



ME & YOU

Myalgic Encephalomyelitis Society of British Columbia Support News Summer 2001 Volume #22

ME/FM News

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Canada Makes History in M.E./CFS and FM Consensus Meeting: a Resounding Success

BY MARJORIE VAN DE SANDE, B.ED., GRAD. DIP. ED.
– CONSENSUS COORDINATOR & DIRECTOR OF EDUCATION

NATIONAL ME/FM ACTION NETWORK: BACKGROUND

Lydia Neilson, who had been helping at a national research organization for M.E./CFS, realized there was a real need for support of the patients. She left her position there to start a national organization that would support Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (M.E./CFS) and Fibromyalgia (FM) patients – the National ME/FM Action Network. Founded on June 18, 1993, it has been granted charitable status. We are an independent organization but are in contact with over 450 support groups across Canada and work cooperatively with them.

Our mission statement is that: The National ME/FM Action Network advances the recognition and understanding of Myalgic Encephalomyelitis and Fibromyalgia through education, advocacy, support and research. The Network seeks to effect positive change in the attitudes, policies and practices of government, business and the general public.”

Our motto is “People Helping People Helping Themselves.” Our logo is the maple leaf with geese flying in “V” formation which portrays working together cooperatively and supporting each other. It is based on the “The Goose Story.” As our name implies, we are an ACTION organization. To this end, we have a second motto, “Don’t React to unfairness but Act for change.”

Our newsletter “Quest” keeps members informed of recent developments in research and legal areas, etc. and keeps them abreast of the progress of our many projects. They are too numerous to mention here but range from being instrumental in having the wording changed in the Disability Tax Credit form, to developing a national registry of doctors and lawyers knowledgeable about these illnesses, to developing a research/legal package. Our current projects include an educational resource book full of information and teaching strategies for teachers and parents of children and youth who have M.E./CFS. We are also making a legal challenge to the Canada Pension Plan on the eligibility criteria for a disability pension, and to Revenue Canada on the eligibility criteria of the Disability Tax Credit. Highlights of some of our accomplishments can be found on our website: www3.sympatico.ca/me-fm/action/ You can also visit our website ‘ARCHIVES’ to read past newsletters.

DEVELOPMENT OF CLINICAL DEFINITION/PROTOCOLS DOCUMENTS: BACKGROUND

The National ME/FM Action Network successfully lobbied the federal government to proclaim May 12th as National ME/FM Syndromes Awareness Day. In honour of that day in May 1995, the Honourable Beryl Gaffney MP and other MPs representing the various provinces presented our

Dr. Bruce Carruthers is the Medical Advisor to the MEBC Board of Directors

petitions with over 15,000 signatures in the House of Commons, requesting recognition of M.E./CFS and FM and funding for research of these illnesses. A few years ago we sent a questionnaire to 200 doctors who were knowledgeable about these illnesses, asking what was the most important thing that needed to be done towards formal recognition of these illnesses and assisting the medical community. Approximately 150 doctors replied and all voiced the opinion that clinical definitions and treatment protocols for these illnesses are of prime importance. The stage was set.

We recruited Dr. Anil Jain of Ontario and Dr. Bruce Carruthers of British Columbia, two of Canada's top experts in these illnesses, who kindly and generously donated their time and expertise to co-author the draft clinical definitions, diagnostic and treatment protocols documents.

Lydia presented the draft documents to Health Canada in July 1999. The Honourable Alan Rock, Minister of Health, responded, "The development of draft clinical definitions for M.E./FM is a milestone in the fight against this complex and tragic condition." The National ME/FM Action Network worked in partnership with Health Canada on the review process for a year and a half.

The Expert Medical Subcommittee established by Health Canada selected two Expert Medical Consensus Panels, one for M.E./CFS and one for FM. This subcommittee of Health Canada also established the "Terms of Reference" for the panels. One of the stipulations was that at least one member of each panel must be nominated by each of the five stakeholder groups of government, universities, clinicians, advocacy and industry. The twenty-five doctors who were selected received over 80 nominations representing numerous nominations from each of the stakeholder groups. Four doctors from outside Canada were allowed to sit on each panel. A wide range of expertise was represented on the panels including rheumatologists, specialists in internal medicine and infectious disease, a neurosurgeon/neuroresearcher, a haematologist, etc. There were treating clinicians, teaching university professors and researchers including world-renowned researcher, Dr. Kenny De Meirleir of Belgium who has approximately 300 scientific publications. His research on the dysfunction of the RNase L antiviral defense pathway may lead to a clinical marker for M.E./CFS.

The panels have been reviewing the documents since December 2000. The consensus meetings were held in Toronto on March 30 to April 1, 2001.

CANADA MAKES HISTORY IN M.E./CFS AND FM AS BOTH EXPERT PANELS CAME TO CONSENSUS ON THEIR CLINICAL DEFINITION / PROTOCOLS DOCUMENT.

It will take several months before these documents will be published. The documents have to be finalized, sent back to the panels and then published in a reputable medical journal. Once they are published, we will be able to release the definitions and diagnostic and treatment protocols to the public.

The existing U.S. Center for Disease Control (CDC) definition for CFS and the American College of Rheumatology (ACR) definition for FM were established for research purposes. While these definitions serve a purpose for research, they are too restrictive in the clinical setting. The focus of the clinical definitions is to have the physician look at the whole spectrum of pathologies of these

**"ME & You"
newsletter team:
Donna Mitchell
Jeanine Madill
John Warren
Diana Inselberg**

MAIL

**You may send letters, articles, notices, etc. to the editor at
MEBC
#462 -
916 West Broadway
Vancouver, BC
V5Z 1K7**

**or e-mail us at
MEandYou@mefm.
bc.ca**

www.mefm.bc.ca

Please note that letters may be edited for brevity and clarity.

illnesses. The definitions are backed up in the documents by research findings. There are sections on diagnostic protocols and treatment protocols. This means that the family physician will have a “manual” that explains how to diagnose and treat these patients. Having the documents reviewed and endorsed by panels of experts gives them credibility and will empower the doctors treating these illnesses. For the patient, it means earlier diagnosis and appropriate treatment which is essential in order to lessen the impact of these illnesses.

The Honourable Allan Rock, who was unable to attend the consensus meeting, sent a written congratulatory message that was read at the meeting. The atmosphere of the welcome reception had an aura of excitement and the positive energy was absolutely electrical. Crystaal Corporation, which sponsored the consensus meeting, was awed at the enthusiasm of the doctors. They said that in all their years of working with the medical community they had never experienced such positive, productive and professional panels!

Dr. Jon Russell and Dr. Thomas Romano, who were both members of the panel that developed the existing ACR research definition for FM, add to the credibility of the clinical definition document. Dr. Nancy Klimas was excited about the unanimous agreement on the M.E./CFS clinical definition and told me she previously had been on two panels in the United States to develop a clinical definition but they could not come to an agreement. When Dr. Dan Peterson, a recognized world expert in M.E./CFS and treating physician for the Lake Tahoe epidemic, was asked what he thought of the clinical definition document for M.E./CFS, his response was, “I love it, I love it, I love it!”

Thanks to: Lydia Neilson for her vision of clinical definitions, her commitment and her ongoing lobbying of Health Canada; Health Canada for selecting excellent consensus panels; members of the Expert Medical Consensus Panels, with a huge special thanks to Dr. Carruthers and Dr. Jain.(their dedication is overwhelming); Crystaal for sponsoring the Expert Consensus Meeting; Ann Hartshorn, director of New Products, and Frank Sze, manager of New Products; Crystaal and Science and Medicine Canada Inc. (which is the company Crystaal contracted as organizers); Science and Medicine Canada Inc., with special thanks to Gary Browne, vice-president of client services, and Dr. Brian Morris, medical director, who facilitated the consensus meetings; Corrine Daymon, Janice Bortoluss and Pat Hislop who worked behind the scenes; Dr. Philipa Corning, our vice president, who acted as secretary for the FM panel at the meeting. And last but not least we thank all of our members for your prayers and good wishes for a successful meeting!

Fibromyalgia Expert Consensus Panel: Dr. Steven Barron; Dr. Bruce Carruthers; Dr. Stu Donaldson; Dr. James Dunne; Dr. Emerson Gingrich; Dr. Dan Heffez, USA; Dr. Anil Jain; Dr. Frances Leung; Dr. Daniel Malone, USA; Dr. Thomas Romano, USA; Dr. Jon Russell, USA; Dr. David Saul; Dr. Donald Seibel.

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Expert Consensus Panel: Dr. Allison Bested; Dr. Bruce Carruthers; Dr. Kenny De Meirleir, Belgium; Dr. Pierre Flor-Henry; Dr. Anil Jain; Dr. Pradip Joshi; Dr. Nancy Klimas, USA; Dr. Martin Lerner, USA; Dr. James McSherry; Dr. Dan Peterson, USA; Dr. Peter Powles; Dr. Jeff Sherkey.

RESOURCES

M.E. & FM Library Materials

(Issue #3) 5,200 pages of newsletters etc. in the library reference section of Prince George, North Vancouver, Vancouver, South Vancouver, Port Moody, Burnaby, Guildford, White Rock, Abbotsford, Chilliwack, Cranbrook, Creston, Nelson, Vernon public libraries. There are four different 8-hour videotapes available through the Surrey Library system. Contact your local support group leader.

M.E. Victoria Newsletter

M.E. Victoria membership includes a quarterly newsletter, \$20 annual fee.
M.E. Victoria,
RPO Fairfield Plaza,
P.O. Box 50032,
Victoria, B.C., V8S 5L8
Phone 888-543-2666

Physician's Column

BY BRUCE M. CARRUTHERS, M.D. (MEDICAL ADVISOR TO THE MEBC BOARD OF DIRECTORS)

FROM PATHOGENESIS TO NAME CHANGE

When the Fukuda et al conceptual framework and set of guidelines for the definition and study of Chronic Fatigue Syndrome were published in 1994 (Ann Intern Med. 1994; 121:953-959), the article ended with the following remarks:

“We sympathize with those who are concerned that this name (Chronic Fatigue Syndrome) may trivialize this illness. The impairments associated with Chronic Fatigue Syndrome are not trivial. However, we believe that changing the name without adequate scientific justification will lead to confusion and will substantially undermine the progress that has been made in focusing public, clinical, and research attention on this illness. We support changing the name when more is known about the underlying pathophysiological process or processes associated with Chronic Fatigue Syndrome and chronic fatigue.”

The question is: Has there been sufficient progress in research to illuminate the underlying cause of this syndrome (set of symptoms) in the intervening seven years that would justify a name change that goes deeper than the current alternatives? Current alternatives only name the major criterial symptom (Chronic Fatigue Syndrome), or add an assumed pathogenesis (Chronic Fatigue Immune Dysregulation Syndrome), or name another one of the major symptoms (muscle pain) and combine it with another assumed pathogenesis (inflammation of the brain and spinal cord) (Myalgic Encephalomyelitis).

Much of the research in the intervening seven years points to widely distributed abnormalities in the immune, endocrine, and nervous system

regulatory networks at many levels, which are expressed by the symptoms of this syndrome. Thus the report of a recent consensus meeting to prepare a new clinical case definition of M.E. starts with the statement “Myalgic Encephalomyelitis (M.E.) or Chronic Fatigue Syndrome (CFS) is a severe systemic illness that predominantly manifests symptoms based on neurological, immunological, and endocrinological dysfunction” (manuscript in preparation). Many such abnormalities have been found in patients with M.E., some of which are quite characteristic for the illness and consistently found, but their very multiplicity and widely distributed nature have proven hard to bring into a coherent picture of pathogenesis. This research is the result of analyzing pieces of the vastly complex regulatory systems mentioned (a bottom-up approach), and unfortunately no one knows yet how to fit all the bits together – a situation very like that of the unfortunate Humpty-Dumpty.

However, top-down approaches from the perspective of the whole organism, including its brain, can at least be expected to provide a general orientation for the deluge of data currently coming up from research at the bottom.

What the immune, endocrine, and nervous systems have in common is that they are all regulators of the whole organism. While these subsystems all have different territories, timings, and strategies of regulation, they remain strongly interconnected in two-way relationships, and when they fail the result is a dysregulation of the whole organism. Because any significant dysregulation is detrimental to the overall

Note: Consult your physician before trying any treatments or therapies presented in this newsletter.

health of the organism, there has been an evolutionary pressure to develop alarm signals to notify the organism when such dysregulation is present. Such signals of dysregulation have both a subjective pole (they are felt as a symptom such as anxiety, pain and/or fatigue) and an objective pole (the change in function is felt directly, such as inability to think, inability to balance, inability to walk, fast heart, sweating, etc.). What they do is help the organism adapt by changing its state in response to environmental and self-induced challenges. Therefore their failure is a failure of adaptation, something which is vital to the survival of the organism, which can only survive if its essential parts (the essential variables) are kept fairly constant, within strict limits. Thus over eons these three interconnected regulatory systems (immune, endocrine, nervous) have learned how to change in order to protect the parts of the organism that cannot be allowed to change (homeostasis). See W. Ross Ashby, "Design for a Brain", 1960 Science Paperbacks London. See also A.R. Damasio, "Descartes' Error", Avon, New York, 1994 especially Chapters 8 and 10).

These evolved signals shape and time our ordinary activities of daily living. When we feel fatigued we stop our action and rest. When we feel pain we stop what we were doing and attend to the painful area to see what is wrong – this could be from an outside injury or from taking a body part out of its normal range. When we feel sleepy we sleep. When we are hungry we eat. When we see a car coming at us we get out of the way fast. These responses are essential to life. When we can't feel pain we allow dreadful injuries to happen, such as destructive arthritis. When we do not allow fatigue by taking too many stimulants, we go on and on until we collapse. When the signal systems are in disarray, they no longer signal what they are supposed to; they fail to protect

the organism against detrimental change and no longer match an appropriate environmental or self event. Thus pain no longer means local injury, and fatigue is no longer a phase in a stretch of activity. Pain and fatigue have become symptoms – they no longer signify an expected event in normal living, but an illness. The normal actions and rhythms of daily living such as those of eating and sleeping become difficult to maintain, and the organism begins to 'crash' temporarily – to cease functioning in a state of total physical and cognitive fatigue.

The immune system is made up of special cells and their products, cells which circulate throughout most of the organism in the blood and lymphatic circulation. Its response time to molecular structures judged as 'foreign' is relatively slow – over days-weeks, but can be almost immediate if the response has been learned already (as in allergic reactions). It is intimately connected to faster response systems which are less discriminating (vascular system, inflammatory response system, fight or flight response, etc).

The endocrine system is composed of different types of localized glands which secrete messenger molecules (hormones) that are released into the whole body via the blood stream to exert widely distributed regulatory effects on various cellular and organ functions with peripheral specificity. Thus hormones, in connection with the autonomic nervous system, put the organism into different complex states, e.g. fight or flight stress response, relaxation response, sexual arousal, sexual withdrawal, warming up, cooling down, speeding up, slowing down. It usually has an intermediate response time (minutes-hours) and its changes are complex and widely distributed. It is closely connected to both the nervous system and the immune system.

RESOURCES

National ME/FM Action Network

\$25 Annual fee,
Newsletter every
two months.
3836 Carling Ave.,
Nepean, ON K2K 2Y6
(613) 829-6667
[www3.sympatico.ca/
me-fm.action/](http://www3.sympatico.ca/me-fm.action/)

Legal/Research Package

Send \$25 cheque
payable to
Marj van de Sande,
Director of Education
(National ME/FM Action
Network)
151 Arbour Ridge Circle NW
Calgary, AB T3G 3V9
Tel/Fax: (403) 547-8799
E-mail:
vandesam@cadvision.com

RESOURCES

Rogers Cable

Rogers and other cable companies in B.C. now have a selection of conferences on tape that they can show on your local cable station.

Contact your station and ask about the 1991 M.E.B.C. conference, the June 1994 Nightingale conference held at John Oliver High School, the October 1, 1995 conference at Burnaby South Sr. Secondary School, and two separate F.M. programs, the first entitled "F.M. 101" the second Rogers "Community Connections" November 14, 1995. Also the Les Simpson video produced by Shaw cable.

The Parents and Youth Web Site

www.geocities.com/youthcanada/first.html

kate_andersen_uvic@yahoo.com

The nervous system has a central component (CNS), but also peripheral components some of which are autonomic (ANS), and its effects travel by discrete nerve fibres to all the regions of the skin and inner body, to exert potentially widespread but also precisely localized effects. It has the fastest response time of all (starting within a few milliseconds) and can change from one overall state to another at a very fast rate. Thus it can match fast moving environmental events and produce complex changes in response almost instantaneously (by our life-world standards) for survival purposes. It also has slower responses and is strongly interconnected to the other regulatory subsystems.

A total bodymind response to a significant change is complex and usually includes fast components and slower ones. It involves at least several of the regulatory subsystems in a coordinated way – e.g. the adaptation of sleep/wake rhythms to time zone change (jet lag) which normally begins right away but is not complete for a week or two (fast and slower response of the CNS,) a suppressive effect on the immune system, since this is a time of vulnerability to infections; and the adaptation to high altitude which starts right away in the respiratory and cardiovascular responses to hypoxia and sleep/wake cycle changes under the influence of the CNS and ANS, but is not completed until several weeks later when the red cell mass increases under hormonal regulation.

In a research project which studies a standardized perceptual function within a conceptual framework that considers the brain to be an organ that can change its function from one

overall attractor state to another at a fast clip (a twinkling brain – see J.A.S. Kelso et al "Multistability and Metastability in Perceptual and Brain Dynamics" in "Ambiguity in Mind and Nature" P. Kruse and M. Stadler, Editors, Springer, Berlin 1995). I have found evidence that patients with M.E. show cognitive fatiguing much more rapidly, or stay stuck in one state more than controls.

If this finding is generalizable, it may mean that the other regulatory systems may become less flexible and remain stuck in sub-optimal states as part of M.E. Thus parts of the immune system may become stuck in an 'up-regulated' state while other parts are 'down-regulated'. Thus the autonomic nervous system and endocrine system may fail to adapt to the upright position, resulting in circulatory failure (e.g. neurally mediated hypotension, orthostatic tachycardia). Thus nocturnal secretions of growth hormone may not respond to the micro-trauma of everyday life that affects the musculoskeletal system, resulting in a failure of healing and consequent pain. Thus fatigue may no longer be related to exertion as a brake, but be delayed and reactive, allowing the unbraked organism to go over its appropriate limits of action.

This is an example of the kind of hypothesis that must be developed and confirmed in order to form the scattered results of current research into a coherent picture of pathogenesis. This overall picture is just beginning to shape itself. When it becomes clear enough, and confirmed, the appropriate name for M.E. and related conditions will become obvious.

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Your Canada Pension Application

BY LAWRENCE PIERCE

When you become disabled because of illness or injury, you should apply to C.P.P. for a disability pension. However, because of recent changes to the rules, these pensions are becoming increasingly difficult to get. If you are lucky enough to get the pension, you will receive about \$750 per month. When you have disability insurance, you must use all efforts to get the C.P.P. benefits, because if you do not, your insurance company will deduct what you might have gotten from C.P.P. from the amount they give you.

The new test at C.P.P. is whether your condition is 'severe and prolonged', and disables you. Make sure that your doctor is aware of this new test so that he/she will keep it in mind when writing on your behalf.

C.P.P. has also been denying claims on the basis that the medical evidence is 'subjective' only. FM and CFS are generally considered by C.P.P. as subjective ailments because the diagnosis of these conditions relies in large part on the report of the patient. However, if a psychiatrist reports that a person has a mental illness, it is not considered 'subjective' even though the psychiatrist's opinion is based solely on what the patient says. A Rheumatologist has just as clear a set of guidelines to diagnose FM as a psychiatrist has to diagnose mental illness.

Your doctor should make it clear that, for example, if you have FM, it has been diagnosed by a Rheumatologist, but that more importantly, it is his/her opinion, exercising clinical judgment, that you present as totally disabled. The best doctor's letter these days is no guarantee of a successful application, but there are several appeals available to you from the first decision.

File your appeal in time, and get legal advice. It is critical to keep filing appeals until you are successful, and it is critical to get the correct medical evidence before the Appeal Tribunal.

Lawrence Pierce is a Vancouver lawyer, with Pierce Law Group, specializing in disability insurance cases. He has recently won judgments against Sun Life, Great West Life, and Unum Life for aggravated damages

Legal

RESOURCES

BC FM Society

PO Box 42504,
New Westminster, BC
V3M 6H5

The Self-Help Resource Association of B.C.

Gives training for support group facilitators.
303-1212 W. Broadway,
Vancouver, BC
V6H 3V1
Phone (604) 733-6186
Fax (604) 730-1015

The B.C. Coalition of People with Disabilities

#204-456 W. Broadway
Vancouver, BC
V5Y 1R3
Phone 875-0188
Fax 875-9227
1-800-663-1278
www.bccpd.bc.ca
Annual membership fee of \$10 includes the "Transition" magazine, 8 times yearly.

Disability Rights and the Law

BY BRIAN SCHMIDT AND MELISSA RAHME

On May 31, 2001, several groups, including the Community Legal Assistance Society (CLAS), sponsored a forum on Disability Rights and the Law at Vancouver Public Library. CLAS has several programs including a Disability Law Program which does legal work on behalf of people with disabilities, and the Law Students' Legal Advice Program at UBC. CLAS has conducted hundreds of cases at tribunals and all levels of court. CLAS can be contacted at (604) 685-3425, or fax (604) 685-7611, or by e-mail: clas@vancouver.net

At this forum, several speakers addressed issues regarding CPP Disability Benefits (Part A) and BC Disability Benefits (Part B). The following notes summarize their presentations.

Editor's note: "Part B" regarding BC Disability Benefits will be included in a future issue of "ME & You".

PART A: DISABILITY BENEFITS UNDER THE CANADA PENSION PLAN

If your application for CPP Disability Benefits is turned down, there are up to three stages in appealing that refusal. The first step is to go before a Tribunal. If they refuse your appeal, then one goes before three judges who form the Pension Appeals Board. Failing that, one needs to go to the Supreme Court of Canada.

TIPS FOR ADVOCATES FROM HAROLD EPP, CHAIR OF THE CPP REVIEW TRIBUNAL

The Review Tribunal consists of three members drawn from different sectors of the community: most often a doctor, lawyer and layperson. It is a quasi-judicial body.

The C.P.P. Review Tribunal isn't there to make a medical decision. The actual diagnosis (label) made by doctors is not that important to them. Rather, the main emphasis is on the person's functional capabilities and impairments. Any submitted medical reports should give detailed observations about such functionality. Even better, it is helpful if the doctors give objective tests of these functional limitations, rather than just drawing conclusions about these from the diagnosis.

The Tribunal hears three cases each day that it convenes, and a decision is made for each case on the day of the hearing. Therefore, on the date of the hearing, it is not wise to present new material. Tribunal members will have no time to absorb it. You must send all materials to the Tribunal beforehand, or ask for an adjournment if that is not possible.

Material presented to the Tribunal is often unfocused, with many redundant documents. This can be confusing for Tribunal members. It is important to present your material clearly, and focus on the essential issues first.

The Review Tribunal aims to arrive at a consensus decision. In a case where there is no consensus, the dissenting member is required to write an opinion. However compelling someone's situation may be, the Tribunal is constrained by legislation and regulations, whether they are fair or not. The decision of the Tribunal can be appealed to the Pension Appeals Board. (see Puga, below)

ADVOCACY BEFORE THE PENSION APPEALS BOARD, SHEILA PUGA, LEGAL SERVICES SOCIETY (LSS) PARALEGAL

RESOURCES

DAWN

(Disabled Women's Network)
PO Box 22003
Brandon, MB R7A 6Y9
Phone toll-free:
1-877-450-9476

Nightingale Research Foundation

Publishes pamphlets, books, and research.
121 Iona St.,
Ottawa, ON K1Y 3M1
Fax: (613) 523-1958
E-Mail:
nightingale@nightingale.ca

Upon being turned down by the Review Tribunal, an appellant has no guaranteed right to appear before the Pension Appeals Board (PAB). An application for leave to appeal must be made, significant new evidence must be presented, or the Tribunal must be shown to have been in error. In the case of people with FM/M.E., there is not a lot of objective evidence, so that leave is most often granted on the basis that the Tribunal was in error. If error cannot be demonstrated, then leave to appeal can be denied.

The applications format is complex and lengthy. Following a negative decision by a Review Tribunal, there are 90 days to file for a leave to appeal to the PAB, then 30 days to review before appeal is granted or denied. Once leave has been granted, there is a one-year waiting date before the actual hearing. The reason is that the PAB only sits in Vancouver twice a year, usually in January and July.

The good news for people with M.E./FM, according to Puga, is that the Appeals Board is often more open to these cases than the Review Tribunals. The Appeal Boards consists of a panel of three people, and a decision is reached by majority vote. Unlike community-based panels, the board is made up of Superior Court Judges from anywhere across Canada. In fact, the Appeals Board is a more formal hearing than the Tribunal, and is closer to appearing in court. Both sides present their case, and cross-examination is possible. The appellant presents first.

A lawyer, who is there to defend the Tribunal's decision, represents the Ministry. CPP will have medical doctors as expert doctors to provide their opinions. It is important to prevent them from stating those at the hearing. Puga suggested that the appellant request from the

Ministry a summary of those doctors' opinions as well as the doctors' CVs at least two to four weeks before the hearing.

The burden of the proof is on you, the appellant. You must prove you are disabled. They do not have to disprove it. The hearing should be approached as a new trial, to be argued from the beginning. There is no need to refute the Tribunal's errors.

It is important to be well prepared for the hearing. Puga offered these tips:

- 1) Spend time at the law library, reading through past decisions of the Pension Appeals Board. Pay close attention to the evidence and arguments that worked, and those that didn't. Also focus on the kinds of questions that were asked.
- 2) Sit in and watch a PAB hearing. In Vancouver, they sit in January and June. You may call them and inquire about dates, locations.
- 3) When you go into your hearing, have a written submission, summarizing your legal arguments, and distribute it to members of the PAB beforehand, so that they have some idea what is to be presented in the hearing.

DEVELOPMENTS IN CPP BENEFITS IN THE SUPREME COURT OF CANADA, FRANCES KELLY, CLAS

Kelly pointed out that all of these avenues of appeal for CPP disability benefits are limited by current legislation and regulations. Under that legislation one has to prove disability, and have made sufficient contributions to CPP in order to qualify for disability benefits. There are three cases currently underway in the courts which are challenging that legislation under the Charter of Rights.

RESOURCES

M.E. & FM Manual

156 pages, non-profit book on 8 1/2 x 11", two columns, spiral binding, summarized from world wide newsletters, 55 symptoms, 48 drugs, 49 therapies, 47 disability benefits, 67 books, 68 organizations, 230 supportive doctors, C.P.P., long term disability, insurance, legal help, dealing with doctors, coping, Table of Contents, Index and the Index to the "M.E. & F.M. Library Materials". Send \$19 to Doug Shore, 2633 Moorland Street, Abbotsford, BC V2T 3V2 857-4874 (Vancouver); 855-9431 (Abbotsford) e-mail dwshore@home.com WEB www.geocities.com/capitolhill/1544

Thank you to all who designated MEBC through the United Way.
Your donations are greatly appreciated.

Winning Your Disability Case in Three Words - Frequency, Severity, and Duration

BY SCOTT E. DAVIS, ESQ.

Scott E. Davis is a social security and long-term disability insurance attorney in Phoenix, Arizona. The majority of their disability practice is devoted to representing individuals with FM and/or CFIDS throughout the United States. In most cases, a fee is charged only if their client obtains benefits. Mr. Davis invites your questions and inquiries regarding representation via email (harris.davis@azbar.org) or telephone at (602) 482-4300.

Editor's note: The following article is reprinted from the e-newsletter "Lisa Lorden – About Guide to Chronic Fatigue Syndrome / Fibromyalgia" (website: www.chronicfatigue.about.com or e-mail: chronicfatigue.guide@about.com). Though the article is written from the perspective of American federal law, most of the points covered apply equally well to Canadian situations.

In a disability case, almost any symptom or limitation can be disabling; but to determine whether they preclude work, the relevant questions are: how frequent, how severe, and how long do they last?

A critical point I make to people who contact me every day is that their disability case is won or lost based on symptoms/limitations and not on their diagnosis! Clearly, under federal law, a disability claimant has to have a legitimately diagnosed physical and/or psychological disorder to even allege disability, but this is only the beginning of the analysis.

Disability cases are almost always won or lost based on the quality (documentation) of your medical records and the subsequent opinions rendered by your treating physicians regarding your ability to sustain full-time employment. The documentation of symptoms and limitations in your medical records is critical, as it provides tremendous credibility to and an understanding of why your doctors have concluded you are unable to work.

Once a diagnosis is established, the disability inquiry immediately shifts to why you are unable to work due to the symptoms and limitations that result from the diagnosis. I tell my clients that of the total time spent in a disability hearing before a federal judge, 5% is spent on the diagnosis and 95% is spent determining the frequency, severity and duration of symptoms and limitations, and whether they prevent all work. Ignoring this fact places the success of your claim in great peril – don't ever forget this!

A common mistake disability claimants frequently make is having "tunnel vision" and focusing solely on their diagnosis, as if the fact that they have been diagnosed with a disorder automatically confirms they are disabled and entitled to benefits. This is especially true of people suffering from chronic pain and fatigue disorders such as Fibromyalgia and Chronic Fatigue Syndrome. I believe this is true because these folks have almost universally been sent on an "odyssey" by the medical community, simply to obtain a diagnosis. Never forget that obtaining a physical and/or psychological diagnosis is the very beginning, and not the end of your disability case.

Thus, the question becomes, “How do I document the frequency, severity and duration of my symptoms and limitations?”

Tip #1: What Should I be Documenting?

Simply put, whatever it is that prevents you from working. For example, let’s use chronic pain and fatigue. It is critical that you distinguish why the pain and fatigue is different from what an average person may experience. If I say “I am in pain and fatigued,” that does not tell you much. Why? From time to time we all experience some degree of pain and/or fatigue. But if you tell your doctor, “I am unable to function as I experience severe daily pain and exhausting fatigue lasting most of the day without relief,” or “I am unable to function two days per week due to migraine headaches that last all day even with medication,” now you’ve given the doctor and the judge an idea of why your symptoms are so debilitating.

Tip #2: Obtain a Copy of Your Medical Records from Your Treating Physicians

After you have followed Tip #1, the next question becomes, “Did the doctor write down what I just told him/her?”

I am often surprised at how many people applying for disability benefits have never seen their medical records. Obtaining a copy of your current treating physician’s records is important because it will give you an idea of whether your symptoms and limitations are being recorded. You may be surprised to find that your complaints do not appear in the records or if they do, the doctor’s notes are totally illegible! Illegible handwriting is a real problem, because the judges who decide your claim are just like you and I—they don’t (and generally won’t) try too hard to decipher what the notes say.

If you are not satisfied with the documentation, address the issue tactfully with your doctor and explain the importance of documentation to your disability case. If they are receptive, I suggest you give them a copy of this article for reference.

Tip #3: Keep a Short Diary of Your Symptoms and Limitations Before Your Next Visit to the Doctor

Whether you know it or not, your daily life tells a compelling story about your inability to work. But how do you remember the frequency, severity and duration of your symptoms especially if you can’t spell your name at times?

I advise clients to keep a short and simple diary one week before their visit with their doctor. For simplicity’s sake, the entries should be short and not detailed (otherwise you will not do it). On a day when you were unable to get out of bed due to pain or fatigue, document it. Or document when you slept for only three hours the night before and then took a couple of naps the next day. Or document the migraine headache that lasted for two days in spite of medication. Then, on your next doctor visit, when he/she asks “How are you doing?” you will have a laundry list of symptoms

QUOTES

“One ought every day at least to hear a little song, read a good poem, see a fine picture, and, if it were possible, to speak a few reasonable words.”

– *Johann Wolfgang Von Goethe*

“There is no worse lie than a truth misunderstood by those who hear it.”

– *William James*

“I believe sympathy is one of the most helpful helps one can bestow upon one’s fellow creatures; and it seems a great pity that so many people feel it is their duty to criticize rather than sympathize.”

– *Hannah Whitall Smith*

When thinking of making a donation to the United Way this year, please remember that the Myalgic Encephalomyelitis Society of BC (MEBC) can be specifically designated as your charity of choice.

and limitations rather than giving them a blank stare!

Of course, winning your disability case is more complicated than this article can address; however, following these tips will significantly increase your odds of winning. Best of luck in your pursuit of disability benefits and remember never to quit!

Healing Touch – and how it can help

BY JANET GIVEN, RN, RPN, CHTP/I

Healing Touch (HT) is an energy-based therapeutic approach to healing endorsed by the Canadian and the American Holistic Nurses Associations, and is considered to be a part of the practice of Nursing in B.C. The HT program is designed to help clear, align and balance the human energy system, using touch and a collection of energy-based treatment modalities to assess and treat the human energy system.

During a HT session, a safe and trusting space is created in which the client rests fully clothed on a massage table (or chair), while the HT Practitioner holds or moves her hands on or above the client's body. The HT Practitioner helps to re-align the natural energy flow, re-activating the mind-body-spirit connection to help eliminate blockages to healing. All healing is self-healing, and the goal in HT is to restore harmony and balance in the energy system to help the person to heal. Individuals are empowered to activate the innate wisdom of the body to help self-regulate and heal all aspects of the self. They are encouraged to fully participate in their healing journey, as the HT Practitioner helps to facilitate their healing process.

Healing Touch can help:

- Chronic Fatigue Syndrome
- general well-being
- pain control
- stress and tension
- headaches / migraines
- anxiety reduction
- neck and back problems
- grief management
- wound and fracture healing
- psychological problems
- disease prevention
- hypertension
- pre / post surgery
- cancer
- arthritis
- rehabilitation
- skin problems
- premenstrual syndrome
- autoimmune disorders
- spiritual growth/enhancement

HT is not a substitute for conventional approaches to health care, but it can complement them. Clients are encouraged to seek medical care from their Medical Doctor or other appropriate health care professional for any health concerns.

In helping to restore wholeness through harmony and balance, Healing Touch can be a powerful part of one's personal healing journey.

Janet Given is a Registered Nurse, a Registered Psychiatric Nurse, and a Certified Healing Touch Practitioner and Instructor. She is also a

board member of the Canadian Healing Touch Foundation. She has ten years experience working in hospitals as a RN, and has studied many healing modalities and aspects of holistic health during the past 24 years. Her private practice is based in Cloverdale, B.C. Janet can be contacted by phone: 604-574-2789 or by e-mail: janetgiven@home.com

Need People to Complete the 2001 International CFS/ME/FM Survey

Purpose of the survey: To identify those with CFS, M.E. and FM who had a childhood illness similar to non-paralytic polio that may be causing fatigue later in life, and those who indeed had paralytic or non-paralytic polio and possibly have Post-Polio Sequelae today, not CFS, M.E. or FM.

Candidate requirements: Candidate must have a solid diagnosis of CFS, M.E., and FM to participate so the survey can estimate the percentage of those who may have had a childhood illness that is causing new symptoms, versus those with an adult illness causing fatigue.

Dr. Richard L. Bruno who is the chairperson of the International Post-Polio Task Force, is conducting the Survey. He can be reached at HarvestCtr@aol.com for further details. You can also visit the website www.members.aol.com/harvestctr/pps/polio.html

For copies of the survey, please contact MEBC at MEandYou@mefm.bc.ca or call us at 1-888-353-MEBC (6322).

You can also receive a copy from the National ME/FM Action Network
3836 Carling Avenue,
Neapean, ON K2K 2Y6.
Telephone 613-829-6667.
Website www3.simpatico.ca/me-fm.action/

AD FOR TRI-CITIES' SUPPORT GROUP

For the Coquitlam/Port Coquitlam/Port Moody area, the support group will have monthly meetings on the first Tuesday of each month, at the Dogwood Pavillion on Poirier Street in Coquitlam. Lucky and Bette are group leaders. Call 604-931-3554 (Marilyn) for more information.

FREE: “The Integrative Medicine Wheel” by Dr. Collinge

A diagram and explanation of various forms of medicine and health care and how they can work together. Now available in its entirety on Dr. Collinge’s website www.healthy.net/collinge.

Also available for free from this site is the book

“Recovering from Chronic Fatigue Syndrome: A Guide to Self-Empowerment” by William Collinge, Ph. D., a consultant and researcher in Integrative Health Care. The book’s Introduction is by Daniel Peterson, M.D., of Incline Village, Nevada.

MEBC is a non-profit society with an annual membership fee of \$20.00

Charitable registration:
(BN) 13117 3239
RR0001

The main focus of the Myalgic Encephalomyelitis Society of British Columbia is to help those suffering with M.E. (also known as Chronic Fatigue Syndrome). We also want to reach those with FM, MCS, and GWS.

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Contact People and/or Support Group Leaders

Abbotsford	Doug	604-857-4874	Pitt Meadows	Lydia	604-941-3131
Armstrong	Sharon	250-546-6176	Port Coquitlam	Lydia	604-941-3131
Burnaby	Jean	604-525-0951	Port Coquitlam	Marilyn	604-931-3554
Castlegar	Deena	250-365-8312	Port Moody	Laila	604-944-0911
Chilliwack	Maureen	604-792-7973	Port Moody	Marilyn	604-931-3554
Coquitlam	Marilyn	604-931-3554	Prince George	Deborah	250-562-7876
Coquitlam	Laila	604-944-0911	Quesnel	Bobbi	250-992-5777
Cranbrook	Diana	250-427-4327	Richmond	Linda	604-277-7450
Creston	Jane	250-428-5159	Richmond	Irene	604-271-5470
Dawson Creek	Carol	250-787-9722	Sechelt	Dr. Lynch	604-885-3133
Delta	Tina	604-946-2285	Surrey	Joan	604-878-7707
Fort St. John	Carol	250-785-4897	Terrace	Eileen	250-635-9415
Fort St. John	Wendy	250-785-4897	Trail	Wendy	250-368-6103
Fort St. John	Susan	250-827-3731	UBC Students	Michelle	michellk@look.ca
Gabriola Island	Ian	250-247-7381	Van. - Mid Main	Margit	604-708-9234
Kelowna	Sharon	250-765-1636	Van. FM West Side	Wendy	604-732-8764
Kelowna	Julie	250-764-0024	Vernon	Cecile	250-545-2998
Kimberley	Diana	250-427-4327	Vernon	Eve	250-549-2468
Langley	Marlena	604-532-9947	West Vancouver	Janis	604-980-3852
Mission	Doug	604-857-4874	West Van	Wanda	604-926-1842
Nanaimo	Scott	250-758-5352	ME Child Advocate	Kate	604-732-6030
Nelson	Deena	250-365-8312		kate_andersen_uvic@yahoo.com	
New Westminster	Jean	604-525-0951	ME Kids & Teens	Sarah	604-937-0517
North Vancouver	Janis	604-980-3852	ME Parents’ Contact	Elinor	604-937-0517
North Vancouver	Wanda	604-926-1842	ME Teachers’ Contact	Ian	250-247-7381
Penticton	Nan	250-493-6598	ME Nurses’ Contact	Pat	604-929-0566



Myalgic Encephalomyelitis Society of British Columbia

MYALGIC ENCEPHALOMYELITIS SOCIETY OF B.C.
#462 - 916 West Broadway
Vancouver, B.C. V5Z 1K7
Van. (604) 878-7707
BC toll-free: 888-353-MEBC (6322)
www.mefm.bc.ca MEBC@mefm.bc.ca

MEBC MEMBERSHIP APPLICATION FOR PROFESSIONALS
For Medical, Mental Health, Legal, and Home Care Professionals

Applications and payment/donations may also be made on our website: www.mefm.bc.ca

Please indicate your professional status:

- M.D.: General Practitioner
M.D.: Specialist:
Naturopath
Chiropractor
Physio- or Massage Therapist
Psychiatrist
Psychologist
Social Worker
Counselor
Lawyer
Public Health / Home Care Nurse
Parish Nurse
Home Support Worker
Other (specify):

Professional's Name: Qualifications:

Organization, Clinic, or Law Firm:

Address:

City: Province: Postal Code:

Telephone: Web Site:

Fax Number: E-Mail:

ENCLOSED: CHEQUE FOR \$20 Membership Fee and/or \$ Tax Deductible Donation

DATE: SIGNATURE:

Please fill in the sections below relevant to your profession. Indicate in the comment section at the bottom how MEBC can be of help to you, and indicate areas in which you are willing to be of assistance to MEBC. Thank you for your interest and involvement.

ALL PROFESSIONS:

May we refer ME/FM patients to you? Yes No If so, may we publish your name? Yes No

Approximately how many ME/FM patients do you deal with in your practice? ME FM

DOCTORS/ HEALTH CARE:

Do you diagnose patients for ME? Yes No FM? Yes No

LEGAL:

Do you handle: ME legal matters? Yes No FM legal matters? Yes No

Do you offer ME/FM patients free initial consultation? Yes No

MENTAL HEALTH:

Do you treat patients with ME? Yes No FM? Yes No

Do you counsel patients with ME? Yes No FM? Yes No

or provide assessments relevant to ME / FM? Yes No

HOME CARE:

Do you provide home care assessments or home care services for ME/FM patients? Yes No

Please add any ADDITIONAL COMMENTS (and names of other professionals who may be interested in MEBC)

Blank lines for additional comments.

Contact Us



Myalgic Encephalomyelitis Society of British Columbia

MYALGIC ENCEPHALOMYELITIS SOCIETY OF B.C.
#462 - 916 West Broadway
Vancouver, B.C. V5Z 1K7
Van. (604) 878-7707
BC toll-free: 888-353-MEBC (6322)
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Name: _____ New Member ___ Renewal ___
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E-mail Address: _____
Occupation: _____ Are you currently employed? Yes ___ No ___

Support Group Name/Contact Person: _____
Do you have M.E.? Yes ___ No ___ FM? Yes ___ No ___ MCS? Yes ___ No ___

Enclosed is \$20.00 to cover membership dues for the coming year. ___

Enclosed is: ___\$5 ___\$10 ___Other \$_____ to help with MEBC's operating and production costs

Are you able to volunteer your time and skills in any of the following areas?

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___ Education ___ Fundraising ___ Legal Assistance
___ Newsletter ___ Research/gathering information on M.E.
___ Special Events ___ Serving on the MEBC Executive or committees
___ Other _____

COMMENTS: Tell us about your situation:

Contact Us

MEBC is staffed completely by volunteers. If you are able to support the efforts of MEBC with a donation, your help will be greatly appreciated. Your donation is fully tax deductible and a receipt will be issued for donations of \$10 or more.

Enclosed is my tax deductible donation to MEBC in the amount of :
___\$100.00 ___\$75.00 ___\$50.00 ___\$25.00 ___Other \$_____

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