

## Quest #15 December 1995

Dear Friends:

This newsletter is dedicated to all the Group Leaders and Contacts who have selflessly assisted all who asked for help. There are very many people involved and it is therefore impossible to name you all by name. Suffice it to say that without your dedicated help, the progress made towards better understanding of ME/FM would not have been possible. Thank you.

We received a Grant of \$35,000 from Health Canada and this will make it so much easier for us to continue with our many projects that we started. We also hope to come up with a manual that groups and contacts can use to aid with their organizations.

We also hope to find a way to become self-sufficient as this is what is necessary because we cannot rely on a Grant. If we did get another Grant, it would only be for another year in about the same amount.

We are looking into self-sufficiency for support groups, with our help, so that it would benefit the group and our National organization.

It is not too early to also start thinking about May 12th and National ME/FM Awareness Day and what we are all going to do to bring increased awareness to the general public, governments etc.

**WE NOW HAVE A FAX:** In an effort to be more available, please note that our Fax No. and Telephone number is the same: **(613) 829-6667.**

### RE-CAP 1995 & UPDATE

#### **PETITION TO THE HOUSE OF COMMONS - UPDATE - NATIONAL TOTAL 14,391 signatures -**

Breakdown by Province: Alberta: 262; British Columbia: 751; Manitoba: 954; New Brunswick: 220; Newfoundland: 39; Nova Scotia: 455; Ontario: 10,848; Quebec: 372; Prince Edward Island: 211; Saskatchewan.

On Thursday, January 18th, 1996, we have a meeting with the Honourable Beryl Gaffney, MP at which time we will be officially handing over the Petitions collected. Ms Gaffney is preparing a Private Members Bill to be presented to the House of Commons. Ms Gaffney will also hand over the Petitions to the MPP [Members of Parliament Provincial] to the Province concerned so that there will be Provincial as well as Federal involvement. At this time, we do not know when the Petitions will be presented in the House but we will keep you informed. In addition, Ms Gaffney has also requested help from The Honourable Roger Simmons, P.C., MP, Chair, Standing Committee on Health and she will keep us advised on developments in that regard.

**Ontario - BILL 26** - If approved would give health-fraud investigators widely expanded powers to collect medical information, including patient records. We have written The Clerk of the Standing Committee on General Government advising them of our alarm with this particular Bill as it seems the only people who could possibly want this type of information would be the insurance industry. Right now, a signed Release must be obtained from the patient before any kind of medical information can be obtained. We have asked for clarification on this most important issue.

You can write to The Clerk of the Standing Committee on General Government, Room 1405, Whitney Block, 99 Wellesley St. W., Toronto, ON M7A 1A2 to raise your objections to this proposed Bill.

**Bill C-7** Threatens Freedom of Choice regarding what foods, herbs, supplements and nutrients Canadians are allowed to consume. If you support freedom of choice in health care and oppose government legislation like Bill C-7 which unjustly restricts your choice, please send a note to: Dr. Grant Hill, MP, Reform Party Health Critic, 619 Confederation, House of Commons, Ottawa ON K1A 0A6 or fax: (613) 996-9770. Note: No postage necessary.

### **INSURANCE:**

We have presented a social policy brief regarding difficulties that injured or ill individuals must contend with to 5 levels of Federal Governments and 5 levels of Provincial Government (Ontario). We advised them regarding the fact that even though qualified doctors support their claim for disability insurance pensions, many claimants are forced to go to Court and sue their Insurers. Some people rather than go to court have abandoned their claim and are either living on a Canada/Quebec Pension or were forced to go on Social Assistance.

We also have asked the Governments to look at updating an over 70 year law regarding Life Insurance and to standardize Life Insurance, as the wording varies from Insurer to Insurer, from Company to Company and Province.

In addition to the Hon. Beryl Gaffney, MP, we are also in touch with Mr. John Baird, MPP who is aiding us with the Ontario Provincial Insurance industry. We will be meeting again with him in the near future.

### **CANADA PENSION PLAN - DISABILITY BENEFITS**

Canada Pension Plan's application for disability benefits has been updated. Be sure to fill out the new form which has blue in its form as opposed to pink on the previous application form].

T I P : We contacted CPP and asked them whether a person can reapply for a CPP Disability pension after all the appeal processes had been used up. CPP informed us that people can again apply and start all over and no limit is set as to how many times you can apply. However, before considering dropping your application and starting all over again, be sure to call CPP if this may apply to you.

### **DISABILITY TAX CREDIT - Form T2201**

We are in touch with The Hon. Paul Martin, P.C., MP, Minister of National Revenue, from whom we are awaiting a reply regarding the unfairness of this Credit to people who suffer from ME/FM.

We asked Mr. Mark Siegel of Gowling, Strathy & Henderson, Barristers & Solicitors, for a legal opinion regarding Revenue Canada's wording regarding the Disability Tax Credit and how this Disability Tax Credit seems to make it very difficult, or even impossible, for any ME/FM individual to qualify for this credit on his/her Income Tax Return. Part of Mr. Siegel's legal opinion is as follows: "....It is to be noted initially that in order to sustain a challenge of the application of a particular provision of the *Income Tax Act*, it is necessary to utilize Section 15 of the Charter. This provision essentially requires the government to treat all people equally in the application of laws. The Supreme Court of Canada has, however, been reluctant to consider Section 15 of the Charter to be of application to income tax statutes.....

In examining Section 118.3 and Section 118.4 of the *Income Tax Act*, a disability tax credit is only available for persons who have an impairment which is considered to be prolonged and lasting for a continuous period of at least 12 months. In addition, an individual's ability to perform a basic activity of daily living is considered to be markedly restricted for the purposes of the disability tax credit if the

person is unable to perform a basic activity of daily living all or substantially all of the time even with the use of therapy or medical devices and medication. An individual's ability to perform basic activities of daily living is also considered to be markedly restricted where their performance of basic activities of daily living requires an inordinant amount of time. It is my belief that persons suffering from chronic fatigue syndrome may more likely fall into this latter category....

Paragraph 118.4(1)(d) specifically provides that no other activity, including working, housekeeping or a social or recreational activity, are considered a basic activity of daily living.

The third provision of relevance in making a determination with respect to a disabled individual is paragraph 118.3(1)a.2). This provision indicates that a medical doctor must certify that a person has an impairment that markedly restricts the persons ability to perform a basic activity of daily living as defined in Section 118.4 of the *Income Tax Act*. Thus, it can be seen that Revenue Canada is in essence delegating to medical doctors the obligation to certify to Revenue Canada that persons are entitled to the disability tax credit under Section 118.3 of the *Income Tax Act*....."

Revenue Canada has indicated that it is willing to discuss the situation affecting persons with unique physical afflictions, and Mr. Siegel strongly suggests that this door be left wide open.

It may be necessary to accumulate substantial data, according to Mr. Siegel, with respect to Revenue Canada's acceptance and denial of claims by persons for the disability tax credit. It would be necessary to compile this data in such a manner so as to show that Revenue Canada is not applying Section 118.3 of the *Income Tax Act* in a manner so as to treat persons of equally significant physical afflictions which interfere with their daily living activities in an equal manner. According to Mr. Siegel, and we feel it can be done, that some of this legwork can be done by the various groups representing persons with unique physical afflictions across Canada.

"....It is to be noted that pursuant to subsection 118.3(4) of the *Income Tax Act*, Revenue Canada can seek the advice of the Department of Health and Welfare with respect to the disability of particular persons. The Department of Health and Welfare can then seek information from persons with respect to their particular impairment to determine if they would qualify for the disability tax credit under the *Income Tax Act*. A method, therefore, exists by which Revenue Canada and the Department of Health and Welfare can co-operate in determining whether persons are entitled to the disability tax credit. In discussions with Revenue Canada, it may be suggested that this type of interrelationship between the two departments be expanded so that Revenue Canada is provided with greater assistance in making its determinations with respect to the entitlement of a person for the disability tax credit.

[Editor's note: 1) We are awaiting replies from the Department of Finance and Revenue Canada in regards to possible changes to the Disability Tax Credit. We will, of course, keep you informed; 2) If you would like a copy of this legal opinion (4 pages), please send us a stamped (\$0.45) self-addressed envelope.

#### **LABORATORY CENTER FOR DISEASE CONTROL (LCDC) CANADA:**

In the Fall of 1995 we received a reply from Dr. J.Z. Losos, Director General of the LCDC regarding its research into ME/FM and were advised that due to budgetary constraints, the Laboratory Centre for Disease Control is not in a position to conduct its own research on ME/FM at this point but will continue to work with NHRDP and MRC to facilitate research in this important area. The National Health Research and Development Program (NHRDP) of Health Canada will continue to entertain research proposals on the subject of ME/FM and similarly that the Medical Research Council (MRC) has also always been open to considering research submissions on this issue through its peer review process.

[Editor's note: If anyone knows anyone who is doing ME or FM research, please let us know.]

### **NATIONAL DOCTORS & LAWYERS REGISTRY:**

We will be stepping up procedures shortly in regards to collecting more names of lawyers and doctors who are involved with ME/FM patients.

### **LEGAL PRECEDENTS OF COURT CASES:**

Our Alberta Director, Marj van de Sande, has been collecting legal precedents regarding ME/FM court cases.. To receive copies of this information, please send \$10.00 to cover photocopy and postage costs to: **Marj van de Sande**, 1824 Varsity Estates Drive N.W., Calgary, AB T3B 2W9.

**WITHDRAWAL PROBLEMS WITH DRUGS:** A fourteen day 'wash-out' period may be advised before stopping or starting any other drug (especially another antidepressant) which is likely to cause adverse reactions. A gradual reduction in dose is the best form of withdrawal. Acknowledgment: Dr. Charles Shepherd, Perspectives, June 1995 - magazine of the M.E.Association (UK).

**NEURALLY MEDIATED HYPOTENSION (NMH) STUDY BY JOHNS HOPKINS:** While the treatment results are promising, the authors stated that "The response to treatment reported herein must be interpreted with caution, as this study was performed in a small number of patients, had a short duration of follow-up, and was not randomised, blinded, or placebo controlled." The National Institute of Allergy and Infectious Diseases (NIAID) in the U.S.A. has stated that investigators at Johns Hopkins University and NIAID are planning a larger, double-blind treatment study to assess the effectiveness of treatments for NMH in people with ME/CFS.

**INTER-GROUP/CONTACT COMMUNICATIONS:** There are many projects that support groups are involved with that we would like to publish and make other groups aware of. Please make sure to let us know so that we may publish that information. It picks up people's spirits to know what is being done but also helps to merge our efforts and become more effective.

**Northern Ontario FM Assoc.has a new phone number - Please Note: 1-800-959-9098**

### **NEWSLETTERS BOOKS, VIDEOTAPES ETC.**

**From Fatigued to Fantastic! A Manual for Moving Beyond Chronic Fatigue and Fibromyalgia by Jacob Teitelbaum, M.D.** This book will be available in bookstores in Spring 1996. However, in the interim, it can be ordered by mail from: **JACOB TEITELBAUM, MD, Deva Press, 466 Forelands Rd., Annapolis, MD 21401 U.S.A.** In U.S.A.Price: \$18.95 U.S. + \$8.00 shipping (Visa,Mastercard,cheque = \$26.95 - In Canada \$23.95 + \$9.00 shipping = \$32.95.

**JOURNAL of MUSCULOSKELETAL PAIN:** Volume 3, No. 1 - Spring 1995 (4 issues); \$Special discounted rate for individuals: \$36; Institutions: \$48; Libraries: \$90 - The Haworth Medical Press, 10 Alice Street, Binghamton, New York 13904-1580 U.S.A. Call Toll free 1-800-342-9678, or fax: (607) 722-6362.

**THE ENZYME CONNECTION FOR FM** (2 pages) and **NUTRITION BASES FOR ME/FM** (3 pages) by **Dr. Philipa Corning - In Canada** Send stamped (45 cents) self-addressed envelop; **Elsewhere:** \$1.00 International Coupon to: Dr. P. Corning, 69 Roblyn Way, Nepean, Ontario K2G 5Z5 Canada.

**RE: SHINGLES:** Q.What is shingles, why does it occur and what is the treatment?

A. Nerves to the skin leave the spinal cord at specific levels and splay out in predictable patterns

called dermatomes. Shingles is a virus infection of one or more of these dermatomes. The cause is varicella/zoster virus, a member of the herpes group.

When a child has chickenpox (varicella), the skin in general is infected, leading to the itchy sores that are characteristic of the disease. Once healing has taken place the sores disappear. The viruses, however, are not killed. They remain in a state of suspended animation in certain nerves in the skin.

These viruses apparently reactivate in some people. The cause of this is not completely known, although stress, re-exposure to varicella virus, and hidden cancer appear to be important factors.

Once the viruses re-activate, they multiply rapidly in one or more dermatomes, leading to the disease known as herpes zoster (shingles). Symptoms include swaths of painful blisters on one side of the body.

Eventually, the blisters break, leaving large areas of painful crusted, raw skin. About 10 percent of shingles patients will progress to a poorly understood complication, called post-herpetic neuralgia, marked by chronic, sharp, stabbing pain.

There is effective therapy available, in the form of prescription anti-virus pills. When given early in the disease the drugs block virus growth and reduce the shingles infection.

[Editor's note: This article appeared in the Ottawa Sun, Monday, October 30th, 1995, page 48. Questions and comments can be sent to Dr. Peter Gott, Newspaper Enterprise Association, 200 Park Ave., New York, N.Y. 10166 U.S.A. - ]

**MEMBERSHIP:** PLEASE SUPPORT US BY BECOMING A MEMBER OF THE NATIONAL ME/FM ACTION NETWORK. Membership costs \$20.00 per year, and includes newsletters every two months.

## **WELCOME TO OUR WORLD**

"It's only our perceptions of our limitations that hold us back" [Jim MacLaren, Quadraplegic.]

Unpredictability: a chance to give 'NOW' your very best.[Lorraine Legendre]

Q: What do you call the filing cabinet of an ME/FM patient?

A: It is a place where you can lose things in alphabetical order.[Lorraine Legendre]

Until next time, take care. Lydia E. Neilson, President C.E.O.

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