Quest #22 February 1997

THE NEXT STEP - MEDICAL PROFESSIONALS' PARTICIPATION - UPDATE

In our last newsletter, we reported that now that the 1994 U.S. ME/CFS Research Definition has been accepted by our Laboratory Centers for Disease Control, we have asked for the help of the medical professionals to join us in requesting the Federal Government to set a standard set of rules for clinically diagnosing ME and FM. A form letter was enclosed with 'QUEST' to be signed by your physician(s) and we had asked you to take this form to your doctor's appointment with you.

We are happy to report that the medical professionals agree with our stand and are therefore signing the letter and returning it to our organization for follow up. If you did not receive such a form, please contact us and we will be pleased to send it to you. This form letter, with instructions, was also sent to all support groups that we know of so that they could distribute this form letter to their members too.

As stated in our previous newsletter, there is no expiration date on this gathering of signatures so that there will be plenty of time for everyone to get involved. Once we have an adequate amount of signatures of the medical professionals, we will request a meeting with the Minister of Health.

MAY 12TH 1997 NATIONAL ME/FM AWARENESS DAY

Remember, this is the day that support groups play an important role by reaching out to the general public with information on ME and FM. Some groups will place a booth in a shopping centre, while others will contact their member of Parliament, write an article for a newspaper or contact the media in some other way to advise them about ME and FM. Please support your group by helping in whatever capacity you are capable of.

INFORMATION ON MEDICAL RESEARCH COUNCIL GRANTS

Researchers applying for grants must have an academic appointment at a Canadian University.

Submission deadline for Grants: **March 1** and **September 15**

Application form can be obtained from the Council's Internet address; or by calling or writing **MEDICAL RESEARCH COUNCIL,** Holland Cross, Tower B, 5th Floor, 1600 Scott St., Postal Locator 3105A, Ottawa, ON K1A 0W9 or by obtaining details from any university.

Tel. (613) 954-1809 Fax: (613) 954-1800

INTERNET: wwwmrc.hwc.ca

BARRIE & DISTRICT ME SUPPORT GROUP GIVES FINANCIAL SUPPORT

Albert Blom, President of the Barrie Support Group has sent us $1.00 for each paid member in his support group to show their support and approval of what we are doing. We would like to thank Barrie's Board of Directors and its members for its financial support.

COMPLAINT TO THE BOARD OF DIRECTORS OF

DRUGLESS THERAPY/NATUROPATH - UPDATE

In our last communication, we advised you that we had written the Board of Directors of Drugless Therapy about an article that had been reported to us by the President, Denis Wright, of the Durham/Scarborough ME Association. He reported to us that a Ms Helena Ovens, ND wrote in the Health section of the LAKESIDER newspaper a highly inaccurate account of CFS (see newsletter #21 for details).

The Board of Directors of Drugless Therapy forwarded us a copy of the letter forwarded to Dr. Ovens in which she was advised to do the following: "1) rewrite the Health article mentioning the exact wording in the article and the relevant corrections with an explanation, e.g. mononucleosis, not CFS, is highly contagious, and can be passed by close contact etc.; 2) include in the retraction, an apology to the readers as this statement is misleading to the public; 3) forward a copy of the retraction letter to the Board for approval [National ME/FM Action Network]; 4) once approved, send the letter to the newspaper (lakesider) as a retraction letter to be published with a copy to Dennis Wright, President of the Durham/Scarborough ME Association" and a separate apology letter addressed to our Network. They also advised Dr. Ovens that 'you proofread any media presentations far more carefully in the future." Signed R.Gatis, N.D. Complaints Committee.

[Ed note: Now that the Board of Directors of Drugless Therapy/Naturopathy have been made more aware of ME/FM, please add them to your mailing list to receive ME/FM <u>scientific information.</u> Their address is 4195 Dundas Street West, Suite 206, Etobicoke, ON M8X 1Y4 - Tel. (416) 236-4593 - Fax (416) 236-4387.]

CALGARY CLINIC CLAIMS TO CONQUER THE AGONY OF FIBROMYALGIA - By: Philipa D. Corning, B.Sc., Ph.D

Myosymmetries of Calgary is a relatively new muscle pain rehabilitation clinic. A FM person apparently turned to this clinic as a last resort to deal with the agony of years of FM pain. After treatment there, she claims that she is pretty well back to where she was before a car accident and pain-free.

The procedure did not call for needles or drugs and the company uses surface electromyographic (EMG) technique, electroencephalogram (EEG), light stimulation called EEG-Driven Stimulation (EDS), and massage to treat the symptoms of FM, ME, and other various chronic disorders.

This clinic is headed by Dr. Stuart Donaldson, a psychologist with an extensive background in neurology and muscle pain research. He developed the concept, which is basically an advanced form of biofeedback. First, he uses sEMG to assess the pain of trigger points (TPs) in a person with FM. Then his treatment combines sEMG, EEG brain-wave training with advanced physiotherapy and massage therapy. The person who went for this treatment required 30 EEG sessions, 10 sEMG and massage sessions and 4 physiotherapy appointments in total. The financial cost of this regime is estimated at $3,600 to $4,000 do , and it is not covered by most health care plans.

Besides the clinic in Calgary, there is one in Edmonton and three in Toronto. The average estimated time for completion of treatment is 4 months in most cases. Benefits gained from treatment seem only to be sustained or increased, unless new trauma occurs.

To illustrate how sEMG works, let's look at research conducted on a muscle group in the neck. With any movement of body parts, muscles work in pairs; one muscle extends a limb while the other muscle flexes or bends it in the opposite direction. In this case, the muscle group is composed of the sternomastoid and the upper trapezius which control the extension and flexion of the chin and front of the neck (or the up and down movement made to indicate "Yes"). In the control group (individuals with no TPs), the pattern of muscular extension/flexion were equal or symmetrical, whereas the group with TPs (pain) the pattern was not equal (asymmetrical). When one muscle works with equal force as the opposing one, there is no pain. However, when one muscle in the pair is overworked, there is fatigue and pain. This was demonstrated in the experiment by the increased EMG activity in the TPs.

At Myosymmetries, relief of chronic pain requires more than just correcting muscle damage, because it also involves a neural component: a nerve ending in the muscle is connected to the brain through nerve tissue in the spine and then there is a return neural pathway which carries a signal back to the muscle instructing it to initiate or inhibit contraction. Traditional treatment focuses on strengthening muscles around the damaged muscle tissue, but does not address the damage to the nerve tissue. In muscle trauma, the inhibitory signal is not doing its job, and the partner muscle becomes hyperactive. Various kinds of trauma disrupts the inhibitory signal, i.e. severe chill or fatigue. In muscle trauma, this disruption of the inhibitory signal is manifested in poor motor control as one of the muscles in the pair is overworked and the opposing muscle is dormant or inactive. This inequity leads to the development of TPs and pain. Eventually, the constant inequity in muscle performance leads to messages for pain bombarding the brain. This constant stimulation of the brain by pain alters the brain's activity, and more parts of the brain become affected by pain. More of these parts in turn send wrong messages to the specific muscles they control. As a result, the biochemical activity of the brain changes and the brain becomes confused along with the messages it sends out to the muscles. The biochemistry of the brain shows depleted serotonin is associated with various muscle dysfunctions.

At Myosymmetries, sEMG is used both as a diagnostic and a treatment tool. In either case, this technique involves the application of electrodes (usually two) to the surface of the skin over a specific muscle, this provides specific information about the muscle and its activity. The presence of TPs can be objectively verified by the increase in electrical activity. After all TPs are located, then this same technique can be used on each dormant or injured muscle in order to reactivate it and thereby address the pain in its overworked and painful partner muscle. The sEMG is used to provide digital computer readouts that demonstrate changes in the muscle physiology. By using the sEMG and a series of "micro" exercise movements designed to restore symmetrical muscle patterns, injured muscle tissue is repaired. In connection with this, the brain must be re-educated through biofeedback to receive and send messages accurately. To do this, EDS is used. This advanced form of biofeedback involves light stimulation (set of tiny lights flash before the eyes) of the brain through the eyes and optic nerve while brain waves are monitored through an EEG. The object of this exercise is to reduce EEG slowing on the scalp. This completes the cycle of muscle reflex and at the same time re-establishes balance to the brain's biochemical activity. Reduced EEG slowing of brain waves increases the alpha and beta waves of normal daytime brain activity, and thereby prevents serotonin levels in the brain from decreasing resulting in increased melatonin production leading to better sleep. With better sleep, the body has the appropriate deep sleep needed to grow and repair cellular structures and operations. The theory is that this will relieve chronic pain, mental fog, forgetfulness, weakness, exhaustion (low energy and endurance) and sleep disorders caused by the derangement of brain chemistry. This all sounds plausible. The massage therapy reduces the pain at the TPs until the neuromuscular training takes effect. In this regard, it is theoretically possible to relieve chronic muscle pain for an indefinite period of time through the use of sEMG. In addition, by re-education the brain to receive and send messages accurately, and re-establishing its biochemical balance, it is conceivable that brain fog, memory problems and sleep disorders can be returned to normal.

In the literature provided by "Myosymmetries**,** it indicates that these procedures are effective in the majority of cases of FM and ME. However, there are some sufferers for which these procedures are not effective.

My overall conclusion is that these treatments offered by Myosemmetries of Calgary may help FM and ME persons to improve their state of health. I do not see how it can be considered a cure for all victims, because FM and ME can have many initiating factors depending on the individual, and with time individuals tend to relapse. In addition, there may be nutritional and hormone factors to overcome in order for their health to improve. The sEMG is used as a method of assessing the sufferers level of pain. After the evaluation is complete, methods such as sEMG with micro-exercises are used to restrore symmetrical muscle function in the absence of pain, and biofeedback i.e. EDS, to re-orient brain chemistry. The bottom line for each ME/FM person, regardless of the nature of a treatment, is: "If it works, use it!"

<u>Assessment</u> $400.00 to $600.00

Treatment:

Electromyographic therapy - 1/2 hr $60.00

EEG Neurotherapy - 1 hr $75.00

Physiotherapy - 1 hr $75.00

Massage Therapy - 1/2 hr $35.00

Myosymmetries, 445 - 10655 Southport Rd. SW

Calgary, Alberta T2W 4Y1

Tel. (403) 225-0900 - Fax: (403) 225-2389

Myosymmetries Edmonton, Denton Centre,

Edmonton, Alberta T5N 2P6

Tel. (403) 483-8542 - Fax: (403) 483-8691

DO'S and DON'Ts of Antibiotics

DO discuss your prescription with your doctor and pharmacist as you need to know how to take antibiotics properly;

DO report any known drug allergies to your doctor and pharmacist AND make sure your doctor and pharmacist are aware of all medication you are taking;

DO take all of your medication and continue taking your antibiotic, even when you feel better. If you don't finish the prescription, you may not kill all the bacteria and you may get sick again. The bacteria still alive can then become resistant, worsening the infection you already have and making it harder to treat;

DO take your antibiotic at the same time each day. You may be prescribed from one to several doses per day. Since medicines stay in your system a certain amount of time, you must take each dose according to the directions for the antibiotic to work best;

DON'T insist that your doctor prescribe an antibiotic. Antibiotics can only cure bacterial infections; they are useless against a cold, flu or other viral infections;

DON'T forget to take your antibiotic. Simple reminders such as keeping them in view of taking them around mealtime, when you brush your teeth, or at bedtime can be very helpful. Your pharmacist can help you with a system to remember when to take your medicine;

DON'T share other people's antibiotics. Only use those prescribed specifically for your current illness. Since individual antibiotics are effective against specific bacteria, don't assume the leftover ones you have in your medicine cabinet will do the trick once again. Ged rid of any leftover antibiotic as you would other old, unused drugs: return them to your pharmacist for safe disposal;

DON'T ignore unexpected side effects; tell your doctor or pharmacist about severe or unusual reactions. Sometimes, your doctor may prescribe a different antibiotic, or a change in the schedule or dosage, that may make it easier to take;

DON'T worry about taking antibiotics. Whether you're young or old, your own natural defenses can sometimes fail and you need antibiotics. They won't decrease your natural immunity to infections. Antibiotics save lives. So take them wisely - don't take them for granted.

Source: Pamphlet of the Canadian Pharmacutical Association/Canadian Infectious Disease Society; Canadian Thoracic Society, Canadian Paediatric Society and Lung Association.

WOMEN'S COLLEGE HOSPITAL - ENVIRONMENTAL HEALTH CLINIC - UPDATE

In a letter of August 28th, 1996 Dr. Frank J. Foley, the Medical Director of the Clinic, advised us that "For your information we do assessments and consultations for persons with Chronic Fatigue Syndrome and Fibromyalgia." He stated also that they did not, however, offer specific treatments but had applied for a Grant.

We have now followed this up asking for the present status of this Clinic as people have advised us that when they called the Clinic for an appointment to get diagnosed and assessed for ME/FM, they were told that they only see people who suffer from multiple chemical sensitivities in addition to ME or FM. We are presently waiting for their reply.

NATIONAL DOCTORS' ROSTER - UPDATE

*DR. SUSAN TAINSH Tel. (905) 685-1381

The Shaver Hospital Fax (905) 685-6035

541 Gledridge Ave.

St. Catharines, Ontario L2T 4C2

*Treatment of ME/CFS only upon receiving a doctor's referral.

*DR. JEFFREY A. SHERKEY Tel. (416) 767-6383

168 Annette St. Fax (416) 767-4898

Toronto, Ontario M6P 1P4 E-mail: "**sherkey@interlog**.com"

*Diagnosis and treatment of ME/FM

NATIONAL LAWYERS' ROSTER - UPDATE

MENZIES & ASSOCIATES Douglas Menzies or Suzanne Coté

Barristers & Solicitors

111 Sherwood Dr.

Ottawa, Ontario K1Y 3V1 Tel. (613) 722-1313 - Fax (613) 722-4712

1/2 hour initial consultation free.

TIP: Effective February 17, 1997 the Postal code information which was obtainable by calling an 800 number will be replaced by **1-900-565-2633**. Customers will be charged 75¢ per call (plus appropriate taxes) and will be allowed 3 postal codes from one phone call. These calls will appear on your telephone bill.

ANOTHER GRANT APPROVED

In the Fall of 1996 we applied for a grant to assist us in bringing our Board of Directors to Ottawa so that we could hold a workshop and hire a professional facilitator who would help us with planning our future. This facilitator will do a two-day workshop with our Board of Directors to help us with our financial planning and organization of our Network. This Grant will allow our Board of Directors from across Canada to come to Ottawa for this workshop.

We have just received a letter from the Hon. David C. Dingwall, Minister of Health advising us that our grant for $25,000 to accomplish the foregoing has been approved. He further stated "I would like to take this opportunity to congratulate the Board, staff and volunteers for their dedication and achievements over the past year, and to wish your organization success for the year ahead."

GENETICALLY ENGINEERED (GE) FOOD THREATENS YOUR HEALTH

From the 14th to the 18th April, 1997, Codex Alimentarious, an international commission of the United Nations, is meeting in Ottawa to discuss the labelling of food produce and their derivatives. This meeting is critical to the entire world's food supply. Regulations are being considered that would allow GE products on the global market. The biotech industry is lobbying Codex to pass international legislation allowing experimental foods, without labelling, in every country and their extensive mixing with other foods.

You may already be eating some of these foods without knowing it. Presently, there are tomatoes containing fish genes, potatoes and corn with toxin genes, and canola and soybeans that allow more pesticide use as the previous levels are now ineffective against pests. Many packaged products also contain some of these GE foods, e.g. baby food, fruit drinks, soy products, cereal.

Why be alarmed? The effect caused by the insertion of foreign genes into a different organism cannot be predicted. New toxins, allergies and diseases can result, e.g. a gene from Brazil nut was inserted into soybean to produce a more complete protein. In testing, some people had a very bad allergic reaction. Furtunately, there were no deaths.

What action can you take? If you would like to see mantatory labelling of GE foods and their derivatives, you can send a letter, or E-mail to your Codex representative. The Head of the Canadian delegation, **Mr. Gerry Reasbeck** on E-mail at "**greasbeck@em.agr.ca**" or **Richard Wolfson, PhD** - Tel. (613) 565-8517, Fax (613) 565-6546, E-Mail at "**rwolfson@concentric.net**" Address: 500 Wilbrod Street, 500 Wilbrod St., Ottawa, ON K1N 6N2.

BOOKS/NEWSLETTERS/VIDEOS/REPORTS ETC.

VIDEO: FIBROMYALGIA: A Whirlwind Tour of the Physical Aspects of Diagnosis (60 minutes long) - By: Dr. David Webster. Professionally produced by Cambrian College. Includes autoimmune diseases, neurendocrine controls to the latest brain imaging techniques as well as points out a peculiar problem of the cortisol levels that could be used in future diagnosis of ME/FM. Price:$29.95 plus $5.00 for mailing and handling. Please send your request to: Fibromyalgia Association of Ontario (formerly Northern Ontario Fibromyalgia Association), 800 LaSalle Blvd., Suite 300, Sudbury, ON P3A 4V4 - Tel./fax: (705)

560-4936, or 1-800-959-9098 - E-mail: Editor: "satori@halhinet.on.ca" - Head Office: "surfdude@cyberbeach.net"

VIDEO - HELP YOURSELF II: Emotional and Legal Issues Facing People With CFS, Environmental Sensitivities and/or Fibromyalgia - by: Shirley Arsenault $18.50 plus $5.00 shipping, payable by cheque or Money Order. Please send your request to: Shirley Arsenault, 1191 J. Jorden Rd., Canning, Nova Scotia B0P 1H0.

CHRONIC FATIGUE SYNDROME and the YEAST CONNECTION - By: William G. Crook, MD. Dr. Crook informed us that he has donated some copies of this book to the International Health Foundation. Dr. Crook advised that Canadian readers of 'QUEST' who would like a complimentary copy can obtain it by sending a mailing label and $6.00 Canadian (or $5.00 American) to Administrator, IHF, Box 3494, Jackson, TN 38303 U.S.A.

THE YEAST CONNECTION HANDBOOK - By: William G. Crook, MD (soft cover) - Cost: $22.50. Available through 'Alive Books' - Tel. **1-800-661-0303 - Fax: 1-800-663-6597 - E-mail: "editorial@ultranet.ca"**

TEN TIPS ON LIVING WITH FIBROMYALGIA - by: Debbie Barrett, Ph.D. (3 pages). Please us a stamped self-addressed envelope with your request for a copy of this report.

INTER-GROUP/CONTACT COMMUNICATION - CHANGE OF NAME

COMMON CAUSE AGAINST THE COMMON FOE CONFERENCE: May 30 & 31, 1997 in SUDBURY, Ontario.

Plan to attend this precedent-setting Conference which will bring together victims, families, health-care professionals and others who are concerned about the growing incidence of the immunological dysfunction diseases such as cancer, multiple sclerosis, Fibromyalgia, Alzheimer's, Parkinson's etc.

In unity there is the strength needed to get Health Canada and its provincial counterparts to become much more serious about the increasing incidence of these diseases.

For information, please write to: **Fibromyalgia Society of Ontario, 800 Lasalle Blvd., Suite 300, Sudbury, Ontario P3A 4V4.**

DR. LESLIE SIMPSON'S BLOOD SAMPLE RESULTS

All the results from the Ottawa blood samples have arrived back from the University of Otage, New Zealand. Out of 72 Ottawa samples, only 1 was within normal limits. To give you an overview of the Ottawa samples, a more detailed description of the results is provided below:

Flat Cells: A reading **above 60.4%** is considered **abnormal** for women.

A reading **above 61.4%** is considered **abnormal** for men.

1. 73 samples showed elevated flat cell percentages.

2. Range of abnormal flat cell values: 52.3 to 89.1%

3. Average Ottawa flat cell count: 72.5%

4. Number of samples with values in 50s: 2

5. Number of samples with values in 60s: 10

5. Number of samples with values in 70s: 46

6. Number of samples with values in 80s: 14

Early Cup Forms: A reading **above 11.3** is considered **abnormal** for women.

A reading **above 10.0** is considered **abnormal** for men.

1. 3 Samples showed borderline or elevated early cup form cell percentages

2. Range of abnormal early cup forms: 0.0 to 24.8

3. Average Ottawa early cup form count: 2.8%

Late Cup Forms:

Dr. Simpson is intrigued by the high percentages of late cup forms seen in Canadian samples to date, but has no explanation for this trend.

Patients had also been asked to rate how they were feeling at the time the blood was taken, with 5 categories to choose from. Our Ottawa replies were as follows:

Severely unwell: 11

Moderately unwell: 31

Slightly unwell: 15

Well with slight symptoms: 11

Well with no symptoms: 1

[Ed. note: If you are interested in having your blood tested, contact the **University of Otago** and they will send you instructions, including a vial already treated for blood collection. **P.O. Box 913, Dunedin, New Zealand - Tel. 64 3 479 7430 Fax : 64 3 479 7431 - E-mail address: genprac@jin.otago.ac.nz**]

'HASTI NOTES'

This is another way to help our organization. A package of four cards helps you to send out a note quickly and at the same time letting people know how to obtain information about ME/FM. This card was designed by Mary Harris, a ME person. The front and the back only have printing but the middle is blank for your message.

Cost: $4.00 per package. Contact us if you would like to order these 'Hasti Notes' and support our organization at the same time..

Our World

Overwhelmed: when more than one thought happens at the same time.

FM: Faulty Machinery

Relapse: Restricted restrictions.

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

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.