support you have given our organization during the year and we extend to you best wishes for the New Year.

Lydia E. Neilson, President CEO

NATIONAL ME/FM ACTION NETWORK

LOW BLOOD VOLUME IN ME, SAYS Dr. David Bell

[Excerpted from an article written by Linda Haist for the Hamilton Spectator, Nov. 14, 2001]

A leading U.S. researcher into the cause of Chronic Fatigue Syndrome says the illness is all in the patient’s head – but only in the sense that it involves the autonomic nervous system.

According to Dr David Bell, there is nothing psychosomatic about the illness, which was once called Yuppie Flu. He says studies he conducted with American endocrinologist Dr David Streeten yielded the startling discovery that patients with the illness have an extraordinarily low circulating blood volume, and that the decreased volume is present in up to 80 per cent of patients.

Dr Bell, guest lecturer at a meeting of the Myalgic Encephalomyelitis Association of Halton & Hamilton-

Wentworth in Burlington, Ontario, said other researchers around the world are also discovering the same abnormality. He noted that the low blood volume could help account for the prevalence of orthostatic intolerance – worsening of symptoms when patients stand – because the limited amount of blood tends to pool in the legs and feet, with a corresponding drop in the amount available to the brain. Low blood volume also reduces oxygen going to the brain, resulting in patients manifesting the same symptoms seen in carbon monoxide poisoning, as well as some of the symptoms seen in high altitude sickness. However, when blood volume is raised to normal through an intravenous saline solution, patients feel good for four to six hours.

Understanding low blood volume and severe orthostatic intolerance helps explain the extreme activity restriction reported by patients, said Dr Bell, stressing that the word "fatigue" comes no where near adequately describing how they really feel.

"I feel this (reduction in blood volume) is the cause of the illness," he told more than 100 people attending the lecture. Although there is no hint of a cure at this time, Dr Bell said a vascular physiologist in Scotland is getting closer to the root of the problem underlying the illness.

A graduate of Harvard University and Boston University School of Medicine, Dr Bell studied child development and behavior at McMaster University [Hamilton, ON]. He was one of the first physicians to recognize the illness, following an outbreak in Lyndonville, New York, in the mid-1980’s.

Dr Bell said patients with the illness, which is now being called Chronic Fatigue Immune Dysfunction Syndrome or Myalgic Encephalomyelitis, need good clinical care. [Note: M.E. was the name used by Dr Bell throughout the lecture]. "This is where doctors really need to be doctors; you have to think and study."

Dr Bell said the principles of treatment include ongoing diagnosis, a check against other diseases occurring; emotional support; symptom reduction, medication to alleviate symptoms such as headaches and joint pain when they occur; educational support. And patients need to know that the illness is not going to lead to life-threatening illness such as cancer.

A copy of **Dr. David Bell’s** Research is available at **www.ncf-net.org/library/Bell.htm**

Dr David Bell’s Lecture of Nov. 10, 2001 on M.E. **and low blood volume problems** is available on an amateur video. **The video includes a one-hour lecture and a one-hour question & answer session**. The cost of the video is **$15. 00,** which includes postage, and can be purchased by contacting **The M.E. Association of Halton & Hamilton-Wentworth, 2230 Mountainside Dr., #5, Burlington, Ontario L7P 1B5 or** by phone at **(905) 319-7966.**

HARVARD CHRONIC FATIGUE SYNDROME/CHRONIC PAIN PROGRAM

By Alan C. Logan N.D.

In the summer of 2001, I attended Harvard Medical School's Clinical Training in Mind/Body Medicine in Boston, Massachusetts. The Mind/Body Medicine Program runs under the direction of Herbert Benson MD, who has devoted much of his career to researching the beneficial physiological consequences of eliciting relaxation. This program is designed to instruct medical professionals on how to introduce Mind/Body techniques to patients in the clinical setting.

In working together with **Dr. Alison Bested MD FRCPC** in her practice devoted to CFS/FM, I thought it would be of real value to learn these skills so that I could pass them on to CFS/FM patients. While at the Harvard course I had the good fortune to meet **Dr. Ellen Slawsby**, Program Director of the Chronic Fatigue Syndrome Program, Division of Behavioral Medicine at Harvard's teaching hospital, Beth Israel Deaconess Medical Center. I was pleased to learn that there is a specialty program specifically for those with CFS, FM and other chronic pain conditions. After it became clear to Dr. Slawsby and her colleagues of my interest and passion in helping the healing process in CFS, I received an invitation to participate in professional training specific to the CFS program. I am so grateful that they were open-minded and respectful of naturopathic medical education in allowing my attendance.

The Harvard CFS program is an education and behavioural therapy group involving 11 weekly sessions. The purpose of the program is to provide the skills necessary in dealing with a chronic illness, symptom reduction, and to identify factors or situations that may be contributing to setbacks or lack of progress. All participants have a copy of Managing Pain Before it Manages You by Margaret Caudill MD PhD, a superb book that serves as a course guide, resource and workbook.

At the first session participants are encouraged to bring a spouse, partner or family member to give support and to provide insight into the effects of CFS/FM on other families. Peer sharing and support make up a significant portion of week one. Also during the first session the physical and psychological consequences of constant stress are discussed as well as the short and long-term benefits of eliciting a relaxation response. The relaxation response can be elicited through various methods, including meditation, focused breathing, guided imagery/visualization, yoga stretching and progressive muscle relaxation.

Throughout the weekly two and a half hour sessions, the various relaxation techniques are discussed and taught. Breath awareness and mindfulness, or the ability to focus on only one thing, are important aspects of getting the most from a relaxation response. Research by Dr. Benson and colleagues shows that repetition of a simple, mental focus via a word, short phrase or breath watching are important, as are keeping a passive mental attitude towards the thoughts and feelings experienced during the session. A comfortable position, a quiet environment and lots of practice are also critical in achieving the physiological benefits.

Each session is devoted to a particular topic such as pacing and activity scheduling, sleep hygiene, nutrition, exercise, cognitive restructuring (reframing), humour, journaling, communication skills and problem-solving. At all sessions the relaxation response is practiced. Homework involves reading a chapter or two of Dr. Caudill's Managing Pain book. The patients in the program state that the word "pain" can readily be substituted for "fatigue" in the book. After completion of the program, patients are encouraged to attend "graduate groups" facilitated by peer volunteers on a monthly basis.

The benefits of properly organized and facilitated education and support groups in the treatment of CFS are being highlighted by medical research (Solderberg, Evengard. Psychother Psychsom 2001). The benefits of Mind/Body techniques have been validated as an effective FM treatment approach in a number of studies (Berman. J Rheumatol 2000; Sephton et al. Psychosom Med 2001; Worrel, et al. Mayo Clin Proc 2001). Unpublished data from the Harvard CFS program indicates that 87.5% of patients felt they were able to manage their symptoms more effectively and showed significant reductions in physical and mental fatigue.

Dr. Bested and I have been facilitating education and support groups at our office in Toronto, Ontario and now we have added to the course content based on my experiences with the Harvard program. We have groups of 10-12 CFS/FM patients and have sessions every two weeks for eight weeks. The response has been tremendous and participants have reported significant benefits from attendance. In 2002 we will have two concurrent eight-session programs. As with the Harvard program, our goals include education, particularly increasing coping skills, stress reduction and pacing. Drawing on Dr. Bested's 10 years of clinical experience in treating CFS, the group process is greatly enhanced. In addition to session specific topics such as exercise, nutrition, Mind/Body techniques, sleep and lifestyle interventions, we also focus on the latest research from an integrative perspective (ie one inclusive of both conventional and complementary therapy). The meetings provide not only medical support but peer support as well. The patients quickly discover they are not alone with their illness; they often make friends within the group and can end the often-encountered social isolation. While it can be physically difficult for some to attend the sessions, almost all state that they were glad they made the effort. Our sessions are held every other week based on patient feedback; we find that our week-to-week attendance is higher when an alternating schedule is used.

In conclusion, the training at Harvard was of real value in enhancing our Toronto-based education and support group content. The group serves as a beneficial complement to other medical interventions and may help to improve the quality of life of those dealing with chronic illnesses such as CFS and FM. Participants have the dual benefit of medical and peer support.

For those in the Toronto area who are interested in attending our group, please call the **CFS/FM Integrative Care Ce**ntre **at (416) 283-0007.** A referral from a GP is required for attendance.

For further information on Harvard's CFS Program please call **Leah Koenigsberg** at **(617) 632-9529**, email: **mbclinic@bidmc.harvard.edu** or visit the web-site at **www.mbmi.org**

To order **Managing Pain Before it Manages You** by **Margaret Caudill** (ISBN # 0898622247) contact **The Guilford Press at 1-800-365-7006** or **www.guilford.com**

FIBROMYALGIA AND ACTIVE LIVING:

By: Susan Romanick BSc.P.T. ,Coordinator Fibromyalgia Program

Halton Health Care Services Corporation , Oakville Site

We have been offering a Fibromyalgia Program at the Halton Healthcare Services Corporation (Oakville Site) since 1991, and from firsthand experience, can recommend the importance of an active lifestyle when dealing with a condition such as Fibromyalgia. The body's natural response to chronic pain is to become less active in order to protect muscles and tissues. Inactivity leads to muscle tightness and deconditioning and your day to day responsibilities become more difficult and exhausting. In a condition such as Fibromyalgia, where pain and fatigue are the major symptoms, a program to increase flexibility, endurance and strength becomes very important. Before you start any new exercise program you should consult with your physician to be aware of any medical conditions which may limit your ability to exercise or that may need to be monitored as you progress. Although the cause of Fibromyalgia is uncertain, a broad treatment plan can make symptoms more manageable; and activity and exercise are important components of that plan. Fibromyalgia pain may worsen with inactivity and exercise helps break the cycle of pain and decreased fitness level.

Benefits of Exercise:

1. Improves strength and flexibility;

2. Improves your energy level;

3. Releases the bodies natural pain relievers-endorphins;

4. Helps reduce emotional tension and stress;

5. Increases your feeling of well being;

6. Improves the general fitness of your heart and lungs; and

7. Helps promote a more restful sleep.

It is important for people with Fibromyalgia to exercise so that muscles can function in a normal way but exercise should always begin at a manageable level. In my experience, sometimes when people are told that exercise is helpful, they start too aggressively and this can cause a flare-up making them fearful of continuing.Your level of physical ability, age, and other existing medical conditions must be taken into account before starting a program. Muscle soreness at the beginning is expected in people who do not regularly exercise and especially in people who have Fibromyalgia . Try not to quit exercising because of this initial tenderness but respect any increase in muscle soreness and decide if you are working within your own realistic limitations. Pacing and scheduling are very important in this regard and keeping a daily journal documenting your periods of activity and exercise balanced with rest and relaxation is essential. A daily log allows you to see your progress over time and identify patterns during the day or week when you are best able to get things done.

There are different components of exercise that you need to think about as you set up your own program. Your body’s response to pain is to move less and this results in tight muscles, particularly in the neck and shoulders. Starting a gentle stretching regime helps to improve your flexibility and allows for more efficient posture and function.Tight muscles also can become weak and incorporating strengthening exercises will help the overall endurance of a muscle. This does not mean you start with a weight program. Often it is sufficient to begin moving your body in an antigravity position such as walking.

In cardiovascular training you are doing aerobic exercise and your body uses oxygen to produce energy. The more oxygen you consume the greater your ability to produce energy and the goal is that as you become fitter you will have a reserve to help you combat episodes of pain and fatigue.

Based on these principles of exercise, we strive to encourage a philosophy of active living in our Fibromyalgia Program. This is an eight-week program in an environment of support that encourages the Fibromyalgia sufferer to regain a more active lifestyle. The goals of our program are to offer education, supervised exercise, and new coping skills to make lifestyle changes that are often necessary when dealing with the sometimes overwhelming symptoms of Fibromyalgia. We have weekly education sessions to better understand Fibromyalgia and what new stragedies can help to deal with daily situations. The role of exercise, relaxation techniques, pacing and energy conservation, pain management, sleep care, and back and neck care are discussed. We are also fortunate to have a pharmacist attend to provide information about the more commonly used medications in fibromyalgia.

We offer a group format of usually fifteen people and the program runs three afternoons a week. One afternoon is devoted to education and on the other two days a thirty-minute, low-aerobic, warm, pool class is offered. Most people feel the pool classes are the most enjoyable part of the program and find they can exercise more vigorously in the water than on land.

To enroll in this OHIP program we require a doctor's referral with a diagnosis of Fibromyalgia. An hour long assessment is then set up to provide more details about the program and to assess the client's suitability. During the initial assessment, we carefully go over the client's medical history and determine any contraindications for the pool program. Cardiac problems, unstable blood pressure, a history of seizures or a fear of the water would all be issues that would not allow participation in the pool. There is the occasional person who attends just the education sessions but we know from experience the maximum physical benefit occurs when attending the entire program.

After the assessment we have a clear idea if the client is appropriate for our group format. The guidelines for admission into the Fibromyalgia program are as follows:

1. Adequate English comprehension to understand the lectures and participate in the group discussion;

2. No acute underlying conditions such as a spinal disc, tendonitis, or cardiac problems;

3. If a client suffers from depression but is well controlled on medication and is receiving support they usually do well. The program can be stressful to someone struggling with medication changes or if feeling emotionally unable to commit to the eight -week time period.

4. The physical endurance to attend the pool and education classes three times a week; and

5. One of the most important criteria is the client's willingness to make the eight-week commitment with regular

attendance. The program is vigorous and in the first two to three weeks there can be an increase in pain and fatigue

which usually levels off and people can start to benefit from the physical conditioning.

We adhere to these guidelines and if someone is not suitable we try to offer suggestions for alternate treatments such as home programs and sometimes we will start a person on a trial of pool classes to build up his/her tolerance for the program.

Home programs are important for the continued success after completing the program. A client has to be self-motivated and take control of his/her lifestyle. There are also people who are unable to attend due to work and family commitments and it becomes important to use services available in the community. Establishing a daily walking program is the first suggestion I make for people who have been inactive. You can start at a very gentle pace, perhaps five to ten minutes a day. It is an activity that is inexpensive and does not require any special equipment.

In 1993, we produced a thirty-minute Fibromyalgia Exercise Video at the request of previous patients. It continues to be useful for home exercise and includes a warm- up portion, aerobics and a cool down. It can be modified depending on your fitness level. It is available at the Oakville site Physiotherapy Department **(905) 338-4613**.

It is very important to choose activities that you enjoy and that have a social component. Having a variety of choices to vary your program will help combat boredom. Remember with any program to start slowly, progress gradually and listen to your body.

SUPPORTING PLAYERS: THE ROLE OF PROFESSIONAL ASSOCIATIONS & UNIONS IN ASSISTING DISABLED MEMBERS

By Richard R. Evenson and Roderick C. Flynn, Lawyers

A great portion of the work done by myself and the other members of this firm involves advocacy and litigation on behalf of disabled workers pursuing disability income claims under employee group disability plans. Many of these claimants suffer from the effects of M.E. (myalgic encephalomyelitis – also known as Chronic Fatigue Syndrome) and/or Fibromyalgia. It is not uncommon that in my practice, I encounter people at or near their lowest ebb – physically or psychologically drained and disabled, financially imperiled, embattled by a lack of cooperation from insurers and employers alike (and sometimes even their own doctors), and despondent at the prospect of an uncertain financial and medical future.

In this context, the individual worker faces an uphill battle in advancing a successful disability claim against a large, financially solid, diversely resourced insurance company. In most cases, the disparity between the energy and facilities which can be mobilized by a single disabled employee and that which can be activated by the responding insurance corporation is vast. The worker has limited financial means, and faces a future of greater constraint in this regard. An individual with an enervating condition (such as M.E. or Fibromyalgia) may be impaired in her or his ability to put together a comprehensive submission regarding his or her case given the effects of his or her disability. Compounding this issue is that the economic duress faced by an individual employee may exacerbate the debilitating effects of his or her condition, further complicating the individual’s capacity to effectively represent herself or himself. The employee, as an individual, may find it difficult to develop an understanding of the disability claim framework within which his or her claim will be assessed. Often, for the individual claimant, it is virtually impossible to obtain a full and complete copy of the governing disability insurance policy. In addition, the disabled claimant may find it difficult to get prompt and/or comprehensive cooperation from physicians or other experts. In short, the employee on his or her own, is simply outmatched: outmatched in one of the most significant struggles of her or his life.

From the point of view of an insurance company, the prospect of responding to an individual disabled claimant must be inviting – knowing that the worker has finite financial and other resources to respond to any denial or pre-mature termination, irrespective of the merits of his or her case. Knowing that the opposition has fewer resources and facilities than you, is seldom a disquieting thought.

That situation may change when a worker is provided resource support. With greater financial and human resources behind her or him, an employee is in a position to do at least three critical things in support of a claim:

- gain access to crucial information about the exact nature of the disability claim framework within which the employee's claim is being assessed. This not only includes the crucial policy provisions defining the insurance coverage in place and the operative terms and conditions of that coverage, but also information about the disability insurance claim context generally and the claims assessment process used by insurers;
- gather relevant medical information from treating physicians as well as other medical experts; and
- develop and present submissions (either to the disability insurer or during court proceedings) in a comprehensive manner which speak to both the strength of the claim she or he is advancing and the failings in the insurer's position.

In my view, if a claimant's union, professional association or employee group is prepared to support an individual's disability claim (in whole or in part), a lot of valid claims which otherwise might be denied, can be successfully advanced – in whole or in part.

I have been extremely fortunate to work in conjunction with an employee association which provides extensive financial and resource support to its members in advocating and litigating disability matters. This assistance addresses both the financial constraints a member may face as well as the individual's fear and fatigue in simultaneously facing an ongoing disability and advancing an argument in support of a claim for disability benefits.

In many cases, financial and staff support from a worker's union (or professional organization or employee group) provides the means to:

- relieve the worker from the burden of organizing and carrying their own case;
- provide legal assistance for consultation, submissions and advocacy on

the worker's behalf;

- consult and mobilize medical and other expert assistance and reports;
- provide the intangible support of conveying to the disabled employee a sense of belongingness and ongoing contact with a group of which that person is a member.

I believe strongly that in most cases, this support from an employee's union or professional association or employee group makes the difference between acceptance and rejection of a worker's appeal or claim.

In many ways, it makes sense for a union, professional association or employee group to extend support for members' disability claims, considering:

1. Many unions devote considerable time and resources to dispute in grievances, acts by the employer which impact even marginally on a member's ability to make a living. An employee's development of a disability amounts to a considerable (and unfortunately very common) interference with that employee's ability to make a living. Accordingly, it is perfectly consistent with a union's desire and commitment to defend the ability of its members to earn a livelihood to support the pursuit of disability benefits. This is particularly so when the disability insurance plan applicable to the disabled member is a benefit or term of employment.
2. Where a member is successful in resolving a contested disability claim (whether through litigation or prior appeals and negotiation), the result is often a lump sum payment of funds by the disability insurer to the member. This lump sum can represent either accumulated arrears of disability benefits, or a one-time "buy-out" of a member's disability claim. This pool of money in the employee's hands can be used (if required) to reimburse a union, professional association or employee group for any financial expenditure made in advance by the supporting body.

More generally, support of a member makes sense for a union, professional association or employee group because it is coextensive with the basic premise that these organizations exist to protect and advocate for the rights of its members. It seems a fundamental organizing principle of unions, for example, that employees must develop strength in numbers by organizing together to withstand the exertion of pressures and powers of a stronger individual party – the employer. By the same logic, a union, professional association or employee group can provide similar sustenance by providing assistance (financial and otherwise) to a member faced with the challenges of battling another large party - an insurance company - for disability benefits under applicable group policies.

While support for members who are disabled poses its own challenges (beyond the financial) –both in selecting and orienting union staff to the terminology and context of the subject matter and to respond to the unique requirements of members who are off work, it also has considerable rewards, not the least of which is the support of members who need and appreciate such aid. For members suffering from conditions such as ME and Fibromyalgia, such support may prove to be the critical nexus between coping with an ongoing disability and being overwhelmed by its challenges.

Richard Evenson and **Roderick Flynn** are lawyers in Toronto, Ontario, with the firm of **Evenson Bundgard Flynn**, practicing in the area disability insurance claims and employment law. They may be reached by email **at r.evenson@ebf-law.com** and **r.flynn@ebf-law.com or by telephone at (416) 482-6588.**

ACCESSING JUSTICE - Reassessments of Disability Tax Credit Applications

By: Hugh R. Scher, Scher & De Angelis LLP, *Barristers & Solicitors*

Many people with disabilities, including Fibromyalgia and Chronic Fatigue Syndrome are being subjected to reassessment of their application for the Disability Tax Credit. This is so, even for many who have been receiving a tax credit for more than ten (10) years. Further, changes in the disability tax credit application form suggest that the government is seeking to limit the disability tax credit to an extremely narrow segment of the disability population. The effect of this apparent shift by the government toward an extremely narrow and exclusive view of eligibility for the disability tax credit would appear to completely ignore the original intent of the tax credit to aide those with disabilities in meeting the added burden of medical expenses and other costs related to disability as well as reduced income on account of disability. Moreover, the narrow approach taken by government in the form T2201 has made it difficult, if not impossible for many doctors to complete the form on behalf of their patients. The reason for this is that the questions in the first part call for yes or no answers. For most people with disabilities, especially those with Chronic Fatigue Syndrome or Fibromyalgia, the answers to questions relating to restrictions in the activities of daily living require more comprehensive explanations than simple yes or no answers.

Despite recent changes in the Disability Tax Credit Certificate, which doctors must complete on behalf of their patients, there has not been any change in the definition of disability or the eligibility requirements for the disability tax credit since 1991. As such, a person is entitled to the disability tax credit where they have a severe and prolonged mental or physical impairment that markedly restricts their ability to perform **a** basic activity of daily living.

An impairment is prolonged where it has lasted, or can reasonably be expected to last, for a continuous period of at least 12 months. The person’s ability to perform a basic activity of daily living is markedly restricted where all or substantially all of the time, the individual is blind or is unable, or requires an inordinate amount of time to perform a basic activity of daily living. A basic activity of daily living in relation to an individual means:

(i) perceiving, thinking and remembering;

(ii) feeding and dressing oneself;

(iii) speaking so as to be understood, in a quiet setting by another person familiar with the individual;

(iv) hearing so as to understand, in a quiet setting, another person familiar with the individual;

(v) eliminating (bowel or bladder functions); or

(vi) walking.

The *Income Tax Act* goes on to further explain that marked restrictions from performing the activities of daily living mean more than simply a complete inability to do housekeeping, social or recreational activities, or to work.

The Disability Tax Credit form is divided into two (2) separate sections. The first requires your physician to answer a series of seven (7) questions with yes or no answers. Part (b) permits your physician to provide greater explanation with respect to diagnosis, impairment and functional limitations on one's ability to engage in the activities of daily living.

Unfortunately, many doctors will complete part (a) of the form and then find that they are not able to provide significant answers in part (b) without contradicting their earlier answers. Doctors are best advised to begin completion of the form by completing part (b) relating to diagnosis, degree of impairment and an explanation of the functional limitation of a patient's disability on their ability to engage in the activities of daily living. The doctor is then best advised to return to part (a) and to answer each of the seven (7) questions in the context of their answer to question (b). As such, it would not be uncommon for a doctor to report in section (b) that the patient experiences Fibromyalgia and Chronic Fatigue Syndrome which is a chronic disability expected to last for greater than 12 months. As such, the condition is prolonged. Further, the condition is a significantly variable condition which means that a patient's limitations and functions will vary significantly from day to day. However, the patient does remain markedly restricted from performing the activities of daily living on a consistent basis almost all of the time. Moreover, a patient will at times be able to pursue certain activities of daily living but may take an extremely long time to perform these activities and may experience significant flares or a worsening in their condition in the period following the completion of any given activity.

In particular, the patient is encouraged to walk for brief periods of time, including for distances of greater than 50 meters where the patient is able to do so. However, there will be significant periods of time in which the patient is not able to do so on account of significant pain and fatigue. Moreover, the patient experiences consistent difficulties with memory, concentration which are attributable to a sleep disorder and chronic fatigue which markedly restricts the patient from engaging basic activities of daily living and which require the patient to spend considerable periods of time, as many as 10 to 18 hours per day in bed. As indicated above, the symptoms will vary from day to day, but are experienced consistently and in a pervasive way by the patient.

With respect to feeding and dressing, it may be noted that for some patients they may not be able to even prepare basic meals for themselves and will experience periods of time during which they are unable to dress themselves on account of chronic pain and fatigue. With respect to eliminating bodily waste, patients frequently will suffer from Irritable Bowel and Irritable Bladder Syndromes which can cause patients significant difficulty in attempting to perform activities of daily living in that the patient will be confined to their household or to a place where they are close to washroom facilities.

Answers such as those above would be common for many people with Fibromyalgia and Chronic Fatigue Syndrome and could be included as part of part (b) of the Disability Tax Credit Certificate as well as supplementary responses to the questions in part (a) in order to provide those questions with a proper, accurate and non-misleading context.

Doctors should be encouraged not to feel compelled to simply answer yes, no answers where those answers are not responsive to the questions posed and where they do not accurately and clearly reflect the nature of a patient’s condition, their restrictions and degree of impairment.

Physicians need to understand that they are not the final decision-maker with respect to a patient’s eligibility for the Disability Tax Credit. Their role is to provide clear and accurate medical information so as to enable the Ministry to make proper determinations.

The Ministry and doctors in completing Disability Tax Credit certificates ought to be guided by case law by the Federal Court of Appeal and other relevant courts with respect to the interpretation of the Income Tax Disability Tax Credit.

In the case of Radage v. Canada (1996), the Federal Court of Appeal ruled that the disability tax credit provisions are to be construed liberally, humanely and compassionately, and not narrowly and technically.

In the case of Froese v. The Queen (1998), the court ruled that "It does seem rather strange that the Department of National Revenue routinely ignores certificates by doctors that a patient has a severe and prolonged impairment, but where the doctor, in the face of all the evidence ticks a box that does not favour the impaired person, this is treated as a conclusive bar to his or her claim. Such an approach is an unacceptable use of technicalities to deny worthy claims. I am not prepared to deny this obviously meritorious claim because of a misplaced tick mark."

Moreover, in Tanguay v. Canada (1997), Judge Dussault took issue with the new Disability Tax Credit Certificate requiring "yes" and "no" responses from the doctor. He noted "I find that, to the extent that one wishes to obtain unequivocal answers, it would appear better to ask complete questions containing all the elements stated in paragraph 118.4 (1)(a)(b) of the Act."

An important point to be made is that inability to perform basic activities of daily living does not mean that a patient must be unable to perform each and every one of the basic activities of daily living. On the contrary, if it can be demonstrated that a patient is substantially unable to perform one (1) basic activity of daily living because of a severe and prolonged condition then this may be enough to satisfy the standard under the *Income Tax Act*.

Many doctors have difficulty completing the Disability Tax Credit Certificate on behalf of their patients for fear of allegations of fraud or professional misconduct against them. Doctors should be encouraged to use their best professional judgment and common sense to clearly answer the basic question posed by the *Income Tax Act* as to a patient's marked restriction from performing one (1) or many basic activities of daily living as a result of a severe and prolonged disability.

In order to ensure fairness in the adjudication of Disability Tax Credit claims, it is imperative for physicians to feel comfortable to provide comprehensive, accurate and meaningful medical information based on their education, training and experience in order to best enable the Ministry, or the courts, to properly adjudicate these claims. In this respect, doctors should not feel constrained by the specific wording of the questions on the Disability Tax Credit Certificate. By contrast, professional responsibility and common sense obligates doctors to provide clear, comprehensive and accurate medical information on behalf of patients when completing these forms.

While Parliament's intent in changing the form of the Disability Tax Credit Certificate may be to eliminate thousands of disabled Canadians from receiving a disability tax credit, patients and physicians should complete their application for the tax credit in a clear, comprehensive and accurate fashion, providing as much detailed information and evidence about a patient's medical condition to assist the Ministry to make a proper determination as to the application of the *Income Tax Act* in each case.

Note on Author: **Hugh Scher** is a partner in the law firm of Scher & De Angelis where he practices civil litigation and administrative law with a focus on insurance, employment, and human rights law especially in the area of disability rights. He also serves as counsel to the **National ME/FM Action Network** and Ontario Fibromyalgia Society 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.

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SUMMARY OF A DECISION OF THE CPP REVIEW TRIBUNAL

DATE OF HEARING: March 21, 2001 – LOCATION: Peterborough, Ontario

DATE OF DECISION: May 1, 2001

APPELLANT: A 53 year-old woman diagnosed with Fibromyalgia

FINDINGS: Having heard the evidence of the parties, the Review Tribunal found the Appellant severely disabled within the meaning of the Canada Pension Plan.

REASONS FOR DECISION: Section 42 of the Canada Pension Plan (CPP) provides that in order to be entitled to disability benefits, the Appellant’s medical conditions must be severe and prolonged. It has been held in many cases that the test for "severe and prolonged" is twofold. The first part of the test is the "severe" criterion. A disability is "severe" only if by reason thereof the person with respect to whom the determination is made is incapable regularly of pursuing any substantially gainful occupation. The second test is the "prolonged" criterion. A severe disabling condition is "prolonged" only if by reason thereof it is long-standing, and of indefinite duration or likely to result in death.

The issues for the Tribunal were to determine whether or not the Appellant’s medical conditions were severe and prolonged and whether or not the onset of a severe disabling condition occurred prior to the end of 1999 and have continued to the date hereof.

The Appellant had been employed as a registered nurse for 30 years and in the early 1990’s developed health problems, which were eventually diagnosed as symptoms of Fibromyalgia. She was only capable of working on a part-time (half-duty) schedule and was finally advised by her medical advisers to leave her job for health reasons.

The Appellant attempted to pursue traditional conservative therapies, including a regular home exercise regimen, various pharmacological interventions, and a regular aquatics program. These have perhaps assisted in retarding a significant deterioration but did not result in any meaningful rehabilitation in terms of her capacity to rejoin the workforce.

Depression resulted and antidepressant medications have assisted and it was not necessary for the Appellant to be referred for psychiatric or psychological therapy. The depression has not been so severe as to constitute a severe disabling condition. However, it is a component in her overall health.

The Minister placed reliance on the fact that an independent psychiatric referral by CPP officials did not disclose any "…major depression…" and the medical evidence did not suggest any serious organic pathology to account for the physical discomfort. The Minister suggested that her emotional condition was, in part, attributable to having left her profession and the death of her mother.

The Tribunal was mindful that cases of Fibromyalgia are difficult given the absence of objective data to substantiate the subjective descriptions of the pain and limitations as expressed by a particular claimant. As such, the Tribunal must be careful to appropriately assess all of the evidence. As has been stated in a Pension Appeals Board decision (The Minister of Human Resources Development v. Chase, 1998, #6540) a finding of severe and prolonged disabling condition is not predicated strictly on objective medical evidence. The interpolation of both medical evidence and subjective experiences in regard to the impact on one's capacity to engage in substantially gainful employment are at the crux of an informed decision.

In this case, it was obvious that the Appellant was well-educated, intelligent and a competent lady. During the course of the hearing, the Tribunal was somewhat sympathetic to the notion that this individual perhaps retained the capacity for some form of less stressful, more sedentary work activity. However, the Appellant's candour and the overwhelming preponderance of medical evidence suggested otherwise.

In addition, there were repeated assertions by the Appellant's family physician that the Appellant was "…totally disabled…", which was confirmed by a number of specialists. A rheumatologist, in several reports, expressed the view that the Appellant was unable to work at any employment. A specialist in pain management stated that she was totally disabled with respect to any kind of gainful employment and should be considered to be permanently disabled. Even the independent psychiatric specialist to which the Appellant had been sent by CPP was of the opinion that the Appellant may not be disabled solely by reason of her depression, the depressive state, in combination with Fibromyalgia was producing an inability to be employable.

A Functional Capacity Evaluation was done on the Appellant but only for one day which suggested that participation in a strengthening and endurance program could lead to a return to work but the Minister failed to introduce compelling medical evidence to contradict the consistent medical opinions proffered on behalf of the Appellant.

The Tribunal must give appropriate weight to all of the evidence which in this case, the preponderance of medical evidence supported the Appellant's claim. When she was advised to leave the workforce for medical reasons, the Appellant was suffering a "severe and prolonged" disabling condition. The Appellant's subjective description of the limitations and pain she endures and the regular efforts she has expended to improve her conditions helped to substantiate a "severe and prolonged" disabling condition.

As to the date of onset of disability, the Appellant had worked until December 1997 and the Tribunal found that she was disabled effective January 1998, which was the month following the month she left the workforce.

INDEPENDENT MEDICAL EXAMINATION LETTER TO

<u>COLLEGE OF PHYSICIANS & SURGEONS OF ONTARIO</u> – November 15, 2001

By: Mary Ellen, Manager – Special Projects

The College of Physicians & Surgeons of Ontario is planning to do a policy review on Third Party medical reports. As a result, the following letter was sent to the College. We received a reply dated November 26th. Please take the opportunity to write Ms **Maureen Boon**, Policy Analyst at the College, who is assisting the policy review group on Third Party Reports, giving your views or experiences regarding IMEs. Please place c.c. **National ME/FM Action Network** at the bottom of your letter and mail us a copy too so that the College knows we are keeping track of complaints. We will keep you advised of developments.

"Ms Katya Duvalko, Policy Analyst

The College of Physicians & Surgeons of Ontario

80 College Street

Toronto, Ontario M5G 2E2

November 15, 2001

We are a registered, Canadian charitable organization dedicated to helping people with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM) through support, advocacy, research, education and the publishing of our bi-monthly newsletter, QUEST. As well as thousands of individuals, hundreds of doctors and lawyers experienced in ME/CFS/FM, our newsletter goes out to over 450 support groups across Canada.

Our organization is most interested in the "Third Party Policy Review Group", the internal look at the issue of independent medical examinations which you are heading up.

Our organization has been hearing from an alarming number of disabled patients all over Ontario who have had their long-term disability benefits denied or terminated based on a report written by an independent medical examiner in spite of the fact that these patients own treating physicians and specialists insist that the patient is severely disabled and unable to work in any capacity. We are aware that many of these patients have sent letters of complaint to the College regarding specific doctors. I am enclosing a copy of our position paper, "INDEPENDENT MEDICAL EXAMINATIONS IN CANADA: THE NEED FOR REFORM" which we hope the members of your group will read and consider while deliberating about this serious issue. The author of the paper is a member of our organization. A Ph.D. in History, Ms. Noel has lectured extensively and written dozens of articles on the problem of human rights. Her book on the subject has won the Governor General’s Award (in French) in 1989 and the updated translation in English, published in 1994 by McGill-Queens University Press has received the American Gustavus Myers Center Award for The Study of Human Rights in North America.

I am also enclosing a copy of the new guidelines for third party evaluators, which was recently published by the Alberta College of Physicians and Surgeons.

I am willing to travel to Toronto to meet personally with the members of your group and discuss this important issue. Protecting the human rights of disabled patients who are requested to attend a third party evaluation is paramount. Patients are entitled to a fair, unbiased evaluation and to be treated with dignity and respect.

Thank you for considering our concerns. I look forward to a reply at your earliest convenience.

Sincerely, Signed: Lydia E. Neilson, President CEO"

Reply from theCollege:

"Your letter of November 23, 2001 addressed to Ms Duvalko has been forwarded to me for response as I will be assisting the policy review group on Third Party Reports.

Thank you for the information you have provided. I will ensure that the group is aware of your interest in this subject. Thank you again for writing to us. Signed: **Maureen Boon**, Policy Analyst"

Please continue to download our Registry Submission Form and pass it along wherever appropriate people may see it. Anyone who was requested to attend an independent medical examination or functional capacities evaluation by a private insurance company, Canada Pension Plan or Workmen’s Compensation is an appropriate person to take part in our confidential survey. If you have already submitted a Form but have updated information, please send us this further information for our records. We want our statistics to be current so that we can continue to lobby the Colleges and Governments on your behalf and interest the media in this important issue. Please help us.

To receive a copy or copies of the simple, confidential, 7 question Registry Submission

Form, please contact: **Mary Ellen**, Manager of Special Projects, Tel. **(905) 831-4744** or by mail: **P.O. Box 66172, Town Centre Postal Outlet, 1355 Kingston Rd., Pickering, ON L1V 6P7** – E-mail: **marye@pathcom.com** or download the Form from our website **at www3.sympatico.ca/me-fm.action/medexam.html**

YOUNG WRITERS' WEB – NATIONAL ME/FM ACTION NETWORK

By: Kate Andersen, M.Ed., Youth Consultant

We are honoured to announce that, **Anelie Walsh**, a highly gifted young writer and YPWC (in remission), is going to help us with a new project, a **Young Writers Web**. Anelie lives in Australia, yet, through her many years of reaching out from the "CFS Sofa", she has acquired a truly international vision of support for YPWC. As you all know, ME/CFS and/or FM respect no borders. Please read Anelie's writings, and those of other YPWC, on the new Young Writers Web at **http://www.geocities.com/ypwcww**

We applaud these courageous young people on their enormous talent and positive spirit.

We would also like you to encourage YPWC in your community to submit their work for publication on our web. Interested writers can email **Kate Andersen** at **canadianyouthmefm@yahoo.ca** or **Anelie Walsh** at **anelie@mac.com**

Submission guidelines are posted on the site at **http://www.geocities.com/ypwcww/submissions.html**.

NATIONAL DOCTORS' ROSTER – ADDITION

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INTER-GROUP/CONTACT COMMUNICATION:SUNNYBROOK AND WOMEN'S COLLEGE HEALTH SCIENCES CENTRE have set up a website called Women's Health Matters **LeClub** at www.womenshealthmatters.ca, a trusted source for information on **environmental health conditions**. Drawing upon the expertise of the health professionals at Sunnybrook & Women's, **Le Club** is a virtual meeting place for women to share their stories, experiences and questions. For more information, contact: **Sheryl Mitchell, Director, Women's Health Partnerships at (416) 813-4751.**

OOOOOOPS!

In the August/September 2001 issue of QUEST (Communication No. 49), the telephone number for the Myalgic Encephalomyelitis Association of Ontario was incorrect. In order to order a ME/CFS brochure in Chinese or Portugese, please call (416) 222-8820 or 1-877-632-6682 (outside (416) area code.).

THE CFIDS ASSOCIATION OF AMERICA SURVEY, Charlotte, NC

On November 15, 2001 **CFIDS of America** released to the media results of a survey they did with the medical professionals in its database. The survey was designed to determine attitudes to and knowledge of CFIDS (ME/CFS) as well as potential barriers to diagnosis and treatment. Copies of its press kit for the survey can be found at the Association's web site at**:**

http://www.cfids.org/resources/cpr-introduction.asp **or**

contact Renée M. Brehio at (704) 364-0466

The CFIDS Association of America reported that three-quarters of medical professionals responding to the survey believe that CFS is as or more disabling than other chronic diseases such as lupus, multiple sclerosis or rheumatoid arthritis. 35% of the surveyed medical professionals feel lack of a known cause of the illness is a barrier to diagnosis and 31% feel there is not enough basic knowledge about ME/CFS among the medical community.

According to the survey, 72% of the medical professionals surveyed rely on exclusion of other common causes for symptoms; 68% use a patient history; and 25% use laboratory tests. They also rely on documenting the presence of symptoms, other than fatigue When respondents were asked what one symptom, other than fatigue, made them more likely to suspect CFS, or without which they would not make a diagnosis, the most common answer was post-exertional malaise (incapacitating fatigue lasting more than 24 hours after physical or mental exertion).

OUR WORLD

NAUSEA – BY-PASSING A CAREER AS AN ASTRONAUT

NUMBNESS – RESPITE FROM PAIN

By: Lorraine Legendre, Ottawa

RESOURCES - TEACH-ME - Sourcebook for Teachers. We are proud to announce that **our Sourcebook for Teachers**, an educational resource book full of information and teaching strategies for teachers and parents of children and youth who have ME/CFS and/or FM., is now posted on the Youth and Parents' Pages at: **http://www.geocities.com/canadianyouthmefm/teachme.html**

Hard Copy will be available shortly.

LEGAL/RESEARCH PACKAGE - **Medical** and **Legal** Information on ME/CFS and/or FM, a resource for lawyers, advocates, doctors and patients. Please make **cheque payable to Marj van de Sande** in the amount of **$25.00** (our Director of Education) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 - Tel/Fax: (403) 547-8799 - E-mail: vandesam@cadvision.com**

MEMBERSHIP: $25.00 per year includes bi-monthly newsletters - Please make cheque payable to:

NATIONAL ME/FM ACTION NETWORK, 3836 Carling Ave., Nepean, ON K2K 2Y6 CANADA -

Tel/Fax: (613) 829-6667

E-Mail:ag922@freenet.carleton.ca - WEB: http://www3.sympatico.ca/me-fm.action/

address and telephone number.

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.