



# ME & YOU

Myalgic Encephalomyelitis Society of British Columbia    Support News    Fall 2001    Volume #23

MEBC News

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**“ME & YOU” IS A QUARTERLY PUBLICATION OF MEBC.**

**OPINIONS AND ARTICLES ARE THOSE OF THE WRITERS AND MAY NOT REFLECT THE OPINIONS OF MEBC OR THE BOARD OF DIRECTORS.**

## MEBC Annual General Meeting

Date: Saturday, January 26th, 2002

Time: 1:00 p.m.

Location: Auditorium – New Westminster Public Library, 716 - 6th Avenue, New Westminster

We hope to show the award-winning documentary “*I Remember Me*” on M.E./CFS. This 74-minute film features soccer star Michelle Akers, filmmaker Blake Edwards, musician Keith Jarrett, & others with CFS. Check out synopsis at [www.zeitgeistfilm.com/current/irememberme/irememberme.html](http://www.zeitgeistfilm.com/current/irememberme/irememberme.html)  
*Bring a comfy lawnchair or foamie if needed!*

## United Way Campaign / MEBC Donations

Thank you for designating MEBC as your charity of choice when making your United Way contribution this year. Your funds are key to supporting our newsletters, website, and phone support. Please remember to specify MEBC on

your United Way donation form and cheque.

You can also make tax-deductible donations directly to MEBC at our mailing address (listed on page 2 sidebar).

## Volunteers

Participate in the International Year of Volunteers! “The value of one. The power of many.”

Volunteers are crucial to our ability to continue serving people with M.E. and their families. We are continually looking for volunteers. We currently have openings for the following:

### 1. EXECUTIVE DIRECTOR POSITION:

MEBC is seeking an Executive Director who would report to its Board of Directors; recruit and support a management team of volunteers; develop & execute a short-term revenue plan; and design a long-term strategic plan. Initially volunteering from home, this role will progress to full-time and compensated. Qualifications: Business &/or non-profit experience, a strong community network, and motivated by accomplishment.

### 2. OTHER AREAS IN WHICH WE REQUIRE HELP:

- Personal Support: friendship, advocacy, and practical help.
- Group Leaders: Nurses, Counselors and Social Workers to lead M.E./Fibromyalgia support groups or therapy groups for families.
- Promotion: Fundraising and public relations experience.
- Administration Help: one person to take Board minutes eight to ten times per year, another to maintain our membership lists (Excel database), and others to help with mailouts, surveys, etc.

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

## M.E. and Mindfulness

BY DR. BRUCE CARRUTHERS, M.D.

In his recent book “A Mind So Rare: The Evolution of Human Consciousness”, Norton, 2001, Merlin Donald states that “The greatly enlarged anatomical loop between the cerebellum and the prefrontal cortex contributed to our (human) expanded capacity for automatized skills. This level of involvement in the conscious control of movement seems to be a distinctively human adaptation, based largely in the newest parts of the cerebellum” (ibid. p 197). This is connected to a key change in hominid evolution – “the extension of voluntary attentional control into the domain of action, especially the control of the limbs and the vocal tract. This change might qualify as the central defining characteristic of human conscious capacity” (ibid. p 196).

This rather technical language describes a system within the human brain through which conscious bodily skills are learned that can then be automatized and stored to be used as subconscious or semi-conscious routines in the future. They can then be appropriated for complex actions by the executive levels of the mind/brain in an efficient and effective fashion without having to start from scratch each time.

All of us store innumerable skilled routines for activities of daily living, which we have been busily learning and modifying since childhood. These were learned consciously at first, but then routinized to the point of leaving conscious awareness. Later in life we continue to learn many additional complex skills involving myriad subroutines, e.g. driving a car, where unconscious or semiconscious subroutines are engaged appropriately by the executive consciousness concerned with the overall driving. Without this automatization, our actions would be very inefficient and our consciousness would be distracted into the details of adjusting the subroutines such as how to use the leg to brake or use the clutch, how to use the hand to shift the gears or the automatic shift or turn the wheel, how to avoid being overly distracted by noise, conversation, radio, etc., and how to bring all the subroutines into the proper rhythm. When driving, consciousness should rather be engaged in its higher executive functions such as overall planning, steering and adaptation of the driving to changing circumstances.

Accompanying each learned and automatized skill is a preset knowledge of how much of it we can do, our sense of endurance for the action, and its limits. These are the expected spatial and temporal parameters accompanying the skills, telling us where we can apply the skill, with what intensity, and for how long.

The cognitive fatigues of M.E. upsets these expected parameters.

Symptoms of fatigue and the deterioration and uncertainty of action intrude upon consciousness, and we can no longer apply our learned skills appropriately to ongoing problems of living. We no longer know what we can do and what we can't, as our expected limits are wrong. Thus we have to relearn those skills affected as appropriate to the new circumstances of having M.E., with a beginner's mind.

**“ME & You”  
newsletter team:  
Donna Mitchell  
Jeanine Madill  
Diana Inselberg**

### **MAIL**

**You may send  
letters, articles,  
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the editor at  
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#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.**

One of the most important self-healing practices that having M.E. invites its sufferers to develop is that of ‘mindfulness.’

In this practice we apply a special form of consciousness to monitor our basic bodily skills, e.g. allowing perceptual form to emerge from background, screening out noise, listening, talking, walking, sitting, standing, going to the toilet, eating, making the bed, cooking, washing the dishes, gardening, etc. This is the practice of mindfulness to observe the new limits and constraints of formerly routinized skills and allow them to modify themselves in the course of a renewed consciousness of them (plus lots of patience and persistence). This modification is a form of non-action rather than willful trying, where the proper quality of consciousness allows new possibilities for action to arise.

A good introduction to applying this practice in everyday activities is “Wherever You Go There You Are” by Jon Kabat-Zinn, Hyperion, N.Y, 1994. On page four the author describes mindfulness as “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally.” It should not be used when higher order executive consciousness must be emphasized, as in driving a vehicle.

Each M.E. sufferer will have a particular pattern of skills affected, so each program of mindfulness must be individualized as to content and duration. Work on the skill whose dysfunction bothers you, and only for as long as the mindfulness itself doesn’t falter. You may want to start with just a few minutes at first, but be persistent over months. If your skills are improved by this practice of mindfulness, they will again return to the unconscious level, and no longer distract the executive consciousness, thus rendering it more effective. If mindfulness is successful in reducing symptoms and improving function, then it provides true self-healing for patients with M.E.

## M.E. vs. Clinical Depression: Research confirms they are not the same thing

*Editor’s note: The following text is an excerpt from the article “What is M.E.?” posted on MEBC’s website. To locate the complete text which includes an extensive compilation of a wide range of research showing that M.E. is clearly a physiological syndrome, and not “all in our heads,” go to [www.mefm.bc.ca](http://www.mefm.bc.ca) and click on “What is M.E.?”*

*You may wish to make copies of this article and the list of abstracts to present to your doctors and/or psychologists, who may be dismissing your M.E. symptoms as depression*

### **DIFFERENTIATING M.E. FROM DEPRESSION IS CRUCIAL**

M.E. is often equated with depression, and as a result, it is often dismissed as such. There are several important consequences of such an equation on medical treatment and research. The distinction between M.E. and depression is crucial for conducting accurate research and formulating appropriate treatments.

Research may find a co-existing depression in some people with M.E., but it needs to be

## **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](mailto:dwshore@home.com)  
 WEB  
[www.geocities.com/capitolhill/1544](http://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

determined if the depression is the result of the various losses and struggles people with a debilitating physiological illness have. What normal person would not struggle with depression when they have an array of unexplainable, fluctuating symptoms (including fatigue levels beyond belief)? Who would not experience grief, when, as a result of their inability to function as they once did, they have lost their jobs, savings, homes, friends, and even spouses? Just because some people with M.E. become depressed *as a reaction to* the consequences of having M.E., this does not mean that M.E. *is* depression.

Confusion of M.E. with depression in research and medical practice may also result from finding people who were *already* depressed when M.E. struck them. Again, this does not mean M.E. is the same thing as depression. It does not stand to reason that depression *causes* M.E., or that M.E. symptoms are part of a depressive episode. In fact, there are many people who became disabled with M.E. at a point in their lives when they were healthy, extremely active and socially involved, and content with life.

By mislabeling M.E. as depression, appropriate treatments for M.E. will be not be properly considered by physicians and mental health workers. Such mislabeling diverts attention to the real issues people with M.E. face.

On the other hand, it is equally important to determine the co-existence, if any, of depression in people with M.E. *If* the reactive depression described above does become a major depressive episode or a recurring clinical depression, *then* treatment interventions for depression would be appropriate. For people who were depressed *when* they became disabled with M.E., it is important that they be treated for the depression so that the depression doesn't complicate their chances of recovery from M.E.

Even if M.E. proved to be a variant of depression (which current research does not bear out), it cannot be “blown off” as something not important. Depression can be a life-threatening illness and needs to be taken seriously. Yet people with M.E. are often not taken seriously because doctors diagnose them as being “simply depressed” as if sheer will power and changed attitudes will do “the trick”.

Both conditions – M.E. and depression – are serious and need to be treated as such. Where they happen to *overlap* in an individual, both conditions need to be treated. Where *either* exists in an individual (unrelated to the other condition), it needs to be treated appropriately, either as M.E. *or* depression in order for the treatment to have any possible therapeutic effects.

## PROBLEMS WITH RESEARCH BIAS

Psychologist Dr. E. Goudsmit notes some conflicting statements by the researchers of a study which compared blood flow to the brain in people with M.E. and those who have major depression. Although the researchers found similarities as well as differences between the two groups, the reviewer notes that while the abstract states that the CFS [M.E.] patients “were not depressed” *according to psychological testing the researchers conducted*, the abstract later refers to them (for no apparent reason) as having “high levels of depression.”

This confusion may reflect a bias on the part of the researchers, that they ignored their own test findings to support a *belief* that M.E./CFS is depression. There were also conflicting statements in the abstract about whether the SPECT scans were taken while subjects performed cognitive tests or when they were at rest.

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

(*British Journal of Psychiatry*, 2000, 176, 550-556 cf. Abstract reviewer: Dr. E. Goudsmit, <http://freespace.virgin.net/david.axford/letter07.htm>)

These problems in methodology and in applying research findings can make an enormous difference in how people with M.E. are viewed and treated. Care needs to be taken when statements about M.E. are made based on supposedly unbiased “objective” research. The unwitting biases of researchers and their funders’ agendas can influence their “results”!

## RESEARCH SUPPORTS BIOLOGICAL EVIDENCE OF M.E. UNIQUENESS

Despite the possible biases in the conclusions by these British researchers, they did note differences on psychological testing and on SPECT scans between those who have M.E. and those who suffer with major depression.

Other numerous studies conducted by different researchers (reported in a variety of medical journals) confirm biological distinctions in people with M.E. as compared to healthy people, people suffering from depression, and those with other illnesses. These biological differences are summarized below.

## COMPARED TO PEOPLE WITH MAJOR/CLINICAL/PRIMARY DEPRESSION, PEOPLE WITH M.E./CFS SHOWED THE FOLLOWING DIFFERENCES:

- CFS and MS groups show significantly lower percentage of self-reproach symptoms on the Beck Depression Inventory than Clinical Depression groups. Depression groups show lower percentage of somatic symptoms than CFS and MS groups.  
*J Affect Disord* 1996 Jun 20;39(1); 21-30

- While CFS and Depression subjects were similar in cognitive performance and differed from MS and healthy controls, the most significant impairment noted was in the information processing speed of the CFS group.

*J Neurol Neurosurg Psychiatry* 1995 Jan; 58(1); 38-43

- SPECT scans showed the average number of regional brain defects (mostly in the frontal and temporal lobes) were 1.66 for healthy controls, 9.15 for subjects with AIDS dementia, 6.53 for those with CFS and 6.43 for those with Major Depression, but the mid-cerebral uptake indexes were significantly lower in the CFS and AIDS groups than in the Depression and Healthy groups. The researchers note that CFS “may be due to chronic viral encephalitis; clinical similarities between [M.E.] and depression may be due to a similar distribution and number of defects in the two disorders.”

*AJR Am J Roentgenol* 1994 Apr; 162(4); 943-951

- “Patients with CFS had marked impairment [in functional health status], in comparison with general population and disease comparison groups [of MS, diabetes, heart disease and depression]. Moreover, the degree and pattern of impairment was different from that seen in patients with depression.”

*Am J Med* 1996 Sep; 101(3); 281-290

- CFS groups were distinguished from MS and depression groups by the following: myalgias, post-exertional malaise, headaches, and a group of infectious-type symptoms (i.e., chronic fever and chills, sore throat, swollen glands in the neck or underarm areas).

*Am J Med* 1996 Jan; 100(1); 56-64

- Test results suggest upregulation of hypothalamic 5-hydroxytryptamine receptors in patients with postviral fatigue syndrome, but not in

## 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](mailto: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](http://www.geocities.com/youthcanada/first.html)

kate\_andersen\_ovic@yahoo.com

people with primary depression.

*British Medical Journal* 1992 Apr 18:304 (6833); 1010-1012

- SPECT results show both CFS and depression patients had increased blood flow in the right thalamus. But CFS patients also showed increased perfusion in the left thalamus not seen in the depressed group, while they showed no reduction in prefrontal perfusion as seen in the depressed group.

*British Jour. of Psychiatry*, 2000, 176, 550-556

- Patients with M.E. (*whether or not they also were depressed*) showed a generalized reduction of brain perfusion, with a particular pattern of hypoperfusion of the brainstem when compared not only with healthy controls, but also with non-M.E. patients with major depression and patients with epilepsy. *QJM* 1995 Nov; 88(11): 767-73

- CFS patients generally performed worse on cognitive tests than healthy controls, but better than patients with severe depressive illness did. Both CFS and depressed groups had markedly impaired *motor function* compared with healthy controls. Depressed subjects showed a significantly greater diurnal improvement in maximal voluntary contraction than healthy controls, and these *diurnal changes* may differentiate depression from CFS.

*Psychological Medicine*, 2000 Mar; 30(2): 433-442

- Compared with healthy controls, and patients with major depression, lupus, and MS, those with CFS have significantly elevated bioactive transforming growth factor-beta (TGF-beta). *J Clin Immunol* 1997 Mar; 17(2); 160-166

- The impaired activation of the hypothalamic-pituitary-adrenal (HPA) axis is an essential neuroendocrine feature of M.E. This HPA dysregulation differs from that seen in melancholic depression, but shares features with other clinical syndromes (e.g. fibromyalgia). *Ann NY Acad Sci* 1998 May 1; 840:684-697

- There is increased serotonin activity and significantly higher concentrations of prolactin in the blood of men with CFS than in other men, whereas depressed individuals have unchanged or reduced prolactin responses to D-fenfluramine "making it unlikely that [M.E.] and depression share a common pathophysiology...." *British Medical Journal* 1997; 315:164-165

- Contrasting neuroendocrine responses have been observed between depression and CFS. Baseline-circulating cortisol levels were highest in depressed groups; lowest in CFS groups and intermediate in healthy controls; whereas prolactin responses to selective 5-HT-releasing agent d-fenfluramine were: lowest in depressed groups; highest in CFS groups, and intermediate in healthy controls. Thus, depression is associated with *hypercortisolaemia* and *reduced* central 5-HT neurotransmission; while CFS may be associated with *hypocortisolaemia* and *increased* central 5-HT function. **"These findings attest to biological distinctions between these two disorders."**

*Journal of Affective Disorders* 1995 Aug 18:34 (4); 283-289 Similarly: *J Psychiatr Res* 1997 Jan-Feb; 31(1); 69-82 for a review of neuroendocrine correlates.

- Urinary free cortisol excretion (UFC) was compared in M.E. patients, melancholic depressives, and healthy controls. Compared with the results in the healthy comparison subjects, UFC values were significantly *higher* in patients with depression, and significantly *lower* in patients with M.E.! Furthermore, 5 of the 21 CFS patients also had a depressive illness, yet this sub-group retained the profile of UFC excretion of those with CFS alone, *suggesting a different pathophysiological basis for any depressive symptoms* that may show up in *some* people who have M.E.

*J Affect Disord* 1998 Jan; 47(1-3): 49-54

- Salivary and plasma cortisol in M.E. patients was compared with levels in depressed and healthy controls. Mean evening cortisol was

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significantly lower in M.E. patients than in both comparison groups, and morning salivarycortisols were significantly lower in M.E. patients (who didn't have psychiatric disorders).

“Clinical Relevance: **Chronic fatigue syndrome is biochemically distinct from community depression.**”

*J Affect Disord 1998 Jan; 47(1-3): 191-4*

## Lies, Lies, !@?#! Lies

BY LAWRENCE PIERCE

Can you expect your disability insurance company to be honest with you? In my experience, the answer is : “NO.”

Here are some examples of ways in which the insurance company will try to discourage you from pursuing your claim by giving you false information.

After going to see their doctor for what is called an “independent medical exam,” you will receive a letter “declining” your claim, or any further payments on your claim, because there is “no evidence” of disability. Often this letter is an outright lie. Demand to see a copy of the report prepared by their doctor to see for yourself what was written about you.

You may be asked to attend a functional capacity exam, which is a test of your ability to do certain physical things. The test results will not be shown to you, and may reveal that you are truly disabled. After your insurance company gets the results they will often write to you and “decline” the claim, or terminate further payments on your claim, based on their interpretation of the test results. You should demand to see a copy of the test report, and discuss it with your doctor or lawyer.

Finally the most pervasive lie told by the disability insurance companies is that you must “prove your disability on the basis of objective medical evidence.” I rarely see insurance policies that require anything other than “written proof of disability,” or “due written proof...” and in either case that is generally accepted to mean a letter from your doctor confirming your disability.

The request for “objective medical evidence” (something that can be seen on an x-ray, or in a lab test) is designed to discourage you from pursuing benefits that you are entitled to.

Some insurance companies pay bonuses to their employees to close files, so they have a direct interest in discouraging you. Furthermore, these people that write to you may call themselves, “Disability Specialists” or some such title, but, in reality they rarely have any formal training or education, and no written materials supplied by the insurance company to help them make a fair decision. They are just winging it, in my experience.

*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.*

## RESOURCES

**BC FM Society**  
PO Box 42504,  
105 - 1005 Columbia St  
New Westminster, BC  
V3M 6H5  
Phone: (604) 540-0488  
[www.alternatives.com/bcfms](http://www.alternatives.com/bcfms)

**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](http://www.bccpd.bc.ca)  
Annual membership fee of \$10 includes the “Transition” magazine, 8 times yearly.

Research

Legal

## CPP Disability Advocacy



Sherri Todd with George Cameron-Caluori

On August 30, 2001, George Cameron-Caluori, an Ottawa-based consultant in Regulatory Law, and publisher of *The Disability Reporter*, spoke on supporting CPP disability pension appeals. The event was sponsored by MEBC.

George covered recent developments at the Pensions Appeal Board, what objective medical evidence is considered important, and how to document subjective evidence that can prove useful. (One item of the process not covered in our last newsletter was that a letter could be

filed for Reconsideration if your application is denied even prior to going to the Review Tribunal.)

George answered questions from the floor and spent another day meeting with people with concerns about their CPP Disability Pension applications. George can be reached via his website:

<http://home.istar.ca/~gcamcal/cmaweb.htm>  
by fax: (613) 232-7763 or by phone (613) 237-2296.

### 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](mailto:nightingale@nightingale.ca)

## 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](mailto: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.

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*Editor's note: "Part A" regarding CPP Disability Benefits was included in the Summer 2001 issue of "ME & You".*

## **PART B: DISABILITY ISSUES IN WELFARE LAW**

### **OVERVIEW OF THE LEGISLATION, DAVID MOSSOP, CLAS**

BC Disability Benefits are currently designed not as a pension system, but a payer of last resort. There are three tests under which a person must submit in order to receive disability benefits from the BC government: 1) Social test, which seeks to establish whether or not a person is disabled; 2) Asset test, under which the individual must disclose all their financial assets/properties; 3) Income test, under which any income which the individual receives is deducted from their benefit.

Under the current system there are a number of exemptions, both for the asset and income tests. One example is in the case of former students of Jericho School for the Deaf, who received lump sum settlements in their legal case against the school. The government declared those settlements to be exempt – i.e. they would not affect individuals' ability to collect their BC Disability Benefits. The government also allows people on BC Disability Benefits to hold a trust, of up to \$100,000, without affecting their eligibility for benefits (see Kramer below).

Mossop stated that he sees two possible directions forthcoming in welfare legislation. One possibility is that of clawbacks on current exemptions. The other is a movement toward a pension approach.

In terms of avenues for advancing welfare rights for the disabled, Mossop pointed to three possibilities:

- 1) The Welfare appeal process. The problem with this avenue is that it has limited power as it is bound by welfare legislation, which must be enforced.
- 2) Under the Charter of Rights. However, the courts are currently pulling back from challenging legislation.
- 3) The third, and most promising at the moment, according to Mossop, is the Human Rights avenue. Mossop also warned against the danger of lawyers taking over the struggle, and warned that it is first and foremost a political struggle and should not be dumped in the courts.

### **TROUBLESHOOTING DISABILITY APPLICATIONS, ROBIN LOXTON, BCCPD (BC COALITION OF PEOPLE WITH DISABILITIES)**

Loxton emphasized the link between disability and poverty in Canada. BC Disability Benefits Level II is currently \$786/month, well below the poverty line, and certainly not enough to cover additional disability costs, over and above the costs of living. As well, the rules to qualify are making it more difficult to get a BC Disability Benefit.

Many people are slotted into Disability Level I (especially those with head injuries, mental illness). The two-tier system discriminates against certain types of illnesses and disabilities. Currently slated to go through the Provincial Legislature in September is legislation drafted by the previous NDP

## **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.*

government to eliminate the two-tier system. The result would be a single disability level. It is not clear whether the new Liberal government will follow through with the initiative. (\*Update: As of October 2001, the new government says that it is still reviewing the proposal for a one-tier disability system. Indicators point to the probability that the new government will shelve the initiative.)

Loxton underscored the importance of describing costs, needs, supports in great detail, and to have the doctor/assessor include and confirm that information as well, when applying to BC Benefits for disability benefits. If an appeal is necessary, it is easier if this information was on the initial application. Also if the client is not already on social assistance, it is important in their application for BC Benefits to indicate that they will be soon. Loxton encourages people to appeal the decision if they are turned down for disability benefits, stating that there is an 80% success rate of those who appeal.

#### **TIPS FOR ADVOCATES FROM THE BC BENEFITS APPEAL BOARD, JERRY BLAKE, BC BENEFITS APPEAL BOARD**

There are approximately 300-375 appeals per year. The board is a mixed group of 11 people, from different walks of life, including some lawyers. All Board members are part time.

Blake made the point that the Board can only consider written submissions, and cannot consider oral hearings. Thus it is important to submit full documentation and submit all the information at the same time. (Be sure to retain copies of all documentation.) Medical evidence should be as clear as possible, stating what the disability is, and what needs flow from it. It is important to provide details pertaining to treatments, benefits, and personal care requirements. It is helpful if personal care providers submit written descriptions of what they do to support/treat the applicant.

When filing a notice of appeal, it is important to remember that there is a 30-day limit. Also, if you are using an advocate, be sure to send signed authorization to speed up the process.

The Appeal Board is not allowed, under any circumstances, to consider new evidence. In the case of new evidence, the appellant must reapply for benefits.

Blake stated that decisions are made on a case by case basis, but recommended that advocates and applicants may find it helpful beforehand to check the website of the BC Benefits Appeals Board, to view other decisions made by the appeal board: [www.bcbab.bc.ca](http://www.bcbab.bc.ca)

#### **TRUSTS UNDER DISABILITY BENEFITS LEGISLATION, KEN KRAMER, CLAS**

In the past, disabled people on BC Benefits would often lose those benefits if they happened to come into a sum of money – for example, through an inheritance or CPP Disability Benefits lump-sum reimbursements. It also meant the loss of medical benefits, long term care costs, etc. The legislation governing BC Disability Benefits now allow for a trust to be established, for a value up to \$100,000, without affecting benefits. That figure can be appealed to the Minister, (subsection 7.2 of the legislation) depending on the extent of the disability and associated costs.

#### **RESOURCES**

##### **Resource Disability Benefits Manual**

Everything from travel deals to ICBC discounts.  
[www.mssociety.ca/bc/pdf/resource.pdf](http://www.mssociety.ca/bc/pdf/resource.pdf)

##### **MS Society Brochure on Canada Pensions**

CPP Disability information covering Eligibility Criteria, the Application Package, the Appeals Process, and Sample Letters and Supportive Documents  
[www.mssociety.ca/bc/pdf/cpp.pdf](http://www.mssociety.ca/bc/pdf/cpp.pdf)

The trust must be monitored by a trustee, which can be the disabled person themselves (called a non-discretionary trust), or by another person (discretionary trust.) In the instance of a discretionary trust, a case can be put forward to further extend the value of the trust beyond the \$100,000 limit, since it remains outside the control of the disabled person and has nominal monetary value to them. In either case, proper records must be kept and an income tax form T3 submitted yearly. According to the legislation (Disability Benefits Regulation, subsection 7.1), the trustee may withdraw up to \$5,484 yearly from the trust for costs related to medical aids, caregivers, education, training, maintenance of principle residence, and more broadly, expenditures for the purposes of promoting individual independence.

Another alternative to a trust is to use a windfall to purchase a home or car, both of which are exempted expenditures.

*(MEBC Editorial note: Trusts can be set up through a lawyer or through a foundation such as Coast Foundation Society which can be contacted at 604-872-3502. Ask to speak to Blandyna.)*

## Changes to BC Disability Benefits under the Liberal Government

The Liberals announced a new monthly nutritional supplement program that will offer up to \$225/month to people receiving provincial disability benefits and suffering serious health problems. The benefit allows for up to \$165/month for nutritional items, \$20/month for bottled water and \$40/month for vitamin and mineral supplementation. Application forms are now available through benefit and employment centres.

However, it is still unclear if people with FM, other serious conditions, or M.E. will benefit from this new program. Robin Loxton of the BCCPD expressed concern in a telephone interview that the criteria to receive this additional assistance is so restrictive that it may exclude most people with serious illnesses. The application itself states the following:

“Eligibility for this benefit is based on strict criteria . . . related to alleviating specific symptoms AND preventing imminent danger to life.” Doctors are asked on the application whether each item (nutritional, bottled water, vitamins) is required “to prevent imminent danger to life.” In addition, Loxton pointed out that anyone who already receives the \$40/month special diet allowance, would lose this benefit if they succeeded in qualifying for the new program. So the maximum net gain from the program would be only an additional \$185/month. It also seems that while the government announced this new nutritional supplement program, it was quietly eliminating a “catch all” provision that had previously allowed people to apply to the Ministry to have various special health-related costs covered.

*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.*

## Now Available – Sourcebook for Teachers of Children with ME/CFS and/or FM,

BY MARY ELLEN, CHAIRPERSON, TEACH-ME TASK FORCE,  
NATIONAL ME/FM ACTION NETWORK

The Sourcebook for Teachers is now posted on the Youth and Parents' Pages at [www.geocities.com/canadianyouthmefm/teachme.html](http://www.geocities.com/canadianyouthmefm/teachme.html)

It offers information and coping strategies for teachers who may have students suffering from M.E./CFS and/or FM. The Sourcebook will help teachers to develop practical approaches to developing modifications to educational plans and the curriculum. The document is available NOW for parents to download and bring to their meetings with Boards of Education or Guidance Counselors who may be helping to arrange modified timetables for students.

### **BACKGROUND TO THE SOURCEBOOK**

Every day Canadian teachers are becoming aware of children and adolescents with M.E./CFS and/or FM. It has not always been this way, partly because M.E./CFS and FM have had a controversial history. Although the number of adults being diagnosed with these illnesses seemed to grow rapidly in the mid-eighties, official recognition of the illness in adults has been slow. Tragically, recognition of the prevalence and devastation of M.E./CFS and/or FM in children has been even slower, leading to many heartbreaking situations. Fortunately, all that is changing. Research on M.E./CFS and/or FM has been increasing rapidly, including research on children and adolescents.

We can expect that in the next few years we will understand these illnesses much better – in people of all ages. Meanwhile, there is much that the classroom teacher can do for a young person diagnosed with M.E./CFS and/or FM.

### **WHO WROTE THIS BOOK?**

The authors of this Sourcebook are Canadian teachers, disabled with M.E./CFS and/or FM, who are members of the National ME/FM Action Network. We developed a unique e-mail conference, known as TEACH-ME, in which we discussed ways that children with M.E./CFS and/or FM could be provided with uninterrupted, high quality education. As people with M.E./CFS and/or FM ourselves, we were devastated to imagine the effects of M.E./CFS and/or FM on young people. As teachers, we remained unwaveringly committed to the importance of providing ongoing and enriching education to all children, no matter how ill or disabled. Yet, as adults who were homebound by the illness, we knew this could not be an easy task – for the young person or for the classroom teacher. We wanted to use our combined expertise in teaching and experience of the illness to help these courageous youngsters.

### **INTERNATIONAL SCIENTIFIC AND REAL LIFE EXPERTISE**

We were very privileged to have the consultation of Dr. David S. Bell, a renowned pediatrician and the leading international researcher on M.E./CFS and/or FM in children, and Mary Z. Robinson, an American educator, research assistant to Dr. Bell, co-author of “A Parent’s Guide to CFS” and parent

### **MONEY STRESS?**

If you are experiencing financial difficulties, and are in need of some counselling or alternatives to your credit problems, Credit Counsellor Margaret Johnson may be able to help. You can contact her at:

**Solutions Credit  
Counselling Service**  
Margaret Johnson  
Phone: (604) 588-9491  
Fax: (604) 588-2005  
#200-10351-150th St.  
Surrey, BC V3R 4B1

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of two children with M.E./CFS/FM. Our collaboration with Dr. Bell and Ms. Robinson enabled us to link our personal experience and teaching expertise with the most up-to-date and sound international research knowledge. Not only that, but Dr. Bell's and Ms. Robinson's knowledge of M.E./CFS/FM is unique in that it has been acquired from following real families and children coping with this illness over many years. Assisting us to coordinate our efforts was Kate Andersen, M. Ed., Youth Consultant for the National ME/FM Action Network, a university educator who has M.E./CFS herself.

### **THE VOICES OF YOUNG PEOPLE WITH M.E./CFS/FM AND THEIR PARENTS**

Young Canadians with M.E./CFS and/or FM themselves, and their families, made special contributions by sharing their real experiences. We thank them enormously for enriching this project.

Finally, we'd like to thank Kate Andersen, the Youth Consultant for the National ME/FM Action Network, whose expertise, talent, and dedication made this Sourcebook possible, and whose original vision inspired us all to use our limited energy for such a worthy cause.

## Sharing Resources

The following examples of sharing resources and information between societies are encouraging. We don't all have to reinvent the wheel! Recently the BC Fibromyalgia Society

(BCFM) elected a new Board of Directors, and we have begun discussions about how we can cooperate in sharing in similar events and resources.

## Valuable Internet Resources

We were pleased that members from the MS Society of BC attended our meeting with George Cameron-Caluori, a CPP Disability Advocate on August 30, 2001. MEBC had sent invitations for this event to several societies for the disabled. The MS Society of BC has created several helpful documents on legal advocacy, the CPP Disability Application and Appeals process, and services available to people with disabilities. You can check out these resources on their website: [www.mssociety.ca/bc/](http://www.mssociety.ca/bc/) Some of these are:

- An excellent 56 page brochure on all aspects of the CPP Disability Pension, including sections on Eligibility Criteria, the Application Package, the Appeals Process, and Sample Letters and Supportive Documents. It is available at: [www.mssociety.ca/bc/PDF/cpp.PDF](http://www.mssociety.ca/bc/PDF/cpp.PDF)
- "What you should know about [Long-Term] Disability Insurance"  
[www.mssociety.ca/bc/PDF/ltd.PDF](http://www.mssociety.ca/bc/PDF/ltd.PDF) and community and legal resources (including addresses):  
[www.mssociety.ca/bc/comm\\_resources.PDF](http://www.mssociety.ca/bc/comm_resources.PDF)  
Addresses applicable to any disability are near the end of all these documents.

### **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 Pavilion on Poirier Street in Coquitlam. Lucky and Bette are group leaders. Call 604-931-3554 (Marilyn) for more information.

- A comprehensive Resource Disability Benefits Manual (48 page web document) which covers gas rebates, ICBC discounts, housing, recreation, CPP and BCD Pensions, and even travel deals for the disabled from cruises, airlines, buses, ferries, and rail. Check it out directly at: [www.msociety.ca/bc/pdf/resource.pdf](http://www.msociety.ca/bc/pdf/resource.pdf)

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



Myalgic Encephalomyelitis Society of British Columbia

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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:
Organization, Clinic, or Law Firm:
Address:
City:
Telephone:
Fax Number:
Qualifications:
Province:
Postal Code:
Web Site:
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)

Horizontal lines for additional comments.

Contact Us

# MEBC

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

## Membership Application Form

(Please Print)

Name: \_\_\_\_\_ New Member \_\_\_ Renewal \_\_\_  
Address: \_\_\_\_\_ City: \_\_\_\_\_  
Province: \_\_\_\_\_ Postal Code \_\_\_\_\_ Home Phone: \_\_\_\_\_  
Work Phone: \_\_\_\_\_ 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?

- |  |  |   |
|--|--|---|
| <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

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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**