Quest #12 June 1995

PETITION TO THE HOUSE OF COMMONS - UPDATE - WE HAVE MORE TIME

The response to our request for signatures for our Petition to the House of Commons was terrific. There was not enough time to present the Petition as they are breaking for the summer. Therefore, we will be accepting Petitions until **Friday, September 15th, 1995**. If you still have forms, feel free to photocopy them front to back so that the forms do not need to be stapled. This form is also available in French. If you have no forms, please let us know and we will send you one. Our finances do not permit us to send another mailer across Canada to all the known support groups

RESULTS - **Total signatures received to date - 13,003.**

Broken down by Province: Alberta: 220; British Columbia: 713; Manitoba: 954; New Brunswick: 211; Newfoundland: 39; Nova Scotia: 455; Ontario: 9,923; Prince Edward Island: 186; and Quebec: 302.

INSURANCE MATTERS -

1) ALBERTA JUDGMENT - Re: Action No. 9201-12776 - MACKIE vs Wolfe - IN THE COURT OF APPEAL IN ALBERTA

UPDATE: by: Marj van de Sande, Chairperson - The Calgary Fibromyalgia Action Committee - Affiliate of National ME/FM Action Network - The Notice of Motion, Memorandum and Affidavit were filed at the Court of Appeal on May 29, 1995. These matters were heard on June 12, 1995. We were denied Intervener Status. However, the Judge did make some statements which could benefit us, if he puts them in writing. We are now waiting for his written decision which will take approximately two months. We will keep the audio tape which was made of the proceedings, in case the Judge in his written statement does not mention anything about it. If that is the case, the audiotape will be transcribed for further follow-up with the Judge.

The response for financial help was terrific so that we have enough money to pay the legal expenses incurred. Lawyers, Maureen Morgan and Deborah Rose Harriet Straw will be issuing a Financial Statement which will be sent to all who donated, as well, it will be published in our Newsletter. In addition, Mr. Denis Morrice, President and CEO of the Arthritis Society of Canada donated $2,000 from the Society to help with the costs of this Status.

2) COURT TO RULE ON INSURERS' ACTIONS by: Mike Martin. Some individuals have challenged and asked the court to rule on whether or not insurers, specifically under company Plans, have a right to treat as well as assess i.e. become our doctors. We are expecting a decision in the very near future and will keep you informed as to the Court's decision. We will continue to challenge the insurance industry. If you have anything to contribute, we look forward to hearing from you.

3) MOTOR VEHICLE ACCIDENTS: by: Wayne Kasbey. We are collecting research on people who became ill with ME/FM due to a motor vehicle accident. Please get in touch with me, whether your case is settled or not. There have been changes that may be of help to you in fighting your claim and/or your experiences in settling may help others. I can be reached at: **44 Concession 11, R.R. #4, Crysler, Ontario K0A 1R0 - Tel. 1-613-987-2405.**

CANADA PENSION PLAN REFORM - On Friday, April 7th in Winnipeg, Lloyd Axworthy announced that CPP Disability Benefits would remain in place for a transitional three-month training period. Also, by cutting out the necessity to re-apply, re-accessing the plan would become easier. Also, the onerous provisions disentitling recipients from engaging in volunteer activities will be lifted. The excuse for identifying some people with disability as "unemployable" is finally on its way to oblivion.Council of

Canadians with Disabilities, A Voice of Our Own" April, 1995, 926-294 Portage Avenue, Winnipeg, Manitoba R3C 0B9 - Tel. (204) 947-0303, Fax (204) 942-4625, E-MAIL CCD@magic.mb.ca

[Editor's note: In speaking with CPP on Thursday, May 25th, 1995 they confirmed that although the above is true, CPP is not yet in a position to provide information in writing at this time. Will keep you informed.]

DEAR DR. JAIN:

Q: My Doctor told me that I have mitral valve prolapse, what does this mean?

A: Mitral valve prolapse is the most common type of VALVULAR heart disease. MVP is most common in women from age 14-30 years of age in the healthy population. Most are not symptomatic and is only picked up on routine physical examinations. They usually represent a redundancy of the mitral valve leaflets, similar to installing a door which is 1/4" bigger than the opening. The door will work, but the edges will not meet smoothly. However, the people will be able to come in and out without a problem.

There are few patients who may have complications in the remote future from MVP, be it bacterial endocarditis, or the mitral valve deteriorating further to develop regurgitation of the blood in the heart, eventually leading to heart valve complications. These complications are, however, not common and other factors usually contribute.

In ME/CFS, the incidence of MVP may be as high as 25%. In all of these cases, this is an incidental finding rather than an actual problem. Many doctors will focus on this, due to the lack of other abnormalities to explain the symptoms. However, if there is no cardiac decompensation, then the MVP will be an incidental finding and should not be a medical concern in these patients.

[Dr. Jain sees ME patients from across Canada, in addition to his regular practice. He can be reached at: 1025 Grenon Ave., Suite 118, Ottawa, ON K2B 8S5. Tel. No. (613) 596-3211.

CDC ATLANTA - UPDATE:

1) The Centers for Disease Control in Atlanta stated that ME/CFS may affect up to 50 times the number previously estimated by them, according to Dr. William Reeves, Chief of Viral Exanthems and Herpesvirus Branch at CDC. Drs. Reeves, Komaroff and Loveless provided testimony at a May 12th, 1995 Congressional Briefing sponsored by Representatives John Porter (R-IL) and Senator Harry Reid (D-NY). Dr. Reeves stated that 76-220 per 100,000 Americans have a CFS-like illness as opposed to earlier estimates which had pinned the numbers at 4-9 cases per 100,000. CDC have recently added CFS to the list of Priority-1 New and Reemerging Infectious Diseases. Other illnesses listed as Priority-1 include E.coli and tuberculosis. Dr. Loveless, an infectious disease specialist who runs an AIDS and CFS clinic stated that "a CFIDS patient feels every day significantly the same as an AIDS patient feels two months before death". His statement was supported by data from his clinical research and by the experience of other CFS experts. [Source: CFS Wire - BBS, Roger Burns]

2) The booklet **"The Facts About Chronic Fatigue Syndrome"** has now been reprinted and **includes the new 1994 case definition.** To obtain a copy/copies write or call: **DOTTIE KNIGHT, Health Technician, Mail Stop A-15, Centers for Disease control, 1600 Clifton Road N.E., Atlanta, Georgia U.S.A. Tel. (404) 639-1338.**

[Note: In six months CDC has responded to over 65,000 requests for copies of the newly revised case definition which was published in December 15, 1994 in the Annals of Internal Medicine.]

INTER-GROUP/CONTACT COMMUNICATIONS:

RECIPE BOOK for sale - the covers are laminated for easy clean-up. Please contact SUE HOBSON, (leader of the **Lamar, Missouri FM Support Group**), P.O. Box 443, Lamar, Missouri 64759 - check or money order in the amount of $7.24 U.S. (includes shipping and handling) U.S. Funds only.

CHANGE OF ADDRESS:

New address for the **M.E. SOCIETY OF EDMONTON**, Box 30402, 1323N 6455 McLeod Trail. S.W., Calgary, Alberta T2H 2W2 - Tel. (403) 248-7773.

PEN PALS - NAME THIS PROJECT - If you are interested in corresponding with people who suffer from chronic pain, please write to: **LINDA BRAUN, NacPac - "Pen Pals" Coordinator, 62 Pinelore Place, N.E., Calgary, Alberta T1Y 3V8, Canada**. In Canada: Please enclose stamped self-addressed envelope or an International Coupon for $1.00 elsewhere. They are also looking to name this project and are interested in receiving your suggestions and/or donations. Please make cheques payable to: North American Chronic Pain Association (NacPac).

NACPAC HEAD OFFICE - NEW ADDRESS & New PRESIDENT: DR. RICK EDWARDS, 150 Central Park Drive, Unit 105, Brampton, Ontario L6T 2T9 - Tel. (905) 793-5230 - Fax (905) 793-8781. **1-800-616-PAIN**

NEW SUPPORT GROUPS- 1) FIBROMYALGIA SUPPORT - OTTAWA WEST, Box 26076, 72 Robertson Road, Nepean, Ontario K2H 5Y8 - Tel. & Fax (613) 831-7129 Sheila Currie Alder or Glenda Bowen at (613) 836-5552. Meetings are held at 8:00 P.M. on the 3rd Wednesdays of the month at St. Paul's Anglican Church, 20 Young Rd, Kanata.

2) FIBROMYALGIA SUPPORT GROUP OF CALGARY, 196 Bow Green Cres. NW, Calgary, AB T3B 4R8 - **Tel. (403) 247-5017 contact: Judy Heynsbroek**

TIP EBOLA VIRUS - For information and a brochure on this virus,

Health Canada has set up a hot line: **1-800-788-1241.**

NEWSLETTERS/BOOKS/VIDEOS/AUDIOS ETC.

Ft. Lauderdale NOTEBOOK SERIES by Kendra Dayger, author of Review of Mainstream CFIDS Research. A series of 8 notebooks produced with the cooperation of the speakers, this is the research conference in concise written form. Available individually by topic or as a complete set. Note that these are not transcripts of the study presentations themselves; these are organized notes, Q & A's, selected transcripts, additional explanations: Notebook #1: Epidemiology; Notebook #2: Interdisciplinary Studies; Notebook #3: Immunology; Notebook #4: Physiology; Notebook #5: Clinical Research Studies; Notebook #6: NIH Grants Workshop; Notebook #7: Neuro Testing Workshop; Notebook #8: Gulf War Syndrome. Total Package, 8 Notebooks: $95.00 or $15.00 per Notebook. Please make out check or money order payable to: **(US funds only) Kendra Dayger and send to: CFIDS Rochester Research Project, 1200 Edgewood Ave., Rochester, NY 14618**

[Kendra is the author of 'Review of Mainstream CFIDS Research' which has many times been reprinted due to its popularity]

Scientific Abstracts are now available which consist of an in-depth compilation of over 450 recent abstracts on Fibromyalgia, Chronic Fatigue syndrome and Myofasical pain syndrome and related topics. Cost: $30.00 U.S. All proceeds go to researching these syndromes. Make checks payable to **AFSA and send to The American Fibromyalgia Syndrome Association, Inc., P.O. Box 9699, Bakersfield, CA 93389-9699 U.S.A.**

TIP: FEDERAL HEALTH DEPARTMENT MEDICAL DEVICES HOT-LINE 1-800-267-9675

TIP: **TRILLIUM DRUG PLAN - PROVINCE OF ONTARIO** - Effective April 1, 1995 people with unmanageable drug expenses can get help through this new plan. To find out details as to qualifications etc., please call 1-800-268-1154, Toronto 314-5518 or ask your local Pharmacist.

1) "The Importance of Nutrient Supplements in the '90's")by Dr. Philipa Corning - 3 pages

2) "The Grieve Process" by Dr. Philipa Corning - 3 pages)

To obtain these report - In Canada, please send stamped, self-addressed envelope (43 cents) to **Dr. Philipa Corning, 69 Roblyn Way, Nepean, Ontario K2H 7V2** - Elsewhere: $1.00 international coupon.

CALL FOR CFS RESEARCH PATIENTS: The **New Jersey CFS Center, Research Division** is actively searching for additional CFS patients to participate in studies which will focus on determining possible cause(s) and treatment of CFS. Studies will also focus on viral/immunological factors, muscle and body metabolism as well as studies to learn the how and why of the memory and concentration complaints in CFS. A current treatment study employs a drug which appears to be a cognitive enhancer but other treatment studies are also planned for the future.

If you are interested in volunteering for these important studies, the first step is to fill out a questionnaire which can be obtained by calling **(201) 982-2552.**

DOCTORS REFERRALS - ADDITION:

BERTRAND PROULX, M.D., C.C.F.P., P.O. Box 128 - 1403 Edward St., Hearst, ON P0L 1N0 - Tel. (705) 362-8262 - Fax (705) 362-4184.

PERSONALS

SHARI G., of Ontario advised that now that the lawn-cutting and chemical spraying is in full force, she is suffering terribly from these effects. She already spends all her time in her home but as lawn-cutting etc. happens weekly, she is constantly ill due to the side effects. Shari wonders if there is any place in Canada where she can go for awhile as she worries how she can deal with this extra and continuous problem. Any information would be very much welcome regarding treatment or accommodation.

KAREEN P., Ontario: It's very hard to let go off the past. Don't be so hard on yourself, this too is part of grieving. A necessary part of recovery. Hang in there, you're doing great.

FINANCIAL STATEMENT of the NATIONAL ME/FM ACTION NETWORK

from APRIL 1, 1994 to year ending MARCH 31st, 1995:

Revenue

Donations: $1,812.72

Memberships: $2,204.32

Miscellaneous: $ 69.00 $4,086.04

Expenses

Bank charges: $ 80.48

Printing, including

ME/FM Info sent: 752.13

Postage: 1,084.83

Supplies: 672.95

Travel: 55.00

Legal Fees: 397.37

Tel./Modem 406.57 $3,449.33

Excess of revenue over expenses $636.71

[Editor's note: our finances are very low. Excluded in above figures of excess revenue is another bill from our corporate lawyer, Jane Burke-Robertson, who keeps our Minute Book etc. The above figures are not in any w in Alberta and will be reported on separately.]

MEMBERSHIP: Annual membership is **$20.00, with bi-monthly newsletters**. Your financial help is needed to help with our many projects.

DONATIONS: Tax receipts issued for donations over $10.00.

WELCOME TO OUR WORLD!:

ME/FM: ENERGY NOT'S

ENERGY CHALLENGED (for the politically correct)

ENERGY LIMITING MEDICAL CONDITION

Thanks to Sandy Shaw, Ottawa.

We hope you have a great summer. Don't let the fact that we did not get the Intervener Status bother you. By fighting back, we have brought everyone's attention to the fact that yes, we can work together and yes, there are things we can do and will do, whenever the occasion calls for it. Take care,

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

The NATIONAL ME/FM ACTION NETWORK is an incorporated non-profit organization solely dedicated to helping ME/FM individuals.

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.

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.