Quest #17 April 1996

PETITIONS TO THE HOUSE OF COMMONS - MAY 10TH, 1996 -

Re:National ME/FM Awareness Day, May 12, 1996

The Honorable Beryl Gaffney MP will be presenting the Petition of the signatures we have collected from across Canada to the House of Commons for which the Agenda is as follows:

Agenda: for May 10, 1996: Parliament Hill Activities

10:00 A.M. Press Conference - Charles Lynch Room: Room 130-S

Centre Block, House of Commons

(Room open to the Press and invited Guests only)

- **12:00 Noon** Presentation of Petitions in the House of Commons

12:30 - 1:30 P.M. (approx.) Reception in the Commonwealth Room

To show that we are all united about this event, not only will our organization be present but also representatives will be attending from ME CANADA; Foundation & Centres "Compassion in Action"; Action Ontario and the Electronic Mail representative.

Ms Gaffney also published her Parliamentary Report for April 1996 and wrote as follows:

"May 12th is the birth date of Florence Nightingale who is believed to have suffered from Myalgic Encephalomyelitis (ME) known today as Chronic Fatigue Syndrome (CFS). This day has been set aside by over 450 ME/FM support groups across Canada to create greater awareness among the public, doctors and educators about two illnesses affecting many thousands of Canadians.

ME (Chronic Fatigue syndrome) is a real and severe disease which impairs its victims in their ability to work. CFS takes perfectly healthy people and creates totally dysfunctional individuals. CFS patients have severe and debilitating fatigue with the pain.

Fibromyalgia (FM) has similar symptoms including fatigue, headaches, memory and concentration problems, sleep disturbances and pain. However, FM patients have an amplification of pain in the muscles and tendons accompanied by severe sleep disturbances.

Prior to May 12, ME/FM Awareness Day, I will be presenting to the House of commons petitions containing 15,000 signatures representing every province in Canada. The petitions call upon the Federal Government to recognize ME/FM as official diseases, to set identification guidelines and to ensure care treatment, comfort and dignity to those afflicted.

As a member of the Standing committee on Health, I will be requesting that the Committee devote time to further study ME/FM. If you have information to share with me, I would be pleased to hear from you. Please write to: Room 553-S, Centre Block, House of Commons, Ottawa, Ontario, K1A 0A6. No stamp is necessary.

The national ME/FM Action Network (829-6667) and the M.E. Association of Canada (563-1565) are two local organizations dedicated to informing the public and assisting those suffering from either ME or FM. They welcome your inquiries."

NATIONAL INSURANCE SURVEY- UPDATE:

We have mailed out the insurance survey to all the support groups and leaders that we are aware of across Canada, as well as to all our members. Please participate by completing this questionnaire and forwarding it to Opinion Search Inc. at the address mentioned on the last page of the survey. If you have not received a survey and would like to participate, please let us know.

If we did not send your support group this survey for distribution, please contact us and we will be more than pleased to rectify the situation. It is very important that as many as possible complete this survey, whether they do or do not get a disability pension. To protect your privacy, no name is necessary for identification. We only request that you put down your postal code for statistical purposes. We are also pleased to report that ME Canada has kindly consented to publish our survey in its June newsletter "The MEssenger" which is expected to be published sometime within the next two or three weeks, so that as many people as possible will have a chance to participate in this survey. Please note that the deadline for this survey is Sunday, June 30th, 1996.

CANADA PENSION PLAN (CPP) UPDATE:

1) CPP is running a trial national project, to provide rehabilitation services to selected clients. CPP rehabilitation services focus on people's abilities and try to help clients who wish to return to the workforce, to find a way to do so.

Who qualifies?

CPP is looking for those CPP disability beneficiaries who are most likely to be able to benefit from rehabilitation services. For instance, people who are: under age 50; not terminally ill; medically stable; resident anywhere in Canada; and motivated and willing to participate.

How does it work?

CPP starts out by a case manager reviewing your file to see if you meet the above conditions. If you do, they then will contact you by phone to explain the rehabilitation process and to seek further information from you and to give you a chance to ask questions. At that time you may give a verbal consent to be considered for the project which will be followed by a consent form by mail for your signature. The consent form allows CPP to release information from your CPP file to a rehabilitation consultant. These consultants are under contract to CPP. These services are provided in your region and that could mean that the work will be done under a sub-contract in your community i.e. in schools, hospital and local assessment units.

What would follow would be a vocational assessment done with a consultant. In addition, your doctor would be asked to provide an opinion on the level of activity or retraining you can undertake, given your medical condition. Your doctor becomes an important part of the team assisting you to recenter the workforce.

If your disability is a physical condition, a qualified occupational therapist or physiotherapist may determine your tolerance levels for activities such as sitting, walking, standing, bending and lifting. They will also review your educztional history and in some cases, the consultant may recommend that CPP fund your return to school for retraining or upgrading your skills. Of course, not everyone needs educational upgrading or retraining and CPP will work with you to identify skills that you may already have which could immediately be applied in a variety of jobs.

Where appropriate, the consultant will contact your previous employers to see what jobs may be available and also consult with Employment and Immigration Canada to see if there are any suitable job training programs available in your region.

Based on all this information and taking into consideration your interests and abilities, the consultant makes a recommendation to CPP on rehabilitation services for you. The recommendation also considers the needs of a potential employer and includes a fully costed plan. The plan is approved by both CPP and you and must be signed before anything can be done.

Who pays for the service?

CPP pays the costs of the consultant to continue working with you and the costs of assessments, tuition, books and other ehabilitation expenses related to the Plan.

What happens to your CPP disability benefit?

You continue to receive your CPP disability benefit during the rehabilitation period.

CPP will also make every effort to help you find gainful employement.

What happens when you find a job?

When you find a job, you continue to receive your disability benefit for three months after you have returned to work. Then your benefit ceases. However, if a suitable job is not immediately available, the consultant continues to work with you and you continue to receive your benefit for a three month job search period. Following this period, since your rehabilitation has been completed, your disability benefit ceases.

When will this rehabilitation trial service end?

It was originally scheduled to end March 1996. However, this rehabilitation **trial service has been extended for an indefinite period of time.** However, they are interested in helping people who could go through rehabilitation and return to work within a year.

How to get more information:

If you receive a CPP disability benefit, and are interested in its rehabilitation services, please call **1-800-461-3422.** CPP will get back to you within 10 working days to discuss your particular situation. When you call, leave your name, area code and telephone number.

[Ed. note: I called the information number and left only my name and phone number and the call was returned by a local representative. She advised me that each province will have its own Branch for CPP.

I mentioned to her that when I called the information line, the recorded message asked for my Social Insurance Number (S.I.N.) together with my name and telephone number and I was a bit leery about that, as I know other people are. She stated that people at CPP have to swear to a confidentiality oath and that when people ask for information, they don't have to worry about about it being used unless and until the proper documents are signed.

ADDITION TO NATIONAL DOCTORS' LIST:

Dr. Sean O'Sullivan

594 Broadway Street

Tillsonburg, ON N4G 5K9 - Tel. (519) 842-3636

Dr. O'Sullivan diagnosis and treats people who suffer from both ME/CFS and FM.

EYE SURVEY UPDATE:

Dr. Walter Potaznick of The New England College of Optometry had assigned Site No. 55 to our organization representing Canada. He advised that he was very pleased with the volume of completed questionnaires he had received from Canada and thanks all who have participated. He now has sufficient data from Canada and no more are needed.

Dr. Potaznick is looking for a possible marker for ME/FM and will keep us advised of the status of his survey.

VISIT TO OTTAWA BY DR. LESLIE O. SIMPSON of the University of Otago in New Zealand.

ME CANADA held a dinner in Ottawa in honour of Dr. Simpson which was attended by some support group leaders residing near Ottawa, together with Dr. Byron Hyde of the Nightingale Foundation, and myself. Dr. Simpson has lectured widely in the United States, Asia, Europe and the Pacific and his research interests have been embodied in 70 plus papers, and by numerous letters to scientific journals. Since his retirement in 1986, he has been a research fellow in the Department of General Practice, where he has developed a red cell shape analysis. This has been used to assess red cell shape in blood samples from patients with Myalgic Encephalomyelitis residing in New Zealand, Australia, the Netherlands, South Affica, United Kingdom and the U.S.A.

His involvement with ME began in 1984 when he suggested that the plothora of symptoms and the variability of presentation, could be due to some unexplained impairment in bloodflow. This was investigated by a blood filtration technique and in a 1986 publication may have been the first record of blood flow problems in ME. As MS is also associated with tiredness and easy exhaustability on exertion, he used the same techniques to show that MS blood was poorly filtrable and this information was published in 1987. This led to scanning electron microscopy of immediately fixed red blood cells to ascertain if there was some visible explanation for poor blood filtrability. The results of that initial study were published in 1989 and led to the technique of red cell shape analysis.

Dr. Simpson is currently involved in the evaluation of about 2000 blood samples which he has collected from ME patients living in New Zealand, Australia, South Africa, England and the United States. Dr. Simpson will be speaking in British Columbia and will be starting his three week tour of support groups throughout B.C. beginning May 12th as well as speaking to the medical community and general public.

To get in touch with Dr. Simpson for possible speaking engagements in the future, he can be contacted at: The University of Otago, P.O. Box 913, Dunedin, New Zealand. Tel. No. International 64 3 479 7430 - Fax. No. International 64 3 479 7431- (e-mail address: LES@jin.0tago.ac.n2)

SUPREME COURT OF CANADA RULED: "Having a mental disability is not a valid reason to cut someone's work benefits"

The Supreme Court of Canada says Battlefords and District Co-operative and its insurance firm can't cut a woman off benefits simply because her problem is mental rather than physical. Ms Betty-Lu Clara Gibbs had complained to the Saskatchewan Human Rights Commission that her employer discriminated against her when it stopped her disability benefits after two years in March 1990. Ms Gibbs, a clerk, suffered from anorexia nervosa, a bowel disorder and panic attacks. The Court said it will release reasons for its ruling later.

Source: From the Internet re: Vancouver's "Province" newspaper dated May 3, 1996.

INTER-GROUP/CONTACT COMMUNICATIONS:

1996 National Conference and Annual General Meeting of the Allergy and Environmental Health Association of Canada (AEHA/AASE) at the Cafeteria, Building D, Woodroffe Campus, Algonquin College - Ottawa, Ontario - featuring Dr. Doris J. Rapp, MD, F.A.A.A., F.A.A.P., well-known pediatric allergist specializin in environmental medicine and internationally acclaimed author about children with learning and behavioural disabilities caused by environmental sensitivities. Date: May 31, June 1 and 2, 1996. Registration: Friday 6:00-7:15 p.m., Saturday 8:30-9:15 a.m.

NEWSLETTERS/BOOKS/ETC.

THE NATURE OF THE HUMAN CONSTITUTION, Homeostasis, Fever And The Chronic Fatigue Syndrome - by Jed Gallagher. Mr. Gallagher is a science historian, philosopher of science and a long-time ME/CFS patient.

This is a DigiBook, only available in digital form on diskette, for screen reading or print-out; it will not be published in traditional book form.

- MS Word 6.0 ASCII Rich-Text and ASCII test files on each diskette. Price: $10.00 U.S. Please send your payment and your name and address to: DigiBook, P.O. Box HP112, Leeds, LS6 2QR, England.

If you experience any problems with receiving your diskette, or have any other queries/correspondence, then please write to : Jed Gallagher, 12 Cliff Road Gardens, Leeds, LS6 2EY, England. (Do not send your payment to this address).

TIP - FOR A DRY MOUTH:

"Dry mouth is a potential side effect of over 300 drugs. Often overlooked by health professionals, it can seriously affect the quality of patients' lives. Here are some steps people can take to reduce both the severity and consequences of this symptom:

- Sipping small amounts of water throughout the day is one of the best ways to combat a dry mouth. While it may be tempting to drink large amounts at one time, this is no more effective than drinking smaller amounts more often.
- Frequent sips of water *while* you are eating makes it easier to chew and swallow food. This is especially true with dry foods (e.g., cereals, crackers) which tend to stick in your mouth.
- Sometimes the simple act of 'chewing' can increase the flow of saliva. Be sure to eat meals that require a chewing action. Chewing sugarless gum between meals can also help.

- Adding moisture to the air with a humidifier is another way to help reduce a dry mouth. This is especially helpful if your mouth gets dry during the night.
- Some people find acidic or sour foods (e.g. dill pickles, lemon juice, tart-tasting candies) ease a dry mouth.
- Do not use candy or chewing gum that contains sugar. Sugar can speed up tooth decay even more in people who have a very dry mouth. Also try to avoid salty foods--these only increase the feeling of thirst.
- Alcohol can also make your mouth feel dry. If you use a mouthwash, make sure it does *not* have high alcohol content. Avoiding or cutting down alcoholic drinks may also help.
- A dry mouth can make it harder to swallow pills. To help pills go down, drink a little water just *before* you take the pill. Then swallow the pill right away with a *full* glass of water.
- Having a dry mouth for long periods of time can increase the chances of gum disease or cavities. To help reduce this effect, brush your teeth after every meal and floss your teeth at least once a day. Use a soft toothbrush especially if your mouth is sore or feels tender.
- If your mouth is very dry, ask your pharmacist about an artificial saliva product. These are almost the same as real saliva and can be used as often as you like to moisten your mouth.
- Tell your dentist if you have been using artificial saliva. These products do not have the same cavity-fighting effect as the saliva produced in your mouth.
- A chronic dry mouth should not be ignored. If the above ideas don't help, be sure to tell your doctor or dentist. He or she may have other suggestions to help this symptom.*

*Note: chronic dry mouth can also be a symptom of other potentially more serious medical conditions.

Source:Canadian Pharmaceutical Journal Dec.93/Jan.94

WELCOME TO OUR WORLD:

MEMORY BLANKS: The umpteenth reading as thrilling as the first and honorary degree in 'living in the immediate present'.

Source: Lorraine Legendre, Ottawa.

MEMBERSHIP: $20.00 per year which includes newsletters every two months. Please show your support by becoming a member and joining the Action.

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 gruops. 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 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. 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.