

Quest #2 October 1993

Dear Friends:

I wish to thank those of you who have either written or called to pledge your support and enthusiasm about our new organisation and for sending us enough money so that we were able to send out this newsletter as well as our past issue free of charge to those who are not yet members. Without your help, this would not have been possible. Thank you also for putting an announcement about our organisation into your newsletters.

The time has come that we will no longer be on the defensive and take the blame for being ill. It is up to us to stand up for our rights that others can take for granted. Yes, each and everyone of you can make a difference in doing your part. For some it may be writing letters while to others it could be telephone contact. Whatever it is, collectively, we have power that can lead to change.

Through our newsletters, we will endeavour to cover the issues that are so pressing to most of us but, we are not perfect. If anything gets overlooked or if there are other needs that have not been addressed, please let us know.

Lydia E. Neilson, President.

AMPLIGEN UPDATE:

CANADA - In reply to my letter of September 1, 1993 to Health & Welfare Canada, Health Protection Branch, regarding the status of Ampligen, Jacques Bouchard, Ph.D. in his letter of September 30th advised the following:

"Ampligen was cleared by the Health Protection Branch (HPB) on November 2, 1992 for clinical investigations in the treatment of Chronic Fatigue Syndrome within the confines of the following two proposed studies:

1. A multi-centre, double-blind, placebo-controlled study of the safety and efficacy of Poly I:poly C12U (Ampligen) in patients with Chronic Fatigue Syndrome (Protocol No. AMP-507).
2. A clinical study to evaluate the activity and safety of Poly I:poly C12U (Ampligen) in patients with severely debilitating Chronic Fatigue Syndrome (Protocol No. AMP-509).

The two cleared clinical protocols have not been withdrawn by the Sponsor of Ampligen. The Sponsor, however, is not required to inform the Health Protection Branch when implementation of protocols is delayed or notify us when clinical trials are not implemented due to administrative reasons. Signed: Jacques Bouchard, Ph.D. A/Chief, Aids & Viral Diseases Division, Bureau of Human Prescription Drugs"

Editor's Note: We have also written to Dr. Irving Salit of Toronto and Dr. Grant Stiver of Vancouver to find out what has transpired, if anything, and are presently awaiting a reply. These physicians were mentioned by HPB as being considered to run the Ampligen trials, in addition to Dr. Dave Thomson of Montreal.

AMPLIGEN - U.S.A. Issue No. 24 September 24, 1993 - Washington, DC CHRONIC FATIGUE SYNDROME Electronic Newsletter. Editor: Roger Burns, 2800 Quebec St. NW, #1242, Washington, DC 20008 U.S.A.

HEM Pharmaceuticals has suspended the Ampligen trials and has stopped supplying the drug to patients who were trial participants and who were receiving the drug on a compassionate plea basis. HEM stated that this action was necessary as a part of its current financial restructuring.

I think Dr. Daniel Peterson sums it up best when testifying before the FDA last May 18th: "Although [Ampligen] appears to have great potential in this disease process, it has been bogged down in a corporate and bureaucratic quagmire and yet the disability and the anguish of the patients and treating physicians remains unaddressed." Quote appeared in an article by Neenyah Ostrom in the New York Native, issue #545, Sept. 27, 1993 and reprinted by Roger Burns.

CENTRE FOR DISEASE CONTROL UPDATE:

The U.S. Centers for Disease Control and Prevention held a meeting on September 27th and 28th to receive testimony related to the current CFS case definition. Many requested that the name CFS be changed while others requested that the definition be broadened to allow patients to be properly diagnosed and/or to allow them to

qualify for disability benefits. Some suggested that CDC should consider creating both a research and clinical definition. Some CDC staff members suggested that only the research definition should be dealt with and that the definition should be narrowed. However, the 14-member CDC panel did not seem to reach any conclusion about any of these matters and decided to reconvene after a month or so to consider making decisions on these outstanding matters. However, they did agree that changing the name CFS to something more appropriate "was not in the cards".

As you know, the CDC decision affects all of us and we are still dealing with the repercussions of the old definition. Now is the time to act and protest. Please write to: CENTERS FOR DISEASE CONTROL, Office of Public Affairs, Building 1, Room 2067, 1600 Clifton Road NE, Atlanta, GA 30333 U.S.A. Please write individually as it has more of an impact. In order to make it easier for those who are not well enough to write their own letter, why not compose a letter, photocopy it and hand it out to all your members so that all they need to do is sign it, and send it off. This will have more value than a petition signed with hundreds of names but is still one piece of paper.

Editor's note: We have sent a letter to the CDC with a copy to the First Lady, Ms. Hillary Clinton, White House, 1600 Pennsylvania Ave., Washington, DC 20006 U.S.A.

INSURANCE QUESTIONS AND ANSWERS:

I contacted the Ontario Insurance Commission on some frequently asked questions. [The Ontario Insurance Commission is a provincial regulatory body and, can only comment on Ontario procedures. Address: 5160 Yonge St., Box 85, North York, ON M2N 6L9 - Tel. 1-800-668-0128] Mr. Bruce D. Green, Insurance Assistance Officer - Market Conduct Branch, in his letter of September 22, 1993 replied as follows:

"Unlike the automobile insurance policy, there is no standardised policy in the disability insurance industry and therefore the answers will vary somewhat from company to company;

Consumer's Right to the Medical Report: When an insurer orders a medical and pays for that report, it becomes their property and the consumer does not have a right to a copy of that report. An insurer may, upon request, send a copy to the claimant's family physician;

Consumer's Right to Refuse Medical: An insurer will exercise the right found in most contracts to have the claimant examined by a doctor or specialist of their choice. If the claimant refuses this appointment, this refusal may place the continuation of benefits in jeopardy;

When an out-of-province doctor is selected by the insurer for an independent medical examination, then the costs incurred in attending this appointment should be borne by the insurer;

Copy of Employer's Policy: A group disability policy is a contract between an employer and the insurance company which provides the benefits to the employees. As the employee is not a party to the contract, however, he/she has no right to a copy. The employee does have a right to a certificate of insurance outlining the coverage afforded under the plan.

Termination of Benefits by Insurer: With disability plans, the medical evidence available to the insurer is the primary factor in the continuation or termination of benefits. If the company has terminated benefits, it is probably due to an absence of objective medical evidence or they have received a medical report which indicates that the consumer is able to return to some form of employment. Many plans contain a change in the definition of "disabled" and as such, the benefits may be terminated at some point due to the claimant's inability to satisfy the new definition of disability.

In many cases, the best way to initiate the continuation of benefits is to provide the insurer with new medical evidence which would satisfy the policy's requirements. Many companies do make appeal processes available to claimants who disagree with a company's interpretation of medical reports, and through these processes, companies are usually quite willing to consider new medical documentation. Should these efforts fail, the claimant may be forced to seek legal advice.

It is critical that each case be analysed within the scope of the policy wording itself, as there is no standardised policy": *underlining by Editor.

To obtain information for your province call, Superintendent of Financial Institutions:

ALBERTA (604) 666-5335 BRITISH COLUMBIA (604) 666-5335

NEW BRUNSWICK (514) 283-5835 NEWFOUNDLAND (514) 283-5835

NOVA SCOTIA (514) 283-5836 ONTARIO (416) 973-6662

PRINCE EDWARD ISLAND (514) 283-5835 QUEBEC (514) 283-5835

SASKATCHEWAN (204) 983-4140 NORTH WEST TERRITORIES (613) 990-7890

MANITOBA (own program) (204) 945-2542

Editor's Note: Call Collect, except for North West Territories.

LAWYERS' NETWORK - ME/FM COURT CASES AND LEGAL PRECEDENTS:

We are pleased to announce that Lawyer, James L. Vigmond, Esq. has agreed to head up our organization's National Lawyers' Network dedicated to ME/FM cases with a view to developing the appropriate protocol and to provide advice to those who need it. Please inform your lawyer about this valuable assistance that is now available. Mr. Vigmond has done extensive legal research on ME/FM and has and is representing ME/FM patients in the courts. He has also lectured on these topics at Local ME/FM support groups. To assist Mr. Vigmond in getting this National Registry started, please send a copy of any court judgments of relevant cases or advise him of details of court cases so that copies can be obtained to:

JAMES L. VIGMOND, Esq, Carroll, Heyd, Vigmond, Solicitors, P.O. Box 548, 89 Collier St., Barrie, ON L4M 4T7 - Fax: (705) 722-0704 - Tel: (705) 722-4400.

INSURANCE DISABILITY BENEFITS:

We are also pleased to announce the appointment of BYRON TIMMERMANS as our National Director, Insurance Matters which includes Workmen Compensation cases. Byron is also President of the Northern Ontario Fibromyalgia Network. He is very familiar with the insurance disability problems experienced by many people and often assists them in trying to obtain disability benefits. Byron will be writing in our newsletter about his progress in insurance, CPP and WCB statistics in future issues.

In order to put us in a better position of negotiating with the insurance companies, it is important we collect certain information to help our case. We are therefore in the final stages of drafting a questionnaire for your completion and return. This questionnaire will be sent out sometime (hopefully) this month and once the data is in will give us a better idea of how many outstanding insurance cases there are, the names of the insurance companies involved, how many cases are pending for trial, how many are settled and so on. This information will be treated with the utmost of confidentiality and the names of the individuals will be replaced by a number so that there is no chance of identifying anyone.

Anyone having problems with collecting their disability pensions and/or with the Workmen's Compensation Board, please get in touch with:

BYRON TIMMERMANS, 720 Downland St., Sudbury, ON P3A 5T3 (705) 560-4936

MEDIA WATCH: We are pleased to announce the appointment of Maxine Verney as National Director - Public Relations. Maxine is in charge of replying to misinformation from all sources. To help Maxine, please send her copies of any articles that appear in newspapers etc. or from any other sources that is misleading or detrimental to our cause. Do not, however, limit yourselves to negative articles as we also want to give praise to sources who give accurate information. Maxine will also keep you advised through our newsletters. Please send information to:

(NOTE: Please make sure that articles contain the name, date, address & phone number of source.)

MAXINE VERNEY, 52 Maplewood Dr. Shelburne, ON L0N 1S0

ME/FM ELECTRONIC RESOURCES - SPECIAL THANKS TO SANDY SHAW who is responsible for repairing my Mac and for installing the communication software needed to communicate via Electronic mail. Sandy also runs a Bulletin Board System (BBS) in Ottawa called "The Wholebit". This BBS is connected to the Fidonet electronic network. He carries a number of international conferences related to ME/FM as well as Files with related information, and is the sponsor on a ME/FM info area on the National Capital Freenet (part of the Internet Network and E-mail system). Sandy has ME/CFS for a long time but uses his BBS and Freenet accounts to keep in touch with others with ME/FM in North America.

Sandy tries to keep up to date on new information on ME/FM and makes this information available on his BBS and FREENET information area. He is a founding member of the CFS/ME Computer Networking Project, run by ME/FM people to facilitate exchange of information, encourage discussion and support for people interested in ME/FM. It is not affiliated with any other organisation and is unfunded. The project is now releasing a 7-page report "CFS/ME Electronic Resources". To receive a copy, send a stamped self-addressed envelope to me and I will pass it on to Sandy. Sandy's BBS can be accessed by computer-modem at (613) 521-3690. Its Fidonet No. is 1:163/221; The National Capital Freenet (613) 780-3733 or through a FREENET or Internet in your area. Sandy's E-Mail address is aa328@FREENET,CARLETON.CA. I can be reached by E-Mail on Sandy's BBS or on Freenet as ag922@FREENET.CARLETON.CA.

CORRECTION: QUACK QUACK -With our Communication #1A we had enclosed a copy of The Goose Story which appeared in Janice Winchester's [SGL - Orilia], newsletter. We wrote "Author Unknown - Large print: Janice Winchester's words". Janice informs us that she is not the author of either The Goose

Story or the large print. We can therefore only credit her for seeing the value of the story and printing it in her newsletter. Thank you, Janice.

RETURNING TO WORK & REGAINING GOOD HEALTH: by Dr. Philipa Corning. This is a short autobiography (5 pages) written by Dr. Corning. Very seldom do we hear from anyone who has recovered and gone back to work within a year. Philipa has done just that. Please send a stamped self-addressed envelope to me and I will forward a copy of Philipa's report to you.

WELCOME TO OUR WORLD:

SPACED OUT: My body is here but my brain is out to lunch.

M.E. SHUFFLE: I am trying to walk slower than my heartbeat to preserve energy.

DRS (Delayed Reaction Syndrome): I can hear you but my brain needs to catch up.

WISH LIST:

TELECOMMUNICATIONS DEVICE FOR THE DEAF (TDD) in order for us to be able to reach our

ME/FM deaf or hard of hearing friends (Cost approx. \$900.00);

FAX MACHINE - (Cost \$600 and up);

FILING CABINET - (Cost \$300.00). Used but workable equipment gratefully accepted.

MEMBERSHIP FEES: *\$20.00 per year. Please make cheque payable to:

NATIONAL ME/FM ACTION NETWORK

and send to 3836 Carling Ave., Hwy 17B

Nepean, Ontario K2H 7V2 CANADA.

Due to limited funds, this will be the last newsletter that we will be able to send free of charge. We need you to subscribe and encourage others to do the same so that we will be able to continue to concentrate on the welfare of all ME/FM individuals. Worrying about where our next mailing funds are coming from, is both stressful and time-consuming and we much rather spend our time on important issues.

N.B. We have applied for charitable status which has not as yet been approved. Therefore, we are unable to issue a tax receipt. We are incorporated as a non-profit organisation.

BOOKS/NEWSLETTERS

The MEssenger - published monthly by ME CANADA and is included with membership of \$35.00/year payable to M.E. CANADA, 400-246 Queen St., Ottawa, Ontario K1P 5E4 Canada. Tel. (613) 563-1565.

Newsletter Exchange Program: LINDO COMMONS, Indiana CFS Association, 810 N. Bancroft, Indianapolis, Indiana 46201 U.S.A. Tel. (317) 252-9223.

The CFS DysPATCH - published bi-monthly, Cost per year: U.S. \$15.00; Canada \$17.00; Foreign \$24.00 (U.S. Currency) payable to: CFS DysPATCH, 997 J Dodds Blvd. #811, Mt. Pleasant, SC 29464-6119 U.S.A. Tel/Fax (803) 881-0216.

International Coalition of Long-term (10+) CFIDS/ME Patients - As you know, many articles and reports claim that people recover from this disease within 2 to 6 six years. This organisation is trying to obtain statistics on patients ill for longer than 10 years and want to hear from you who fall in that category. Please contact: MAGGIE MCKENZIE, 171 Naubuc Ave., East Hartford, CT 06118 U.S.A. - Tel. (203) 569-4091 or ROBERT FONTANETTA, 257-20 Hillside Ave., Floral Park, NY 11004 U.S.A. - Tel. (718) 347-4509.

International Health Foundation, Inc. Founded in 1986 to help people with yeast-related health disorders. Publishes Quarterly newsletter "Healthline". Cost \$25.00 per year. Address: P.O. Box 3494, Jackson, Tennessee 38303 U.S.A. Editor: William G. Crook MD, a well-known candida expert and author of Chronic Fatigue Syndrome and The Yeast Connection, and other books.

Review of Mainstream CFIDS* Research in the U.S.A. 1990 through June 1992 by Kendra Dayger BS,MS. This book is still available but due to its popularity, its author was unable to say how much longer. Cost \$22.00 U.S., including postage. Cheque payable to: CFIDS-JCC and send to CFIDS Rochester Research Project, 1200 Edgewood Ave., Dept. NC, Rochester, NY 14618 U.S.A.

Recovering from Chronic Fatigue Syndrome by William Collinge M.P.H., PH.D.Excerpt: "If, on the other hand, recovery means re-establishing a sense of equilibrium, control, harmony and quality in your life, then your recovery is desirable and possible." Available from local book stores - Canada \$18.50 - U.S. \$13.50

Editors Note: The title of this book should not be interpreted as promising a cure for ME/CFS.

TIP: Tax Information for People with Disabilities "Services for People with Disabilities - Claiming the Disability Tax Credit" Booklet P149(E) - Call your local District Taxation Office for this booklet.

DISCLAIMER: The NATIONAL ME/FM ACTION NETWORK serves as a clearing house for ME/FM information. The ideas expressed by each columnist are strictly his/her own. 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.

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Until next time - Take care and remember you are not alone.

10/93 Lydia E. Neilson, President