Quest #9 December 1994

Dear Friends:

Much research is going on and more doctors are now receptive towards us. However, if it wasn't for the dedicated doctors who have supported us from the beginning and our very active support groups, no inroads would have been made. At this time, we take the opportunity to thank each and every one of you who have made ME/FM easier to carry.

With our newsletter is our first annual Financial Statements for period ending March 31, 1994 prepared by our auditors, Deloitte & Touche.

Warm wishes for this holiday season

INSURANCE MATTERS

JUSTICE BONNIE RAWLINS, an Alberta Judge, ruled for the third time that "Fibromyalgia doesn't exist ...." and that it "has become a court-driven ailment that has mushroomed into big business for plaintiffs". She apparently based her opinion mainly on the testimony of a Dr. Keith Pearce, a Psychiatrist and Dr. Ian Clarke, Anaesthesiologist. This decision can have major consequences and set a dangerous precedent for future claims and set us back decades.. It could affect us in the following ways: any research funding could be cut , disability pensions could be terminated, availability of doctors seriously hampered, credibility lost. The negative impact of this judgment may seriously jeopardise all our efforts. We will be setting up a fund to fight this latest case. We are presently making arrangements for all groups to unify its efforts regarding this matter. We will be advising you of developments shortly. Hang in there.

CENTERS FOR DISEASE CONTROL (CDC) - UPDATE

The long-awaited case definition on Chronic Fatigue Syndrome has just been published on December 15, 1994 issue of in the Annals of Internal Medicine; 121;953-959. A thorough medical history, physical examination, mental status examination, and laboratory tests must be conducted to identify underlying or contributing conditions that require treatment. Diagnosis or classification cannot be made without such an evalution. Clinicall evaluated, unexplained chronic fatigue cases can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (I.E., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social or personal activities.

2. The concurrent occurrence of four or more of the following symptoms:

substantial impairment in short term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post exertional malaise lasting more than 24 hours. These symptoms have persisted or recurred during 6 or more consecutive months of illness and must not have redated the fatigue.

[Note: this replaces the 1988 case definition (Ann Intern Med. 1988; 108:387-389).

NEWSLETTERS/BOOKS/VIDEOS ETC.

Free Radicals, Antioxidants, and Essential Oils by Dr. Philipa D. Corning - 7 pages -In Canada, send stamped self-addressed envelope to Dr. Corning, 59 Roblyn Way, Nepean, Ontario K2G 5Z5 Everywhere else: enclose International coupon for $1.00.

THE CFIDS ADVOCATE - the newsletter put together primarily by the Ann Arbor and Dearborn Support Groups. It is published bimonthly by Sandy Becker, Publisher.To receive a copy write Sandy or Deyo Becker, The CFIDS Advocate, 1123 Wines Drive, Ann Arbor, MI 48103-2539. U.S. stamps or donations appreciated as this is the means by which they operate.

FIBROMYALGIA EXERCISE VIDEO available - Features three main components of exercise: warm up stretching and flexibility, low impact aerobic and Cool down: Relaxation. This video was created by health care professionals working in the field of rehabilitation for FM patients. Please make cheque payable to OAKVILLE-TRAFALGAR MEMORIAL HOSPITAL (OTMH), 327 Reynolds Street, Oakville, Ontario L6J 3L7 CANADA. For further information, please call Pauline Mihok or Julie Thomson at (905) 338-4613.

PAYMENT REFUSED by William M. Shernoff, with Thelma O'Brian - Foreword by Ralph Nader. - Richardson & Steirman, Inc. 246 Fifth Avenue, New York, New York 10001. Copyright 1986, 1988 by William M. Shernoff. Mr. Shernoff is a lawyer who wrote a book on the insurance industry regarding disability pensions and refusal of same.

"Actually the book is out of print now and very difficult to find in the bookstore. However, if people would write to me, at my law office, I would be happy to send them a copy, as I still have a supply of them....."Signed William M. Shernoff. Send request to William M. Shernoff, Esq., Shernoff, Bidard & Darras, 600 South Indian Hill Boulevard, Claremont, CA 91711-5498 U.S.A. Tel. (714) 621-4935 Fax (714) 625-6915.

INTER-GROUP INFORMATION

PLEASE NOTE NEW ADDRESS FOR NORTHERN ONTARIO FIBROMYALGIA NETWORK INC., 800 LaSalle Blvd., Suite 300, Sudbury, Ontario P3A 4V4 (705) 560-4936

"Where's The Pain? by Randy Mathias (3 pages) - send stamped self-addressed envelop - $0.43 stamp or $1.00 international coupon for out of Canada to us..

KANSAS OUTREACH FOR FIBROMYALGIA, Inc. (K.O.F.F.) is in the process of collecting poems for a second poem booklet (proceeds of this will go toward advocacy). Please forward your pem/s to: Rebecca Robbins, 1216 Appleton, Parsons, Kansas 67357 U.S.A. (316-421-3881).Booklet No. 1 can be obtained by making check or money order payable to K.O.F.F.,Inc. (U.S. Funds) $6.21.

MITRAL VALVE PROLAPSE - For information call or write: MITRAL VALVE PROLAPSE CENTER, 880 Montclair Road, Suite 280, Birmingham, AL 35213 U.S.A. - Tel. 1-800-541-8602. for U.S.A. only - Other locations: Tel. (205) 592-5765

MAY 12TH NEWS - Governor Finney passed and signed a proclamation which officially acknowledges the whole month of May Fibromyalgia/Chronic Fatigue Syndrome Awareness Month and May 12th has been declared ME/CFS Awareness Day. Congratulations to Rebecca Robbins and Kansas Outreach for Fibromyalgia (K.O.F.F., Inc.), 1216 Appleton, Parsons, Kansas 67357 U..A. Now is the time to start thinking of how your organization will mark this most important event.

STATISTICAL INFORMATION: DR. JUANNE N. CLARKE AND SUSAN C. BROWNING, WILFIRD LAURIER UNIVERSITY, Department of Socialogy - Preliminary Report on the experiences of those who suffer from Chronic Fatigue Syndrome or Myalgic Encephalomyelitis: - Waterloo, Ontario May 1993 - Conclusion: In summary, the study of the experiences of those who suffer from Chronic Fatigue

Syndrome is important for several reasons. First, in terms of the medical and therapeutic community, although the medical arguments are complex and continuing, many with C.F.S. are not getting the medical support they expect and need. Second, in terms of those with C.F.S. as social being, the social support expected when labelled "sick" in our society seems to be lacking. Third, the costs to the whole community resulting from the loss of productivity amongst people with this disease, as well as the costs involved in various disability and insurance policies, are significant. Further research and education on Chronic fatigue Syndrome can only prove beneficial. - Collingwood M.E. Support Group Newsletter No. 19, September 1994, 250 Pine Street, Collingwood, ON.

ADDITIONS TO OUR BOARD OF DIRECTORS

DOUG SHORE - Director for British Columbia

#235 - 32550 MacLure Road, Abbotsford, BC V2T 4N3 - Tel. (604) 855-9431.

MIKE MARTIN - Director Liason/Advocacy - 16 Stone House Crt., Nepean, ON K2J 3V4 - Tel. (613) 825-2019.

TIPS ON TAKING MEDICATION WISELY: ALWAYS READ THE INSTRUCTIONS ON THE LABEL and keep the following tips in mind:

*When you need to take your medication on an empty stomach, do so at least one hour before a meal or 2-3 hours afterward. If you're taking medicine with meals and you miss a meal, don't skip the medication too. Take your medication with a light snack and water as soon as you remember.

*Use water to swallow medication. Tea, coffee and other hot drinks can change how some drugs work.

*Alcohol and drugs should not be mixed. Even some cough medicines - when combined with alcohol - can lower your reflexes and make you drowsy.

*When taken together, some medicines can cause harmful side-effects. Make sure to let your doctor(s) know exactly what medication you are taking. For a free medication booklet to records the medicines you are taking, call the Pharmaceutical Manufacturers Association of Canada toll-free at 1-800-363-0203.

*To keep track of your medication schedule (what to take, when and how), make a chart or use a pill organiser. Your doctor or pharmacist can help you.

*Don't grab for medications in the dark or read the label without your glasses. You could take the wrong one.

*Store medicine in a cool, dry place, not in the bathroom. Moisture and heat can damage our medication.

If you have any questions about your medication, ask your doctor or pharmacist.

Source: "Knowledge" Winter 1994/1995" newsletter of the Pharmaceutical Manufacturers Association of Canada, 302-1111 Prince of Wales Drive, Ottawa, Ontario K2C 3T2 - Tel. 1-800-363-0203 - Call if you want to be on its mailing list to receive future newsletters etc.

TIP If reading is difficult for you, why not take out an audio book from the library to which you can listen. Some are condensed, some are acted out and some are read by the author. Many bookstores now also sell audio books.

TIP When replying to questions from an insurance doctor, make sure you hear the question before you reply. Take your time and remember that it takes you longer than it did before.

LAURA SEGUIN ARTICLE send stamped self-addressed envelop (43 cents) to National ME/FM Action network to receive copy of letter addressed to the hospital for sick children in Toronto. Laura is Vice-President of the Northern Ontario Fibromyalgia Network in Sudbury. - You might want to send a letter to Sick Childrens to support Laura's stand and those of other parents of little children and adolescents.

WELCOME TO OUR WORD:

HEADACHE: reassurance that your head is not complete 'brain fog'

MYALGIA: a crash course in the anatomy of muscles

FORGETFULNESS: mini-vacation from worry.

Thanks to Lorraine Legendre

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 2397, Washington, DC 20036 U.S.A.
Please note: for mailing outside of Canada or the U.S.A., please include an International Reply Coupon.

REMINDER - Eye survey and insurance survey still available, if you want to participate. Remember that the more people get involved, the more worthwhile information we will get. Call or write if you want the forms.

MEMBERSHIP NOTICE - WANT TO JOIN US? - Membership to the NATIONAL ME/FM ACTION NETWORK is $20.00 per year and includes newsletters every two months.

Until next time, take care.

Lydia E. Neilson,

President C.E.O.

COPYRIGHT NOTICE: The NATIONAL ME/FM ACTION NETWORK newsletter is published every two months. Its contents are (c)1993 by the NATIONAL ME/FM ACTION NETWORK, EXCEPT where individual items are copyrighted by the author. Articles may be reproduced by other non-profit publications as long as copyright notices are included and items are clearly attributed to to the NATIONAL ME/FM ACTION NETWORK citing its name, address andtelephone number. To use individually copyrighted materials, however,written permission must be obtained from the author.

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 hypothesism or product and assumes no responsibility for any treatment or action undertaken by its readers.