

## Quest #3 December 1993

Dear Friends:

The year is almost over and looking back on it, there is good reason for optimism for the accomplishments achieved in 1993. In an interview with the Montreal Gazette, I was asked why there all of a sudden was such a big interest in ME/FM and what did I think was the cause of it? I advised her that it was not all of a sudden but that a lot of hard work had been done by many people to accomplish this change of attitude and increase in awareness. I told her that the support groups and its members are mainly responsible by working together and individually and that they deserve most of the credit for all that has happened in 1993. This remark never reached the printed page but it is true nonetheless.

The rest of the credit goes to some very dedicated physicians and researchers who are overworked and under-funded but who nevertheless believe in us. With them lies our hope and because of them, we will keep going.

Congratulations to each and everyone of you for your hard work and perseverance. It takes a lot of courage to keep going in the face of adversity and problems that seem insurmountable. I think it is a great way to end 1993, knowing that we are making progress.

Best wishes for the Holiday Season to you and your loved ones and Health & Happiness throughout 1994.

Lydia E. Neilson

**TIP:** We all know how difficult it is to read and retain anything. When there is something you want to read and "remember", try using a highlighter to outline the sentences that are important to you at the same time as you are reading it. This way, instead of having to read the whole article again, all you will need to do is read the highlighted segments that are of particular interest to you.

**CENTERS FOR DISEASE CONTROL (CDC) UPDATE:** The CDC has revised its ME/CFS information booklet and were apparently ready to publish it. However, their boss, Dr. Philip Lee - U.S. Assistant Secretary for Health, said that the revision would be recirculated for further public comment. According to our U.S. friends, the proposed definition again fails to take into consideration the CNS problems that play an important part in ME/CFS. Please continue writing stressing this important point. Remember that NOW is the time to act as it will be too late when the booklet goes to press.

**ATTENTION PARENTS OF ME/FM CHILDREN & YOUTHS:** I would like to suggest that in order for the CDC to understand the full impact of this disease and how it affects anyone, regardless of age, parents of ME/FM children and youths could write a one-page report on their child or young adult outlining a small before and after ME/FM history and perhaps attach a small picture of their child to it and send it to: Dr. Philip Lee, Department of Health & Human Services, Hubert H. Humphrey Bldg., 200 Independence Ave. SW, Washington, DC 20201 U.S.A. AND TO: Dr. William C. Reeves, Chief, Viral Exanthems & Herpesvirus Branch, Centers for Disease Control, Mail Stop G-18, 1600 Clifton Road, NE, Atlanta, Georgia 30333 U.S.A.

### AMPLIGEN UPDATE - CANADA

"In regard to your inquiry about Ampligen trials, there are no trials being conducted in Canada. The Health Protection Branch has approved two trials on Ampligen,..... I have heard nothing from HEM for more than 6 months. I am sorry I cannot be of further assistance." Signed D.M.P. Thomson, M.D., PH.D., F.R.C.P.(C), Division of Clinical Immunology and Allergy, The Montreal General Hospital.

Editor's note: We are awaiting replies from Dr. I. Salit of Toronto and Dr. G. Stiver of Vancouver. The other two physicians who were being considered for the Ampligen trial.

**MEDIA UPDATE: NBC APOLOGY (sort of ):** On October 2nd, 1993 the NBC's Nightly News presented a segment on Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) wherein its Science Reporter, Mr. Robert Bazel, erroneously called CFIDS :Chronic Immune Deficiency Syndrome instead of Dysfunction as well as, in our opinion, show a narrow view about ME/CFS. We therefore wrote NBC and received the following reply: "NBC News never questioned whether the condition is real. We described its' impact and pointed out that its' cause and cure are unknown. One of the doctors interviewed expressed doubts about whether it was a SINGLE DISEASE. Another, from the CDC, commented on successful efforts to get more federal funding.

You are absolutely right about our inaccurately decoding the acronym by which some refer to the condition. We regret our error, but continue to feel that our overall story was fair.

Chronic Fatigue Syndrome is a medical mystery which turns active, healthy people into invalids. Until its' precise cause(s) and verifiable cures are found, it will remain a controversial and important topic. We will continue to monitor developments, and will do more stories as warranted." Signed Rod Prince, Executive Producer, NBC News, 30 Rockefeller Plaza, New York, NY 10112 U.S.A. - Tel. (212) 664-4444.

Editor's Note: 1) Mr. Prince advised he is drafting a response to all viewers who commented on this program. 2) Please add NBC to your mailing list to receive scientific information about ME/FM.

**NATIONAL LAWYERS' NETWORK - ME/FM Court Cases & Legal Precedents** - Lawyer, Jim Vigmond, who spearheads this Network will be leaving the law firm of Carroll, Heyd, Vigmond and going into private practice, effective December 15, 1993. Mr. Vigmond apologises for the inconvenience this may cause but stresses that he will give our cause high priority. However, there will be a slight delay due to setting up etc.for about a month or two. We will announce his new location in the next newsletter.

### **ANNOUNCEMENT:**

#### **MAY 12th INTERNATIONAL CFIDS/ME AWARENESS DAY**

Tom Hennessey, Organiser and Founder of this International event, has now formed a non-profit corporation to help promote this Day. Under the name RESCIND (Repeal Existing Stereotypes about Chronic Immunological and Neurological Diseases), Tom hopes to make the 1994 event even bigger than last year's. Contact: RESCIND, INC., 253 Byram Shore Road, Greenwich, CT 06830 U.S.A. RESCIND also hopes to print T-Shirts, Caps etc. to mark this event and is looking for ideas from everyone. They also need donations. National ME/FM Action Network has already registered with RESCIND as a participant. [Editor's Note: The 1993 event prompted 42,000 calls, letters and faxes to government offices in North America.]

**Paul Walker - Vice President, is our National Coordinator for this event.** Paul can be reached at: 139 Beech Fern Drive, Stittsville, Ontario K2S 1E2 CANADA - Tel. (613) 836-3466.

**AIDAN WALSH**, of Montreal, Quebec is coordinating a "walk" on Parliament Hill in Ottawa, Ontario which will be an all-day event. Aidan is the Co-ordinator for both the media and the public for this event. Please send us your name, address and phone number and Aiden will be in touch with you. Aidan has been contacting top government people by sending out hundreds of letters to them requesting research funds and help for all ME/FM people in Canada.

**PLEASE PARTICIPATE AND SEND US YOUR IDEAS as well as what you will be doing for that day.** We will publish the Agenda of events as they develop so that you will be able to keep your media informed and up-to-date for their participation and reporting.

### **INTER-GROUP NEWS:**

#### **CANADA:**

The **Myalgic Encephalomyelitis Society of B.C. (MEBC)** publishes a quarterly newsletter "**M.E. & You**" and in its August 1993 issue included a 12-page RESOURCE GUIDE for B.C. detailing help available for ME/FM people ranging from Financial Assistance to Home Support etc. in that Province. In its newsletter, it also published excerpts from a presentation by Dr. H. Grant Stiver (Associate Professor and Assistant Head, Division of Infectious Diseases, Department of Medicine, University of BC, Victoria General Hospital) to the Westside Support Group on April 15, 1993. This is an extremely well-done presentation and contains lots of information and a Question and Answer section. For those who are interested in receiving a copy of the presentation, please forward a stamped self-addressed envelope to us and we will forward it to you (9 pages). [Transcript edited by D. Robertson, edited for "M.E. & You by E. Hockin]. In the U.S. please forward a self-addressed envelope with a cheque for \$1.00 for postage or an international stamp.

Editor's Note: **Subscriptions to "M.E. & You"** are obtained with membership to MEBC, P.O. Box 462, 916 W. Broadway, Vancouver, BC V5Z 1K7 - Tel. (604) 526-3993. The membership fee is \$15.00 per year. MEBC is a registered non-profit Society.

**TIP FOR BRITISH COLUMBIA:** If you think you have been discriminated against because you are disabled and you wish to make an official complaint under the Human Rights Act, you can apply for Legal Aid Services. You can call a lawyer in your area who takes Legal Aid cases and tell them you want to file a complaint under the Act through Legal Aid. Whatever your financial situation is, you will be given legal aid for a Human Rights complaint. However, you may be asked to make a contribution towards your legal aid expenses, if you can afford it.

**"WHAT'S UP WITH M.E." published by the Barrie and District Myalgic Encephalomyelitis Support Group Inc:** In its' November '93 newsletter, it was reported that a Nurse in their group examined the throats of ME/FM patients. Of the 15 checked, 14 had crimson crescents. The 15th person was on antibiotics and had an inflamed throat but once she was off the antibiotics, she too showed the crimson crescents. Albert advised that they are sharing this information with doctors in their area and that some are cooperating by checking their patients for Crimson Crescents. This is not a scientific study but Barrie's President, Albert Blom, suggested that other groups might try this also. Dr. Cunha, of Barrie, advised that in 3 to 5% of the healthy population, crimson crescents are also present. It will be interesting to see what a survey in your support group would indicate and perhaps this could lead to a scientific study. If you have done this survey or plan to do so, would you please forward the results to **Albert Blom**, and we will publish the results in a later issue.

**Subscriptions to "What's Up with M.E."** newsletters are included with a yearly membership fee of \$10.00 to the Barrie and District M.E. Support Group, 33 Doris Drive, Barrie, Ontario L4N 5W2 - Tel. (705) 728-7133.

#### **UNITED STATES:**

**CONGRATULATIONS TO MARION NELSON, President, MANASOTA CFS/CFIDS Support Group.** Marion was chosen to receive the Florida Rehabilitation Association's State Citation for the many hours she has spent in the support of people ill with CFIDS. The award was presented to Marion on September 9th, 1993 in Daytona Beach. Although Marion is ill with CFIDS herself, she founded the Manasota support group in 1991 which now has approximately 200 CFIDS members, family and friends. The Manasota

group is dedicated to world-wide advocacy on behalf of patients who have this disease and continues to foster a positive attitude on the part of the medical profession toward this end.

Marion and her group can be reached at SARASOTA CFS/CFIDS SUPPORT GROUP, INC., 4930 Windsor Park, Sarasota, FL 34235 U.S.A. - Tel. (813) 371-6944.

Editor's Note: Sarasota's newsletter includes an "Ask The Doctor" section by Philip K. Nelson M.D.

### **BOOKS/NEWSLETTERS PLUS:**

**CORRECTION: REVIEW OF MAINSTREAM CFIDS RESEARCH IN THE U.S.A. 1990 through June 1992** by \*Kendra Dayger BS, Ms. Cost: In Canada: \$18.50 plus \$7.00 postage for a total of \$25.50 U.S. In the U.S.A. \$22.00 including postage. Please make cheque payable to: CFIDS-JCC and send to CFIDS Rochester Research Project, 1200 Edgewood Ave., Dept. NC, Rochester, NY 14618 U.S.A.

Editor's Note: \*Kendra reports that the Journal of the American Medical Association (JAMA) has agreed to list her book. Congratulations, Kendra!

**SAN JOAQUIN CFIDS/ME/FM SUPPORT NETWORK - 1) CFIDS In Children, A Compilation** \$5.00 U.S., Plus Postage \$2.90 1st class or \$1.05 book rate., 2) **Bearly Cookin'**, A Cookbook Compiled by San Joaquin CFIDS/ME/FM Support Network - Cost: \$7.00 (U.S. ) each or 3 for \$20.00 plus \$1.25 Postage & handling. Please send your request to: P.O. Box 724, Woodbridge CA 95258-0724 U.S.A. Editor's Note: Also publishes newsletter "Snail Mail".

**SUSAN F. DION, Ph.D.**, is author of the book ***Write Now : Maintaining a Creative Spirit While Homebound and Ill*** . This 90-page Guide is **free** to patient groups, caretakers, and related agencies and is made possible by a grant through the Puffin Foundation, Ltd. It provided monies for a limited number of printings, while author Susan Dion worked without remuneration. To receive a print copy of WRITE NOW: In the U.S., please send a self-addressed and stamped (one \$0.29 and four \$0.23 stamps) 6 x 9 (OVERSIZED) envelope; In Canada please forward \$3 or \$4 to cover the cost of mailing it. This Guide is also available for desktop publishing (Macintosh; Microsoft Word 4.0) in two formats (consecutive page and printer's saddle stitch). To receive the desktop publishing formats, send a 3.5 in. disk (DD or HD) and self-addressed appropriate-sized return mailer with correct postage or funds.

**PLEASE SEND REQUESTS TO: S. Dion**, 432 Ives Avenue, Carneys Point, NJ 08069 U.S.A. Donations toward a second run of print copies are welcome. (Please make Cheques payable to S. Dion/Write Now).

**DISABILITY INSURANCE - FEDERAL:** In reply to our letter of October 12th to the Office of the Superintendent of Financial Institutions Canada, they advised in their October 18th the following:

"I sympathize with the concerns raised in your letter. Under the division of powers set out in the Constitution Act, the federal government's authority in insurance matters is limited to ensuring, to the extent possible, that federally registered companies remain in a financial position to be able to meet their contractual obligations to policy holders. The Office has no jurisdiction over provincial Superintendents of Insurance.

The regulation of provincial insurance companies, matters of contract, general business practices and underwriting criteria of all insurance companies fall exclusively within provincial jurisdiction.....

The Office's role in dealing with consumer complaints is limited to that of mediator. We contact financial institutions to ask for comments or explanations in the hope that we can contribute to resolving disputes. Although we do not have the power or mandate to settle disputes, we hope that our intervention assists in bringing both parties together so that differences can be worked out. If this does not work, consumers can

choose whatever other course of action they deem appropriate." Signed: Michel Beaudry, Acting Director, Communications and Public Affairs, Office of the Superintendent of Financial Institutions Canada, 255 Albert St., 13th Floor, Ottawa, Ottawa, ON K1A 0H2 - PHONE: 1-800-387-0700

Editor's note: 1) The phone numbers of the provincial superintendents were listed in our October 1, 1993 newsletter - Communication #2. 2) underlining done for emphasis by editor.

**TIP:** Call 1-800-387-4456 Office for Disability Issues - Government of Ontario and ask for the GUIDE to ONTARIO GOVERNMENT PROGRAMS & SERVICES for PERSONS WITH DISABILITIES and for Statistical Profile of Disabled Persons in Ontario, Volume II

### **ADDITIONS TO OUR BOARD OF DIRECTORS:**

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

**Vice-President: Paul Walker** - 139 Beech Fern Drive, Stittsville, Ontario K2S 1E2 Canada - Tel. (613) 836-3466. Paul is also in charge of the MAY 12th ME/CFIDS Awareness Day;

**Treasurer: Michael Diplock**, 982 Alenmede Cr., Ottawa, Ontario K2B 8K5 Canada - Tel. (613) 726-1868. Mike hopes to publish our Financial Statement in our next issue, February 1, 1994;

**National Director - ME Education: Ken Coleman**, 200 Dora Spencer Rd., Apt. 915, York, Ontario M6M 5G5 Canada - Tel. (416) 245-4001. Ken is presently drafting a national ME/FM survey and we will be writing more about that in our next issue;

**Director - Steering Committee: Otto Cepella**, 1771 Rhodes Cr., Ottawa, Ontario K1H 5T1 Canada - Tel. (613) 737-3790. Otto's son, Rick of BC, has ME/FM;

**Director - New Brunswick: Grant Tyreman**, Juvenile Settlement, Hoyt, New Brunswick E0G 2B0 - Tel.(506) 687-4336.

**EFAMOL NEWS - U.S.A.** "Evening Primrose Oil made by Efamol was officially relaunched at Expo East in Baltimore last September. The only aspect to note is that Evening Primrose Oils sold in the U.S. do not contain the antioxidant vitamin E as this change was necessary to comply with FDA requirements. If the US support groups would like to explore the possibility of group purchases they should contact Karl Liffirth at Nature's Way Products, Inc. 10 Mountain Springs Parkway, Springville, Utah 84663 U.S.A. Tel. (801) 489-3635, Fax (801) 489-3639". Signed: Michael Winther, Laboratory Director, Efamol Research Inc., Nova Scotia, Canada.

**TIP:** Human Rights Issues can fall either under Provincial or Federal Jurisdiction. To find out where your complaint falls under, call your local Labour Canada or Human Rights Office.

**INSURANCE SURVEY UPDATE:** As discussed in Communications #2, our Survey Questionnaire is now completed. It took a little longer than we thought but we wanted to make sure all our Directors had a chance to look at it and put in their suggestions. Thanks to Byron Timmermans, Maxine Verney and Ken Coleman. This form will go out the moment we have enough money for copies and postage. Confidentiality details are set out in the questionnaire.

**WANT TO START A SUPPORT GROUP but don't know where to start?** Send a stamped self-addressed envelop (\$1.00 for U.S. or international stamp) to me and I will send you a 10-point How-To for Beginners.

**WELCOME TO OUR WORLD:**

SET BACK: Taking two steps backwards after taking three.

CRASHED: Taking four steps backwards after taking three.

RELAPSE: Start at crawl position.

**Quotable Quotes:** "The only predictable thing about ME is its unpredictability" Dr. Philipa Corning in her own testimonial "Returning to Work and Regaining Good Health" (5 pages) Still available by sending: In Canada: a stamped (\$0.43) self-addressed envelop to me. In the U.S. please send \$1.00 instead of postage or an international stamp obtainable from Post Office.

**SUBSCRIPTIONS** to the NATIONAL ME/FM ACTION newsletter which is published every two months, is included with an **annual membership fee of \$20.00.**

### **PARTICIPATE IN THE ACTION AND BECOME A MEMBER.**

**N.B.** We are incorporated as a non-profit organization. However, we have not yet been approved for charitable status and therefore are unable to issue tax receipts.

Until next time, take care.

Lydia E. Neilson, President

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