Quest #14 October 1995

HEALTH CANADA GRANT: Minister of Health, The Honourable Diane Marleau, has just announced the approval of grants to National Voluntary Health Organisations for 1995-1996 and she has informed us that our organisation has been approved for a Grant of $35,000 to help with our National projects. Ms Marleau congratulated our Board, and volunteers for their dedication and achievements over the past year and wished our Organization success for the year ahead. We should be receiving our Grant in about four to six weeks.

PETITION TO THE HOUSE OF COMMONS - UPDATE: National Total: 14,279

Breakdown by Province: Saskatchewan: 222; Ontario: 10,793; Quebec: 372; Manitoba: 954; Nova Scotia: 455; British Columbia: 751; Prince Edward Island: 211; New Brunswick: 220; Newfoundland: 39, Alberta: 262.

We have been working very closely with M.E. Ontario and Northern Ontario Fibromyalgia Network Inc. and as a result we have successfully secured the help of Ms. Beryl Gaffney, who is a Federal MP and is preparing a Private Members Bill to be presented to the House of Commons. We would like to encourage you to write to Ms Gaffney and thank her for her efforts, along with a note as to how ME/FM have impacted your life. It certainly would not hurt also if included with your letter or instead of a letter, proper scientific literature is sent with it. Please address your correspondence to **MS BERYL GAFFNEY, MP - HOUSE OF COMMONS, OTTAWA, ONTARIO K1A 0A6** and put her on your mailing list**.**

PROVINCIAL GOVERNMENT - ONTARIO

We have had written and verbal discussions with the present Harris Government re: Insurance Legislation and will be meeting with them in the next few weeks and once we have met with them, we will be in a better position to advise what kind of assistance we may require. Although we are presently dealing with the Ontario Government, the same will be done for each Province and Territory.

DISABILITY TAX CREDIT - Form T2201

As many ME/FM people have been denied this Credit, we instituted talks with Revenue Canada. We pointed out to them that this Credit was virtually impossible to obtain due to its stipulated wording. From our conversations, it was suggested that if you are denied this Credit 1) Appeal; 2) If Appeal denied, advise Revenue Canada that you wish to take your case to Tax Court. There is no costs involved in doing so. This will delay any payback for up to one year. This can be done easily without legal help. In the meantime are discussing with a Tax lawyer challenging this legislation in Court in order to address the unfairness of the legislation. Please remember to contact me if you are experiencing difficulties. **MIKE MARTIN, 31A Kadeer Way, Nepean, Ontario K2J 1J6 - Tel. (613) 825-2019.**

ONTARIO'S TEACHERS' FEDERATION: Northern Ontario Fibromyalgia is considering filing a grievance with the Human Rights Commission due to the Federation's approach to teachers who have been disabled. Please contact us if you are having problems with this Ontario Federation. Please call or write: **Northern Ontario Fibromyalgia Assoc., 720 Downland Ave., Sudbury, ON P3A 5T3 - Tel. ((705) 560-4936.**

LABORATORY CENTRE FOR DISEASE CONTROL - CANADA

We had written the LCDC on July 14th, 1995 requesting information as to what LCDC was going to do in Canada now that the new December 1994 definition and criteria had been published from the Centers for Disease Control in Atlanta. As no reply had been received, we followed up our request asking for a reply which we finally received via Courier on October 19th, 1995 and is quoted in its entirety:

"Thank you for your letter and information package on the above-named subject. I apologize for the delay in responding.

While I fully appreciate and share your concern about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia (ME/CFS/FM), these conditions, unfortunately, remain a very complex and intriguing group of diseases. Although many theories have been put forward to explain their causes, there still remains many unresolved issues that need further research and elucidation.

To this end, the Laboratory Centre for disease Control (LCDC) held a workshop on CFS/ME in September of 1989, to explore the diagnosis of the illness, its proper case definition and promising areas for future research. Its proceedings were published in January 1991, and are believed to have assisted the scientific community to formulate research studies to investigate the case of this disorder. LCDC also provided funds for a further workshop organized by the Nightingale Research Foundation in Vancouver in May 1991. Experts from Canada and abroad attended this workshop targeted to the need for precise research protocols and the care of patients.

In June 1992, a group of Canadian experts met to discuss the allegation of an association between hepatitis B vaccine and CFS. This working group concluded that there was no evidence to justify further research on a relationship between CFS and hepatitis B vaccine. However, postmarketing surveillance for side effects related to hepatitis B vaccine, including CFS, will continue. If surveillance data suggest a possible relationship, further work will be undertaken.

Over the years, the National Health Research and Development Program (NHRDP) of Health Canada has funded various research projects to investigate into the cause and other aspects of ME/CFS/FM, and will certainly continue to entertain research proposals on the subject. Similarly, the Medical Research Council (MRC) has always been open to considering research submissions on this issue through its peer review process.

As alluded to in the Minister's letter to you in June, because of budgetary constraints, the Laboratory Centre for Disease Control is not in a position to conduct its own research on these diseases at this point. We will, however, continue to work with NHRDP and MRC to facilitate research in this important area.

I appreciate very much your writing to me on this matter. Hopefully, with continuing government funding and dedicated research efforts of the scientific community, we will continue to make progress in resolving this important health problem." **Signed: Dr. J.Z. Losos, MD,DECH,FRCPC,FACPM, Director General, Laboratory Centre for Disease Control, Tunney's Pasture, Ottawa, Ontario K1A 0L2.**

[Editor's note: As far as we know, no follow ups were ever instituted after the original workshops in 1989 and 1991. Please put Dr. Lozos on your mailing list].

BOOKS, NEWSLETTERS VIDEOS ETC. "Fibromyalgia, Chronic Fatigue Syndrome, and Repetitive Strain Injury - Current Concepts in Diagnosis, Management, Disability, and Health Economics" by Andrew Chalmers, MD; Geoffrey Owen Littlejohn, MD; Irving Salit, MD; Frederick Wolfe, MD - Price: $36 U.S. (reg.$45) Publisher: The Haworth Medical Press, 10 Alice Street, Binghamton, NEW York 13904-1580 U.S.A. You can order by mail, by phone: 1-800-342-9678; by Fax: 1-800-895-0582 or by E-Mail Subscribe@haworth.com .

TIP: **JANCANA** (JOB ACCOMMODATION NETWORK IN CANADA is for people with disabilities who often require job accommodations in order to perform to their potention. What alternatives are available for employers and employees? **Call 1-800-526-2262 for more information.**

SEATTLE, WASHINGTON - CONFERENCE: FIBROMYALGIA, CHRONIC FATIGUE & RELATED DISORDERS - February 2 - 5, 1996 - FOR PATIENT & DOCTOR, For information: **Phone/Fax (206) 362-2310**, or write: **Seattle Fibromyalgia International Team, Inc., P.O. Box 77373, Seattle, WA 98177-0373, U.S.A.**

JOHNS HOPKINS UNIVERSITY - **UPDATE** on Neurally Mediated Hypotension. Johns Hopkins are pleased to assist those seeking more information about Chronic Fatigue Syndrome and Neurally Mediated Hypotension. You can call: 1-410-821-7253. Callers can also request a copy of the Press Release on this matter, and/or an information sheet about an upcoming randomized-controlled trial in the Baltimore/Washington region.

TIP: To learn more about: Allergies, Sensitivities, and Asthma - Contact: Allergy and Environmental Health Association (AEHA) at **1-800-695-9271**

MOTOR VEHICLE ACCIDENT - UPDATE: The efforts to complete a thorough study into insurance industry conduct, have now reached its initiation stages. Upon completion of this study, we will document related data, example cause/effect of outdated insurance tactiques., cause/effect on patients/family/friends, and other related compounding factors....of abuse. I cannot stress enough the importantance and the need for absolute efficiency in gathering this information, and the absolute need of your involvement. Study questionnaires will be distributed to all participants.

We require 1,000 persons for our control group and we require 1,000 persons for our sample group. The definition of each group will be carried out internally, based on the information you give us. All participants are guaranteed the utmost confidentiality. Upon application, you will become known to us by a computor designated code. The deadline is January 31, 1996. All applicants will be immediately sent the survey which can be completed by the patient, and another to be completed by your significant other. This data will allow us to prepare a legal manual of statistical information for future lobby efforts; law reforms; for litigation purposes; and for medical criteria to be supplied to a study team. YOUR IMMEDIATE PARTICIPATION WILL DETERMINE THE SUCCESS OF OUR FUTURE. Please contact: **WAYNE KASBEY, 44 Concession 11, R.R. #4, Crysler, Ontario K0A 1R0 - Tel. (613) 987-2405.**

POSSIBLE FUNDRAISING PROJECT: A new fundraising idea is presently being considered. We are planning to co-write a book that has been tentatively titled "Non-Disclosure" The Truth About Group Insurance Plan. This book would have about 9 or 10 chapters of individual's stories about their unfair treatment by their employers and insurers.

We would like to request that you submit a brief essay on why you feel your story would be of interest and may be considered for the book.

INTER-GROUP/CONTACT COMMUNICATIONS

NAME CHANGE: THE M.E. SOCIETY OF CALGARY has officially changed its name to **THE MYALGIC ENCEPHALOMYELITIS/FIBROMYALGIA SOCIETY OF ALBERTA.** Like ourselves, they found that they have an increasing number of members who have been diagnosed with FMS and by changing its name, it more accurately reflects the changing nature of its membership and its increasing role in the larger community of Alberta. Their address is still Box 30402, 1323 - 6455 MacLeod Trail S.W. Calgary, AB T2H 2W2 - Te. (403) 248-7773.

DOROTHY HILTZ of the **Collingwood M.E. Support Group** is stepping down as Leader after the October 1995 meeting to "give more time and energy to personal things". Dorothy has worked very hard and we thank her for her unselfish devotion. Take care, Dorothy, and thank you.

[We do not yet know as of this writing who her replacement might be].

FIBROMYALGIA CONVENTION - OREGON 96 "A NEW ERA OF UNDERSTANDING, Planned by patients for patients" - September 6 - 8, 1996. Fore more information, Contact: Oregon Fibromyalgia foundation, 1221 SW Yamhill, Suite 203, Portland, OR 97205 U.S.A. Tel. (503) 228-3217 or Fax: (503) 273-8778.

ENTEROVIRUS EVIDENCE FOUND BY PCR A study by a Glasgow, UK research team has found evidence of enteroviruses in some CFS patients, and that most of these enteroviruses do not match those that have been previously identified by scientists. This study used polymerase chain-reaction (PCR) to make a sensitive analysis of blood and throat swab samples to identify the sub-class of enterovirus, and the kinds of enteroviruses whose PCR profiles are currently known were mostly excluded by this study.

Enteroviruses are a class of virus that include the polio virus, and many British researchers and others have long believed that enteroviruses may play a role in CFS in many patients. Previous studies on this topic by Gow, Behan and others, have shown contradictory results, however. CFS-News, July 31, 1995.

[Enterovirus: a proposed genus of viruses that includes poliovirus types 1 to 3, coxsackieviruses A and B, echoviruses, and the enteroviruses. (page 338 of the Stedman's Concise Medical Dictionary - 2nd edition].

PERSONALS

CONGRATULATIONS to**Jan Montgomery and Marya Grambs of the CFIDS Foundation, San Francisco**, California who advise that the Foundation has been closed as of July 1, 1995. However, due to their continuous fight to establish a clinic for ME, their efforts were successful and a ME Clinic will operate out of the Neurology Department of the University of San Francisco School of Medicine.

DORIS M., Pickering, ON. - No one has the right to make you feel like that. The doctor/patient relationship has changed. You must play an important role in your health and therefore become a partner in your care with your doctor.

RE: ALBERTA JUDGEMENT - INTERVENOR STATUS - BALANCE SHEET

F.A.C.T.Alberta received the following donations: British Columbia: $10.00; Alberta: $3,253.00; Manitoba: $260; Ontario: $1,450; New Brunswick: $100.00; P.E.I. $10.00; Newfoundland: $75.00 - Tota: $5,169.00 Plus: CFAC Flower Sale: $1,383; Rebate for Extra-Provincial License: $175.00; Royal Bank Interest: $0.18; **TOTAL: $7,726.18**

BREAKDOWN: Printing & Photocopying: $1,154.61; Office Supplies: $807.50; Postage & Mailing: $707.29; Parking: $123.66; Phone/Fax: $942.25; Bank Charges: $73.56; Fund raising supplies/Costs: $963.00, Legal Fees/License/Secretary overtime: $780.85; Miscellaneous: $838; *Future Expenses (Balance) $335.26.which includes sending out complimentary copies of the educational research package which is a follow up of the Intervenor Status Application and additional expenses. Should any monies be left, they will be transferred to the National ME/FM Action Network, Ottawa.

N.B. This financial statement includes all expenses and disbursements related to Intervenor Status which were incurred by our lawyers (Maureen Morgan and Deborah

Straw); the Calgary Fibromyalgia Action Committee; the National ME/FM Action Networ; Drache, Burke, Robertson & Buchmayer Legal (Ottawa) and the cost of obtaining an Extra-Provincial License for Alberta. The financial statement also includes the cost of sending our thank you letters and a copy of the judgment to those who kindly gave donations. **Marj van de Sande, Director for Alberta, National ME/FM Action Network and Chairperson of CALGARY FIBROMYALGIA ACTION COMMITTEE (F.A.C.T.), C/O 1824 VARSITY ESTATES DR. N.W., CALGARY, AB T3B 2W9.**

[Editor's note: A special thank you to **MARJ VAN DE SANDE**, without whom we would not have been able to accomplish what was necessary in the Intervenor Satus in Alberta. She worked very hard to make everything look easy but actually took lots of time and 'energy']. A special thank you also to **BOB VAN DE SANDE**, Marj's son, for his computer expertise regarding intervenor status and for designing the thank you certificates.

WELCOME TO OUR WORLD

CONFUSION: Warning to avoid multiple choice questions.

DIFFICULTY TO PLAN AHEAD: a crash course in 'SPONTANEITY'

The NATIONAL ME/FM ACTION NETWORK is an incorporated non-profit organization solely dedicated to helping ME/FM individuals. Its newsletter 'QUEST' is published every two months. MEMBERSHIP is $20.00 per year and includes newsletter.

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