

## **Quest #19 August 1996**

### **CANADA POST CHANGES OUR NETWORK'S POSTAL CODE**

Please note that our postal code has been changed and it is also no longer necessary to put highway 17B in our address. Therefore our address is now: 3836 Carling Avenue, Nepean, Ontario **K2K 2Y6 Canada**.

### **RESULTS OF ANNUAL MEETING OF VOTING MEMBERS/DIRECTORS:**

On September 21, 1996 we held an annual meeting of of voting members/directors and the following are the Board of Directors:

Lydia E. Neilson, President C.E.O. Philipa Corning, Ph.D., Vice-President

Michael Diplock, Treasurer Glenda Bowen, Director Special Projects/Secretary

Ken Coleman, Director Education Richard Green, Director Steering Committee

Byron Timmermans, Director Insurance Carlyle Andryo, Director Manitoba

Grant Tyreman, Director New Brunswick Marj. van de Sande, Director Alberta

Rodica Copilu, Co-Director Quebec Daniel Fodor, Co-Director Quebec

Ian Waymark, Director British Columbia James Vigmond, B.A.,LL.B., Honorary Director

[Ed.note: to obtain a copy of Board of Directors' addresses and phone numbers and/or a copy of the President's report highlighting accomplishments of the Network, please send a stamped self-addressed envelope.]

### **REPLY TO OUR PETITION TO THE HOUSE OF COMMONS:**

On Tuesday, September 3rd, 1996 a meeting was held in Mrs. Beryl Gaffney's office regarding the Government's response to our Petition which

was presented to the House of Commons on Friday, May 10th, 1996 requesting official recognition of ME/FM and Multi Chemical Sensitivities (MCS) as well as requesting that monies be set aside for research purposes for these illnesses. Present at this meeting were the following people: Beryl Gaffney MP and her Legislative Assistant, Helen Burton; Kristin Brulé, Special Assistant to the Hon. David Dingwell, Minister of Health; Karl H. Benne, Senior consultant, Health Care & Issues Division - Health Canada; Dr. Felix Li, Director, Cardio-Respiratory Diseases and Diabetes, as well as ME/FM/MCS and representing Dr. Losos, Director General of the Laboratory Centers for Disease Control; Lydia Neilson and Mike Martin of our organization; Tina Harvey, Director of Medical Research and John Warren, Director of Communications of ME Canada.

Dr. Li stated that in addition to his function of representing MCS in his Department, he also was in charge of ME/FM/MCS. As far as he knew, there were no other individuals working on these important issue.

From our meeting, it became painfully obvious that as Dr. Li discussed the Conferences that were held on ME/FM/MCS, the recommendations outlined in these conferences did go no further by putting someone in charge of making sure the recommendations were carried out.

A lengthy discussion followed and it was mutually decided that a sub-committee should be set up under the umbrella of the Standing Committee on Health which would specifically address the issues of ME/FM and MCS. We therefore wrote the Hon. Roger Simmons, P.C., MP, Chair of the Standing Committee on Health, to request that he set up a sub-committee so that there will finally be one location that both doctors, researchers and the general public could access for information on ME/FM/MCS. This sub-committee would meet and have the input from the National organizations as well as the provincial groups so that this matter can be dealt with once and for all. It was pointed out that both ME Canada and our organization stand united in our quest to help to further awareness and information for ME/FM/MCS and in that way convince the governments that it is important to admit that these illnesses must be studied so that our people will be treated with respect and compassion.

[Ed. note: Please support our request for a sub-committee by writing to: The Hon. Roger Simmons P.C. MP, Chair - Standing Committee on Health, Room 458, Confederation Building, House of Commons, Ottawa, ON K1A 0A6. If you would like a copy of the Minutes of the above meeting, please send us a stamped self-addressed envelope.]

### **BERYL GAFFNEY, MP REMOVED FROM STANDING COMMITTEE**

We were advised this week that due to the cabinet shuffle, Beryl Gaffney is no longer a member of the Standing Committee on Health. However, her office assures us that she is committed to keep working with us as she has in the past. We take this opportunity to thank her for all the progress we have made due to her and her staff.

### **MEDICAL EXAMINER OF JUDITH CURREN SPEAKS UP:**

Dr. L.J. Dragovic, Forensic Pathologist & Neuropathologist and Medical Examiner performed the autopsy on Ms Curren who you may recall committed suicide on Thursday, August 15, 1996, with assistance by a physician, Dr. Jack Kevorkian. Ms. Curren was reported to have suffered from ME/FM but apparently Dr. Dragovic, through the media, reported that he found no evidence of disease in her.

Dr. Dragovic defended his position and states as follows: "There has been much unfortunate abreaction on the part of some of your members to some rather inaccurate reports through media networks. Contrary to what has been mistakenly transmitted, I never stated or believed that CFS and fibromyalgia are not serious clinical conditions that cause well documented suffering. The last thing that would come to my mind would be to try to minimize the medical and social importance of this condition. However it is my professional statement that: 1) CFS is \*not\* a terminal disease; 2) CFS is \*not\* a fatal disease; 3) There is no defined anatomical substrate for CFS and hence, no evidence of this condition at autopsy; 4) CFS is a treatable condition and there is ongoing research to better understand, treat and cure it; 5) Thousands of patients have been successfully cured of CFS and many more are being cured each day; 6) EUTHANASIA IS NOT AN APPROPRIATE TREATMENT FOR CFS. Please forgive me for the imposition, but I am only paid for what I know and if they are to pay for everything I don't know, there would not be enough money in the world for that."

[Ed. note: Dr. Dragovic put #6 in large print. He had contacted The CFIDS Association of America and asked them to disseminate this communication.]

### **WOMEN'S COLLEGE HOSPITAL - TORONTO**

We received a letter from the Dr. Frank J. Foley, Medical Director of the Environmental Health Clinic at Women's College Hospital. They advised that they have received a three-year grant from the Ontario Ministry of Health to do the following:

1. Provide a consultation and assessment service for people with multiple chemical sensitivities;

2. Collaborate with the University of Toronto's Research Unit on Environmental Hypersensitivities to improve the management of these disorders; and

3. Develop a provincial network of physicians who are more knowledgeable about multiple chemical sensitivities.

In their follow-up letter to us of August 28, 1996 as we asked them how that would help ME/FM patients, they replied that they do not offer specific treatments since they are only funded as an assessment and research clinic. They stated that they do assessments and consultations for persons with Chronic Fatigue Syndrome and fibromyalgia. They have, however, submitted a proposal to the Ministry of Health in Ontario for a treatment clinic, and the Ministry is reviewing the proposal at this time.

If you wish to be assessed at The Environmental Health Clinic, Room 538 at the Women's College Hospital, please call: 1-800-427-7092 or (416) 351-3764 - Fax (416) 323-6130.

Address: 76 Grenville Street, Room 538, Toronto, Ontario M5S 1B2.

### **CANADA PENSION PLAN - DISABILITY PENSION - CHANGE IN TELEPHONE NUMBER**

The new number for contacting the Canada Pension Plan is **1-800-277-9914 English or 1-800-277-9915 French)**

**TIP:** Don't know a postal code that you need? **Call the Post Office at 1-800-267-1133.** All you need is the address and the City/Province and they will provide you with the postal code.

### **NATIONAL DOCTORS' ROSTER**

**GARY ADAMS, D.C.**

**DURHAM CHIROPRACTIC & REHABILITATION CENTRE**

**420 Cawthra St.**

**Whitby, ON L1N 3R5 Tel. (905) 430-0830 Fax (905) 430-0153**

This clinic is made up of chiropractors, psychologists, massage therapists and an exercise kinesiologist and state that they treat many people who suffer from ME/FM. Dr. Adams stresses to his patients the importance of taking a large view with respect to their illness and treatment. By this he states that "a successful approach usually involves a combination of different treatments. It is similar to a puzzle that is made up of a number of different pieces. We have found that 2 important pieces of the puzzle are chiropractic adjustments and a specific stretching and exercise regimen.....Misaligned vertebrae or 'Subluxations' may block or interfere with the flow of energy just as stepping on a garden hose may block the flow of water. Adjustments of the spine not only relieve pain and restricted spinal movement but also may allow a more normal flow of healing energy in the body."

**DR. YEN CHOW - MD CCFP - Diagnoses/Treatment of Fibromyalgia**

**105 Progress Cres., Suite 5**

**Kapuskasing, ON P5N 3H5 Tel. (705) 335-6269 Fax (705) 335-6022**

### **DISABILITY TAX CREDIT - UPDATE:**

We received a letter from Ms Jane Stewart, P.C., MP of the Minister of National Revenue's office dated July 12th, 1996. In this letter she stated that there have been many issues raised surrounding this tax credit and Revenue Canada has undertaken an extensive review of this disability tax credit program and concluded that many individuals did not understand the eligibility requirements for the credit. In order to improve this situation, Revenue Canada, in consultation with the Canadian Medical Association, stated that they have substantially revised Form T2201 to make it easier to complete and to provide more information about the eligibility requirements.

Ms Stewart stated that she has initiated a number of changes to the administration of the Credit within Revenue Canada to ensure each case is handled with compassion and that uncertainty is removed for those who apply for the credit. She cited as an example, that "new applications for the disability tax credit will now be reviewed **at the time of initial assessment to ensure that the eligibility requirements are met.**" She stated that this will significantly reduce the possibility of individuals claiming the credit only to find at a later date that they were not eligible. This means that a person will not be approved one year, only to find out later that he/she owes the tax department a lot of money due to the credit being denied at a later date when audited, resulting in other years being reviewed and disallowed.

Ms Stewart has asked our organization for its input of the draft 1995 version of the Disability Tax Credit Certificate and we therefore in turn sent a copy of the draft to some of the ME/FM specialists, Provincial Support Groups and our own Board of Directors. We were given a deadline of August 16th, 1996 so our time was limited but are pleased that they felt that we should be consulted due to our constant intervention of private individuals and the ME/FM people as a whole who are having this Certificate denied to them and owing sums of money that they can ill afford to pay. They assured us that our comments and suggestions will be given serious consideration.

We are pleased to say that about 3 people that we know of have been successful in reversing the decision of Revenue Canada and we are awaiting replies on others. If there is anyone who needs our help, please send us details of your problems with the tax department and enclose a Direction signed and dated authorizing us to intervene on your behalf. One of our members has volunteered to help us with this task. He has successfully challenged Revenue Canada.

We also received a copy of a letter from a member who had received it from the Hon. Paul Martin, PC, MP., Minister of Finance, dated August 9, 1994 in which Mr Martin stated ".....I would like to explain the policy rationale that underlies the measure. The disability tax credit is intended to recognize the effect of a severe and prolonged disability on an individual's ability to pay tax."

We have therefore filed an ACCESS TO INFORMATION APPLICATION on July 26, 1996 under the Access to Information/Privacy Act requesting such things as the original intent of Section 118.4 of the Income Tax Act. We had contacted people in Revenue Canada asking them what the original intent of the Disability Credit was and they were unable to tell us that. They advised and the Finance Minister confirms that Revenue Canada only "administers and interprets the Income Tax Act." Somehow with all the changes in the past the intent has been buried. We therefore felt it was important to file the above Application to continue our intervention.

[Ed note: underlining by editor for emphasis.]

### **MAJIC 100 RADIO STATION "WAS NOT AWARE THAT CFS IS AN ACTUAL ILLNESS"**

In June 1996 we were made aware by private individuals and ME Canada's Tina Harvey that Majic 100's Show hos, Kim Taylor, referred to the fact that the traffic was so slow that everyone must have had Chronic Fatigue Syndrome. We immediately made phone calls to the Radio Station, followed up by a letter in which we enlightened them about ME/FM Chronic Fatigue Syndrome and that their comments were irresponsible. We pointed out to them that they would not have said that everyone came down with AIDS and therefore the traffic was slow

The response was immediate. Mr. Kent Newson, Program Director wrote us on July 4th, 1996 and stated that Ms Taylor did recall relating CFS to that morning's traffic conditions and that she was not aware that CFS is an actual illness. She now regrets she made the comment. Mr. Newson told us that he was "impressed by your organization's passion and drive to educate people about this illness [ME/FM] and motivate decision makers to do what they can to advance the treatment of ME/FM." Mr. Newson offered Majic 100's assistance by informing their audience of "any upcoming events and/or fundraisers your organization has planned in the future." He also stated that when we neared May 12, 1997 - National ME/FM Awareness Day, they would be most pleased to make any announcements we would like to make.

{Ed note: if you would like a copy of Majic 100's letter, please send us a stamped self-addressed envelope.}

#### **ADDITION TO NATIONAL LAWYERS ROSTER:**

\*J. ROYAL (ROY) NICKERSON

Nickerson Roberts, Barristers & Solicitors

#300, 10004 Jasper Avenue

Edmonton, AB T5J 1R3

Tel. (403) 428-0041 - Fax: (403) 425-0272

E-Mail: [nickrob@oanet.com](mailto:nickrob@oanet.com) - Internet: <http://www.tgx.com/nickrob>

\*Note: Mr. Nickerson advises that he handles ME and FM cases and would be pleased to see potential clients for the first half hour free of charge.

#### **RESULTS OF REHABILITATION SURVEY - BY GLENDA BOWEN, DIRECTOR**

We send out 158 surveys to randomly- picked Rehabilitation organizations across Canada and we received 52 replies with the following are the results:

Payment for Treatment by: self: 6 Insurance company: 18

Referrals for treatment by: self: 13; Insurance company: 13 doctors: 22

The remainder referrals were by WCB, lawyers, chiropractors, dentist, arthritis society and rehab consultants - 1 per each category.

TREATMENTS: massage: 5 exercise: 13 acupuncture: 7

drugs: 5 aquatics: 2 relaxation: 11

manipulation: 2 whirlpool: 1 laser: 2

nerve stimulation: 2 biofeedback: 1 social support: 2

cranial social theory: 1 homeopathic: 1 behavior mod. 6

occupational therapy: 2 education: 1 nutrition: 1

#### **UPDATE OF SUPPORT GROUPS WHO REPORTED VOLUME OF ME/FM MEMBERS:**

TOTAL NUMBER REPORTED TO DATE: **5,094**

**[Please take a moment to let us know how many people are attending your support group (both ME and FM); what is the name of the organization; the address and phone/fax numbers and support group leader's name. We need this information in writing. It is time that we have a figure to work with that represents Canada.]**

#### **BOOKS/NEWSLETTERS/VIDEOS ETC.**

**Memo from Doug Shore: The 1996 ME & FM Manual Newsletter (Issue #4 - 155 pages)** has now been completed. This is an annual non-profit publication which summarizes all the world-wide newsletters into point form for easier reading. The manual is laser quality printed on 8 1/2 X 11" paper with two columns and a spiral binding. It contains a list of 55 symptoms, 48 drugs, 49 therapies, 47 disability benefits, 67 books, 68 organizations, 186 supportive doctors, C.P.P., long term disability, insurance, legal help, dealing with doctors, coping. Call or write, sending a draft for \$19 Canadian and I will mail you a copy of the manual. Your name will be placed on the mailing list and notification will be sent when the next issue will be available. If you are having financial problems, send what you can and I will mail a copy, as long as my budget will low. The content of the Manual is available for viewing on the Internet at "www.geocities.com/capitolhill/1544" E-Mail "dwshore@direct.ca". At this site I have jump points for other Web sites and E-Mail for the World. **ME & FM Manual, Doug Shore, #235-32550 MacLure Road, Abbotsford, B.C. Canada V2T 4N3 Tel. (604) 855-9431.**

[Ed note: Doug Shore is Vice-President of M.E.B.C. and has been a support group leader since 1991.]

Summary of Dr. Saul's Presentation on his "**New Neuro-Endocrine Theory**" and Summary of Dr. Saul's Presentation on his "**Metabolic Treatment for ME**" which was presented by these Doctors at a recent support group meeting of MESH Ottawa' both by **Dr. Philipa D. Corning, B.Sc., Ph.D.** Please send stamped self-addressed envelope to us to receive a copy].

#### **FEDERAL HEALTH INSPECTORS SEIZE MELATONIN FROM HEALTH FOOD STORES**

Melatonin, a synthetic hormone and popular sleep remedy, was seized from health food stores in British Columbia and Alberta. The health food stores across Canada were warned by their own organization and by the federal government over a year ago that it is illegal to sell melatonin because its safety has not yet been proven. Crown counsel are now deciding whether to recommend that store owners be prosecuted. Source: The Ottawa Citizen, Tuesday, August 27, 1996.

#### **PACIFIC BIOTECH STUDYING NEWLY RECOGNIZED BACTERIUM**

**PACIFIC BIOTECH INTERNATIONAL, INC.**, A Research and Development Company in Houston, Texas under the direction of Luther E. Lindner, M.D., Ph.D., believe they have found the underlying cause of Chronic Fatigue Syndrome and state that it apparently also underlies Fibromyalgia and Multiple Sclerosis. However, bacterium is also present in normal individuals as well although typically at a lower level. Uncontrolled clinical trials have shown a good correlation between reduction in these bacteria and improvement in symptoms. However, they won't have definite proof until there are controlled trials and the immunology is studied. Dr. Lindner also states that this bacterium is resistant to most ordinary treatment regimens but that they have had some success with treatment with specific regimens. His research also indicates that the majority of patients test out resistant to antibiotics. He therefore cautions that antibiotics

should not be given without testing because there is a peculiar phenomenon with this bacterium where antibiotics will sometimes make things worse.

[Ed note: If you would like a copy of the experimental protocols and nutrition and lifestyle suggestions in relation to Biotech's bacterium, please send us a stamped self-addressed envelop (12 pages)]

**ELECTRONIC MAIL:** our e-mail address: [ag922@freenet.carleton.ca](mailto:ag922@freenet.carleton.ca)

**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 United States: CFS/ME Computer Networking Project, P.O. Box 11347, Washington, DC 20008-0547 U.S.A. Please note that for mailing outside of Canada include an International Reply Coupon.

**OUR WORLD:** PLATEAU: feeling not too good but not too bad.

Dear Friends: As you will note, our newsletter has been put into a different format and a different size so that it will be easier to file. This is the first time we tried to put it into two columns, so please bear with us and let us know how you feel about this new format.

Until next time, take care.

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Lydia E. Neilson

President CEO

**MEMBERSHIP: \$20.00 PER YEAR, INCLUDING NEWSLETTERS EVERY TWO MONTHS.**

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