

Quest #27 December 1997

COMPUTER GEEK REPORT - BY: Al Neilson

PAST NEWSLETTERS: We now have an **archive website** for past issues of QUEST newsletters (going back to 1993). This archive site is easily accessible by clicking on the NEWS button in our website. You will find a link to the archive site at this point.

For those of you with access, you might want to scan some of the issues that were available before you actually became a member of the National ME/FM Action Network. For my own interest, I did some back-reading recently and it gives you a good idea of just how quickly the organization has progressed over just a few years.

To be fair to our current paying members, we will delay publishing on the archive site by a gap of two newsletters (i.e. four-month delay). This we consider to be only fair to members who pay for the privilege of current up-to-date newsletters. We do, however, ask the electronic version readers to become members, if they enjoy hearing from us.

Many thanks to **SANDY SHAW** for providing the web space for the archive site and for the set-up. Look to see many more interesting things at this site in future.

PROBLEM: For those of you with access to computers and internet accounts, you probably have sent Email with or without attached files to other addresses, with success. There is a slight problem when sending email to Lydia, however. All of Lydia's incoming Email, at the ag922@freenet.carleton.ca address comes through a collegiate Freenet system. This Freenet system, although partly internet-based, is a UNIX system based in plain-text language. It cannot recognize MIME-encoded documents, such as WORD-processed text or WORDPERFECT-coded text. When you try to send us a message using both of these wordprocessor programs, we end up receiving hexadecimal hieroglyphics.

SOLUTION: When you wish to send a message, please save your message in plain text or RTF (Rich Text Format) before sending --- please do not attempt to attach a file to any message you send. UNIX does not recognize attachments of any sort. If you must send a file, please use the cut-and-paste method to your message and that way we will receive it embedded in your message.

If it is absolutely necessary to send a document or an attached file beyond the above instructions, please contact us for further instructions. This will invariably resolve a lot of constant re-communication with senders due to the fact that we cannot read the incoming Email properly, in some cases.

ONTARIO HUMAN RIGHTS COMMISSION TAKES A STAND ON ME/FM

In the past, people with Chronic Fatigue Syndrome and/or Fibromyalgia had difficulty getting the Human Rights Commissions to take these illnesses seriously. Usually,

people were told to see a psychiatrist for help or were advised that they could not help them, without any explanation..

We have been working with the **Fibromyalgia Society of Ontario in Sudbury** (formerly the Northern Ontario Fibromyalgia Network) to get this matter addressed in Ontario. We feel that by having one Human Rights Commission take a favorable position on ME/FM, the rest may follow.

The Chief Commissioner, **Mr. Keith C. Norton**, Q.C., B.A., LL.B. advised us that he had reviewed our concerns about ME/FM people with his senior staff at the Ontario Human Rights Commission to identify possible solutions. He assured us that under the Human Rights Code, "persons with ME/FM have the same rights and protections as any other person in Ontario." If a person claims to have a handicap resulting from ME/FM, then the Commission will deal with the matter as it would in any disability complaint. He pointed out that section 17 of the Code makes it clear that persons with handicaps are to be accommodated in accordance with their individual needs.

Mr. Norton also pointed out that the education component extends to the Commission's own staff and advised us that the Corporate Services Branch will be developing a staff training session to address the needs of persons with disabilities. These sessions are planned for the next fiscal year. [1998].

[Ed.note: **1)** We will be contacting all other Human Rights Commissions in all provinces and territories to get the same commitment from them as we have from the Ontario Chief Commissioner. If you would like to get in touch with **Mr. Norton** about any human rights problems you have experienced and to offer your support, Mr. Norton can be reached at **180 Dundas Street West, Toronto, ON M7A 2R9 - Tel. (416) 314-4541; and**

2) You only have **six months to file a complaint** with the Humans Rights Commission i.e. six months from the date when the incident occurred]

DISABILITY TAX CREDIT, FORM T2201 - REMINDER

Soon it will be time to file out your Income Tax Return. Remember that if you have been approved for the Disability Tax Credit and there are no changes in your medical condition, you do not need to complete a new Disability Tax Credit form and just take the credit on the Income Tax return.

If this is the first year that you are claiming a disability tax credit, you will be advised at the time of them processing your Return whether or not your disability Tax Credit is accepted and approved. Before the changes to the disability tax credit, you could be approved but later on when your return was audited and reassessed, the Tax Credit was denied, putting many people into the situation of owing taxes to Revenue Canada. This will not happen again. You will either get accepted or denied at the time they

process your income tax return, not years later.

Another important fact to remember is on Part B of Form T2201, there is a note to the Physician reminding him/her that if it takes the patient an inordinate length of time to perform an activity of daily living, then the answer by the doctor should be a resounding NO - you cannot do that activity.

It is also important that every question gets answered. A YES or NO must be placed in the appropriate spot on this form. If every question is not answered, your chances of getting a refusal are increased.

[Ed.note: We have been receiving some calls from ME/FM people who have advised that they have received a new application of Form T2201 from Revenue Canada, requesting an update status from their doctors].

HEALTH STATUS AND DISEASE SEVERITY IN FIBROMYALGIA:

RESULTS OF A SIX-CENTER LONGITUDINAL STUDY -

ARTHRITIS RESEARCH CENTER & UNIVERSITY OF KANSAS SCHOOL OF MEDICINE - Ref. Arthritis Rheum 1997 Sep;40(9): 1571-1579

"OBJECTIVE: To determine the intermediate and long-term outcomes of fibromyalgia in patients seen in rheumatology centers in which there is special interest in the syndrome.

METHODS: We conducted a longitudinal outcome study by mailed comprehensive Health Assessment Questionnaire, administered every 6 months to **538** patients from 6 rheumatology centers whose median duration of disease at first assessment was **7.8 years**. The final assessment took place after 7 years.

In addition, there was a study follow-up on **85** patients who had attended the Wichita Center for **>10 years**.

RESULTS: Although functional disability worsened slightly and health satisfaction improved slightly, measures of pain, global severity, fatigue, sleep disturbance, anxiety, depression, and health status were markedly abnormal at study initiation and were essentially unchanged over the study period. Correlations between first and last assessment values were as high as $r = 0.82$. For some variables, abnormalities were 3 times greater at one center compared with another.

CONCLUSION: Patients with established fibromyalgia, seen in rheumatology centers in which there was a special interest in the disease and followed up for as long as 7 years, have markedly abnormal scores for pain, functional disability, fatigue, sleep disturbance, and psychological status, and these values do not change substantially over time. Half the patients are dissatisfied with their health, and 59% rate their health

as fair or poor. There are marked differences in disease severity among the various centers, but < 14% of the variance in outcomes can be explained by demographic or center factors. Values at the first assessment are predictive of final values."

Ref.: Wolfe F, Anderson, J, Harkness, D, Bennett RM, Caro XJ, Goldenberg DL, Russell IJ, Yunus MB

ARTHRITIS RESEARCH CENTER and University of Kansas School of Medicine,
1035 N. Emporia, Suite 230, Wichita, KS 67214 U.S.A. - Tel.(316) 263-2125 - Fax
(316) 263-0761

The Neurological Basis of Chronic Fatigue Syndrome & Fibromyalgia

(Dr. Jeff Sherkey - Sudbury Conference September 1997)

by Marj van de Sande, Alberta Director

Since Dr. Sherkey developed ME/FM in 1993, he has been actively seeking the best information about and treatment for the illness. He spent a week in Dr. Goldstein's clinic in 1996. His brief synopsis is primarily based on Dr. Goldstein's book "Betrayal by the Brain: The Neurological Basis of Chronic Fatigue Syndrome, Fibromyalgia Syndrome and Related Neural Network Disorders".

Although many doctors tell patients their symptoms are psychosomatic, the overwhelming evidence indicates that ME/FM is a neurological illness. The myriad of seemingly unrelated symptoms are manifested by the brain. Sensory information is not managed properly in the brain due to

neurotransmitter/receptor dysfunctions.

Neurotransmitter/Receptor Dysfunctions

SPECT Scans show regional hypoperfusion in the brain, particularly in the right hemisphere. The right brain deals with novel cognitive activities and uses the neurotransmitter, norepinephrine. The

left hemisphere of the brain uses the neurotransmitter, dopamine, and deals with repetitive, routine activities. There are low levels of both of these neurotransmitters. Any stress to the body such as a chronic viral infection depletes norepinephrine. **PET scans** show decreased metabolism of glucose in the frontal lobe. Malfunctioning of the inferior parietal cortex may lead to inappropriate

sensations, emotions and behavior.

Gating is the process in which the prefrontal cortex (PFC) processes sensory information from within the body as well as the external environment and assigns

relative importance to the information.

The concept of Signal to Noise Ratio involves giving high importance to the signal, which is what you are concentrating on or trying to do, and low relevance to other sensory information. This is similar to trying to tune in one station (high relevance) on a radio and exclude all noise from other stations (low relevance).

When there is abnormal gating, as in ME/FM, the PFC gives insignificant distractions, such as a bit of background noise, high relevance. This may cause overwhelming fatigue. Walking a block may seem like a mile, or previously tolerated foods and odors can make one sick.

Norepinephrine, which increases the signal to noise ratio, is low in ME/FM patients. Substance P, which broadens the receptive field for pain and lowers the signal to noise ratio, is approximately three times the upper limit of normal in the cerebrospinal fluid of ME/FM patients - higher than in rheumatoid arthritis patients. Elevation of substance P can cause night sweats, bruxism, nocturnal panic attacks and nightmares.

There are abnormal levels of the neurotransmitter, glutamate, which transmits the gated information from the PFC through a neuropathway to the thalamus. The thalamus acts as a relay station and modulates the signals that control pain, appetite, mood, sleep, autonomic nervous system, libido and the neuroimmunoendocrine system, all of which are abnormal in ME/FM.

Abnormal gating can lead to symptoms related to any of these. Walking in a shopping mall, for example, where there is a high noise to signal ratio, can trigger any number of symptoms, such as a panic attack or overwhelming fatigue or a worsening of fibromyalgia pain.

Pain - In FMS, the brain misinterprets touch as pain. There was a case of an immunologist who had familial Parkinson's disease and then developed ME/FM. His shaking became uncontrollable particularly on his right side. A surgeon cut the globus pallidus in his left brain. Not only did it stop the shaking in the right side of his body but it also stopped the FM pain in his right side. This illustrative case shows that the pain is coming from the brain.

Sleep - is a very complex mechanism and involves various structures and numerous neurochemicals. In ME/FM patients, parts of the brain are wide awake and parts are sleeping. You do not get into a deep restorative sleep as alpha (fast) waves intrude on the delta (slow) waves, or you have little or no deep sleep.

The reticular nucleus of the thalamus, by gathering information, causes a transition from the state of being awake to that of being asleep. As it is dysfunctional, there is impaired sleep onset and lack of slow wave sleep, which is necessary to restore glycogen stores used during waking hours. This causes further deterioration of sleep.

Dysfunction of the reticular formation in the brainstem can cause insomnia.

Memory - The PFC regulates the hippocampus in new memory production so when there is dysfunction of the PFC, situations are erroneously interpreted as novel since there is no cognitive repertoire for them. This produces anxiety and other inappropriate responses. Nitric oxide diffuses into presynaptic neurons and increases glutamate production, which strengthens the synaptic connection. Memory production occurs if there is an increase in post synaptic nitric oxide production. This is dysfunctional in ME/FM.

Nitric oxide increases brain serotonin, norepinephrine and dopamine - all of which are at lower than normal levels in the brain. If nitric oxide is decreased, then serotonin, norepinephrine and dopamine are decreased which leads to increased fatigue, anxiety and behavioral changes. Short term memory is strengthened by repetitive hippocampal neural firing during slow-wave sleep. REM sleep is also vital for consolidating new memories. Both are dysfunctional in ME/FM therefore short-term memory is impaired.

Fatigue is a dysfunction of the thalamic area of the brain. Electrode stimulation of the medial temporal lobe causes a sudden onset of severe fatigue.

Exercise causes an increase in blood flow in the brain in a healthy individual. In ME/FM patients, exercise causes a decrease in cerebral blood flow.

Immune System - White blood cells have receptors for every known brain neurotransmitter. Therefore your immune system is in direct communication with your brain. If your brain is sick, your immune system is sick.

Autonomic Nervous System - Neurally mediated hypotension, low blood pressure, Reynaud's phenomenon, rapid heart rate, low body temperature and weird skin sensations are symptoms of dysfunction of the autonomic nervous system.

Misshapen Red Blood Cells - Red blood cells lose their normal concave shape and have difficulty traveling through the capillaries. It has been suggested that the person's capillaries are too small. However, Dr. Goldstein found that if he added physiological amounts of the neurotransmitter nitric oxide to the misshapen blood cells, they regained their normal shape and elasticity, indicating that the problem is dysfunction of neurotransmitters/receptors.

Cognitive & Language Tasks - The cerebral cortex, dorso lateral PFC, thalamus, Broka's language area, cerebellum and brainstem are all involved in word finding, counting, sequencing, predicting, error detecting, shifting of attention, adaptation and learning. Many of these abilities are impaired in ME/FM patients.

Treatment - Dr. Goldstein's protocol includes many pharmaceuticals such as nimodipine, gabapentin, oxytocin and baclofen. If a medication helps alleviate

symptoms in an individual, the results are usually seen quickly.

Dr. Sherkey has also had patients tested for mycoplasma infection and uses Dr. Garth Nicholson's protocol for those patients that test positive. (See last issue for article on Dr. Nicholson's research.)

Dr. Goldstein's book may be obtained from the **Haworth Medical Press - 1-800-342-9678**.

Thanks to Dr. Shirkey who kindly reviewed this report for accuracy.

NOTE: Dr. Sherkey's practice is full. Please do not phone his office for an appointment. You may provide your doctor with this information. If, after reading this article, your physician would like further information about Dr. Goldstein's protocol, he/she may contact Dr. Sherkey at (416) 767-6383.

"MYOSYMMETRIES INTERNATIONAL INCORPORATED" - FEEDBACK WANTED

We have been receiving requests from ME/FM individuals on Myosymmetries located in Edmonton, and Calgary, Alberta.

If anyone has gone through this biofeedback at this organization, would you please report to us your experiences with same.

NUTRITIONAL BASIS FOR ME AND FM - Part IV

By: Philipa D. Corning, B.Sc., Ph.D. -

Acid-Forming Food and Drinks:

To sustain life, the body must maintain not only a constant temperature but also a constant level of acid-base balance in all body fluids. The vast majority of body fluids are basic (alkaline), specifically the blood, lymph, and fluid within each cell. Only the stomach and the skin are acidic environments. The blood plasma acts as a buffering mechanism by providing compounds containing alkaline-producing minerals that are essential to maintain slightly alkaline blood and body fluids.

As the body carries on metabolism, it produces **waste** products which are **acidic**. These acidic waste products tend to increase with over-consumption of carbohydrates, over-exercise, the hectic pace of life, stress, intake of drugs, and over-consumption of meat and soda pop (one glass of cola is so acid that it takes 32 glasses of alkaline water to neutralize it). Also, certain foods cause body fluids to become more acid than

others.

There are two types of wastes produced: **organic acids** (containing carbon, hydrogen, and oxygen molecules), and **inorganic mineral**. The organic waste products are acids, whereas the inorganic ones can be either acid or base. It is the specific inorganic minerals in food which determine its acidity or alkalinity. Alkaline forming minerals are potassium, magnesium, calcium, sodium, and iron, while the acid forming ones are sulphur, phosphorus, chlorine, and iodine.

Because our ancestors ate more natural and raw food than we do, their waste products were not totally acid, and the blood could carry them away from the cells. Today the amount of acid waste produced is overwhelming, and it cannot all be removed by the blood. Thus, much of it remains within the cells and body fluids, and overloads our buffer (blood) and disposal systems (kidneys, skin, and lungs) leaving the body in an acid imbalance. Simply put, the consumption of too little fruit and vegetables combined with the over-consumption of meat, fat, refined carbohydrates, and soda pop leads to acid formation in the body.

In this acidic environment, many cellular processes are hindered. For example, enzymes that control all the chemical reactions within the cells, including energy metabolism, only work in a slightly basic environment; they will not work in an acidic one. Furthermore, acids coagulate the blood, leading to poor circulation, which in turn leads to the sluggish function of organs, because of the slow delivery of nutrients and oxygen to the cells and the slow removal of cellular wastes, including carbon dioxide. Such malfuncions at the cellular level will only lead to disease at the macro level.

Essential to maintaining acid-base balance in the body is the intake of **alkaline minerals**. These minerals will help buffer the acid wastes in the body and return the body to a better acid-base balance. The consumption of natural minerals and/or drinking of alkaline water will help improve this critical balance.

Toxic Substances:

Unfortunately, these substances are obstacles that we have placed in the way of the body's repair processes. We have dumped chemicals into our planet's air, water, and soil. They do not go away; instead they just accumulate until they reach a level where they interfere with the normal functions of plants and animals. The fact that doctors see many puzzling diseases such as allergies, environmental sensitivities, ME/CFS, and FM is a good indication that something is wrong in earth's environment. In fact the chronic "fatiguers" are looked upon as the "canaries of the 21st century".

To increase the shelf-life of processed food and increase its visual appeal, food preservatives and colouring agents respectively are added. Food processing that extends shelf-life and preparation of convenience foods removes, destroys, or changes the nutrients present in food, and adds more fats and refined sugars. We have replaced the fruits, grains, and vegetables of a century ago by fats and refined sugars. To

"enrich" these products, synthetic vitamins and inorganic minerals are added; our bodies cannot use these man-made compounds. They only get in the way of normal cellular reactions. All this interferes with the body's ability to work or function properly.

In the meat industry, for example, most livestock contains steroids and antibiotics. Almost all poultry, 70% of cattle and 90% of pigs raised commercially in the United States are given antibiotics in their feed. Some residues of these substances remain in the meat and are transferred to us.

Periodic detoxification of the body with a protein drink containing amino acids, essential fats, fructose, glucose polymers, vitamins, and chelated minerals will cleanse the body of toxic and harmful substances. Increasing fiber intake will also help to pick up toxins in the colon and remove them from the body in the faeces.

QUEST #28 - Hectic Pace and Stress of Life. [See newsletters, 24,25, 26, for Parts I - III]

CONFERENCE -MULTI-DISCIPLINARY APPROACHES ON FIBROMYALGIA

DATES - MAY 23 TO MAY 25, 1998

The **National Fibromyalgia Research Association (NFRA)** in Salem, Oregon is holding this Conference in the New York Hilton & Towers, in New York, NY.

For **more information** and conference application, please contact: **NFRA**, P.O. Box 500, Salem, OR 97308 U.S.A. - **Tel. (503) 588-1411 - Fax (503) 315-7212** - email: **nfra@teleport.com** - Web site: **<http://www.teleport.com/~nfra>**

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LEGAL IMPLICATIONS OF FIBROMYALGIA, CHRONIC FATIGUE SYNDROME/M.E., AND OTHER CHRONIC MEDICAL CONDITIONS: ICBC CLAIMS AND DISABILITY INSURANCE

By: Brad Garside, Barrister and Solicitor - Partner at Paine Edmonds, Vancouver, B.C. - Please send stamped self-addressed envelope to our Network (**90¢**). This is of

particular interest to those of you who live in British Columbia. However, it also has general information in it that will be of interest to others elsewhere.

LYME DISEASE - To get the latest of information on Lyme Disease, send \$10.00 to **LYME BORRELIOSIS SUPPORT GROUP**, 365 St. Davis Street South, Fergus, ON N1M 2L7 - Tel. (519) 843-3646.

INTER-GROUP/CONTACT COMMUNICATION:

By: Patricia Stephenson-Cino, President of the ME Association of Halton/Hamilton-Wentworth

and a Director on the Board of ME Ontario.

- 1. The M.E. Association of Ontario** is inviting all interested persons to its **annual meeting** at 10:00 A.M. to Noon, **February 28, 1998** at the North York Community Centre, 5100 Yonge Street;
- 2. This year for M.E. Awareness Day, May 12th, the M.E. Association of Ontario** will focus on lobbying the Provincial Government to provide a billing code for M.E. and also to provide regional clinics. Please send the accompanying letter in QUEST to the **Ontario Minister of Health, or MPP** and/or **use a similar letter to be sent to other Provincial Ministers of Health;**
- 3. Recently, the M.E. Association of Ontario**, in conjunction with the **Hamilton Association**, made a presentation at the annual conference of the Ontario Community Support Association. This opportunity allowed these organizations to educate the health professionals who work in the community about ME and provide them with effective treatment methods. They were able to interact with nurses, occupational therapists, physiotherapists, nutritionists and Home Care casemanagers. They had a large display and distribution educational material.

'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 .

Dear Friends:

As you know, we are presently collecting Doctors' petitions. These doctors have kindly joined us in our quest for a standardized clinical definition for both ME and FM for all of Canada.

We will continue to accept doctors' petitions so please urge your doctors to sign the form we have provided for this purpose. If you don't have this form for the doctors' signatures, please contact us and we will send you it immediately.

We would also like to remind all support group leaders to inform us of their existence. Please drop us a note advising us the name of your organization and other pertinent details so that we know at all times where to refer ME/FM people who need help.

We have also asked in the past that you would let us know how many ME/FM people are in your group and/or contacted your group. Our organization and the Laboratory Center for Disease Control are particularly interested to know these statistics. Your assistance is very much needed - please help.

Best wishes for 1998.

Take care. Lydia E. Neilson

President CEO

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ELECTRONIC MAIL: our e-mail address: ag922@freenet.carleton.ca

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

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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