Quest #16 February 1996

Dear Friends:

We like the fact that our newsletter gets circulated and is read by many more than are members. We would very much appreciate it, if you enjoy our newsletter, to become a member of our organization. The more people who join us, the more credibility and impact we will have. Besides that, we need the funds to survive.

We received a grant from Health Canada for $35,000 but that is spoken for and is for the projects we are doing i.e. national insurance survey; national doctors/lawyers lists for referrals; Canadian ME/FM definition; a Guide for support groups; and related matters.

Your financial support would be very much appreciated and we thank you in advance for your help.Take care,

Lydia E. Neilson

President C.E.O.

PETITIONS TO THE HOUSE OF COMMONS: Final signature totals:**ALBERTA: 262; BRITISH COLUMBIA: 751; MANITOBA: 954; NEW BRUNSWICK: 220; NEWFOUNDLAND: 39; NOVA SCOTIA: 455; ONTARIO: 10,848' QUEBEC: 372; PRINCE EDWARD ISLAND: 211; AND SASKATCHEWAN: 375. Grand Total: 14,487.**

These signatures were handed over to the Hon. Beryl Gaffney, MP on January 18th, 1996. Ms Gaffney, in turn, is handing over the signatures to the Provincial MPPPs who in turn will contact their Provincial Parliaments requesting official recognition for ME/FM.

Ms Gaffney has pledged to help us in which ever way she can and has contacted the relevant government authorities regarding research funds, recognition etc.

She also is still working on the Private Member's Bill to the House of Commons and we will keep you advised on her progress.

DISABILITY TAX CREDIT UPDATE: We have heard from a few people who advised us that they appealed to Revenue Canada regarding its refusal to allow the Credit. When they wrote their letter of Appeal, they received the response that their request was reconsidered and their Tax Credit was now allowed.

We also have been contacted by a person who went through a Tribunal review and she also was approved for a Tax credit.

We also received a reply from the Deputy Minister, Pierre Gravelle Q.C., who in his letter to us of February 13th, 1996 advises that should an individual have a balance outstanding, he would invite them to contact the Assistant Director of Revenue Collections at their local tax services office, in order that a review of their current financial situation may be completed and an arrangement concluded. He also stated that interest relief may also be considered in instances where an individual is experiencing financial hardship and has no ability to pay the liability in full, interest relief could be a possiblity.

We have written Mr. Gravelle again on February 26th in which we itemized ME/FM symptoms in accordance with their criteria list for a Tax Credit and how we felt it applies to ME/FM people. We will keep you advised of developments.

[If you would like a copy of our reply to Mr. Gravelle and/or a copy of Mr. Gravelle's letter to us, please send us a SSAE in Canada, or $1.00 International Coupon elsewhere]

NATIONAL DISABILITY INSURANCE SURVEY UPDATE:

One of our Projects for which we asked money was the National Insurance Survey. We have hired Opinion Search Inc. to do this survey for us.

Therefore, we will shortly be contacting everyone we can and supply you with this questionnaire. We will be contacting all known support groups also so that these groups may furnish a copy of this questionnaire to all their people for completion and return.

To assure that more people will complete this survey, the name of the individual is not need but we do ask for the postal code. This will help us with the statistical information we are looking for.

Please participate, not only if you have been denied a pension but also if you do get one so that our data reflects a fair appraisal of the insurance industry and ME/FM people.

ADDITIONS TO BOARD OF DIRECTORS:

GLENDA BOWEN, Director of Rehabilitation.

124 Contry Lane West

Kanata, ON K2L 1J5 Tel. (613) 836-5552

Glenda is researching, across Canada, what the rehabilitation industry is doing for ME/FM people i.e. special program set up; how it tests for rehab candidates etc. If you have information or first-hand experience with the ab industry, please contact Glenda;

IAN WAYMARK, Director of ME/FM research.

R.R. #2, Site 21, Comp 35

Gabriola, BC V0R 1X0 Tel. (604) 722-0084 Fax (604) 722-0087

Ian is compiling information on what ME/FM research is presently being carried out. If you have any information help Ian, please contact him.

RESIGNATION: JEAN TRANOR, RN, Director P.E.I.

57 Mariner Drive, Charlottetown, P.E.I. C1C 1M3 - Tel. (902) 892-8147.

Jean was a real ME/FM pioner in Prince Edward Island and was very active in advocacy and support, as wels being a Support Group Leader. However, Jean's health does not permit her to continue. Thank you Jean, for all your hard work. You will be missed.

NEW FMS TEST?

David A. Zohn, MD is a well known fibromyalgia syndrome (FMS) specialist. At a recent lecture for other physicians held in Virginia, he noted that the diagnostic procedure of tender points in FMS has weaknesses because it is so arbitrary. He says FMS patients are tender all over and patient response will depend upon severity at that particular time. Because of this, he uses another procedure to test for FMS. "Skin rolling" is the term Dr. Zohn uses for his diagnostic FMS procedure. The skin of the upper and lower back is picked up and rolled with the fingers, pushing the tissue forward and the thumbs following. He grades this deep tendon reflex from 1+ to 4+ based on the amount of tissue adherence. Normally, the skin glides smoothly. Loss of this smooth gliding produces pain. FMS patients also show redness at the sight of rolling, which persists long after the test. This points to an autonomic abnormality.

This same method is used in myotherapy (deep muscle massage) to reduce FMS pain. To date there has been no clinical study to validate Dr. Zohn's method of skin rolling.

[Source: The Mass.CFIDS Update, Winter '95, 808 Main St.,Waltham, MA 02154 U.S.A.]

WHAT'S UP at the NEWCASTLE RESEARCH GROUP U.K.? Dr. John Richardson replied in his letter of January 31, 1996 as follows: "Firstly, we are looking at viral mediated disease in all its aspects. This means that ME/CFS is one of the varied group, but other aspects of brain or other CNS components can be equally well affected by viruses or other pathogenic agents. This is important because it seems to be a concept in some medical areas that ME is the usual result of such assault. This is not correct, but added to this is the fact that there are sequelae which can be defined - like polio - and are known to have a viral origin. The net result of these conflicting concepts - and as ME and certain other CNS pathological results are NOT easily defined by positive signs - then they are not understood and or sadly, denied. Our own group take all this into consideration and we try three approaches to seek to define the level of CNS system which is affected. Moreover, in those who are defined as suffering from ME, we find that 20% have other sequelae which are due to the original aetiological agent. In the old days of polio epidemics, it was found by those of us who actually investigated the patients carefully, that 20% had concomitant cardiologic consequences i.e. myocarditis; of these 20% died from the heart condition and NOT the CNS condition. Likewise diabetes and other hormonal mediated syndromes can occur with ME. Thyroid antibodies occur in about 20% of cases but only a few cases go on to thyroid failure. This is just a brief summary.

Thus as the years have passed we have been able to do further in-dept studies to endeavour to show the location of the areas of affection in the CNS. Chiefly these include brain scans and spinal cord if needed, then tests for autoimmune mechanisms which may be involved and also biochemical tests to try to show the resultant cell mediated biochemical failure.

SPECT SCANS. We do not limit these to ME and have shown that, whilst the caudate nuclei, hypothalamic and brainstem areas, do show a hypoperfusion, and this is peculiar to ME, other areas can be affected. Some have areas where epileptiform features in the temporal lobes have been found by EEG and show hypoperfusion also but not all have epileptic fits. This is like the thyroid cases who do not go on to gland failure. This is a wide subject and these are only a few brief words about the need for careful assessment and conclusions. One such question would be, is the hypoperfusion an actual cause of the illness or is it a result? The fact is that there may be a dual reason - as in a polio limbs, where temperature is lower than in the normal limbs, so in the brain this may apply BUT certainly does not help to promote healing either.

AUTOIMMUNE TESTS. These of course in the initial stages involved antibody tests as well as IgM and IgG etc. Unfortunately the primary stage is often missed but in some IgM persists and of course IgG develops as late manifestation of infection. We go on to look at VP1 and PT/PCR to try to identify the virus and this helps at a research level also to define which may be the prevalent strain. Perhaps, this may, eventually lead to the prospects for a vaccine.

BIOCHEMICAL EFFECTS. Amongst the varying tests for say thyroid antibodies we would look for evidence of thyroid failure. This would apply to the pancreas for diabetes and also to the thymus. We have had cases of myasthenia gravis misdiagnosed as ME. I also devised the diurnal/post buspirone cortisol/prolactin test. This can reflect on hypothalamic-pituitary function. This was published in the Journal of Chronic Fatigue as you well know. The hypothalamus is also involved in the regulation of the absolute number of circulating RBCs at 5,000,000 per cu mm. In the odd case this can be reduced (as in one boy) to 2,500,000 per cu.mm. and totally remit when they improve - it is rare. If muscle is markedly affected i.e. fibromyalgia, and particularly if there are infarcts, then the liver CPK can show a rise. This can also occur if there is a myocarditis.

Amongst the other signs, pupillary reactions are not rare and affect vision. In young people especially I have videoed the pupils where the reversal of the Argyl-Robertson pupil has followed a viral encephalitis. The pupils in these cases are fairly widely dilated at rest also.

SCORE CHART. We have our own score chart which list the results of the insults in tissues at these various levels and it is very accurate in delineating these effects.

MRI scanning is also used and the UBOs (unidentified bright objects) are seen to be in the areas of arterial flow. One such case came to autopsy here and I had his brain most-carefully examined and we found virus in the perivascular spaces, with excess lymphoid CSF. This is mentioned in the text book also by the Nightingale Foundation.

MUSCLE - we have numerous biopsies performed and the signs are like those seen in the aging process and of course the mithochondria are seen to be affected and this was shown by the Glasgow group also.

Finally I think that it is along these various lines that we should proceed and indeed we are proceeding. Thus we will define not only ME but also other pathological consequences of insult. In this connection it should be kept vividly before us that other co-factors can and are sometimes involved. These include toxic substances such as insecticides to which we are increasingly exposed as well as food additives e.g. aspartame.

This is very brief but maybe of some help in showing our line of research. Signed Dr. John Richardson".

AN ALTERNATIVE TREATMENT FOR SHINGLES & MORE - by Dr. Jozef J.Krop, MD,F.A.A.E.M.

It is true that the antivirus pills could definitely help some people, unfortunately, many people with ME are unable to tolerate certain pills due to the fillers used. I would like to mention that there is also another form of therapy for shingles which could be used in conjunction with the pills or alone which consists of treatment with the fluogen vaccine. The fluogen vaccine, the so-called flu vaccine, is prepared in some of the offices of doctors who practice environmental medicine and it is diluted and then it is tested on the skin. Once the neutralizing dose is achieved during the testing, this dose is then injected by the patient or by the doctor every 2 - 4 hours depending on the symptoms and in the first two or three days of acute sickness. Later on the dose is only given once of twice per day until there is total disappearance of the shingles. This type of treatment is extremely effective and speeds the process of healing and usually within three days the shingle lesions change into crust forms. This type of treatment is also very effective for acute flu as well as measles and also during the outbreak of mononucleosis.

This treatment was developed by Dr. Miller in Alabama and is widely used by the doctors practicing environmental medicine who know the technique of serial dilution end point titration and neutralization. Additionally, this treatment also helps people with the so-called post-herpetic neuralgia.Signed: J. Krop, MD,FAAEM.

[Ed note: Dr. Krop practices environmental medicine and can be reached at: R.R. #6, 6901 Second Line

West, Mississauga, ON L5M 2B5 - Tel. (905) 564-0122.]

BOOKS / NEWSLETTERS / REPORTS / VIDEOS ETC.

FIBROMYALGIA/MYOFASCIAL PAIN SYNDROME - A guide for Relatives and Companions by Dr. Devin Starlanyl, M.D. - 2 pages. In Canada: **.**Stamped self-addressed envelope to Network - Elsewhere: $1.00 International coupon.

DOCTORS GET POOR MARKS FOR COURTESY - Headline of the Ottawa Citizen newspaper, February 17, 1996 edition. According to the College of Physicians and Surgeons of Ontario, there were 1,566 complains investigated by the college last year, 612 alleged a communication breakdown. "Until recently, doctors-in-training were force-fed facts about anatomy and pharmacology. Empathy and communication just didn't make the course list" says Dr. Byron Lemmex, head of the Ottawa Academy of Medicine." Dr. Peter Walker, dean of medicine at the University of Ottawa and a practising physician says that "patients are much more informed and intelligent...and some doctors are having a hard time adapting to the '90s."

[Ed.note: If you would like a copy of the whole article, please send a stamped self-addressed envelope (SSAE} for $0.45 in Canada or $1.00 International coupon elsewhere.]

NEW ADDRESS: CHARLES W. LAPP, M.D., has left The Cheney Clinic effective August 8, 1995. He has moved his practice to a building nearby at 10724 Park Road., Suite 105, Charlotte, NC 28210 U.S.A. - His new Telephone number is **(704) 543-9692**.

FIBROMYALGIA/MYOFASCIAL PAIN SYNDROME - A guide for Relatives and Companions by Dr. Devin Starlanyl, M.D. - 2 pages. In Canada: **.**Stamped self-addressed envelope to Network - Elsewhere: $1.00 International coupon.

Videotape of **Paul Cheney's, MD.,Ph.D**. early fall educational workshop lecture, including question and answer period: Please send a check made out to Mass.CFIDS for $19.95 U.S.(includes S&H) at 808 Main St., Waltham, MA 02154 U.S.A.

"Effectively Treating Severe Chronic Fatigue States" by *Dr. Jacob Teitelboum MD - 4 legal pages. In Canada: Send stamped self-addressed envelope (SSAE) to us with $0.45 stamp - International Coupon for $1.00 elsewhere.

[Ed: 1) *Author of "From Fatigued to Fantastic - A Manual for Moving Beyond Chronic Fatigue and Fibromyalgia"; 2) Dr. Teitelbaum is willing to come on a lecture tour in Canada, after April 18th, 1996 - at least 100 people must be present - Tel. (410) 224-2222.}

VIDEO - "HELP YOURSELF" has been produced to help people understand Chronic Fatigue Syndrome, Environmental Sensitivities, and Fibromyalgia. Dr. Donald Neily, MD; Dr. Ward MacDonald, Chiropractor,;Dr. Cheryl Lycette, Naturopath; Mary Lynn McKenna, Physiotherapis; Heather Purdy, Massage Therapist, volunteered their time to this video. Cost: $15.00 plus $4.28 S & H. Cheque to be made payable to **Shirley Arsenault, 1191 J. Jordan Rd., Canning, Nova Scotia B0P 1H0 - Tel. (902) 582-1368. In addition, there is a questionnaire (30 pages long) "Helping yourself In Getting Better" and costs $3.00 plus $1.65 S & H.**

IS IT ME OR M.E.? by Ms Lorna Burns, Ireland.(8 pages). Her experiences and observations of M.E. To obtain a copy of her report, please send us a SSAE ($0.45) in Canada; and International coupon for $1.00 elsewhere.

COPING OR HOPING by Ian Waymark, BC (1 page) Please send stamped self-addressed envelope

(SSAEj) to us to obtain a copy.

INTER-GROUP/CONTACT COMMUNICATIONS

Congratulations to **Gail R. Kansky**, on behalf of The Massachusetts CFIDS Association. Gail is the first person to receive the first Iverson Award "in recognition of excellence in commitment and dedication to the CFIDS community". The Iverson Awards were created by the CFIDS association and named after their founder and president, Mark M. Iverson.

APPEAL FOR DR. ANNE MILDON, of Toronto, Ontario. Dr. Mildon was for many years a crusader for those with ME/CFIDS. She fought and won many cases with the insurance industry and the medical profession in general. Dr. Mildon had to close her practice in March 1995 because of severe health problems, including arthritis in her hands. She needs a voice-activated computer to help her finish her book on ME/CFIDS. The cost is approximately $6,000. If you want to help financially, please send your gifts of money to **Dr. C. Anne Mildon, c/o The Bank of Montreal, 2234 Queen St. E., Toronto, ON M4E 1G2.**

[Ed note: Submitted by Joan Paterson, former patient of Dr. Mildon]

NEW NUMBERS: Northern-Ontario Fibromyalgia Network Inc. , 800 LASALLE BLVD., SUDBURY, ON P3A 4V4 - New Phone Number: 1-800-959-9098 - Tel/Fax: (705) 566-7332.

NEW ADDRESS: NEW BRUNSWICK M.E. SUPPORT GROUP, 15 Rosewood Drive, Fredericton, NB E3B 7G8.

THE **DURHAM REGION CHRONIC FATIGUE GROUP** and the **AJAX FIBROMYALGIA GROUP** have been offered free canes (with tips on and can easily be sized) by a Toronto-based company. If you know of any charitable organization that may need some of these canes, please send your request to: **SUZANNE DANIELS, 988 Vistula Dr., Pickering, Ontario L1W 2L9 - Fax No. (905) 839-3586.**

[Ed.note: This appeal is also to support groups]

OOOPS! ! !

In our newsletter #15 Dec95./Jan 96 we advised that to obtain copies of legal precedents could be obtained by sending $10.00 to Marj van de Sande to cover photocopying and postage. The information is a FM legal research package - mostly abstracts to give the lawyer background in **FM**, not for ME/CFS. We apologize for any inconvenience this may have caused you. Marj. address is 1824 Varsity Estates Drive N.W., Calgary, AB T3B 2W9.

[Ed.note: Please help by sending any legal precedents you may have access to us so that we may keep as up-to-date a record as possible. Both ME/FM and other relevant cases, such as Multiple Chemical sensitivities.]

LEGAL PRECEDENT SET IN B.C.: The following appeared in the 'Ottawa Citizen' newspaper on Saturday, February 3, 1996: "Nelson, BC - An employee who was treated shoddily by the Royal Bank is $338,000 richer. A civil jury in B.C. Supreme Court awarded the money to Lorraine Dopf, 47, a sales-support worker at the Royal in Nelson. She was fired last February for violating the bank's rules of conduct. "She was on a disability leave when the bank called her in and gave her seven minutes to tell them why she shouldn't be fired"said Tim Pearkes, Dopf"s lawyer. Dopf sued for wrongful dismissal."

MEMBERSHIP: Please consider becoming a member of the National ME/FM Action Network.

Membership

is $20.00 per year and includes a bi-monthly newsletter.

WELCOME TO OUR WORLD:

I am only one, But still I am one. I cannot do everything, But still I can do something; And because I cannot do everything, I will not refuse to do something that I can still do.

Edward Everett Hale, Helen Keller's Friend.

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