

Quest #4 February 1994

Dear Friends:

When the Canada Geese fly South for the winter, they fly in "V" formation. As each bird flaps its Wings, it creates an Uplift for the bird immediately following. By flying in "V" formation, the whole flock adds at least 71% greater flying range, than if each bird flew on its own.

Some of you will recognize this as part of "The Goose Story" which I originally saw in Janice Winchester's newsletter that she publishes for the Orilia ME Support Group. We enclosed a copy of this Story with one of our newsletters. You all liked it so much that I have seen it published in many newsletters since then.

We therefore thought it fitting to adopt the Canada Goose as our mascot and my son, Steve, designed our letterhead to include our Canada Geese and Maple Leaf as our Logo. Hope you like it.

The Thesaurus defines Quest as a verb, to try, undertake, strive and as a noun the act of seeking something, a search. We thought it would be a fitting name for our newsletter.

Geese honk from behind to Encourage those up Front to keep up their Speed. Please remember that none of us can go it alone, we need your encouragement in the manner that you are able to do it. For some it may be financial by becoming a member, for others it may be helping of another sort. All we ask is that you help in whatever manner you are capable so that we can keep up our Speed.

Hang in there, and we promise to do the same.

Lydia E. Neilson, President

CLAIMING A DISABILITY TAX CREDIT: Ask your District Taxation Office for Booklet P149(E) English or P149(F) French - "Tax Information for People with Disabilities Services for People with Disabilities Claiming the disability Tax Credit". This booklet also contains form T2201 as well as handy examples and suggestions.

ELIGIBILITY: You can claim this credit if you have a **severe and prolonged** mental or physical impairment. It could be an impairment with which you were born, or one that developed. It is the effect of the impairment on your ability to perform basic activities of daily living, not the ailment or condition itself, that determines whether or not you can claim the disability tax credit. [This tax credit may also apply to a dependant child] **IMPORTANT NOTE:** Receiving a disability pension does not automatically make you eligible to claim the disability tax credit.

TIP: One of our members advises that he has been allowed to deduct Fitness Club costs on his Income Tax Return and marks it "Fitness Program, Recommended by Doctor". Thanks to Neal, Niagara Falls, Ont.

EDITOR'S NOTE: If you have visual impairments, call 1-800-267-1267. If you call Revenue Canada, you can order large-print copy of any type of income tax return.

ADDITION TO OUR BOARD OF DIRECTORS: We are pleased to advise that ALBERT BLOM, President of the Barrie Support Group, has accepted the position of Director for Ontario for our National ME/FM Action Network.

AMPLIGEN UPDATE - U.S.A.

Ampligen was granted FDA approval on December 22nd, 1994 for the treatment of Chronic Fatigue Syndrome and invasive malignant melanoma under the Orphan Drug Act, according to its manufacturer, HEM Pharmaceuticals Corporation in Philadelphia.

The HEM press release points out that, "Although the etiology of CFS is unknown, a significant segment of the medical community believes that it may be caused by a virus because the onset of the condition is usually characterized by flu-like symptoms, followed by chronic tiredness that can continue for years. CFS is often accompanied by a disturbance of the patients immune system, as measured by lower levels of natural killer cell activity and/or lower lymphocyte counts."

Ampligen is an "RNA therapeutic" which is believed "to act by switching on enzymes which are critical to anti-viral and anti-tumor defense mechanism, and by regulating the level of immune system modulators," HEM reports, noting that the company has five U.S. patents relating to RNA therapy for the treatment of CFS, and that the Ampligen family of drugs is "believed to have broad spectrum anti-viral, anti-tumor, and immune modulating capabilities."

Source: The New York Native, Issue 559, January 3, 1994 posted by Roger Burns on the CFS Newswire on January 2, 1994 - Author: Neenyah Ostrom.

EDITOR'S NOTE: We have written the manufacturer, HEM, 1) to find out the status of a Canadian Ampligen trial study; 2) which patients in the U.S.A. will benefit from the FDA approval under the Orphan Drug Act.

TRANSFER FACTOR: A videotape about Transfer Factor called "Your Immune System - A Miracle We Take for granted" is available for \$19.95 U.S. (plus postage) from Dr.H.H. Fudenberg at: NEURO-IMMUNO THERAPEUTICS RESEARCH AND EDUCATION FOUNDATION, 145 N. Church Street, Suite 102, Spartan, SC 29306 U.S.A. or call 1-800-323-3842 or (803) 591-4236 - Fax (803) 591-4255.

PAIN AND SEROTONIN

"Serotonin is a chemical messenger that is found in many different parts of the body, including the digestive system, blood and nervous system. In the nervous system, proper serotonin balance is important for mood, sleep, and analgesia or pain control. When serotonin is low, people can become depressed, have poor sleep, or have increased levels of pain. Any one of these problems can occur separately, and sometimes they occur together. Antidepressant medication, like amitriptyline, work by correcting imbalance in serotonin. Because serotonin imbalance is important for more than just mood, "antidepressants" may also be prescribed for other problems, like sleep disturbance or some types of chronic pain. Interestingly, in patients with some type of pain who do not have any depression, "antidepressants" are effective in reducing pain. In addition, non-medication treatments, like biofeedback and relaxation, used to treat chronic pain also change serotonin levels in a similar fashion to medication like the antidepressants. This may explain at least part of the reason these treatments are useful in reducing pain." By: Dawn A. Marcus, MD, Pain Evaluation and Treatment Institute, University of Pittsburgh Medical Center. Article published in the "Peterborough Track" newsletter, [affiliated with the North American Chronic Pain Association], 1408 MONAGHAN RD., PETERBOROUGH, ON K9J 5M7

LAWYERS' NETWORK - LEGAL MATTERS - COURT CASES & PRECEDENTS

As originally announced in our October 1993 newsletter and followed-up in December, we are pleased to advise Mr. Vigmond is again operational, after having moved to a new location and law office:

JAMES L. VIGMOND

OATLEY, PURSER, Barristers & Solicitors

151 Ferris Lane, Suite 200 Tel. (705) 726-9021

P.O. Box 760 Fax (705) 726-2132

Barrie, Ontario L4M 4Y5 CANADA

Mr. Vigmond's new law firm has just hired a new Research Assistant who will greatly assist in getting the Network moving quickly. Mr. Vigmond is available to both lawyers and individuals who need help from across the country.

BOOKS/NEWSLETTERS

'The MEmo' a monthly newsletter published by the WATERLOO-WELLINGTON ME ASSOCIATION, P.O. Box 20075, Pioneer Park Postal Station, Kitchener, ON N2G 4G8 CANADA - Membership \$25.00 per year, which includes "The Memo" free of charge. ME Information line: (519) 623-3207.

CFIDS, AN "OWNER'S MANUAL" - Cost: \$20.50 (U.S. Funds) Now again available through BBNS Publishers, Nancy Smith, P.O. Box 1343, Randolph, MA 02368 U.S.A. - Tel. (617) 961-2042.

"the UPDATE" published by MASSACHUSETTS CHRONIC FATIGUE IMMUNE DYSFUNCTION SYNDROME ASSOCIATION, 808 Main Street, Waltham, MA 02154 U.S.A. Tel. (617) 893-4415 - Membership is \$20.00 per year, includes: "the UPDATE" newsletter, published quarterly - Editor: Gail Kansky.

WINSTON-SALEM CFS SUPPORT GROUP, 2507 Lullington Drive, Winston-Salem, NC 27103 U.S.A. - Annual Newsletter Subscription Rate: \$12.00 U.S. President: Debbie DiSantis, Newsletter Editor: Wanda Rabb.

U.S.A. - ACPA CHRONICLE: Published by the AMERICAN CHRONIC PAIN ASSOCIATION (ACPA), P.O. Box 850, Rocklin, CA 95677 U.S.A. Subscription: Donation of \$10.00 U.S. or more and includes newsletter.

CANADA: NORTH AMERICAN CHRONIC PAIN ASSOCIATION (NACPAC) [Affiliated with American Chronic Pain Association] 6 Handel Court, Brampton, ON L6S 1Y4 - Tel. (905) 793-0746 - Diane Kent, President. Membership \$1.00, charitable donations gratefully accepted - tax receipts issued.

"BEARLY COOKING" Cookbook now available - Cost \$7.00 per copy, or 3 for \$20.00, or \$1.00 discount if you contributed a recipe (U.S. Funds). SAN JOAQUIN CFIDS/ME/FM SUPPORT NETWORK, P.O. Box 724, Woodbridge, CA 95258-0724 U.S.A.

INTER-GROUP/CONTACTS COMMUNICATIONS

INFORMATION WANTED

1) RE: EYE PROBLEMS: As you know, many of us experience eye problems. However, one of our members is in the process of getting a pair of trifocals. Her eye doctor told her that her eyes tended to wander which resulted in the readings constantly being different, making it difficult to find a proper prescription to suit her. She asked if other ME/FM people who have this problem would please write in and advise what kind of glasses helped them to overcome this problem i.e. trifocals, bifocals?

2) RE: ESTROGEN: " I am interested in conducting a small tracking study on how Estrogen impacts on ME/FM in general, but particularly on Menopausal women. Should you wish to share your experiences on Estrogen theory, good or bad, please contact: CUSTOM MARKETING, c/o Joan Trowell, P.O. Box 92016,

2900 Warden Ave., Scarborough, Ontario M1W 3Y8 CANADA. All submissions will be treated in strict confidence."

CHANGE OF ADDRESS:

BRENDA DUFFY, SGL, 15 Rosewood Dr., Fredericton, NB E3B 7G8 - Tel.(506) 446-6954

STATISTICS: PAUL R. CHENEY, MD., Ph.D., Charlotte, NC testifying before the FDA Scientific Advisory Committee, February 18, 1993: at The Cheney Clinic in Charlotte, NC {devoted entirely to the diagnosis and management of CFS} they have evaluated over 1200 cases in the past three years, of which 78% meet the CDC case definition of CFS. Half have abnormal MRI scans, 80% have abnormal SPECT scans, 95% have abnormal cognitive evoked EEG brain maps. Most have abnormal neurologic examinations. 155 cases have random CD4 counts below 500, 62 cases below 400, 21 below 300 and 3 below 200. An estimated two-thirds of these cases will persist below 500 on repeated determinations. 40% have impaired cutaneous skin test responses to multiple antigens. Most have evidence of T-cell activation and 80% have an up-regulated 2-5A antiviral pathway on a single determination. Source: Thanks to Gail Kansky, Editor of "The Update", Waltham, MA.

EDITOR'S NOTE: To obtain a copy of Dr. Cheney's two-page testimony: please send - in Canada: a stamped self-addressed envelope to the writer; or in the U.S.A. or International: International postage coupon or cheque for \$1.00.

MAY 12TH INTERNATIONAL CFIDS/ME AWARENESS DAY UPDATE:

MAIN ORGANIZER: RESCIND, INC. 127 West Putnam Avenue, #170, Greenwich, CT 06830 U.S.A. Fax 1-203-531-4135. Please note that the deadline for each month's May 12th update is the first of each month. Please remember that RESCIND depends solely on donations to cover the expenses involved with promoting this event. All donations tax deductible in the U.S.A. Information packages available. Rescind will continue to provide monthly updates so make sure you stay in touch. [Internet e-mail: m.straznitsk@genie.geis.com]

** RESCIND asks that this month you advise your local media about the up-coming event so that they have plenty of notice to get involved to write a story or attend functions organized.

EDITOR'S NOTE: The National ME/FM Action Network is writing all provincial and federal health Ministers etc to request recognition of this important Day

IN CHARGE OF CANADIAN GROUPS: LORI GLOVIS, P.O. Box 1445, 3680 Main St., Hinnsdale, NY 14743, U.S.A. - Tel.(716) 557-2260.

WALK ON PARLIAMENT HILL - Aidan Walsh, Organizer, 6210 Somerled St., Apt. 8, Montreal, PQ H3X 2B3 - Tel. (514) 487-6620. Please contact him as soon as possible if you, your family and friends would like to participate. Medical professionals gratefully welcomed.

INFORMATION BOOTHS AT LOCAL SHOPPING CENTERS: The BARRIE & DISTRICT ME Support Group is: 1) planning to set up information booths at the local shopping centers for that Day. They already have a commitment for a booth in the Kozlov Mall in Barrie; and 2) Planning to ask the Mayor of Barrie to declare May 12th officially ME Awareness Day.

Contact: Albert Blom, 33 Doris Drive, Barrie, ON L4N 5W2 - Tel. (705) 728-7133.

ME CANADA - MANITOBA CHAPTER - 35 Pine Bluff Rd., Winnipeg, MB R2J 2N6 - Tel./Fax (204) 257-2624 Wants to hear from other groups re: suggestions, ideas and communications. Contact: FRANK FOWLER or JOAN CURRAN

V.I.P. MAILING LIST ADDITION

HONOURABLE DIANE MARLEAU, Minister of Health

House of Commons, Room 256

Confederation Building

Ottawa, Ontario K1A 0A6 CANADA

Tel.(613) 957-0200 or Toll Free: 1-800-268-1154

TREASURER'S REPORT as of December 17, 1993

- 1) Business related travel (Para transpo, busses) \$162.00
- 2) Equipment & Furnishings: Computer desk (used) 50.00
- 3) Membership fees: CFS Dyspatch, Price Club, Freenet 74.45
- 4) Computer Upgrade/repair 549.50
- 5) Office Supplies & Stationery:
 - stamps & envelopes 520.21
 - photocopy services 168.57
 - supplies 233.49 922.27

Total Expenditures \$ 1,758.22

Donations Received to Date: 1,778.01

BALANCE: \$19.79

Michael Diplock, Treasurer

NATIONAL ME/FM ACTION NETWORK

WELCOME TO OUR WORLD

ME NAP - taken between rest and sleep.

LISTEN TO YOUR BODY - The act of ignoring fun.

JOIN THE ACTION - BECOME A MEMBER

MEMBERSHIP \$20.00 per year, bi-monthly newsletters included.

N.B. The National ME/FM Action Network is an incorporated non-profit organization. However, we have not yet been approved for charitable status and therefore are unable to issue tax receipts. **{Charitable Registration #0977702-19 - Approved March 1994}**

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Lydia E. Neilson,

President