

Quest #11 April 1995

MAY 12TH UPDATE - NATIONAL ME/FM AWARENESS DAY:

NATIONAL PETITION: We, the National ME/FM Action Network, in co-operation with Canadian provincial-based organizations, particularly M.E. Ontario and Northern Ontario Fibromyalgia Association, is doing a National Petition to be presented in the House of Commons. This Petition has been sent to all known Support Group Leaders/Contacts and to our members. We have asked everyone to get 25 signatures to be returned to us no later than May 31st, 1995. This closing date was chosen so that everyone could take advantage of May 12th to get additional signatures from the general public.

The Petition will be presented and read to the House of Commons by a prominent member (MP) of the Federal Government. This opportunity allows us a chance to influence the Government of Canada to officially recognize ME/FM and chemical sensitivities with regards to cause/effect and to implement research initiative. The proposed means will have the Petition read to the House, it will allow our team to be present for the reading, and give us media coverage through a press release. A successful proposal and media coverage will mean a very large step in building the necessary platform in Canada's political and medical environment. We enter this endeavour with great hopes.

This is an official Petition and was therefore pre-approved as to form and content by the Federal Minister of Health's office of Diane Marleau's office so that it can be officially presented in the House of Commons. Special thanks to Leni Johnson and Bill Leeming of M.E. Ontario for their financial support and input into our Petition and to Byron Timmermans of the Northern Ontario Fibromyalgia Association for his help in getting the Petition approved as to form, content and its French translation.

INSURANCE MATTERS - ALBERTA JUDGMENT Re: Action No. 9201-12776 In the Court of Queen's Bench of Alberta, Judicial District of Calgary - MACKIE vs Wolfe

History: Madam Justice Rawlins found, on the testimony that the Court was given, that Mrs. Mackie to have suffered a neck strain that would have normally healed in six to eight months. (Mrs. Mackie claimed that a 1985 car accident was the cause of her Fibromyalgia). Basing her decision primarily on the evidence of Dr. Keith Pierce and a Calgary Pain Specialist, Ian Clark, Justice Rawlins found Mrs. Mackie to have had a hysterical conversion disorder which was "related to the accident". Justice Rawlins then went further to hold that this could mean one of two things: a) either Mrs. Mackie does not have Fibromyalgia (implying that Fibromyalgia in that circumstance may well exist but she didn't have it); or b) fibromyalgia does not exist at all as a physical condition. She went on to further say that Fibromyalgia has become a Court/Driven illness that has, in essence, mushroomed into big business for Plaintiffs.

The Canadian Judicial Council replied to our letter of February 22, 1995 regarding what options available in regards to Justice Rawlin's statement that "Fibromyalgia does not exist" and replied as follows: "Chief Justice McEachern has considered your letter of February 22, 1995, but has asked me to advise that the question is not whether fibromyalgia is recognized as a disease in some quarters, but whether a judge on a trial is entitled to reach and express conclusions about that "disease" in Reasons for Judgment".

Chief Justice McEachern also expressed the view that an Appeal is the proper way to pursue this matter. For this and the other reasons he stated in previous correspondence [to M.E. Calgary], his Council shall not take any action in this matter. Signed: Jeannie Thomas, Executive Director.

Therefore, the Calgary Fibromyalgia Action Committee has been formed, with Marj van de Sande as Chairperson. Marj has been instrumental in obtaining two lawyers, Maureen Morgan and Deborah Straw, who are so concerned about the ramifications of this ruling that they are prepared to waive their legal fees for intervention to the Alberta Court of Appeal. However, it is essential that we provide financial assistance for legal research and other documentation costs, and the necessary funds to cover

disbursements that can be substantial, before the lawyers can begin work. The first legal documentation must be filed by the beginning of June, so there is some urgency in raising funds. We therefore need your help to accomplish the vital task of refuting a potentially harmful court decision. Your donations are tax deductible, as this is all being done under the umbrella of our Network. All necessary permits needed for fundraising in Alberta have already been completed. We now need your help to continue our fight in this important case. Please make cheques payable to F.A.C.T. (Fibromyalgia Action Committee Trust) and send to Marj van de Sande, 1824 Varsity Estates Dr. N.W., Calgary, AB T3B 2W9. - Tel. (403) 247-2868.

Please note that Intervener Status shall not address Mrs. Mackie's concerns on appeal directly, it is anticipated that Intervener Status on appeal would at least bolster her and her counsel psychologically and from a public relations perspective. What it does do is intervene with Judge Rawlins decision regarding Fibromyalgia.

NEWS RELEASE - FEBRUARY 1, 1995

The Ontario Minister of Health, Ruth Grier, announced details of a new \$75 million program to provide financial help to more than 240,000 individuals and their families facing unmanageable prescription drug expenses, effective April 1, 1995 called The Trillium Drug Program. Ms Grier stated that "No one should have to choose between health and financial hardship because of high expenses for prescription drugs." For more information and a brochure call 1-800-268-1154, from Toronto call 314-5518 or check with your local pharmacy.

COMPUTERS FOR THE DISABLED

A free report can help those disabled acquire computers. "Resources the Disabled Can Use to Acquire and Find Computers" is available by sending a legal sized self-addressed stamped envelope to TWIN PEAKS PRESS, P.O. Box 129, Vancouver, Washington 98666 U.S.A. **(hold till reply received)**.

INTER-GROUP/CONTACT COMMUNICATIONS

M.E. Ontario held a Fashion show "Spirit of Spring '95" on April 13th. There were 475 people present at this event. The guest speaker was Dr. Lefebvre, affectionally known as Dr. Froggy, from the Sick Kids Hospital in Toronto. She spoke about children with M.E. This event was held at the prestigious "Granite Club" in Toronto and all proceeds will go towards the use for young adults with M.E. We thank the committee members of M.E. Ontario who have invested many, many hours of volunteer labour to organize this event on behalf of the Ontario ME community.

NORTHERN ONTARIO FIBROMYALGIA NETWORK INC. please change address back to 720 Downland Street, Sudbury, Ontario P3A 5T3 - Tel. (705) 560-4936. It was found that the new address was too difficult for postal pick-up.

M.E. B.C. - the lieutenant Governor of British Columbia, The Honourable David C. Lam, has Proclaimed and Declared May 12th of this year to be: **'M.E. Awareness Day'** in B.C. Congratulations to MEBC for its efforts to make this day a reality.

MESH (ME SELF-HELP) OTTAWA, is celebrating Awareness Day, MESH by inviting anyone interested in finding out more about ME to attend a special presentation by **DR. ANIL JAIN** entitled **"The Experience of M.E."**. Location: Hintonburg Community Centre, 1064 Wellington Street, Ottawa, Ontario. **DATE: Saturday, May 6th, 1995 - Time: 1300 hours to 1400 hours.** For more information phone: **(613) 789-MESH.**

NEWSLETTERS/BOOKS/VIDEOS ETC.

JOHNS HOPKINS UNIVERSITY - Interview with Dr. Rowe by CFS-Newswire (Roger Burns) re: Neurally Mediated Hypotension - This interview deals with the research of seven teenagers who were diagnosed with this Hypotension, some of whom have ME/CFS. These findings were published in the British Lancet - (12 pages). In Canada: Please send self SASE 86 cents - Elsewhere \$1.00 international coupon.

Synopsis of the Johns Hopkins Research by Philip K. Nelson, M.D. (2 pages) - stamped self-addressed envelope for Canada (\$0.43 cents); international \$1.00 coupon elsewhere. Dr. Nelson is the Medical Advisor for the Manasota CFIDS Support Group Inc. in Sarasota, Florida who graciously is permitting us to

TRACKING DOWN CFIDS by Dr. Charles Lapp (2 pages) send stamped self-addressed envelope in Canada or \$1.00 international coupon elsewhere

"Q: What is the difference between having attendant care provided by your spouse or a monkey? **A** You can get a tax credit for the monkey." This is the headline of **"Arch Type"**. Their Mar/April 1995 issue has excellent information on the tax credits. Subscriptions to Arch Type: \$15 for individuals or \$25.00 for organizations. International: Add \$5.00. Address: 255-40 Orchard View Blvd., Toronto, Ontario M4R 1B9 Canada - Tel. (416) 482-8255 - voice; (416) 482-1254 (TTY); Fax (416) 482-2981.

ESSENTIAL FATTY ACIDS by Paul Beattie

How does essential fatty acids (Evening Primrose Oil) play a role in your every-day well being? For more information, contact Paul Beattie at 121 Lakeshore Road, Oakville, Ontario L6K 1E2, Canada. - Tel. (905) 849-1674. Please send self-addressed stamped envelope in Canada or International Coupon of \$1.00 elsewhere.

EXERCISE PRACTICES FOR ME/CFS by Dr. Philipa Corning (5 pages) - in Canada, enclose stamped self-addressed envelope and send to 69 Roblyn Way, Nepean, Ontario K2G 5Z5, Canada - Elsewhere: \$1.00 International coupon.

THERMO-REGULATORY HYDROTHERAPY PROGRAMME - COLD WATER THERAPY - FOR MORE INFORMATION, PLEASE CONTACT THE BEATRICE HYDROTHERAPY CENTRE, the address 1 Cadogan Gardens, London SW3 2 RJ Attention. Vicky Wright Tel: +44 71 730 5319 or Fax +44 71 730 5321 or contact: Professor Kakkar, Thrombosis Research Institute, Emmanuel Kaye Building, Manresa Road, Chelsea, London SW3 6LR Tel: +44 71 351 8300 or Fax + 44 71 351 8324. If you would like the training program kit, consisting of water thermometer and waterproof copy of the day to day chart, please send a cheque payable to The European for 9.99 pounds to The European, 200 Gray's Inn Road, London WC1X 8NE Tel. +44 171 418 7777 or Fax +44 71 713 1870.

"Resources The Disabled Can Use To Acquire and Fund Computers" by Helen Hecker. To get this new report, send \$5.00 U.S. cheque or \$8.00 U.S. for audio cassette and the words "Computer Report" to Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666 U.S.A. or call (360) 694-2462 or Fax No. (360) 696-3210. for more information.

PERSONALS

Sharon Walk has been extremely ill and has been hospitalized for the past two months. She will be going home shortly. Sharon founded the CFS Youth Outreach organization which has become a lifeline for many ME/FM young adults. Please send her get well wishes at: 9901. at her home at: 14 Shetland Road, Florham Park, NJ 07932 U.S.A.

A.J. Ontario - I'm so glad that you are able to start working again, for now, on a part-time basis and hope you will continue to improve.

Norma G. Ma., USA My heart goes out to you and pray you will have the strength to go on.

Nancy S.MA., U.S.A. Hang in there, Nancy, it's got to get better. Please keep in touch.

BIOMAGNETIC THERAPY: Anyone interested in knowing more about this therapy, please contact Kim Wood, 6 Planer Pl., Brampton, ON L6W 4C5 - Tel. (905) 279-6326.

SAFER ALTERNATIVES - Booklet printed with soy ink lists items now available for the chemically sensitive and the environmentally aware. For information, call or write Karen L. Stalie, 546 Olympic Street, Redding, CA 96003 U.S.A. - Tel. 1-800-574-8144 - Fax: (916) 243-1352.

NEW DRUG TRIAL

"CFS DROPS" HAVE BEEN TESTED ON PEOPLE WITH ME/CFS IN PHASE I - The Federal Drug Administration (FDA) has delayed giving IND status to this new therapy pending more testing. The drops are sublingual and contain very diluted forms of neurominidate and rubella virus in an aim to jump-start the immune system. The drops are absorbed through blood vessels under tongue and are not swallowed. Phase II will consist of approximately 200 CFS people. Initial study shows "noteworthy success". Some people have been able to discontinue the treatment while others are on a maintenance dose of one drop per week. In Phase II study they will look at lymphocyte subsets to see if the absorbed medication has re-regulated the immune system. This drug was originally developed for rubella by the researchers from South Carolina and Rhode Island.

THERAPEUTIC BENEFITS OF COLD-WATER BATHING - The Beatrice Hydrotherapy Center will be pleased to answer any questions you may have about cold-water therapy. They are currently in the process of writing an official scientific paper on their initial results which will be available in late summer. However, if you have any queries or questions, please contact them at the Beatrice Centre as their nurses, doctors and staff will be pleased to help. Victoria Wright, Centre Manager, Beatrice Hydrotherapy Center, Number 1, Cadogan Gardens, London SW3 2RJ, Tel. 0171 823-4592 - Fax: 0171 730 5321.

ADDITIONS TO:

BOARD OF DIRECTORS: MARJ van de SANDE, Director - Alberta, Canada - 1824 Varsity Estates Drive N.S. Calgary, AB T3B 2W9. Marj is also Chairperson for F.A.C.T.

DOCTOR REFERRAL LIST: **BOB SAGER, M.D., Acupuncturist** - 22 Nelson St. West, Meaford, Ontario L4L 1R1 - Tel. (519) 538-2821 - Fax (519) 538-1063

[N.B. for diagnosis and treatment only. Unable to do reports for legal purposes.]

NATIONAL LAWYERS' NETWORK: **MARK LERNER, Esq.,** Lerner & Associates, Barristers & Solicitors, 80 Dufferin Ave., Box 2335, London, ON N6A 4G4 - Tel. (519) 672-4131 & 672-45100 - Fax: (519) 672-2044. Mr. Lerner is very knowledgeable about fibromyalgia cases and the literature about fibromyalgia. He has three cases going to trial this spring in which he is acting on behalf of clients suffering from fibromyalgia.

SURVEYS & QUESTIONNAIRES: It is still not too late to get involved with the Insurance Survey. As a matter of fact, we need more insurance questionnaires completed, in order to come up with statistical information. We still need more ocular surveys completed also for Dr. Potaznick's research in the U.S. so that he will have Canadian input also. Let us know if you need the forms.

MEMBERSHIP: If you approve of what we are doing, join us and become a member. Our annual membership fee is \$20.00 per year which includes bi-monthly newsletters. We need your help to succeed.

DONATIONS - tax receipt issued for donations \$10.00 and over.

WELCOME TO OUR WORLD

DIFFICULTY WRITING: opportunity to develop a new hand-writing style

DIFFICULTY READING: back to the fun of basics

M.E.: mastering enthusiasm

FM: faulty muscles in motion

Thanks to Lorraine Legendre, Ottawa.

Until next time, take care,

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

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