

Quest #6 June 1994

Dear Friends:

ADDITIONS TO BOARD OF DIRECTIONS

We are pleased to announce the additions of the following people to our Board:

DR. PHILIPA CORNING - Scientific Director. Dr. Corning has a Doctorate in Microbiology and is Past President of MESH OTTAWA. She is also the author of many articles that she makes available to all our members, free of charge.

CARLYLE ANDRYO - Director - Manitoba. Carlyle is the Public Relations Officer (Board Member) of The Nightingale Research Foundation, M.E.s.h. Network/Manitoba Chapter which is a Chapter of The Nightingale Research Foundation. She also networks with many groups in an attempt to form alliances for the benefit of all.

AL NEILSON - Director BBS and Office. Al takes care of the electronic networking and assists in an administrative capacity wherever he can, in addition to being my husband.

COMPUTER & PRINTER WANTED: We now have charitable status across Canada and can therefore issue tax receipts for donations. We are looking for a newer computer and printer. Do you know of anyone who might be able to help us with this? Our little old Mac Plus is barely able to keep up and will probably give up in disgust due to overwork.

KUTAPRESSIN UPDATE: The following reply was received from SCHWARZ PHARMA in its letter of April 22, 1994: "As you may know, KUTAPRESSIN is not labeled for Chronic fatigue Syndrome, but is labeled for certain skin disorders that have associated inflammation and edema. KUTAPRESSIN has not been evaluated for Chronic Fatigue Syndrome in any SCHWARZ PHARMA sanctioned clinical trials, nor has it been evaluated for the indication by either the U.S. Food and Drug Administration (FDA) or the Canadian Health Protection Branch (HPB). SCHWARZ PHARMA is aware of literature reports of independent investigators performing preliminary investigations in this area. At this time, SCHWARZ PHARMA personnel are reviewing these reports to determine what, if any, steps will be taken by the company to address this interest. SCHWARZ PHARMA can not recommend usage of this product for Chronic Fatigue Syndrome, however, we would be happy to send published literature relating to its indicated uses to any patients Health Care Professional in the U.S. or Canada.

We regret to inform you that KUTAPRESSIN is presently not marketed in Canada. SCHWARZ PHARMA is presently re-evaluating marketing the product on a limited basis in *Canada.....Signed Kurt D. Schlehle, Drug Information Specialist II, Technical Services Department, P.O. Box 2038, Milwaukee, WI 53201 U.S.A. Tel. (414) 354-4300 - Fax (414) 354-4309.

EDITOR'S NOTE: *CANADA: See newsletter #5 re: Emergency Drug Release Programme of the Bureau of Human Prescription Drugs.

INSURANCE MATTERS:

TIP:., Contact the CANADIAN LIFE & HEALTH INSURANCE ASSOCIATION for its **FREE** booklet **'Where Will The Money Come From - If you're Disabled'** They also have counselors who are trained in answering questions regarding insurance and disability. Advise them this Network referred you. **CALL: 1-800-268-8099, in British Columbia 112-800-268-8099 and in Toronto 977-2344.**

Contact Byron Timmermans before you make any decisions about your disability insurance so that you will have all your facts beforehand. Byron can be contacted at 720 Downland Ave., Sudbury, ON P3A 5T3 - Tel. (705) 560-4936.

PATRICIA SINDLER - of 3034 Bel Air Dr., Los Vegas, Nevada 89109 U.S.A., Tel. (702) 735-8830. Pat has ME/FM but became severely ill after being involved in a motor vehicle accident. If this is similar to your history, please contact her as she needs help in obtaining data that the accident was responsible for her worsening condition.

BRITISH COLUMBIA TEACHERS' FEDERATION (BCTF)

1) Ray Worley, President of BCTF in his reply to our letter requesting clarification as to whom the BCTF stated in his April 12th letter as follows: ".....The BCTF self insures its own Salary Indemnity Plan. The BCTF has an administrative services only (ASO) agreement with Great West Life Assurance Company (GWL), that is the Long Term plan is administered on behalf of the BCTF by GWL. Policy development and administrative policy decisions are done by the Income Security Committee (ISC) of the BCTF. The ISC is composed of five teacher members from around BC. They regularly review the nature of the services of GWL.....It was the BCTF's ISC in 1989 which established the criteria for receipt of Long Term Disability benefits for chronic fatigue syndrome - myalgic encephalomyelitis, as those outlined in the Annals of Internal Medicine. GWL immediately applied those criteria to our plan on our instructions. GWL now uses this criteria for its own insured plans as well.

[Editor's Note: A copy of Chronic Fatigue Syndrome: A Working Case Definition by Gary P. Holmes et al (1988) has been sent to us by BCTF as being the criteria presently being used]

Mr. Worley goes on to state that there are presently 50 teachers on LTD benefits who have ME/CFS "whose benefits have not been called into question. For those very few who have been advised that their benefits are being terminated, the Salary Indemnity Plan has an appeal process which involves a tri-partite medical arbitration panel, staffed by three doctors, one selected by the member, one by the plan, and one to chair, who has been jointly agreed to by the other two doctors."....."The results of this appeal process are binding on both parties".

2) To our concern regarding fair treatment by ME/FM teachers, Mr. Worley's reply in his letter of May 11th, 1994 states as follows:....."You express a concern at the composition of the medical panel which considers appeals from teachers who have had their benefits terminated. The panel is composed of three doctors. One of those is directly appointed by the teacher. Obviously, the teacher has the opportunity to name a doctor who is knowledgeable about ME/CFS. That doctor, in turn, jointly chooses the chairperson of the panel and would presumably not agree to a chairperson who did not have an understanding of the condition. We believe therefore that there is due process and protection for our members." [Signed: Ray Worley, President, BC Teachers Federation, 100 - 550 West 6th Avenue, Vancouver, BC V5Z 4P2 Tel. (604) 871-2281 or 1-800-663-9163]

READ ON:

Mr. Larry A.W. Neilsen, Deputy Superintendent, Insurance and International Financial Business, Province of BC, states as follows: "Part 5 of the Insurance Act of British Columbia does not provide for an alternate dispute resolution method other than the commencement of a civil action. Participation in any other dispute resolution method, such as binding arbitration or mediation, would have to be reflected in the provisions of the policy or agreed upon at a later date by both the insurance company and the insured...." In reply to whether an insurance company has the responsibility to send the claimant to a doctor who is knowledgeable on the disease the claimant suffers from or is claiming under, Mr. Neilsen states: "Part 5 of the Insurance Act does not address this issue. An insured should consult the terms of his or her disability insurance policy or insurance certificate for further information with respect to this issue. As well, you may wish to consult with your local office of the Insurance Bureau of Canada and with

CLHIA [Canadian Life & Health Insurance Association, Inc.] to determine what, if any, industry practices there are with respect to the insurer's responsibility to choose a physician that is qualified to diagnose the disease at the claimant alleges he or she has." Signed Larry A.W. Neilsen, Deputy Superintendent, Insurance and International Financial Business, Province of BC, 1900, 1050 West Pender Street, Vancouver, BC V6E 3S7 - Tel. (604) 660-2947 - Fax (604) 660-3170.

LAWYERS' NETWORK

LAWYER: JOSEPH E. MURPHY of the law firm of MURPHY, BATTISTA, 2020-650 West Georgia St., Vancouver, BC V6B 4N7 - Tel. (604) 683-9621 - Fax (604) 683-5084. Mr. Murphy advises that none of his ME/FM cases have not yet gone to court but that depending on the facts of the individual cases, he may be prepared to act on behalf of other ME/FM persons.

CONFERENCE ANNOUNCEMENT:

2ND ATLANTIC REGIONAL CONFERENCE ON FIBROMYALGIA 'LIVING WHILE COPING WITH FIBROMYALGIA' to be held on August 26-28 on the Saint John Campus of the University of New Brunswick - Sponsored by: Donihee Books and Educational Resources. **AUGUST 26 - 28 1994 - Registration Fee: \$85.00.** For Information write or call: FIBROMYALGIA CONFERENCE, P.O. Box 22008, Lansdowne Postal Outlet, Saint John, NB E2K 4T7, CANADA - Tel. (506) 652-6645.

NEWS RELEASES

1) ENVIRONMENTAL ILLNESS: On May 9th, 1994 the Ontario Health Minister, the Hon. Ruth Grier, announced funding of \$2.5 million for Canada's first environmental illness research and clinical program. The Ministry of Health, Women's College Hospital and the University of Toronto are partners in the project. The scope of the research on environmental sensitivity will include diagnosis, treatment and prevention. However, the initial focus of the research will be on clarifying the definition of the disorder and establishing guidelines for diagnosis. A new provincial advisory committee will be established so that information may be provided to doctors, other caregivers and consumers. For information on the program you can call toll-free at **1-800-417-7092**.

2) M.E. ONTARIO - has announced its new Executive and Board of Directors for 1994-1995. The executive Board consists of President: Leni Johnson, 1st Vice-President: Bill Leeming, 2nd Vice-President: Stephanie Burke, and Treasurer: Colleen Lenaghan. It will also

be contacting everyone on its mailing list regarding the particulars of its meetings with the Ontario Minister of Health, The Hon. Ruth Grier. However, copies of ME Ontario's letter have been kindly provided to our organization so that we could inform our members also. We thank both ME Ontario and the Halton & Hamilton Wentworth ME support group for their active involvement with the Ontario Government on all our behalf and deserve our thanks and support. ME Ontario can be reached at 90 Sheppard Avenue East, Suite 108, North York, ON M2N 3A1 CANADA - Tel. (416) 222-8820 - Fax (416) 224-2181.

MAY 12TH UPDATE -

Walk on Parliament Hill - Aidan Walsh of Montreal coordinated this event and hundreds of ME/FM information bulletins were distributed to members of Parliament. Aidan also was able to hand over his written request for research to the National Minister of Health, The Hon. Diane Marleau. A copy of Aidan's letter is enclosed.

INFORMATION WANTED ON MAY 12TH activities: - Please send us a memo outlining your activities for that Day so that a report can be made up for distribution to you and to Tom Hennessey, founder of May 12th and RESCIND INC.

NEWSLETTERS/BOOKS/REPORTS/VIDEOS

- 1) THE INTER-ACTION OF THE IMMUNE AND ENDOCRINE SYSTEMS DURING ACUTE AND CHRONIC STRESS - 3 pages;
- 2) CHRONIC STRESS AND THE CONTROL ISSUE - 3 pages;
- 3) THE EMOTIONAL IMPACT OF ME - 3 pages;
- 4) MENTAL FITNESS PROGRAM - 1 page;
- 5) RECOVERING FROM ME AND RETURNING TO WORK - 1 page;
- 6) STRATEGIES FOR RETURNING TO WORK - 1 page; and
- 7) SUGGESTED APPROACH TO WRITING UP DISABILITY - 1 page.

PLEASE SEND YOUR REQUESTS for any or all 7 articles TO: DR. PHILIPA CORNING, 69 Roblyn Way, Nepean, Ontario K2G 5Z5 CANADA.

IN CANADA send stamped self-addressed envelope as follows:(1 to 7 sheets 43 cents, 8 to 12 sheets 69 cents);

IN U.S. and International: send self-addressed envelope and include cheque for \$1.00 or or an international postal coupon of \$1.00.

C.Y.O. NEWS - The official Newsletter of **CFS YOUTH OUTREACH - Membership \$15.00 per year** - Contact: Sharon Walk, 14 Shetland Road, Florham Park, NJ 07932 U.S.A. Great newsletter consisting of peer articles, coping skills, advocacy and May/July issue contains a CYO survey questionnaire.

"I.C. - M.E.?" by Vera Mahina. This is a report (3 pages) written by Vera on Interstitial Cystitis (I.C.), a chronic inflammation of the bladder wall. To obtain a copy, please send a stamped (\$0.43) self-addressed envelope to me. For International send cheque for \$1.00 or international coupon).

NOTICE: The charter issue of the **Journal of the Chronic Fatigue Syndrome** should be off-press in 6 months. The Haworth Press, Inc, and its Publisher, Bill Cohen urges that readers write in for a free sample of the Journal and not send any money, as they do not have the manuscript in-house yet and cannot guarantee the delivery date. Address: 10 Alice Street, Binghamton, NY 13904-1580 U.S.A.

TIP: , Want to keep ME/FM articles of interest easier? Buy a 2-inch, three-hole punch binder, an alphabetical Loose Leaf index tabs, mark articles with appropriate letter e.g. 'I' for immune system, 'P' for pain etc. so that anytime you want to reread an article it will be easier to find.

INTER-GROUP/CONTACT COMMUNICATIONS

GULFCOAST CFS/CFIDS ASSOCIATION, INC. are creating a 1995 calendar which which feature Art by ME/FM persons. Please contact: **MARILYN STEWART** 752 J Avenue Estancias, Venice, FL 34292-2316

U>S>A> - Tel. (813) 484-0706 to get more information regarding the purchase of this Calendar for fundraising etc.

As of March 30th, 1994 in recognition of National ME/CFS Awareness Day, the NEW BRUNSWICK ME/CFS ASSOCIATION was founded. Brenda Duffy, President, Carol Hough - Secretary-Treasurer, Mary MacDougall - Education, Medical Advisor - Dr. Paul Smith, and Legal Advisor - Allan A. Murray. The address of this Association is: P.O. Box 1030, Station A, Fredericton, NB E3B 5C2 CANADA.

PERSONALS

CONGRATULATIONS AND BEST WISHES to **SUZANNE & BILL KROHN** Kalamazoo, Michigan who got married on Valentine's Day in Hawaii. Suzanne was formerly known as Suzanne Spencer. Both Bill and Suzanne suffer from ME/FM.

Studies have shown that biomagnetics have been significantly effective with arthritis patients (i.e. they were able to decrease the amount of their medication). There are reports that biomagnetics have been beneficial to CFS and FM patients. I am currently trying the insoles, mattress and flex pad. If you would like more information, please contact me, **JANICE WINCHESTER, R.R. 2, Coldwater, ON L0K 1E0 - Tel. (705) 327-7444.**

SURVEY REMINDERS: DR. POTAZNICK'S **optical survey** and the National ME/FM Action Network's national **disability insurance survey**. We hope to start publishing data on the insurance survey in our August 1994 issue so please keep sending in your completed forms.

WELCOME TO OUR WORLD

Nausea: a quick stay on the 'Love Boat'

Myalgia: a crash course in the anatomy of muscles

M.E.: Mapping your Efforts. [Submitted by: Lorraine Legendre, Ottawa].

MEMBERSHIP FEE: \$20.00 per year which includes our 'Quest' newsletter issued every two months. **DONATIONS will be cheerfully and gratefully accepted.**

Sincerely,

NATIONAL ME/FM ACTION NETWORK

Lydia E. Neilson, President C.E.O.

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DISCLAIMER: The NATIONAL ME/FM ACTION NETWORK serves as a clearing house for information on Myalgic encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia Syndrome. some of the information contained herein is intended to help patients and their physicians make informed decisions about their health. However, the NATIONAL ME/FM ACTION NETWORK does not dispense medical

advice or endorse any specific medical hypothesis or product and assumes no responsibility for any treatment or action undertaken by its readers.