Quest #13 August 1995

PETITION TO THE HOUSE OF COMMONS - UPDATE

Results to date: 13,661 - Breakdown: Alberta: 262; British Columbia 751; Manitoba: 954; New Brunswick: 211; Newfoundland: 39; Nova Scotia: 455; Ontario 10,452; Prince Edward Island: 211; and Quebec: 326.

Feel free to keep sending us the signatures and we will keep adding them on until the Petition goes into the House. We are in touch with a local MP and we should have some idea of the date in the not too distant future.

NATIONAL HEALTH & WELFARE - HON. DIANE MARLEAU

We received the following reply from Ms Marleau in response to our question about research funds for ME/FM: Our letter was sent December 23, 1994:

".....M.E. and Fibromyalgia are extremely distressing disorders which, because of their many causes, are difficult to diagnose and treat. In my correspondence with many patient-support groups concerned with the M.E. and other related disorders, such as Fibromyalgia, I have repeatedly expressed awareness and concern for the distress and suffering experienced by patients diagnosed with these disorders. Also, my Department has acknowledged the frustrations experienced by those patients who, while in pain, see their disorder dismissed as non-valid or non-existent by the general public and, sometimes, even by their own physicians....I would encourage organizations like yours <u>to contact researchers to persuade them to submit proposals to funding agencies</u>. <u>Perhaps, if advocacy and patient-support groups were successful in directly attracting the attention of researchers and academic institutions, granting agencies could benefit from a larger pool of submissions on M.E. and related diseases, and individuals would benefit from a larger output of soundly researched data</u>....Signed: Diane Marleau, Minister of Health c.c. The Hon Allan Rock, Minister of Justice and Attorney General of Canada.

[The underlining was done by us for emphasis. Now that Ms Marleau has given us some ideas as to how they would listen, we will be working towards that goal as outlined in her letter).

INSURANCE MATTERS:

1) BRITISH COLUMBIA TEACHERS FEDERATION (BCTF)

The following is a written copy of the Medical Review Panel's decision which was sent to us so that we could advise you of the outcome. First of all, the claimant states: "...the essential ingredient is choice of the chairperson, as well as your doctor, and of course it is important to ensure that the doctor you choose as your nominee will be an advocate for you."

In this particular case it cost the Claimant over $2,000 for her portion of the medical review panel plus approximately $8,000 in lawyer's fees - none of which she was reimbursed for. This does not take into account the letters she wrote, the phone calls and stress etc.

Re: Medical Review Panel - Three doctors made up the panel, one <u>appointed</u> as Chair <u>by the University of British Columbia</u>; one <u>nominated by Claimant</u>, and one <u>nominated by the BCTF</u>.

The panel reviewed all the written submissions (and the surveillance videotapes) and at a three-hour meeting. They also interviewed the Claimant, as requested by the Panel.

The sole question the panel was requested to address was:

"Was Ms A. suffering from a severe physical or mental disability so prolonged that she was unable to perform the duties of any substantially gainful employment for which she might be qualified by reason of education, training or experience on, as per Article 14.1 (b) of the Salary Indemnity Plan dated September 1, 1986).

The panel reached some unanimous conclusions:

1. Yes, Ms A. was so disabled, in accordance with the definitions in the Plan, [here it states date of illness];

2. We [the Panel] therefore expect reinstatement of her benefits, retroactive to...(states date of illness);

3. We [the Panel] recommend implementation of an impartial rehabilitation program which shall:

a) be mutually acceptable in all its aspects.

b) include, among other dimensions, a comprehensive psychosocial-psychiatric assessment.

(This is not a condition or a requirement; it is a recommendation, a strong suggestion made with the hope of encouraging recovery.);

4. We [the Panel] consider the practice of surreptitious surveillance to be counter-productive to a healing environment and eventual patient recovery.

Minority opinions: a) One doctor did not accept the diagnosis given Ms A.

b) One doctor requested that the following be appended to the recommendations:

c) the rehabilitation program is to be kept independent and observably fair to all concerned parties.

d) no conditions concerning acceptability, attendance and results of the rehabilitation programme are to be tied to benefit reinstatement and continuance.

2) ALBERTA JUDGMENT UPDATE RE: Re: Mackie vs Wolfe
In the Court of Appeal in Alberta - Action No. 9201-12776
APPLICATION FOR INTERVENOR STATUS JUDGMENT
Highlights: Although the Alberta Court of Appeal dismissed our Application, we consider this judgment to be a **very important victory for all those who suffer from fibromyalgia**. Our postition in our request for Intervenor Status was that it was not the function of the court to determine the existence or non-existence of an illness.

One of the criteria we had to meet was to demonstrate that we might be adversely affected by the appeal decision. In the Judgment, the Honourable Mr. Justice J.A. Kerans stated that we could not be adversely affected as the court "will not, in this appeal, and as a matter of law, say that there is or is not such a thing as fibromyalgia. **That is not our function."** By stating that **the Court of Appeal would never make a Rule of Law that spoke to the existence or non-existence of a disease entity and it is not the function of the court to rule on the existance of a disease, he implies that no Court should. This was our goal!**

Although the Court would not classify Madame Justice Rawlins comments as *obiter dictum* (judge's learned ramblings which do not set precedence), it did acknowledge the decision was based solely upon evidence presented in Mackie v. Wolfe. They further acknowledged that other judges in other cases may come to completely different conclusions. This statement paves the way for more positive judgments such as Gilchrist.

In terms of public exposure of this issue, the decision certainly minimizes if not extinguishes the controversy over the existence of fibromyalgia. If we had gained intervenor status this controversy would have escalated as a live issue in the media.

The Court did not question that the Mackie decision had adversely affected those suffering from fibromyalgia such as being challenged about disability insurance claims.

It is our legal counsel's opinion that the court inferred that it was the insurance industry and possibly the media who failed to understand the basic principles of the law when **the court apologized at the end of the judgment by expressing regret for the effect Madame Justice Rawlins' decision had on those who suffer from this disease.**

Aside from the positive results for FM sufferers, I was pleased that Justice Kerans stated, "Morgan [our Counsel] has argued most eloquently". **It is rare to find a judgment where the Court both apologizes for the adverse effect that the decision has had on the litigants and compliments the lawyer presenting their case. We are most pleased with these results**.

Marj van de Sande
Director for Alberta - National ME/FM Action Network
Chairperson - Calgary Fibromyalgia Action Committee.

3. COLLEGE OF PHYSICIANS & SURGEONS OF ONTARIO (CPSO) v. JOZEF KROP M.D.

Dr.Krop practices alternative or complementary medicine and feels everyone should have the right to chose a doctor who best meets your individual needs. The CPSO does not think so. Enclosed is a flyer outlining what you can do, if you agree with Dr. Krop. This decision could have dire consequences, if the medical colleges start challenging doctors who practice homeopathic medicine. If you would like more flyers etc., please contact Dr. Krop and he will happy to send them to you.

NEWSLETTERS/BOOKS/VIDEOS/AUDIOS ETC.

Health Action Network Society (HANS) Head Office: #202-5262 Rumble Street, Burnaby, BC V5J 2B6 (604) 435-0512 or 435-1561 Fax. Alberta Chapter: 7012 Huntbourne Rd. NE, Calgary, AB T2K 3X7 - Membership: $25.00 per year - quarterly newsletters.

FIBROMYALGIA and YOU, by Executive Producer, I. John Russell, MD, PhD. - 90 Minute Professional Videotape with four integrated Sections on What is Fibromyalgia?; Diagnosis and Possible Causes; Approaches to Treatment; and How to Live with Fibromyalgia: $34.95 U.S. funds per Videotape, check or money order payable to: Fibromyalgia Information Resources P.O. Box 690402, San Antonio, TX 78269 U.S.A.

MYOPAIN '95 - 3rd World Congress on Myofascial Pain and Fibromyalgia, San Antonia, Texas, U.S.A. July 30-August 3, 1995 Edited by I. Jon Russell MD, PhD, Associate Professor of Medicine, University of Texas Health Science Center (165 one-page synopses of presentations on new medical and laboratory research in this field. Prices: Individuals: $15., Institutions: $25; Libraries $35 soft. Call Toll FREE (in U.S. and Canada) 1-800-342-9678 or Fax your order to (607) 722-6362 - The Haworth Medical Press., 10 Alice Street, Binghamton, New York 13904-1580 U.S.A.

DOCTORS' REFERRALS ADDITION: **ANKE ZIMMERMAN, B.Sc.,N.D.**, Equinox Naturopathic Centre, 431 Timothy St., Newmarket, ON L3Y 1P7 - Diagnosis & treatments ME/FM patients -Tel. (905) 895-8285 Fax: (905) 895-0957

DISABILITY TAX CREDIT - FORM NO. T2201

Our Director, Mike Martin, is presently looking into the Disability Tax Credit which is in the majority of cases denied for people who suffer from ME/FM. Please get in touch with him, either by mail or phone, and let him know whether you have been denied this disability. He can be reached at 31A Kadeer Way, Nepean, Ontario K2J 1J6 - Tel. (613) 825-2019.

WORKMEN'S COMPENSATION BOARD:"The Nova Scotia Nurses' Union is claiming a victory in getting some recognition for environmental illness. For the first time a nurse suffering from the illness has won a fight to have the Province's Work's Compensation Board pay for her treatment. Jean Carter reports... Ann Thompson is one of 100 nurses in Nova Scotia suffering from environmental Illness. They experienced memory loss nausea and other reactions while working in Camp Hill Hospital in Halifax. To cope they take vitamins and injections. Treatment can cost up to five-hundred Dollars a month. A cost the Workers' Compensation Board would not cover until now. The Appeals Board has ruled Thompson must be compensated for Treatment. But the one hundred other nurses won't automatically get the same decision. David Stewie is head of the Workers' Compensation Board. He says each case is assessed individually.

He Also says the Board has relied on the medical community for direction. That in itself causes a problem because doctors have been divided on whether environmental illness exists and how it should be treated. "Dated: Wednesday August 16 1995 Transcript of CBC Radio Works Web Page 1995 16:00 hrs

INTER-GROUP/CONTACT COMMUNICATIONS:

THE BURLINGTON CHAPTER OF THE ME ASSOCIATION announce that **In Burlington on Saturday, September 30th, 1995 Timothy Kenny, author of "Living with Chronic Fatigue Syndrome"** will be giving a talk. It is expected to be an afternoon talk. Please contact either BARBARA TAYLOR AT (905) 332-4292 Address: 2101G Meadowbrook Rd., Burlington, ON L7P 2A5 or SALLY HANSEN (905) 528-9760, Address: 903 Unsworth Ave., Burlington, ON L7T 1R2. For out of town people who wish to stay overnight, there is a discount available at the TRAVELODGE HOTEL in Burlington, provided you mention you're attending the CFS talk on the 30th. A pamphlet on the hotel will be included with tickets.

ECOFRESH SHOPPES INC. 121 Lakeshore Rd. West, Oakville, Ont L6K 1E2; which supplies EFAMOL EPO (as low as $24.99/large bottle) wishes to announce they now carry and ship the full line of Genestra Brands high quality supplements and homeopathic formulas direct to ME/FM patients and support groups at 30-40% savings. Support group leaders are invited to call PAUL BEATTY COLLECT at (905) 849-1674 for information, price lists and catalogues.

INTERNATIONAL SYMPOSIUM, presented by the Post Polio Awareness and Support Society of British Columbia (PPASS), starts Nov. 2nd and runs through Nov. 5 at the Delta Pacific Resort Hotel in Richmond B.C. The symposium features top speakers from Canada and the United States who will offer the latest in managing post polio issues. For registration form etc., please write to PPASS SYMPOSIUM, PO BOX 6579 DEPOT 1, VICTORIA, B.C. V8P 5N7. Tel. (604) 477-8244 - Fax (604) 477-8287.

M.E.B.C. has assembled an impressive panel of experts for a public meeting in Burnaby on October 1st at 2 p.m. Tina Harvey of M.E. Canada will be a featured speaker and a panel participant. Other panelists will be lawyers Lesley Tough from Winnipeg and Greg Steele of Vancouver. Jacqueline Young, of the organizing committee expects a prominent neurologist to serve as moderator.

The meeting will be in the auditorium of Burnaby South Senior Secondary School, Rumble St. at MacPherson. The cost will be $10.00 for M.E.B.C. members, $15.00 for non-members. However, the auditorium holds about 600 and Ms Young says advance reservations are preferred. Call M.E.B.C. at (604) 526-3993.

TIMOTHY KENNY, Author of Living with Chronic Fatigue Syndrome, will give a talk on Saturday, September 30th, 1995 at 2:00 P.M.at the Notre Dame High School, 2333 Headon Forest Drive, Burlington (Wheelchair accessible). Cost $6 per ticket. Tickets will be available via mail upon receipt of cheque or money order made payable to "M.E. Association- Burlington Chapter" and send to Barbara Taylor, 2101G Meadowbrook Rd., Burlington, Ontario L7P 2A5 Tel. (905) 332-4292 or Sally Hansen, 903 Unsworth Ave., Burlington, Ontario L7T 1R2 - Tel. (905) 528-9760.

TIP: **SLEEP/WAKE DISORDERS TEL. 1-800-387-9253.** They will send you information on insomnia, CFS etc. Quarterly newsletters for $30 a year. Address: 3089 Bathurst St., Suite 3094, Toronto, Ontario M6A 2A4

NATIONAL LAWYERS' NETWORK - ADDITION:

MAUREEN MORGAN RN B.N. LL.B.

DEBORAH ROSE HARRIET STRAW

404 6TH AVE. S.W. SUITE 327 Fax: (403) 264-1328

ALGARY AB T2P 0R9 Tel. (403) 233-2215

BOOK REVIEW: 'CHRONIC FATIGUE SYNDROME: THE HIDDEN EPIDEMIC'

AUTHORS: JESSE A. STOFF, M.D. and CHARLES R. PELLEGRINO, PH.D.

Finally! A CFS Book that people with CFS can actually read and understand.

Dr. Stoff is a medical doctor who treats the Co-Author, Dr. Pellegrino, who has CFS. Both Doctors offer real hope and help! They use homeopathic medicines to treat the liver (for toxicity), the digestive system, the thyroid gland and fatigue. They discuss the use of Echinacea (a herb) for immune system stimulation; as well as which vitamins are actually beneficial. They also give specific doses to take.

This book takes a serious look at CFS with humour laced throughout. It is the most comprehensive book I have yet to read on CFS that didn't put me to sleep or leave me more confused than before. It is written in layman's terms - no scientific mumbo-jumbo. A must read for people with CFS.

Reviewed by Sylvie Brazeau, Nepean, Ont.

WELCOME TO OUR WORLD:

RECOVERY: good coping skills

SPACED OUT: an out-of-body experience

NORMAL: in control

We hope you have had a great summer. Until next time, 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. 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.

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.