

Quest #23 April 1997

THE NEXT STEP - MEDICAL PROFESSIONALS' PARTICIPATION - UPDATE

As of the end of May 1997, we have received 108 positive replies from medical professionals all over Canada, and only one negative reply from a doctor who believes that ME/FM does not exist. A copy of the letter to the medical professionals was included with our newsletter and also sent to all support groups across Canada, requesting that they make copies for their members who in turn would give the letter to the doctors who treat them.

For those Support Groups who have not made a copy of our letter to the medical professionals, please do so and pass a copy to each of your ME/FM people, with a request for them to take it in to their doctors for signature and return to our office.

For anyone who does not have this letter and would like one, please contact us and we will be pleased to send you one.

We need YOUR participation and support.

FORM T2201 DISABILITY TAX CREDIT - UPDATE

In the past couple of months, a new questionnaire (3 pages) has surfaced from Revenue Canada. This questionnaire is sent directly to the patient's doctor and seems to be a follow-up to the doctor's completion of Part B of Form T2201.

We have written a letter of complaint to Ms Jane Stewart, Minister of Revenue, as the questionnaire gets into so much detail that it will make it even more difficult to get this Tax Credit.

[Ed note: To receive a copy of the questionnaire and/or letter to Ms Stewart, please send us a stamped self-addressed envelope.]

NATIONAL DOCTORS' ROSTER

*BRIAN PRIMROSE, MD, C.M.C.C.F.P.

P.O. Box 1110 Englehart St.

Englehart, Ontario P0J 1H0

Tel. (705) 544-2321

E-mail: aprimros@online.net

*diagnosis and treatment of both ME and FM

NATIONAL LAWYERS' ROSTER

**RICHARD M. BOGOROCH - (416) 868-3218 of

THOMSON ROGERS, Barristers & Solicitors

390 Bay Street, Suite 3100 (416) 868-3100 Main number

Toronto, ON M5H 1W2 (416) 868-3134 Fax

**Initial consultation free.

Mr. Bogoroch is a Specialist in Civil Litigation certified by the Law Society of Upper Canada. He has extensive experience in representing chronic pain people. He is also willing to speak to support groups on legal issues surrounding Chronic Pain, Chronic Fatigue Syndrome and Fibromyalgia. In addition, he normally agrees to wait to get paid until case is concluded. He stated that on the vast majority of personal injury cases, fees are paid at the conclusion of the litigation out of the proceeds of settlement or judgment.

***LESLIE TOUGH

LOEWEN MARTENS & REMPEL

1101 Henderson Highway Tel. (204) 338-9364

Winnipeg, MB R2G 1L4 Fax (204) 338-8379

***Initial consultation: 1 hr free or as long as it takes. Ms Tough also is very involved in the ME/FM community and has just recently settled favourably another claim.

****DE GRANDPRE CHAURETTE LEVESQUE (NOTARIES) Jacqueline Bissonnette

2000 McGill College St., Suite 1600 Tel. (514) 287-9335

Montreal, QC H3A 3H3 Fax (514) 499-0469

****1/2 hr initial consultation - free

TIP: Are you having problems keeping your doctors' appointments straight? To avoid embarrassment, why not call the day before and confirm the time and date of your appointment.

NEWSLETTERS/BOOKS/REPORTS/VIDEOS ETC:

The National Coalition for the Chemically Injured, Please direct your request for information to: 2400 Virginia Ave. N.W., Suite C501, Washington, D.C. 20037 U.S.A. Contact: Ms Susan Malloy - Tel. (520) 536-4625.

J.A. SHERKEY, MD, C.C.F.P. report on neurological explanation for the myriad of ME/FM symptoms and treatment protocol based on Dr. Goldstein's new book "**Betrayal by the Brain: The Neurological basis of Chronic Fatigue Syndrome, Fibromyalgia Syndrome and related neural Network Disorders**" (7 pages) Please send stamped self-addressed envelope to obtain a copy of this report.

NEURALLY MEDIATED HYPOTENSION - NEW TREATMENT (1 PAGE) By: Philip K. Nelson MD - Please send stamped self-addressed envelope to our Network to receive a copy of this report.

THE FIBROMYALGIA SUPPORTER - BY: MARK j. PELLEGRINO, M.D. - A book for families of people with Fibromyalgia. Dr. Pellegrino gives readers specific 'how to' advice based on his experience treating Fibromyalgia and having it himself. Cost: **\$15.50 plus \$3.50 Postage and Handling - U.S. Funds**

To order: Contact: Anadem Publishing, Inc. in Columbus, Ohio - Tel. 1-800-633-0055

INTER-GROUP/CONTACT COMMUNICATION:

FIBROMYALGIA ASSOCIATION OF ONTARIO (formerly Northern Ontario Fibromyalgia Network Inc.) have made a donation to our organization that represents \$2.00 for each membership they have received. We thank the Board of Directors and the members of that Association for their financial support. PLEASE NOTE **NEW HEAD OFFICE LOCATION: 62 Frood Road, Unit 254, Sudbury, ON P3C 4Z3 - Tel. (705) 669-0103 or 1-800-959-9098.**

[Ed note: To keep the confidentiality of this organization as to how many members it has, we have chosen not to disclose the amount donated to us. The same had been done for the Barrie ME Support Group - see issue No.22]

In a Report of a joint working group of the **Royal Colleges of Physicians, Psychiatrist and General Practitioners (England)** dated October 1996, this joint working group stated that it **prefers the term "CFS" and dismisses the term "ME". The ME/CFS Charities Alliance** (ME Association, Action for ME, National ME Centre and Westcare) **England**, have responded to the Royal Colleges' report and we have been furnished with a summary of the Alliance's report dated 31 January 1997, courtesy of Ms Mavis Moore, Administrator of the ME Association in Essex, England. To receive a copy of same, please send us a stamped self-addressed envelope.

M.E. Association of Halton/Hamilton-Wentworth have:

1) successfully completed their first year of operation as a Volunteer Resource Centre. They were able to provide a telephone line, information packages, on-site Resource distribution and public lectures. If any groups would like information about setting up and operating a similar project, please contact this group at **255 West Avenue North, Hamilton, ON L8L 5C8 - Tel. (905) 522-1947; and**

2) McMaster Medical Centre Continuing Education Department held a one-day session for health professionals on Myalgic Encephalomyelitis. The **M.E. Halton / Hamilton-Wentworth Association** promoted this effort by distributing over 600 professional portfolios containing information about ME to the Health Professionals in their area. It has proven so successful that Doctors are now giving their patients information that they received from the portfolio. The impact has been very positive.

Any group interested in receiving a complimentary portfolio, please contact the Halton/Hamilton-Wentworth group, as mentioned above. Ms Patricia Stephenson-Cino, President, suggested that groups could approach a Rotary Club etc. for funding to distribute the portfolios so it could become a community project.

THE MIGRAINE ASSOCIATION OF CANADA - NEW ADDRESS: 365 Bloor Street East, Suite 1912, Toronto, ON M4W 3L4 - Tel. 1-800-663-3557 or (416) 920-4916 - Fax (416) 920-3677.

THE NORTH AMERICAN CHRONIC PAIN ASSOCIATION OF CANADA PEN PALS PROGRAM is cost-free and provides an opportunity for anyone living with long-term pain to correspond with individuals experiencing similar symptoms. Pen Pals is a vehicle for sharing experiences and pain management techniques for those unable to attend support groups meetings and those isolated or unable to attend. Membership also includes an annual newsletter. For more information, please write: **Nacpac Pen Pals, 62 Pinelore Place N.E. Calgary, AB Canada T1Y 3V8.**

ATTENTION: SUPPORT GROUP LEADERS

RE: ME/FM People in YOUR Group

We have heard from **42** support groups representing a total of **4,470 ME/FM** people. We are aware of over 450 ME/FM Support Groups. For us to get an accurate figure as to the volume of people ill with ME/FM, we need your input.

The information you provide to us about your individual group will be confidential. However, we do need your numbers to add to our growing total.

STATISTICS: For the year April 1, 1996 to March 31st, 1997 our organization has sent out 351 free ME/FM information packages to individuals who contacted our organization. In addition, we sent out free information to doctors who have come to our attention.

We would like to continue to send information to anyone who needs it and therefore ask for your support by becoming a member or by a donation. Help us to Help You.

TIP: To get information on the Canada Pension Plan changes, please call 1-800-277-9914.

GOVERNMENT APPOINTS FIRST INSURANCE OMBUDSMAN FOR ONTARIO

Ms Lea Algar, formerly dealt with complaints as Director of Market Conduct for the Ontario Insurance Commission. She is the first government-appointed insurance ombudsman in Canada. The same legislation which created her position has also set up a framework that should help consumers resolve complaints and also get better access to information that could prevent problems in the first place.

Since last November [1996] all insurance companies in the province have been required to have a formal system in place that spells out who will review consumer complaints that aren't resolved satisfactorily at the front office level. The Ontario Ombudsman will get involved in cases only after they have gone through the insurance company's own process. A senior person at each company must sign a letter, stating what the company's final position is on the issue, before she will initiate a review. At that point, Ms Algar's staff will look into the complaint and see if they can resolve it. If their decision favors the consumer, they'll ask the company to take another look at their decision. Consumers may appear an unfavorable decision to the courts.

To find out the name of the person designated to deal with complaints resolution, you may contact the company directly or contact the Insurance Ombudsman's office at the Ontario Insurance Commission. Telephone number **1-800-668-0128**. Internet site: **<http://www.gov.on.ca/OIC>**

HOW THE INSURANCE OMBUDSMAN CAN HELP CONSUMERS WITH COMPLAINTS:

The Office of the Insurance Ombudsman, or Insurance Ombudsman for short, has been created to assist you with any complaint you may have with insurance companies that are licensed to operate in Ontario.

The Insurance Ombudsman is a last resort for the informal resolution of complaints about the business practices of insurance companies in Ontario. The Insurance Ombudsman thus performs a special role, adding to what is already performed by the Ontario Insurance Commission (OIC) in the areas of regulating the insurance industry. The Office of the Insurance Ombudsman is located within the OIC.

Only when the insurer is unable, for whatever reason, to resolve your complaint can you use the complaint handling services available through the Insurance Ombudsman's Office.

If you and your insurer cannot arrive at an agreement, the insurer must send you a letter stating the reasons for its decision. A copy of this letter *must be part of your request* for the assistance of the Insurance Ombudsman.

Below are several of the most frequently asked questions about Ontario's Insurance Ombudsman and the answers to those questions.

Q1. What exactly does the Insurance Ombudsman's Office do?

A1. The Insurance Ombudsman's duty is to deal with complaints from insurance consumers about the business practices of insurance companies in Ontario, and to make a final report on a complaint. The report is not binding.

The Insurance Ombudsman:

encourages insurance companies to resolve complaints when they are first lodged at the companies;

provides an accessible service to the public who have complaints about the business practices of insurance companies, that have not been resolved after going through the insurer's complaint process;

protects the public by ensuring that insurers have fair business practices, that the practices do not conflict with the public interest, and that they fully comply with the law; and

fosters public confidence by examining each complaint and looking carefully at all aspects of each case as they relate to the law.

Q2. What the Insurance Ombudsman can do and cannot do to help complainants:

A2. Here's what the Ombudsman *can* do: The Ombudsman can look into complaints about the business practices of insurance companies.

There are several specific things, however, that the Ombudsman *cannot* do. The Ombudsman cannot inquire into a complaint that:

has not been submitted to the insurance company and gone through the insurer's complaint process, which is officially known as its Complaint Handling Protocol;

is being or has been dealt with by a court of an alternative dispute resolution process, or where the individual has a statutory right of appeal under the *Insurance Act*;

has already been dealt with by the Insurance Ombudsman; and

is frivolous or vexatious, in the opinion of the Insurance Ombudsman.

Q3. How does the insurance company's complaint handling protocol work for me?

A3. The complaint handling procedure that every company has put in place aims at discussing any complaint you may have and reaching an agreement to resolve the complaint.

There are various steps in the company's complaint handling process. If an agreement cannot be reached, or it is taking an unreasonably long time to reach an agreement, the company is required to send you a letter stating its final position on the matter. You will need this letter when contacting the Insurance Ombudsman for assistance with the complain.

Q4. If I don't have a letter from my insurance company, can I still complain to the Insurance Ombudsman's Office?

A4. You can still complain to the insurance Ombudsman's Office, only if your company refuses to provide a letter. You may not make a complaint if you simply did not receive a letter and did not ask for one.

Q5. What happens to my complaint after I have sent it to the Insurance Ombudsman's Office?

A5. The Insurance Ombudsman will, first of all, review the complaint and advise you promptly if he or she can act on the complaint.

If the complaint can be acted on, you will be advised of the name and telephone number of the person in the Insurance Ombudsman's Office who will be inquiring into the complaint.

At any stage of the inquiry, the Insurance Ombudsman may decide that the complaint should be dealt with by another organization. In such a case, the Insurance Ombudsman will inform you of the situation and if you, as the complainant agrees, the complaint will be referred to the organization.

When the inquiry is completed, the Insurance Ombudsman will send you a final report in writing. Please note that the report is not binding. You may decide to pursue the matter further through another alternative dispute resolution method or the courts.

Q6. How do I go about submitting my complaint to the Insurance Ombudsman's Office?

A6. To obtain the Insurance Ombudsman's services in dealing with your complaint, you must write a letter. In your letter, you must outline the nature of the dispute you have with the insurance company as well as describe what you want the company to do. Before mailing your letter, you must also enclose a copy of the letter from the company stating its final position. This should be done as soon as possible after receiving the company's letter. It is easier to resolve complaints if they are dealt with early.

If you have retained a lawyer to handle the matter, he or she should send the complaint to the Insurance Ombudsman.

If you are writing to the Insurance Ombudsman on behalf of a friend or a relative, you should include a note signed by the person for whom you are acting, stating that the person is authorizing you to do so. In those instances, when it is not possible to obtain such authorization, you should explain the circumstances in writing.

Your letter of complaint, enclosing the insurance company's letter stating its final position, should be sent to:

The Insurance Ombudsman

Ontario Insurance Commission

5160 Yonge Street

Box 85

North York, Ontario M2N 6L9

Fax (416) 590-8480

Source: Ontario Insurance Commission - Information bulletin.

MANITOBA A/SUPERINTENDENT OF INSURANCE OFFERS ASSISTANCE WITH CLAIMS

Ms Lucy M. Couture, A/Superintendent of Insurance in a letter to our organization dated May 13, 1997 advised that the office of the Superintendent of Insurance for, if contacted in writing by consumers, will approach insurance companies outlining the concerns of which they are made aware. The Superintendent's office in Manitoba will mediate disputes between consumers and their insurance companies.

The Insurance Act however does not empower the Superintendent to compel insurance companies to pay claims nor to determine how much a claim is worth. If the parties are unable to negotiate a settlement then the matter as a civil matter, may be taken to the courts.

Please contact: **Ms Lucy M. Couture, A/Superintendent of Insurance, Manitoba, Consumer & Corporate Affairs, Woodsworth Building, 1142 - 405 Broadway, Winnipeg, MB R3C 3L6 - Tel. (204) 945-2542, Fax: (204) 948-2268 - TOLL FREE IN MANITOBA: 1-800-282-8069.**

TIP: For people who have problems with typing on their computer, there is software now available that is voice-activated: call:

1) IBM VoiceType Dictation - **1-800-426-2255** - Specialist

(Internet: **www.software.ibm.com/is/voicetype**) (cost approximately \$900)

2) DragonDictate PC Dictation Program - **1-800-825-5897 - \$150 & up??**

E-mail: info@dragonsys.com

Internet: <http://www.dragonsys.com> (cost ranges from \$99.00 to \$1,600.00)

STUDY OF TWINS WITH CHRONIC FATIGUE SYNDROME OR FIBROMYALGIA - UPDATE:

Two years ago, Harborview Medical Center at the University of Washington began the development of a new twin registry on ME/CFS and Fibromyalgia (FM). They received 60% of the completed surveys back from those twins. The Medical Center has again asked for our help with their continuing study and we therefore would like to pass on their request.

Do you know anyone with Chronic Fatigue Syndrome (CFS) or Fibromyalgia (FM) who has a twin?

The office of Debra Buchwald, M.D., at the University of Washington School of Medicine, is developing a registry of fraternal **and** identical twins. The registry is seeking twins where one or both of the twins have CFS and/or FM. This registry will be used for studies of genetic and environmental influences on immunological, virological, psychological and sleep-related disturbances in CFS and FM.

If you know of any twins with either CFS and/or FM, please contact us or have the twins contact us directly. Individuals need to meet the published criteria for CFS or FM. If you are a twin (or know of a twin) who has not yet been diagnosed with one of these conditions, but have suggestive symptoms, we would be happy to follow-up and confirm the diagnosis. You may contact us by one of the following means:

Nicolette Vajtay, Suzanne Hartman, Research Assistants - Twin Registry

University of Washington

Harborview Medical Center Tel. (206) 521-1932; (206) 731-3325 (messages only)

325 Ninth Avenue, Box 359780 Fax (206) 5211930

Seattle, Washington 98104 U.S.A. nickyv@u.washington.edu or shartman@u.washington.edu

All registry members will be asked to complete a comprehensive booklet and to sign a consent form approved by the University of Washington. Thank you very much!

CONFERENCES:

FIBROMYALGIA: RESEARCH & REALITIES -

4TH NATIONAL PATIENT CONFERENCE - OHIO - AUGUST 8 - 10, 1997

For more information call: Fibromyalgia Alliance of America (614) 457-4222

'HASTI NOTES' - A QUICK WAY TO SEND A MESSAGE

A package of four different cards was designed for us by Mary Harris of Peterborough, a ME person. The front of the card shows a picture of a turtle and the back of this card contains information on who we are and how to obtain information on ME/FM. **Cost: \$4.00 per package.** Contact us for ordering these 'Hasti Notes' and have the satisfaction of helping our organization at the same time .

Our World

FM: FAULTY MUSCLE IN MOTION

REMISSION RELAPSE RECOVERY

Step Forward Back-UP Walk On

Thanks to Lorraine Legendre, Ottawa.

Dear Friends:

It has come to our attention that some of you see your doctors but do not really relate to them your symptoms as you don't want to complain. Some of you also don't see your doctors on a regular basis so that they are unable to really follow your progress or lack of it. Unfortunately, when it comes time for your doctors to write a medical report to support your disability pension, or Tax Credit, the doctor does not have enough information on file to help your claim.

In addition, although we have mentioned this before in our newsletters, please discuss your symptoms with your doctors, especially new symptoms. Just because you have ME/FM does not mean you cannot get another illness and remember many illnesses can be treated.

It is also a good idea to use the same pharmacy all the time for your prescriptions and have a good relationship with your pharmacist. He/she will become familiar with you and your medications so that if you forget to mention to your doctor what medications you are taking, your pharmacist will be able to verify whether or not your new medication will clash with your other drugs.

Take care, and have a great summer.

Sincerely,

NATIONAL ME/FM ACTION NETWORK

Lydia E. Neilson,

President CEO

MEMBERSHIP: \$20.00 per year which includes newsletters every two months. Please show your support by becoming a member or by making a donation.

ELECTRONIC MAIL: our e-mail address: ag922@freenet.carleton.ca

A free Guide to the many information resources available via Computer for chronic Fatigue syndrome/Myalgic Encephalomyelitis and Fibromyalgia. For an individual the guide shows where to get information and have discussions with others interested in ME/CFS and FM. For a Support Group, the guide is a resource for obtaining newsletter articles for your newsletters, and to communicate with other support groups. You can obtain a free copy by mailing a self-addressed stamped envelope to:

In Canada: CFS/ME Computer Networking Project, 3332 McCarthy Road, P.O. Box 37045, Ottawa, Ontario K1V 0W0, Canada.

In the United States: CFS/ME Computer Networking Project, P.O. Box 11347, Washington, DC 20008-0547 U.S.A. Please note that for mailing outside of Canada please include an International Reply Coupon.

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