

Quest #24 June 1997

Dear Friends:

For those of you with access to the electronic world, you will be pleased to know that the National ME/FM Action Network now has a web page on the internet highway. There has been much to do in the way of learning how to manipulate and address the web site but we feel confident that things can only improve from now on. Although not all of the pages are intact at this writing, they soon will be.

We have endeavored to put the web page together with both business and fun in mind. If you have access to a computer and the internet, please check us out at:

<http://www3.sympatico.ca/me-fm.action/>

We hope to be able to reach every corner of the world with our message and help via this media, in addition to our regular newsletter, correspondence and direct telephone contact. Please let us know how you like the new web page and by all means, spread the word to friends and medical or legal contacts.

Al Neilson,

Computer Geek (husband of the boss)

GRANT UPDATE:

We have received another grant from Health Canada in the amount of **\$20,000**. This grant has enabled us to hire an assistant to help with our ever-increasing workload.

FINANCIAL STATEMENT - APRIL 1, 1996 - MARCH 31, 1997

Prepared by Hughes LeBel, Chartered Accountants.

Revenues

Donations \$ 3,079

Memberships 5,831

Grant 25,000

Interest 44

Miscellaneous 2,175

36,129

Expenses

Amortization(depreciation) 3,481

Bank charges & interest 77

Information packages 4,694

Insurance 462

Office supplies 2,634

Postage 3,743

Printing 3,254

Professional fees

(legal & C.A.) 5,007

Rent 1,500

Repairs & maintenance 658

Telephone 2,289

Travel 904

Utilities 132

Total Expenses 28,835

Excess of Revenue Over Expenses: \$7,294

BOARD OF DIRECTORS:

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Ian Waymark, Director British Columbia, R.R.2, Site 21, Comp 35, Gabriola, BC V0R 1X0 - Tel. (250) 722-0084

Fax (250) 722-0087

We have also appointed a Director of Fundraising in July 1997 and we welcome her on board:

Carol Roy, Director Fundraising, 1244 Donald St., Apt. 1611, Gloucester, ON K1J 8V6 -

Tel. (613) 748-3968.

GEORGETOWN UNIVERSITY MEDICAL CENTER is studying a co-enzyme called NADH which is an enzyme facilitator that occurs in all living cells and plays a central role in the body's energy-producing capacity. The FDA recently approved a clinical trial of NADH for treatment of ME/CFS. This study began in April 1996 and is now at the half-way point. The proposed mechanism of action of NADH is to replenish the depleted cellular stores of adenosine triphosphate (ATP), the body's storehouse of energy, thus improving the fatigue and cognitive dysfunction.

This is a double-blind crossover study and although the researcher is unaware of who has received NADH and who has received a placebo in this on-going study, he stated that "some CFS patients participating in the study showed marked improvement over time". Based on these preliminary findings, Georgetown's Immunology Department is now expanding the study and recruiting more patients.

For more information, please contact: Ms Nancy Whelan - Tel. (202) 687-5100, Georgetown University Medical Center Public Relations, 2233 Wisconsin Avenue N.W. #317, Washington, D.C. 20007 U.S.A. - Tel. (202) 687-5178.

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await confirmation

BOOKS/NEWSLETTERS/REPORTS/VIDEOS ETC.

THE FIBROMYALGIA SUPPORTER - By: Mark J. Pellegrino, MD - Dr. Pellegrino combines compassion, humor and empathy with his professional expertise to provide specific steps to achieve a real 'partnership' in dealing with Fibromyalgia. Published by **Anadem Publishing Inc.**, P.O. Box 14385, Columbus, OH 43214-9856 U.S.A. - Tel. **1-800-633-0055**. Cost: **\$15.50 plus \$3.50 (U.S. Funds)** shipping and handling.

MYCOPLASMAL INFECTIONS - By: Garth L. Nicolson, Ph.D. and Nancy L. Nicolson, Ph.D.

DIAGNOSIS AND TREATMENT OF GULF WAR ILLNESS/CFIDS PATIENTS (8 PAGES)

To receive a copy of this report, please send us a stamped self-addressed envelope (**45¢**) to our Network.

From Human Resources Development Canada - Office for Disability Issues. "Living with Disabilities in Canada: An Economic Portrait" - By: Gail Fawcett, Ph.D. , FREE: Call: 1-800-665-9017 , leave your name and address to receive a copy. .

RATING GUIDE TO ENVIRONMENTALLY HEALTHY METRO AREAS - U.S.A.

By: Robert S. Weinhold, M.A.

In this book, the author has rated all 327 U.S. metro areas in 10 critical categories to determine the potential toxic loads that U.S. residents may be exposed to. Mr. Weinhold is a Freelance Journalist, covering Health and the Environment. Price: **U.S.\$16.00 plus \$2.00 S & H. Address: Robert S. Weinhold, P.O. Box 9094, Durango, CO 81302-9094 U.S.A. Tel. & Fax: (970) 259-8823,**

Email: RWeinhold@compuserve.com

***MYALGIC ENCEPHALOMYELITIS BRAIN MAPPING RESEARCH**

Brain Mapping Research of Dr. P. Flor-Henry

BY: Marj van de Sande

***Dr. FlorHenry kindly reviewed this article for accuracy.**

Dr. Pierre Flor-Henry is director of the Clinical Diagnostics & Research Centre, Clinical Professor, University of Alberta and Clinical Director of Acute Psychiatry Services of the Alberta Hospital in Edmonton. This article is taken from his lecture of April 17, 1997 at the Foothills Hospital Auditorium in Calgary. The lecture was sponsored by the ME/FM Society of Alberta.

Dr. Flor-Henry is engaged in research on *Brain Mapping* of myalgic encephalomyelitis (ME) which is also called chronic fatigue syndrome (CFS), and fibromyalgia (FM) patients in order to determine differences between the functions of their brains compared to healthy controls.

ME and FM are fundamentally the same illness but have different triggers. ME/CFS is usually triggered by a viral infection while FM is often triggered by a physical trauma, particularly whiplash injuries. The age of onset is usually between 38 and 43. As ME/FM is an illness which affects the brain, immunological system and the endocrinological systems (hypothalamic/pituitary/adrenal axis), the symptoms are numerous and include:

Alcohol intolerance Hand swelling

Anxiety Incoordination

Arthralgia Loss of appetite

Bladder dysfunction Mood swings

Chills Myalgia

Dreams of being paralyzed Light sensitivity

or sleep paralysis Night sweats

Depression Nausea/vomiting

Difficulty concentrating Odd skin sensitivities

Diarrhea Paresthesias (numbing/tingling

Dizziness Pain on breathing

Difficulty sleeping Palpitations

Earaches Rashes

Eyelid swelling Sore throat

Fatigue Stomach pain

Fever Swollen lymph nodes

Heat/cold intolerance Weight loss

Headache

Hair loss

As standard medical tests do not show abnormalities and approximately 80 percent of those inflicted are women, some suggest that its origin is psychogenic. However, research findings indicate that ME is an immune disease with dysfunction of the nervous system which is usually triggered by a viral infection. Infectious Mono has some of the same symptoms as ME and is often its precursor. Dr. Flor-Henry believes ME is not caused by a single virus but rather a variety of agents, usually viral in nature. Although some symptoms mimic depression, psychogenic conditions do not produce symptoms such as fevers, chills or muscle pain. Some research findings indicate ME is an autoimmune disease. There is impaired activation of the hypothalamus/pituitary/adrenal axis. A glucocorticoid deficiency causes debilitating fatigue. The dysfunction of the hypothalamic-pituitary-adrenocortical axis is shown by the low levels of twenty-four hour urinary free cortisol. Dr. J. Goldstein and Dr. M. Ichise have used SPECT scans to show reduced circulation in the frontal and temporal regions of the brain. A number of subsequent SPECT scan studies have confirmed these findings (Cousins & Gonzalez, 1997). The changes in ME brains are not structural, as indicated in normal results of MRI tests, but rather are functional in nature.

Serotonin modulates some immunological functions and stimulates natural killer cell activity, both of which are impaired in ME. Serotonergic antidepressants such as Elavil have been found to be beneficial in alleviating pain for some patients when given at about one-tenth the dosage given for depression. This is because the beneficial effect is not through the antidepressant effects of tricyclics but because at low dosage they normalize the immunological system.

Although Dr. Flor-Henry tested both those diagnosed with ME and FM, he only reported his findings for ME patients. He employed brain mapping using a multi-channel EEG Cartography, a computerized, diagnostic test for one's mental state. Two hundred fifty-six samples were taken per second. The Annett Handedness Questionnaire was given. The study was limited to right-handed patients as information processing may be handled differently in brains of left-handed people. The findings of thirty-two (32) right-handed ME patients were compared to those of thirty-nine (39) healthy controls. Twenty (20) ME patients were not depressed and twelve (12) ME patients also suffered or had suffered from secondary depression.

Neuropsychological investigations have shown that the left hemisphere of the brain of ME patients is dysfunctional in word retrieval, comprehension, organization, problem solving and memory. There were identical findings for FM patients. Depression patients do not show these selective left hemisphere brain dysfunction. This proves that ME and FM are not depressive states. Using a computerized Personality Inventory, all personality dimensions were found to be normal except there was elevated pain.

Spectral Analysis tested spatial and verbal cognitive tasks. Brain activity was monitored for two to five minutes while engaged in both verbal and spatial tasks. The verbal section involved word-finding tasks. It began with the definition, "A very large piece of floating ice", the correct response being, "an iceberg", and progressed to more difficult vocabulary. Only 'correct answer' brain activity was included in the results. The results showed abnormal activity/dysfunction in the left hemisphere during word retrieval tasks but ME subjects were all normal when engaging in right hemisphere spatial tasks.

Forty-three (43) sites of the brain were monitored in the brain mapping tests. EEG parameters of power and coherence were measured. The EEG of ME patients was quite abnormal: EEG changes/abnormalities were found in theta (4 - 7 Hz) and beta (20 - 50 Hz) frequencies. The alpha (8 - 13 Hz) and delta (1 - 3 Hz) frequencies were normal. An excessive fast activity was found during word finding activities and less power during the spatial tasks, with a shift from the right to left hemisphere. During cognitive activation the EEG disorganization is present only when the left hemisphere (dominant) is engaged in a verbal task. When the right hemisphere is engaged, it is similar to normal controls. Patients who also suffered from secondary depression exhibited less fast brain wave activity.

The left hemisphere of the brain is employed for language and verbal thought. It also controls or is a feedback system over many functions of the right hemisphere such as fine mobility. Frontal and temporal regions in both the sides of the brain show abnormalities in ME.

No single etiology (cause) has been found for ME but immune abnormality may preexist. Left brain lesions lead to a 50% reduction of T cells and a 50% reduction in natural killer cell cytolytic activity resulting in a lowfunctioning system, whereas similar lesions in the right brain have no influence on the immune system.

Dr. FlorHenry expects to submit his research paper for publication soon and hopes it will be published within the next eighteen months. Although his testing methods can be used now to diagnose these abnormalities in ME and FM patients, his work will have to be replicated by other researchers before it can be accepted as a standard, specific test for ME and FM. Following submission of his present research paper, he plans to tabulate the results of the FM patients whose onset of the disease was triggered by a motor vehicle whiplash injury. Dr. FlorHenry can be contacted at the Alberta Hospital, Box 307, Edmonton, AB. T5J 2J7. Phone (403) 4725395. Fax (403) 4725291.

Ref: 1. My notes taken during his lecture.

2. Brain Mapping Research Could Lead to a Specific Diagnostic Test. Heynsbroek J. The FMS/CFS Communicator, 1997 May.

Nutritional Basis for ME and FM - By: P.D. Corning, B.Sc., Ph.D.

There is Hope:

Indeed, there is hope for ME and FM sufferers to regain a part or all of their former health. While the majority of conventional medical doctors and researchers are out chasing the elusive causal virus and searching for the magic drug to cure these maladies, some sufferers, and doctors such as Dr. Majid Ali (author of "The Canary and Chronic Fatigue"), have found success through the consumption of organically grown foods and/or natural supplements. I finally tried the latter method, after three years of

following the advice of conventional doctors, i.e., taking drugs and eating from the "**Five food groups**" at the supermarket, and getting nowhere.

The reason that the conventional approach does not help is because doctors, and the public in general, do not understand what has happened to our nutrition since 1945. The nutritional quality of food has steadily decreased resulting in many essential nutrients missing from our food. Like everyone else today who buys food at the supermarket, I have come to suffer from **malnutrition** over the years; this slowly reduces the strength of the immune system and the rest of the body. As a result, it is no wonder that we get ill after contending with the unrelenting stress of life today, the hectic pace of life in the 90s, and the constant assault on the body by pollutants, etc. Our immune system cannot cope with it all. Thus, I believe that **POOR NUTRITION** forms the basis and **sets the stage** for the development of chronic degenerative diseases today, including ME and FM.

A poor immune response resulting from poor nutrition explains why the treatment of ME and FM has been frustrating for conventional doctors. The cause is **multi-factorial**. If the immune system is run down because it has not been maintained by the proper building materials (i.e., nutrients), any major stressor has the potential of initiating a total system dysfunction. This explains why ME and FM can result from a viral infection, an operation, a car accident, prolonged stress, over-exercise (especially with competitive athletes), a tragic incident, allergies, candida, etc. The immune system cannot cope with all the stressors, and thus becomes **hyperactive**. Without the proper nutrients, it stays there and the sufferers remain sick.

In this paper, I discuss the nutritional basis for chronic degenerative diseases, including ME and FM, and share some ways that have worked for myself and others on our struggle back to good health. These methods are **NOT** proposed as medical cures, and readers are advised to consult a health professional before trying anything. Furthermore, I caution all readers that what works for one person may not work for another. We are all unique.

Technology Fails:

During this century, there have been many spectacular advances in technology, yet North America is plagued with a steady increase in illness and chronic degenerative disease: ME/CFS and FM, allergies, and environmental sensitivities are just a few. Our grandparents were healthier than we are as they reached advanced years.

Many people such as myself have always eaten healthy, balanced meals and exercised regularly, yet we fell seriously ill with some of the diseases already mentioned. We recuperated and still ate nutritious food, but we regained only a small portion of our former health. During this struggle, I investigated many avenues in search for a cure. Then I slowly began to see the connection between our lack of proper nutrition in this technological era and the increase in chronic degenerative disease. The immune system is run down through malnutrition and is being assaulted by harmful substances in both our food sources and environment.

Lifestyle Factors:

I have found that many of the chronic degenerative diseases seen today share a common base of the following factors: a. Poor nutrition; b. Free radical damage; c. sugar-damaged protein; d. Too much cooked and processed food; e. acid-forming food and drinks; f. presence of toxic substances: pollutants, pesticides, drugs, food additives, and preservatives; h. hectic pace and stress associated with life today.

These lifestyle factors are all forms of stress placed on our bodies, and the **main site of their impact is our immune system**. I will discuss each of these factors, their effect on the immune system, and measures found successful by myself and others seeking to regain our health.

[To be continued in next issue]

SUDBURY CONFERENCE -

EMERGING VIRUSES -

Where are they coming from? How can they be stopped? What is the status of current treatment? Plan to attend this important CONFERENCE being held in:

SUDBURY, ONTARIO

AT THE HOLIDAY INN

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The **theme** of this landmark Conference is: **A COMMON FRONT AGAINST THE COMMON FOE!**

By a united effort to discover the secrets of this unconventional virus...more aptly termed a 'sub-viral' microorganism...we will stand a greater chance of bringing all of these diseases under control. This conference will set the course for that united effort.

OUR KEY-NOTE SPEAKER WILL BE DR. LEONARD HOROWITZ, AUTHOR OF THE SIGNIFICANT NEW BOOK: EMERGING VIRUS ; FROM AIDS TO EBOLA.

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For **Hotel Reservations** Book Direct:

Holiday Inn. (705)-675-5602.

'HASTI NOTES' - A QUICK WAY TO SEND A MESSAGE

A package of four different cards was designed for us by Mary Harris of Peterborough, a ME person. The front of the card shows a picture of a turtle and the back of this card contains information on who we are and how to obtain information on ME/FM. **Cost: \$4.00 per package.** Contact us for ordering these 'Hasti Notes' and have the satisfaction of helping our organization at the same time .

Our World

M.E.: Measure Endurance

FM: Free Myalgia

SYMPTOMS: Silent broadcaster for the body's condition.

Dear Friends:

We have not increased the cost of our newsletter since we started four years ago. We hope to still not increase our price and therefore ask you to join us by becoming a member or by a donation so that we may continue to help anyone who needs it.

Thank you for your support, and take care.

Lydia E. Neilson

President CEO

MEMBERSHIP: \$20.00 per year which includes newsletters every two months. Please show your support by becoming a member or by making a donation.

ELECTRONIC MAIL: our e-mail address: 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 please include an International Reply Coupon.

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