



ME&You

Myalgic Encephalomyelitis Society of British Columbia Support News Spring 2001 Volume #21

MEBC News

Inside



MEBC News



Medical



Research



Legal



Bits & Pieces



Contact Us

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May 12, 2001 is M.E./FM Day Events

On May 12, 2001 the MEBC Board will be meeting with legal and medical professionals to discuss the issues that people with M.E. face. A full summary will be provided in our Summer issue of “M.E. & You.”

Radio Interview with Dr. Carruthers

Dr. Bruce Carruthers will be interviewed by Philip Till once again, in honour of M.E. Day. Last year’s interview was quite informative, and drew a huge response from listeners.

Date: Friday, May 11th, 2001
Time: 2:00 p.m.
Station: CKNW (AM 980)
Program: “The World Today”

Summary of Annual General Meeting, January 27th, 2001

MEBC had its Annual General Meeting on January 27th, 2001. The following nine existing directors were re-elected by acclamation: Sherri Todd, President; Brian Schmidt, Vice President; Bev McLachlan, Donna Mitchell, Joan Navratil, Audrey Pihach, John Touzel, Mark Vollman, and John Warren. We wish to thank the 24 members who attended.

Steve Sharpe (counselling psychologist) was our speaker this year. Steve offered an interesting resource called “Diagnosing and Treating Chronic Fatigue Syndrome.” This resource covers information about M.E. It can be found at www.afme.org.uk/info/book0010.txt

During the discussion, it quickly became evident that the number one concern of members was dealing with the insurance companies, particularly in regards to IMEs (independent medical exams). One member made recommendations about signing release forms to insurance companies and suggested that you create your own form to release specific information to specific doctors for a specific time period.

Another member shared how she lost faith in lawyers after being “dumped” by her lawyer just before trial. While it is easy to understand this loss of trust as a result of such disappointing tactics on the part of this one lawyer, other members reminded the audience that this experience does not summarize all experiences with lawyers. The Sharon Baillie case is a prime example of lawyers helping to set a winning precedent.

Members also mentioned that family and friends often cannot understand or relate to our experience of M.E., but when they read about it on a website or in a book, they start to understand what we go through. After sharing the bookwork by artist Deborah Koenker (who has M.E.), people were excited about the idea of using the arts to communicate our experience. The Board encouraged members to also visit our website (www.mefm.bc.ca) now that we have updated its content.

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

MEBC News

Medical

**“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.

MEBC Executive Director Position Available

MEBC is looking for an Executive Director to take our society to the next level. This role would report to a supportive Board of Directors and would entail recruiting and supporting a management team of volunteers and potentially compensated personnel. It would also include developing and executing a short-term revenue plan and designing a long-term strategic plan.

Initially a “work from home” volunteer position, this role is intended to become full-time and compensated. If you know of anyone who has these skills or would be interested in making a difference for a worthy cause, please contact Sherri Todd at smtodd@home.com or at 604-942-4026.

Dr. Carruthers' Lecture

BY BRIAN SCHMIDT

“Updates on M.E.”

On November 4, 2000, approximately 40 people attended a lecture by Dr. Carruthers on new ideas regarding Myalgic Encephalomyelitis (M.E.) Dr. Carruthers outlined the varying effectiveness of a range of treatments; common problems encountered with doctors regarding diagnosis; and his development of a simple method to diagnose cognitive impairments in people with M.E. and Fibromyalgia (FM).

DEMOGRAPHICS

Dr. Carruthers reported that 3.4% of the population are estimated to have FM¹ while 0.42% of the population have M.E.² FM is 7 to 10 times as common in women as men³ and M.E. is twice as common in women¹. (Applying these percentages to BC's current population of over 4 million, an estimated 156,000 British Columbians have FM and 17,000 have M.E. Combined, that's 173,000 people in B.C.!)

INCONSISTENT TREATMENT EFFECTIVENESS

Dr. Carruthers explained that in his clinical experience with any treatment used for M.E., only a minority of patients find them to be effective. In a patient survey evaluating the effectiveness of various treatments⁴, M.E. patients rated as most effective (in this order): 1. Pacing activity; 2. Changing one's outlook; 3. Avoiding chemicals; 4. Sleep; 5. Massage and bodywork therapies; 6. Pain relief; 7. Avoiding certain foods; 8. Yoga, Tai Chi and Chi Gong; 9. Cognitive Behavioral Therapy; and 10. Herbal remedies.

Among the least effective treatments reported by the survey group were aggressive rest, increased salt (for low blood pressure), antidepressants, magnets, B12, and amalgam removal. In roughly 20-30% of cases, people reported some treatments to cause harmful side effects. These included beta blockers, colonics, Florinef, Clonazepam, antidepressants, too much bed rest, and graduated exercise programs.

SLOW BRAINS (AMONG OTHER THINGS)

Dr. Carruthers explained that three regulatory systems in the body are affected in these two diseases. First, the Immune System is either over- or underactive. Second, the Endocrine System reacts abnormally to stress and exercise (cortisone levels don't go up as they should in these situations). Third, the Brain and Central Nervous System show fluctuating, rather than fixed, defects. What each of these regulatory systems have in common is that they are meant to help a person adapt efficiently to what is going on in the environment.

What is clear is that people with M.E./FM have bodies that don't adapt as they once did. When fatigued, their brains cannot integrate sensory and motor information properly. Processing speed also slows down. These changes in the frontal lobe function of the brain are similar to those found in the aging brain. (It is of interest that increasing the rapidity of stimulus presentation in healthy young people will cause them to experience similar cognitive impairment temporarily⁵.) These research findings help to explain why people with M.E./FM need to slow their pace of activity and reduce sensory stimuli.

Dr. Carruthers also pointed out that while Cognitive Behavioural Therapy (CBT) helps patients address irrational beliefs (thereby helping them to cope better), CBT doesn't address the impaired body regulatory systems. That's why Dr. Carruthers prefers to prescribe life adjustment changes which encourage "Silence, Serenity, and Simplicity" to help us live a more fulfilled life.

(He mentioned that insurance companies prefer that M.E./FM patients undergo CBT, because any improvements that result from coping better can then be "explained" by *their theory* that these diseases are "all in the head". As Dr. Carruthers noted, everyone has irrational beliefs and everyone would benefit from addressing such beliefs regardless of their mental health status!)

DIFFICULTIES WITH DIAGNOSIS AND DOCTORS

Dr. Carruthers explained some of the difficulties involved in diagnosing FM and M.E. First, most diagnostic tests are designed to measure fixed symptoms. Therefore, they do not capture the dynamic and fluctuating nature of M.E. symptoms. A second difficulty is that specialists are not aware of the full spectrum and severity of the cognitive difficulties experienced by people with M.E./FM. Dr. Carruthers did a quick survey of audience members who were having trouble concentrating on his lecture because of outside traffic noise or the noise from florescent lights. Many in the room indicated that they were adversely affected by these stimuli.

He gave an example of how unaware doctors have been regarding how such common everyday factors can influence the ability of an M.E. patient to function at any moment. By contrast, he noted that insurance doctors often encourage M.E. and FM patients to come to "independent" medical exams as rested as possible. Furthermore, these doctors conduct tests in rooms which are devoid of the kind of sensory stimulation that goes on in the typical work place and which generally overtax M.E./FM patients' systems.

Finally, Dr. Carruthers noted that FM patients typically are sent to *rheumatologists* for diagnosis, while M.E. patients are sent to *infectious disease specialists*. Neither group of doctors is specifically

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

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

qualified to assess the *cognitive* disturbances common to these conditions, but the medical specialists trained in this area – the neurologists – tend not to deal with M.E./FM. Instead, neurologists concentrate on such diseases as M.S. and Parkinson's.

HOPE FOR A SIMPLE DIAGNOSTIC TOOL FOR THE FUTURE

To help doctors diagnose cognitive difficulties that impair normal functioning when people with M.E./FM are exposed to the sensory stimuli of modern daily life, Dr. Carruthers is developing a simple test to assess M.E./FM cognitive impairment. Already, within the early stages of testing with this tool, he reports seeing distinct differences between healthy controls and M.E./FM subjects. Such a tool offers hope in educating doctors regarding the cognitive aspects of these diseases. This simple test may well offer the vital confirmation of impairment that people with M.E./FM need in their fight for proper recognition and aid.

REFERENCES:

1. *Harrison's Principles of Internal Medicine*. 14th edition. 1998. McGraw-Hill.
2. "Shattering the Myths: Recommendations from a community-based study of CFS." *CFS Research Review*, Winter 2000; Vol. 1, Issue 1: pp. 4-5.
3. Goldenberg, D.L. (MD). *Chronic Illness and Uncertainty*. Newton Lower Falls, MA: Dossel Press; 1996.
4. Hol, David. "1999 Chronicle Reader Survey". *CFIDS Chronicle*, July/August 1999: pp. 6-9.
5. Homer-Dixon, Thomas. *The Ingenuity Gap*. New York: Knopf, 2000. P. 217.

Rivex Article

Editor's note: In the Fall 2000 issue of "ME & You" we included an article entitled "Isoprinose® Study." In the interest of making it easier for most of our members to read, it had been edited from its original version to remove some of the technical medical terminology. We have since received requests to provide the article in its entirety. The following is the complete, unedited version of this article.

At the Immunology 2000 Conference held in Seattle during May 2000, an evaluation of the clinical impact of Isoprinose® (inosine pranobex), an immunomodulator/antiviral on various immune functions in CFS patients, was presented by Dr Ashok Kumar of the Children's

Hospital of Eastern Ontario, Ottawa, Canada.

Chronic fatigue syndrome (CFS) is associated with several immune abnormalities, such as decreased NK cell mediated cytotoxicity and dysregulated production of cytokines. In this trial the effect of drug treatment on various immune functions in 16 CFS patients diagnosed according to the CDC CFS definition was assessed.

The patients were followed for a total of 28 weeks (12 weeks blinded; 4 weeks treatment free; 12 weeks open label phase). CFS patients at baseline compared to normal controls exhibited a significantly decreased NK cell activity

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as well as decreased mitogen-induced production of IL-10 and IL-12, as well as IFN- γ in PBMC.

Clinical improvement based on the clinical staging was observed in 6 out of 10 patients (60%). The clinically improved patients showed a significantly enhanced NK activity, which correlated with the duration of treatment.

A significant increase in IL -12 production by T cell mitogen stimulated PBMC was also observed in clinically improved patients treated for 28 weeks compared to patients on placebo. Treatment with Isoprinosine® for 12 weeks did not appreciably influence the production of IL -1 α and IL-10. Discontinuation of treatment, however, resulted in enhanced production of

both IL-1 α and IL-10 only in clinically improved patients. When treatment was recommenced at week 16, significantly decreased production of these two cytokines was observed.

Treatment with Isoprinosine® for prolonged periods (28 weeks), also resulted in an enhanced number of CD4+ T helper cells, CD4+ and HLA-DR+ T cell numbers in peripheral blood only in clinically improved patients.

The results of this trial suggest the safety and efficacy of Isoprinosine® and its potential to enhance NK cell activity. In view of the small number of patients, further studies are required to investigate the contribution of Isoprinosine® -mediated immune effects to the pathogenesis of CFS.

Volunteers Still Needed

Volunteers are still needed for the University of British Columbia's research study about how to cope with CFS. 200 volunteers are needed in total.

PURPOSE OF THE STUDY:

To identify the illness perceptions, coping, and social support strategies people with CFS use to deal with their illness, and how these perceptions and strategies influence functioning, anxiety, depression, and the utilization of health care services. The study **DOES NOT FOCUS ON CAUSES** of CFS but instead, **it focuses on what people with CFS can do to make themselves better by caring for themselves.**

Investigators: Dr. Grant Stiver and Kenna Sleigh, RN, MSN (PhD candidate in the Experimental Medicine Program at UBC). Study procedures include one screening visit followed by four sets of questionnaires that can be mailed in. You are required to be already diagnosed to have CFS. **People who find the paperwork and computer work too overwhelming can choose to cancel.**

Call 875-5555 ext. 62366, or pager 871-5263.

****MEBC MEMBERS**** Please show your interest and support to these researchers who are interested in helping us. By taking part in this project, YOU are making a difference!

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 Independent Medical Examination: Venturing into the Lion's Den

BY STEPHEN GREY

"ME & You" is pleased to have Stephen Grey provide us with the following article. Stephen has been practicing law since 1982 as a trial lawyer, primarily in the areas of personal injury and insurance law. He is currently a partner in the firm of Grey Robinson & Associates in Richmond.

Virtually every disability policy allows the Insurance Company to have a Claimant examined by a medical specialist of the company's choosing. During the initial "claim pending" phase, the company may require an examination by more than one specialist. The number and frequency of these examinations must be reasonable. After the claim is approved the company can have you examined periodically, but usually only once per year would be considered reasonable.

The company can decide what type of doctor or specialist will conduct the examination. It may be a medical doctor or psychologist. It is not for you to question the company's choice of doctor to assess you. Refusal to undergo a required assessment is sufficient grounds for denying you benefits under the policy.

You should be aware that the company is not obligated in law to provide you or your doctor with a copy of any of the medical reports obtained by them. I would therefore recommend that you try to obtain the company's agreement – in advance of the examination – to provide a copy to you or your doctor .

You are entitled to take a spouse/friend with you who can be present throughout the examination and assessment (i.e. for moral support and as a potential witness as to how long the examination took, what areas were examined,

etc.) You can also tape the interview, although I would recommend it not be done surreptitiously. Tell the doctor you are going to tape the interview to ensure the accuracy of the information provided to him. The tape needs to be carefully preserved until it is no longer needed. Any attempt to alter it will seriously undermine the reliability of it and its potential admissibility in a court of law. During the assessment, expect to be asked a lot of questions about your background, work history, personal relationships, physical activities, difficulties, emotional concerns, etc. Also expect a physical examination.

I would recommend that you try to be cooperative and responsive during the course of the examination and assessment. While it is true that the company's IME doctor may well be biased in favor of the company, it is not necessarily the case. In any event, it will not help matters if you exhibit distrust or contempt for the doctor. Keep in mind the fact that the company is entitled to a so-called independent medical assessment, even though you feel like you are in the lion's den. When you get home after the examination, write out in as much detail as possible what happened during the assessment – how long were you examined for, what areas of your body, what did the doctor say to you, etc. This will help to refresh your memory later, if necessary.

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What is ‘Objective Medical Evidence’?

BY LAWRENCE PIERCE

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.

Often Disability Insurance Companies will demand that you prove your disability on the basis of objective medical evidence. There is a difference between ‘objective’ and ‘subjective’ medical evidence. Generally ‘objective’ means the sort of things your doctor can see on an x-ray or lab test report, while ‘subjective’ means the things you report to your doctor. For example, if you point to your arm and say it hurts, that is subjective, but if an x-ray shows a broken bone, that is objective.

Do you have to provide objective medical evidence of disability to your insurance company? Generally the answer is “no.” Most insurance policies do not require that the disability be proved with anything more than written proof of disability. The request for objective evidence is one more tactic used by insurance companies to try to discourage you and your doctor from pursuing a claim. In my experience, the insurance company will tell claimants with perfectly good claims that they do not qualify, and that the company needs more proof. Often the claimant is asked to file an “appeal.” Often the “appeal” is another time-waster and no real appeal at all.

Illnesses such as FM or CFS are considered subjective by the disability insurance industry. Even though the medical profession can confidently diagnose them, the doctor must rely on the patient’s report to some degree.

You need not prove that your condition has a name, or that it can be diagnosed objectively. It is enough that your doctor is willing to certify you as totally disabled.

When in doubt, confront the disability insurance company, and ask for a copy of the policy provision that requires proof of disability with objective medical evidence.

Book & Article Reviews: Understanding M.E. and Moving On!

It’s difficult for family and friends to relate to M.E. Many think our symptoms can’t be as bad as we claim. They believe we should push through our pain and fatigue to function exactly as they do. If we don’t, they may view us as lazy hypochondriacs who like to whine a lot to get attention. But when they stumble across an article, or others they respect who have M.E., a light bulb often goes off, and they begin to understand and even validate our experience.

Several biographical resources can not only help others understand M.E., but can also encourage us to move ahead with our lives despite our M.E.

LYNN VANDERZALM. FINDING STRENGTH IN WEAKNESS: HELP AND HOPE FOR FAMILIES BATTLING CHRONIC FATIGUE SYNDROME. (Grand Rapids, MI:

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.

Legal

Bits & Pieces

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

Zondervan, 1995) Forward by Dr. David S. Bell. (286 pages)

The author and her daughter acquired CFIDS in 1988. In this book, she outlines the processes people go through as they seek to recover from this devastating illness. Vanderzalm interviewed 70 men, women, and children affected by M.E. for this book.

She deals extensively with the hallmarks of this invisible disability (symptoms, triggers, relapses, and crashes) and the grieving process as it relates to the many losses resulting from M.E. Vanderzalm offers comprehensive suggestions about how to move on in life, from practical solutions for *physical* limitations to ways to stay healthy *emotionally*. She challenges readers to evaluate not only what causes them to *lose* energy, but also what helps to conserve and even *gain* energy.

While she outlines how to enlist others' help without overwhelming them, she also states that we can't expect total understanding: "Even *we* don't know how to respond to ourselves from day to day. We can ease the pain if we keep in mind . . . two things: Expect that many people won't understand . . . [and] Value a few close friends . . ." (p. 118).

Two chapters are devoted to understanding and advocating for *children and youth* with M.E., and one chapter outlines ways to build a healthy *marriage* in spite of M.E. As with the rest of the book, the resource section is also comprehensive with a list of CFIDS organizations, a long bibliography, and a sample letter to schools (on behalf of children).

A key focus of this book is on maintaining *spiritual* health in the midst of suffering. Vanderzalm shares struggles she and others have with their faith, as well as the comfort they find in God. While readers may not share

her distinctly Christian perspectives, they can still benefit greatly from the processes she outlines in terms of dealing effectively with M.E. on the *physical, social, emotional, relational, vocational, medical, educational, and spiritual levels*.

The only aspect she doesn't cover is the struggle over disability coverage. Otherwise, this is an excellent resource book for people with M.E., their family, and friends.

GARY L. GILBERT. *DEBILITATED: A JOURNAL OF ONE MAN'S EXPERIENCE WITH CFS*. (Haverford, PA: Buy Books on the web.com, 2000). (63 pages) Available through www.buybooksontheweb.com.

Gary, an MEBC member from Fort St. John, chronicles the first two years of living with M.E. He writes, "The purpose of this book is ... to share my own ordeal in how I learned to live and cope with my illness." It's clear that Gary is motivated to educate journalists, insurers, and others about how M.E. impacts us.

His observations include the shock of how his insurer dealt with his condition. "Remember that the insurance company is not a person. It is a profit-making corporation. You are a liability to them and they will do everything in their power to eliminate that liability. Acting in your best interest is not their priority. Keep meticulous records.... It is imperative to get [things] in writing." (p. 53).

Gary includes an article by a doctor on *men* with M.E., some encouraging research breakthroughs, lists of relapse triggers and impacts, coping tips, some resources, and a brief history of M.E. Through his experience, Gary encourages readers to look for those "little wins" which help us move on in life.

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

JENNIFER FREY. “AGAINST THE ODDS: LAURA HILLENBRAND SURMOUNTED [CFS] TO CROSS THE FINISH LINE WITH ‘SEABISCUIT’.” *Washington Post*, March 9, 2001, Page C01. On the web: www.washingtonpost.com/wp-dyn/articles/A43937-2001Mar8.html

This review is available on the web and can easily be e-mailed to friends from the website (above). 33 year old Laura Hillenbrand has M.E. and has written a book about a sorry little horse who, with his half-blind jockey and almost mute trainer, won a famous race in the 1930s – a metaphor for Hillenbrand’s own struggles. While many don’t understand her condition, her boyfriend has stuck by her. Through his practical attention to her smallest of needs, she was freed up to write a book, which is getting rave reviews. Hillenbrand views the term “CFS” as a “ridiculous name for the disease that has ravaged her life.” “‘This illness is to fatigue what a nuclear bomb is to a match,’ she says. ‘It’s an absurd mis-characterization.’” This book/author review will inspire as well as educate many about M.E. Check it out.

TIMOTHY KENNY. *LIVING WITH CHRONIC FATIGUE SYNDROME: A PERSONAL STORY OF THE STRUGGLE FOR RECOVERY.* (New York: Thunder’s Mouth Press, 1994). Forward by Dr. Paul Cheney. Epilogue: A Spouse’s Tale by Hettie Kenny. (228 pages).

The cover notes summarize the value of this autobiography: “Kenny . . . recounts his own battle with the illness – from his high-profile career in television news to . . . eventually becoming housebound. His story . . . will resonate deeply with CFS patients . . . forced to deal with the skepticism of doctors, employers, and peers. He writes poignantly of the loss of his career, the strain on his marriage, and his eventual sacrifice of nearly everything to get well. Kenny details how doctors [and insurers] routinely dismiss CFS . . . This book provides an eye-opening and inspirational look at the realities of CFS and the will to survive.”

Chapter titles show the breadth of coverage Kenny provides: “Real Men Don’t Get Sick”; “The Ampligen Trial”; “Unemployment ‘Compensation’”; “The Disability Wars”; “The ‘F Word’” [Fatigue]; “Why Me?” and “New Beginnings”.

Medical / Legal Resources

THE NATIONAL ME/FM ACTION NETWORK’S LEGAL/RESEARCH PACKAGE:

If you’re dealing with an IME or have had to resort to retaining a lawyer, *this package is a must!* Marj has done an *awesome* job of compiling almost 300 pages of excellent resource materials. There are several articles dealing with *IMEs* with helpful advice regarding medical release forms and challenges to some of the testing used.

About 1/3 of the package is a compilation of over 200 *medical abstracts of recent research* on M.E., FM, and whiplash, on top of *articles* dealing with important M.E./FM medical findings. Finally, there are articles on tips for litigation and summaries of *numerous relevant Canadian legal judgments and precedents and CPP appeals*, including a review of the Sharon Baillie case. The package will save lawyers a lot of time searching out similar information; it’s a good starting point for further investigation and well worth the \$25.

Send a \$25 cheque payable to Marj van de Sande, Director of Education
 151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 Tel/Fax: (403) 547-8799
 E-mail: vandesam@cadvision.com Web site: www3.sympatico.ca/me-fm.action/

THE BC HEALTHGUIDE, sent to every B.C. residence, is a monumental step forward in B.C. in recognizing M.E. and FM as legitimate illnesses. No longer can doctors in B.C. write M.E. or FM off as bogus! This Guide has been reviewed and endorsed by the BC Medical Association, the Ministry of Health, the BC Center for Disease Control, the BC College of Family Physicians, and Registered Nurses Association, among other medical associations. Photocopy pages 135 and 142 and give the web address (www.bchealthguide.org) to medical professionals you see – especially if they think your M.E./FM is “all in your head”!

MEBC’S WEBSITE UPDATES: www.mefm.bc.ca

In case you haven’t checked it out since the end of January 2001, we have updated the *content* to our site. There is now an extensive research review under the section “*What is ME?*” It has lots of useful information for medical and legal professionals, as well as the general public. Also, there are links to websites we deem valuable. We hope to update the *format* of our site soon. Stay tuned!

Support Group / Contact Person

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 Moody	Laila	604-944-0911
Castlegar	Deena	250-365-8312	Port Moody	Reiner	604-941-9902
Chilliwack	Maureen	604-792-7973	Prince George	Deborah	250-562-7876
Coquitlam	Reiner	604-941-9902	Quesnel	Bobbi	250-992-5777
Coquitlam	Laila	604-944-0911	Richmond	Linda	604-277-7450
Cranbrook	Diana	250-427-4327	Richmond	Irene	604-271-5470
Creston	Jane	250-428-5159	Sechelt	Dr. Lynch	604-885-3133
Dawson Creek	Carol	250-787-9722	Surrey	Joan	604-878-7707
Delta	Tina	604-946-2285	Terrace	Eileen	250-635-9415
Fort St. John	Carol	250-785-4897	Trail	Wendy	250-368-6103
Fort St. John	Wendy	250-785-4897	UBC Students	Michelle	michellk@look.ca
Fort St. John	Susan	250-827-3731	Van. - Mid Main	Margit	604-708-9234
Gabriola Island	Ian	250-247-7381	Van. FM West Side	Wendy	604-732-8764
Kelowna	Sharon	250-765-1636	Vernon	Cecile	250-545-2998
Kelowna	Julie	250-764-0024	Vernon	Eve	250-549-2468
Kimberley	Diana	250-427-4327	West Vancouver	Janis	604-980-3852
Langley	Marlena	604-532-9947	West Van	Wanda	604-926-1842
Mission	Doug	604-857-4874	ME Child Advocate	Kate	604-732-6030
Nanaimo	Scott	250-758-5352		kate_andersen_uvic@yahoo.com	
Nelson	Deena	250-365-8312	ME Kids & Teens	Sarah	604-937-0517
New Westminster	Jean	604-525-0951	ME Parents’ Contact	Elinor	604-937-0517
North Vancouver	Janis	604-980-3852	ME Teachers’ Contact	Ian	250-247-7381
North Vancouver	Wanda	604-926-1842	ME Nurses’ Contact	Pat Woods	604-929-0566

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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Bits & Pieces

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)
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 Deductable 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)

Three horizontal lines for additional comments.

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Membership Application Form

(Please Print)

Name: _____ New Member ___ Renewal ___
Address: _____ City: _____
Postal Code _____ Home Phone: _____ Work Phone: _____
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?

- | | | |
|--|--|---|
| <input type="checkbox"/> Art work | <input type="checkbox"/> Article and letter writing | <input type="checkbox"/> Telephoning |
| <input type="checkbox"/> Clerical assistance | <input type="checkbox"/> Computer work | <input type="checkbox"/> Media Contact |
| <input type="checkbox"/> Education | <input type="checkbox"/> Fundraising | <input type="checkbox"/> Legal Assistance |
| <input type="checkbox"/> Newsletter | <input type="checkbox"/> Research/gathering information on M.E. | |
| <input type="checkbox"/> Special Events | <input type="checkbox"/> Serving on the MEBC Executive or committees | |
| <input type="checkbox"/> 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 \$_____

PLEASE MAKE CHEQUES PAYABLE TO MEBC