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DIAGNOSTIC MARKER FOR CFS? THE POKER GAME GOING ON IN OUR GENES

This article is based on a taped conversation with Dr. Cheney and has been reviewed and edited by him.

Dr. Cheney read a newly published study on Gulf War Veterans this summer and glimpsed a possible diagnostic marker for CFS. Test subjects included three Gulf War Veterans, seven healthy control subjects, and two people with active polio-virus. Researchers probed their blood for both RNA and DNA. They found thousands of different sized RNA segments floating around in the serum of veterans, a small amount in the polio subjects, and none in the healthy controls. Serum is what's left after you remove all the various cells and things that travel around in the blood—the remainder. The researchers called this, "Voyager RNA" since it travels *outside* the cells rather than inside the red or white blood cells or platelets where it's normally found.

This finding in the veterans is highly unusual on four counts. Not only did they have RNA segments in their blood, there were a *lot* of RNA segments in their blood. Additionally, they had a lot of *aberrant* RNA segments in their blood, and they all the *same* aberrant RNA segments in their blood. Comparatively, the segments from the three veterans varied by less than 1%.

After isolating the aberrant sequence, the researchers examined it in detail and began recognizing certain pieces, which all came from part of chromosome 22. It appeared that this section of chromosome 22 had been sliced up, rearranged, pieces from somewhere else inserted, and the whole thing reconnected. Amazingly, a section of chromosome 22 appears to be altered, and it's altered the same way in all three veterans!

Since the veteran's symptoms were identical to CFS, Dr. Cheney began testing CFS patients. Almost all had this same aberrant RNA segment. This strongly suggests that the veterans and the CFS patients have the same illness, and that the aberrant segment of RNA is very likely a diagnostic marker. Dr.

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COGNITIVE PROBLEMS? REBOOT YOUR BRAIN!

Do you struggle with brain fog? Does trouble with short term memory, concentration, processing speed, and word searching affect you at work or school? Neurophysiologist and psychophysiologist Dr. Myra Preston, has found a simple way to "reboot" your brain when the brain fog thickens and slows you down. She's developed a patented QEEG test and biofeedback treatment procedure for the cognitive dysfunction of CFIDS. She and her assistant have worked with numerous patients in teaching them to shift out of the delta and theta waves associated with sleep and into the beta waves associated with thinking.

finding virtually unique to CFIDS and so abnormal that Dr. Preston thought her equipment was malfunctioning the first time she tested a CFIDS patient! During these biofeedback sessions they observed that when patients could no longer maintain beta function and slipped into theta or delta, exactly three minutes of completely resting the brain had the effect of restarting it—like rebooting a computer. The three-minute break restored beta function and reduced the number of biofeedback treatment sessions needed to reach peak performance. Less than three minutes or more than three minutes was not effective for the vast majority of patients. Some sort of

CFIDS patients show significant delta and theta activity when pushed cognitively—a

continued on page 2

Cheney suspects that this marker only appears well into the illness, and will not be found close to onset. He also believes that the amount of aberrant RNA in the blood serum may correlate with illness severity.

Why would patients with CFS and GWS have an aberrant piece of RNA, and why would they all happen to have the same one? Dr. Cheney uses a wonderful analogy to explain it—a poker game. When the body faces an extreme health threat, it plays poker with its DNA in order to find something that will help. The body breaks some of the DNA up into “cards” and shuffles them to see if it can deal a winning hand.

There are three possibilities in poker hands. There's the winning hand. That's possibly what this RNA segment found in both CFS and GWS is—a winning hand. The body shuffles its way to something that it senses might help, so it remembers it and makes a lot of copies. These segments float around in the blood on their way to other cells to make more copies, and they show up on the test more easily because there are so many of them. The potential diagnostic marker is actually a winning hand, or as close as the body can come to one. And it's a marker because everyone with the same illness will eventually shuffle to the same solution. Same problem, same helpful answer.

A second possibility is a bust hand. You don't win or lose—the new segment doesn't help, but it doesn't hurt either. The third possibility is bad news. Every so often you deal a hand with the joker in it. The body shuffles and deals out a segment that is a metabolic toxin. If it is extremely poisonous it will destroy the cell in which it was created, thus destroying itself. The real problem is the minor toxins, the ones that make you sick but won't kill you. You shuffle out enough of these bad hands and it can keep you from getting well.

The hope lies in the new treatment Dr. Cheney is testing, fetal bovine growth factor, which will, hopefully, be able to destroy some or all of these aberrant segments of RNA.

More research is needed to confirm that this segment of RNA is a diagnostic marker, but Dr. Cheney believes this is by far the best candidate yet. He also notes that while it would be a genetic marker, it is not one we are born with. It is one our body creates in response to this illness.

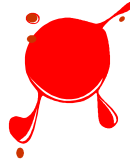
The study mentioned above, titled, “RNAs in the Sera of Persian Gulf War Veterans Have Segments Homologous to Chromosome 22q11.2,” was written by Urnovitz, Tuite, Higashida, and Murphy, and published in Clinical and Diagnostic Laboratory Immunology in May 1999, pp. 330-335. You can read a transcribed interview with Urnovitz about the study at members.aol.com/rgm1/privateltranscr.htm.

CLINICAL STUDY OF FM: PARTICIPANTS NEEDED

The National Institutes of Health are considering funding a clinical study of the effectiveness of natural treatments for FM, conducted by Dr. Jennifer Pettibone, a Dallas chiropractor. Treatments include chiropractic manipulation, acupuncture, myofascial release/trigger point therapy, Pilates-based exercise (a cross between yoga and tai chi), and nutrition. Dr. Pettibone is looking for women (research participants) between 21 and 65 who are not pregnant and not planning surgery in the next 12 months. It is not necessary to go off current medication to participate in the study.

Recent literature in this area has focused on Chiari Malformation and Cervical Stenosis, conditions in which the brain stem or upper

portion of the spinal cord is compressed. This compression contributes, theoretically speaking, to brain fog, memory loss, confusion, concentration problems, dizziness, vertigo, ringing in the ears, TMJ, etc. Following this theory, adjusting the upper cervical spine and applying traction can be quite beneficial to those with these symptoms, and will be part of Dr. Pettibone treatment for the study. You can contact her at 214.691.5537 to volunteer as a participant for the research. Dr. Pettibone plans to speak at a future meeting about her treatment protocol and research. We look forward to this interesting meeting!



alarm will be needed to indicate when the three minutes are up since you need to remain motionless with your eyes closed in as close to a meditative state as you can achieve. It's also necessary to have some control over your environment, since there should be no distracting phone calls or conversations. If you are working or studying, it may necessary to do this two or three times an hour for maximum effectiveness. Dr. Preston has a website at www.siberimaging.com.

QEEG: A POWERFUL DISABILITY TEST

Dr. Myra Preston is willing to come to DFW from Charlotte, North Carolina and perform QEEG brainmappings if enough people are interested. Even those who perceive their cognitive problems as mild or moderate usually discover that the test reveals significant abnormalities in brain function. The test is non-invasive and specifically designed and patented to detect the particular cognitive dysfunctions of CFIDS patients. The test costs \$1450, and Dr. Preston's office files insurance for you. Contact Carol if you are interested in having this test done.



OVERLAP OF CFS AND FMS IN MCS

One hundred consecutive new patients diagnosed with MCS (Multiple Chemical Sensitivity) at a private practice specializing in occupational and environmental medicine were evaluated for CFS and FMS (Fibromyalgia). The group consisted of 68 women and 32 men. Eighty-eight percent of the MCS patients also had CFS. Slightly more men than women had CFS (91% vs. 87%). FMS was two times more common among female MCS patients (59% vs. 28%). Fifty-six percent of the women had all three disorders, compared to only 28% of the men. MCS alone was diagnosed in only 10% of the women and 9% of the men. Even rarer was the overlap of MCS and FMS without any CFS, found in just two women.

Authored by Donnay and Ziem, this study was published in the Journal of Chronic Fatigue Syndrome, Vol. 5, No.3/4, 1999.

FETAL BOVINE GROWTH FACTORS: EXCITING NEW CFS TREATMENT?

This article is based on a taped conversation with Dr. Cheney and has been reviewed and edited by him.

Dr. Paul Cheney recently completed an initial trial of a new treatment for CFS, with very promising results. Hopes are high that this will be the first viable treatment for stage three CFS, resuscitating injured brains and repairing damaged DNA. (See the article on the possible diagnostic marker for information about the damaged DNA.)

The treatment consists of injections of fetal bovine growth factors, processed from cattle that are specially bred in Canada and tested many times for health. Recombinant growth factors have been approved for research by the FDA, and the first one (nerve growth factor-1) is about to be released for treatment of spinal cord injuries.

What are fetal growth factors and what do they do? Growth factors are naturally present in extremely large quantities in fetuses, but decline as we mature. This may explain why young people with chronic illness recover faster than adults. Fetal growth factor is responsible for generating organ systems in the developing fetus by directing cell migration, differentiation and integration. Most amazingly, it is believed to “circuit test” each cell it generates to see if it works. If it doesn’t, it destroys it and generates another. Dr. Cheney quoted the following passage from a 1992 text on human embryology in which Lewis Thomas, a famous biologist,

describes himself as a fetus. “By the time I was born more of me had died than had survived. It is no wonder I cannot remember. During that time I went through brain after brain for nine months, finally contriving the one I would be born with.” The hope is that FBGF can “circuit test” our bodies, locating injured and damaged cells, destroying them and generating healthy replacements.

Five moderately ill patients, two still working, received injections of fetal bovine growth factor (FBGF) for ten weeks. First, they received mesenchyme, a substance extracted from the fetus shortly after fertilization, when a mass of cells has developed but not yet differentiated into any organ systems. This FBGF contains the earliest messages to the cells about migration and differentiation. The patients then received injections of brain-derived FBGF. This stage of FBGF likely contains messages concerning further differentiation, integration and “circuit testing.” Given its potential, this treatment is relatively inexpensive, in part because it is not given for very long. The first two weeks of treatment were underwritten, and the final eight weeks cost about \$800.

How did the patients respond to ten weeks of therapy? Three experienced improvement, some significant, some moderate. One patient who had not been able to work is now working again. One of the five felt no better, and the sickest felt slightly worse. Patients who were the least sick felt pretty well during

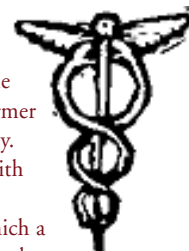
treatment. Dr. Cheney believes that sicker patients might take a temporary nosedive while on the treatment, primarily in the form of hypersomnia. The sickest patient felt energized on the mesenchyme, but when she received the FBGF extracted from the brain she went to sleep – for nine weeks. Her husband had to wake her up to eat. Dr. Cheney tested her melatonin levels and discovered that they were sky high all the time, not just at midnight. It was as if the FBGF spiked her melatonin levels to put her into a healing sleep. In addition, perhaps all her energy was needed for the “circuit testing” process of destruction and regeneration.

More research is necessary because many questions remain. What dosage should be given, how often, and for how long? Will sicker patients need a different protocol, such as more mesenchyme, or lower doses less often? This is an extremely powerful clinical treatment, but there is a long way to go to fully fathom what it can and cannot do. Still in the experimental testing stage, it will be some time before it is available to patients in general.

NINE FM/CFS DOCTORS SHARE THEIR BEST TREATMENTS

The October issue of the national Fibromyalgia Network newsletter has an outstanding article in which nine nationally known specialists list the therapies they have found most beneficial. If you would like a copy of the newsletter, call the FM Network at 800.853.2929; their website is www.fmnetnews.com.

One of our members is trying a treatment recommended in the article by Dr. Charles Lapp, a former partner of Dr. Paul Cheney. After sharing the article with her doctor, he prescribed Ketamine for her pain, which a compounding pharmacy makes into a gel. This is a powerful anesthetic used in procedures such as cardiac catheterization and endoscopy. The pharmacist mixes it with PLO to make a gel, which she then uses topically to provide powerful pain relief.



The DFW Lighthouse Credits

Published quarterly, the *DFW Lighthouse* strives to inform its members and the public about a variety of topics relating to Chronic Fatigue Syndrome and Fibromyalgia and provide information on advocacy issues. The CFS/FM Support Group of DFW is as a clearinghouse for information about Chronic Fatigue Syndrome and Fibromyalgia. The Support Group does not endorse particular products or services, and the ideas expressed in the *DFW Lighthouse* are strictly those of the authors or quoted individuals. The CFS/FM Support Group of DFW, and the *DFW Lighthouse* assume no liability for any medical treatment or other activity undertaken by readers. For any medical advice, consult your health-care provider.

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DR. CHENEY'S NEW OXYGEN TREATMENT

This article is intentionally detailed and technical so those who wish to try this treatment can share it with their doctor. It is based on a taped conversation with Dr. Cheney and has been reviewed and edited by him.

Dr. Cheney recently began prescribing oxygen for patients with alkaline venus blood. Up to an hour of oxygen in the morning can provide half a day of significant improvement and numerous benefits. He has been seeing alkaline blood results in patients for years, but dismissed it as insignificant, based on his medical school training. His growing suspicion that it was a very significant factor was confirmed when a speaker at an international conference on fatigue in London began a presentation by announcing "Ladies and gentlemen, I'm here to tell you that CFS patients are alkalotic."

Blood alkalosis inhibits the transport of oxygen to tissues and organs, constricts the blood vessels, and lowers overall circulating blood volume. The putative cause of the alkalosis is the glutathione deficiency that is pervasive in CFIDS. Low glutathione causes an elevation in citrate, which in turn lowers a substance (2,3 DPG) that controls the release of oxygen from the hemoglobin. Our blood could be full of oxygen, but without enough of this substance it cannot break free of the hemoglobin and get into the cells. This causes oxygen deprivation in the tissues (hypoxia), which makes the body switch over to anaerobic metabolism, and that produces tissue acidosis, which can be painful. The acidosis here is unusual because instead of generating a lot of carbon dioxide, it generates a lot of organic acids that stay inside the cell. The body compensates for tissue acidosis by increasing renal bicarbonate reabsorption, and developing blood alkalosis.

This blood alkalosis is unusual in that Cheney usually sees venus blood pH values over 7.4 and urine pH values under 6.0. (Optimum venus pH values are 7.30 to 7.35.) When both blood alkalosis and urine acidosis are seen, it's a metabolic problem—not a psychogenic reaction to a needle stick. A blood pH above 7.4 shows impairment, and above 7.5 there is significant impairment—almost no oxygen transport at all. A urine organic acid test will also reveal this problem: elevated citrate and/or low 2-oxo-glutaric are markers.



The really terrible thing is the presence of a vicious cycle. The blood alkalosis further lowers the levels of 2,3 DPG (inhibiting the release of oxygen), causing tissue hypoxia, which causes tissue acidosis and pain, which then causes blood alkalosis, which lowers 2,3 DPG even further. And around and around we go.

The ultimate treatment for this situation is Immunocal or IMUPlus, the undenatured whey protein supplements that help restore glutathione. However, some patients cannot afford this, and it does not work on all patients. An immediate solution to the oxygen transport problem is to use a partial rebreather mask set at 35 to 40% FIO₂ (Fraction of Inspired Oxygen), which requires a flow rate of about 10 liters per minute. Try to do an hour a day, broken into one, two, or three sessions. You can do more than one hour a day, but do not do more than one hour at a time. Do not breathe heavily—breathe normally. Most CFS patients have headaches, and this can help those headaches. If the prescription is written for headaches, insurance may cover it. One hour of oxygen a day on a partial rebreather can run \$75 to \$100 a month.

Oxygen through nasal prongs will not work. Oxygen alone in a mask will not work. It has to be a partial rebreather mask, which has a bag attached. This allows you to rebreathe your expired carbon dioxide along with the oxygen that is flowing into the mask. Breathing increased levels of both CO₂ and O₂ at the same time is essential. The CO₂ breaks the cycle. It corrects the alkalosis and frees the O₂ in your blood to move into your cells. With proper functioning, vessels dilate and you start perfusing your brain and tissues, bringing out the toxins and bringing in the nutrients. Raising oxygen levels will also help kill off yeast and other pathogens. Lack of oxygen allows them to multiply.

It is important to the function of the rebreather that the bag contract and expand with the breathing cycle. It can fully expand when you exhale, but it must collapse when you inhale, though no more than two-thirds. It's not working properly otherwise. If the flow rate is too high (usually above 10 Lpm) the reservoir bag will remain expanded during the entire breathing cycle and there will be insufficient rebreathing of CO₂. If the flow rate is too low, the reservoir bag will collapse fully when breathing in. It must not collapse more than two-thirds. If the bag will not

collapse well, check for leakage around a poor fitting face mask. The openings on the mask near the nose can be left open, or fitted with the rubber disks that turn the openings into one-way valves. An open mask has less rebreathing potential. With one-way valves, the CO₂ rebreathing potential is increased.

The speaker at the London fatigue conference sends his patients to breathing experts like Teresa Hale, who wrote *Breathing Free*. Most patients are walking around over breathing and thus becoming more alkaline. Learning to under breathe properly can help address the alkalinity of the blood and improve oxygenation.

Two problems can be seen in some patients on a rebreather mask. 1) Rapidly correcting blood alkalosis or overcorrecting (that is, acidosis) can provoke vasodilatation. If there is significant blood volume contraction some patients may become hypotensive and feel dizzy or faint. Taking oxygen lying down and expanding the blood volume with an isotonic electrolyte drink such as Gookinaid ERG (Electrolyte Replacement with Glucose), found at members.aol.com/Gookinaid, 800.283.6505, can prevent this. Reducing the time spent on the mask rebreather will also address this problem. 2) Patients with a history of migraine may provoke a migraine in the moments just after going after going off the rebreather. Again, expanding blood volume and reducing the time on the rebreather can help with this side effect.

CFS STUDY: PARTICIPANTS NEEDED

Judy Pollachek, a nurse and doctoral candidate at Rutgers University, is conducting a study of variables that affect the well-being of CFS patients. Her goal is to find areas where nurses can make a difference for CFS patients such as coping with the ramifications of the disease. She will send you five short questionnaires that can be completed at home and returned in the included postage paid envelope. The questionnaires will only have numbers on them; no one will be given your name. You'll receive a copy of the results when completed in May 2000. If you're interested in participating, contact Judy at JBPoe83@aol.com 908.832.7575, or fax her at 908.832.7605.

BRAIN INJURY INDICATED

Researchers at UT Southwestern Medical Center in Dallas, www.swmed.edu/library/consumer/gulfwar2.htm, have found indications of brain damage in Gulf War veterans caused by exposure to neurotoxic chemicals. The results suggest substantial loss of brain cells in the brain stem and basal ganglia. These parts of the brain control reflexes, movement, memory and emotion. Injury to these areas can cause problems with attention, concentration, pain, balance, depression and mood swings.



Magnetic resonance spectroscopy (MRS), which uses radio waves to measure body chemistry, found the veterans had up to 25% less of a particular brain chemical (N-Acetyl-Aspartate) than healthy veterans. Given the similarity in CFS and GWS, it is interesting that this test also picks up many abnormalities in the brains of CFS patients. Several CFS researchers believe there is neurotoxic injury to the lower brain in CFIDS patients, though not necessarily due to exposure to toxic chemicals.

NIH FUNDS THREE CFS RESEARCH CENTERS

The National Institute of Allergy and Infectious Diseases announced new research awards totaling \$1.9 million dollars to support three Chronic Fatigue Syndrome Cooperative Research Centers. The centers will conduct research addressing the clinical and epidemiological aspects of CFS, including its causes, characteristics, and treatment.

The four-year awards will be made to the University of Medicine and Dentistry in Newark, NJ, the University of Washington in Seattle, and the University of Miami. Dr. Benjamin Natelson in Newark, a grant recipient since 1991, is focusing on heart and nervous system abnormalities. Dr. Dedra Buchwald in Seattle, receiving her second grant, is conducting a CFS twin study. Dr. Nancy Klimas in Miami, a first-time recipient, will focus on “cognitive-behavioral” stress management therapy in persons with CFS. Each of the three centers will also conduct multifaceted projects in other areas of CFS research.

This information came from an NIH news release posted by the CFIDS Association of America.

DR. SIMPSON'S SEMINAR AND TREATMENT PROTOCOL

In October, Les Simpson, Ph.D. spoke on abnormal red blood cell morphology (shape) in CFIDS, FM, MS and other chronic conditions. He discussed the six shapes of RBCs (red blood cells) and presented slides showing a direct correlation between changed shape populations and severity of illness. Healthy RBCs are flexible enough to squeeze through the capillary system, carrying oxygen and nutrients to tissues and organs. Comparatively, the RBCs of chronically ill patients are more rigid and change shape. The increased rigidity and altered shapes of the RBCs compromise capillary blood flow and impair the delivery of oxygen and nutrients to tissues and organs of patients. Dr. Simpson has also found that chronically ill subjects often have smaller capillaries, further compounding the problem of blood flow.

Dr. Simpson had four treatment recommendations to reduce the rigidity and altered shapes of RBCs, thus improving circulation and reducing symptoms.

- (1) Reduce stress—it alters RBC shapes, impairing flow.
- (2) Engage in physical activity, however modest, to improve circulation, but avoid any activity that leads to relapse.
- (3) Take Evening Primrose Oil. A double-blind study revealed EPO improved capillary blood flow in a significant number of patients. Dr. Simpson recommends the brand Efamol, though any product that contains less than 10% GLA should be effective. Seacoast

Natural Foods, 800.555.6792 or www.seacoastvitamins.com, carries an Efamol EPO product called “Restore” for less than half the normal retail price. Take two 500 mg. capsules with each meal and two at bedtime. If EPO is going to help, improvement will be seen within six weeks. One group member reported after several days of taking Efamol EPO she had warm hands for the first time in years. An alternative to EPO is salmon oil and/or ginkgo biloba. He recommends the brand Ginkoba. There is also a prescription drug called Trental which has a similar effect.

(4) Dr. Simpson has found that injections of hydroxycobalmin (British B-12) positively affect on RBC shape, thereby improving blood flow.

A video tape of Dr. Simpson's seminar is available for \$19 (including \$5 contribution toward his current research). To order, send a check payable to Carol Sieverling at her address listed in this newsletter.

Dr. Simpson expects to have all blood work reports completed by end of January. There is a problem with some of the test results: two forms listed the same number 6474 (last four digits of social security number), but only one vial matched that number. Two vials, 0892 and 5494, do not have matching forms. If any of these numbers are yours, please contact Carol.

SECOND WORLD CONGRESS ON CFS

Researchers, doctors, and patients from around the world gathered at Brussels in September for this conference, organized by Dr. Kenny McMeirleir. He is noted for his work on the RNase-L antiviral pathway and the drug Ampligen, which were among the many topics covered at the conference. Discussions also included subgrouping of patients, treatments, memory and learning, CFIDS in adolescents, exercise capacity, and GWI (Gulf War Illness).

A detailed report can be found at www.co-cure.org/infocn1.htm. Thanks to Roger Burns for publishing this information.

INTERNATIONAL CONFERENCE: MYCOPLASMA, STEALTH VIRUSES, PEDIATRIC OUTBREAK, RED BLOOD CELLS

The Common Cause Medical Research Foundation held their first annual International Conference in August. Four well-known researchers spoke: Dr. Garth Nicolson on Mycoplasma; Dr. David Bell on the Lyndonville pediatric CFS outbreak; Dr. John Martin on Stealth viruses; and, Dr. Simpson on red blood cell abnormalities in CFS. Notes of the first three presentations and a full transcript of the last are available at www.cfsaudio.4biz.net/ccf/firstconf.htm.

SENATOR CALLING FOR CRIMINAL INVESTIGATION OF CDC NEEDS YOUR HELP

On November 9, Senator Harry Reid of Nevada asked the US Attorney General to launch a criminal investigation into CFS misspending at the Centers for Disease Control (CDC). Earlier this year the Inspector General of Health and Human Services determined that CDC officials lied to Congress about the 12.9 million dollars diverted from the CFS research program.

This is 57% of the total CFS research funds allocated by Congress, who directed the CDC to restore the funds. Support from other senators is **critical** to persuading the Department of Justice to launch an investigation. Please contact your senators and ask them to write to Attorney General

Janet Reno in support of Senator Reid's request.

There is an obvious lack of urgency in changing the name and revising the case definition. There also appears to be a psychological bias in the grant awarding process at the NIH. Decry the pervasive institutional attitude at both the CDC and NIH that CFS is mild, transient, primarily psychiatric, and not worthy of serious consideration. If you wish to express your dismay at this pathetic situation, a sample letter is available by email, regular mail from Carol, or at www.cfids.org/advocacy/cdc/justice.html. Find the names and addresses of your senators at www.congress.org.

FM SEMINAR IN HAWAII

The Mind-Body-Spirit Tour 2000, www.painalliance.com, will be held March 6-13 at the King Kamehameha Kona Beach Hotel. Mary Essert and Sue & Mick Nelson will offer a variety of workshops on water exercise, surviving FM, stress management, pain management therapy, etc. The seminar includes round-trip airfare from California, seven night's accommodation, and a daily breakfast buffet. The seminar cost is \$1799 for a full participant, \$1599 for a companion with a seminar limit of 30 people. Contact the Nelsons at 888.446.8165, or turswim@slotec.net.

DRINK MORE OXYGEN!

That's the slogan of Rain Fresh Water, who provided free bottled water at the Les Simpson Seminar. Their water goes through a 24 step process, including triple carbon filtration, KDF media, micro filtration, ozonation, ion exchange, reverse osmosis, magnetic treatment, ultra violet lattices, and enrichment with medical grade O2.

This process is designed to reproduce rain water from an unpolluted environment, the healthiest type of water. Many thanks to Obbie and Lori Loving of Rain Fresh for their generosity. You can contact them at 817.577.3800.

INTERNATIONAL FM CONFERENCE

FAME 2000, www.fmAware.com, will convene May 19-21 at the Sheraton Universal Hotel in Los Angeles, California. Topics include research, treatment, disability, and pain management. The relationship between FM and several conditions such as CFIDS, IBS, facial pain, hormone abnormalities, Chiari Malformation, depression, sleep, and migraines, will be explored.

An impressive lineup of speakers includes many noted CFS medical experts: Robert Bennett, Sharon Clark, Daniel Clauw, Stephen Katz, Mark Pellegrino, Jon Russell, Jacob Teitelbaum, Daniel Wallace, and Muhammad Yunus. Conference cost before April 15 is \$200—after, \$240. Contact Lynne Matallana, 714.921.0150, or fax at 714.921.8139 to make reservations. Hotel reservations can be made at the Sheraton, 818.509.0888, for the conference rate of \$125 per night, per double room.

HYPNOTHERAPY

Recently featured on NBC's local news health segment, hypnotherapist Edward Joseph is one of the few practitioners in Texas of EFT (Emotional Freedom Techniques). EFT involves tapping on the body's energy meridians to eliminate negative emotions. One of his FM patients reports that she feels better than she has in ten years through the use of hypnotherapy and EFT. Ed can be reached at 827.589.7407.

MEDIA BITES

The October 31 issue of *Parade* magazine featured a two-page article on CFIDS quoted Dr. Isadore Rosenfeld commenting that while he used to be skeptical, he now believes CFS is a real disorder. He mentioned that an unknown virus, bacteria, allergy, or hormonal imbalance could trigger the immune dysfunction of CFS. Dr. Rosenfeld's closing remark was, "It's not all in your head."

To get this article, send an email with the message GET CO-CURE.CFS to LISTSERV@LISTSERV.NODAK.EDU. Since it's an automated system, don't put in any additional text or a subject in your email. The CFIDS Association of America provided this information.



CNN aired an excellent story on CFIDS in its "CNN/Time" segment in October. People featured included soccer star Michelle Akers, Dr. Dan Peterson and two of his patients, Dr. Dedra Buchwald and two of the twins in her study, and CDC officials. A transcript is posted at listserv.nodak.edu/scripts/wa.exe?A2=ind9910d&L=co-cure&F=&S=&P=1490. If this link doesn't work, try listserv.nodak.edu/scripts/wa.exe?A2=ind9910d&L=co-cure&F=&S=&P=2048 or the original link at: cnn.com/TRANSCRIPTS/9910/24/impc.00.html. Thanks to the CFIDS Association of America and Co-Cure for posting this information.



Dateline and the Wall Street Journal did stories on the brain surgery many CFS/FM patients are undergoing to treat Chiari Malformation or Cervical Stenosis, conditions in which the brain stem or upper portion of the spinal cord is compressed. It isn't clear how many CFS/FM patients have these conditions, or if they are responsible for their symptoms. The WSJ story came out Nov. 11, and the Dateline program aired December 14. Additionally, Dateline aired an FM story on January 4, www.msnbc.com/news/347373.asp.

FM: DECADE IN REVIEW

The transcript for an excellent discussion of the research and treatment breakthroughs of recent years can be found at my.webmd.com/member/532393. The moderator for the discussion was Kim Jones, RN, M.N., F.N.P. Kim teaches in the School of Nursing at Oregon Health Sciences University, the site of some of the most cutting-edge research into FM.

ONE-TO-ONE

Susan, who has CFS/FM, reports that she has felt remarkably better since switching pillows! She discovered this while staying with relatives. They had big, fat pillows on the guest bed. She slept on her back with her head tipped forward slightly, chin toward chest. Since she never sleeps on her back, she was sure she wouldn't be able to sleep well.

To her surprise, she "awoke the next morning feeling quite good. The mind fog was gone. I felt energetic. Every morning since then, I have had the same result. I continue to feel much more alive. That's the best way to explain it. I can THINK, I feel like DOING THINGS, COOKING, GOING PLACES, LAUGHING. Like my personality has come back. Like I am no longer half dead."

You may not get the same result, but unlike many treatments, this one costs very little! And it actually makes sense, given the occurrence of Cervical Stenosis and the Chiari Malformation in FM/CFS, in which the brain stem or upper portion of the spinal cord is compressed. Susan believes she may have the Chiari malformation, since tipping her head back has always caused discomfort.



Like many of us, Tonja's pain and other symptoms led her from doctor to doctor without any significant relief. She was finally diagnosed and experienced some benefit from "strain counter-strain therapy." However, it has been herbs that have helped her recover. She went on a complete program designed by her herbalist. One year later she was free of pain. It has been five years now, and she considers herself free of FM. Tonja has since become a Certified Natural Health Professional. You can reach her at 817.485.7239 or at TonjaWells@aol.com.



One FM patient reports significant relief from pain through hypnotherapy. With hypnotherapy and EFT (Emotional Freedom Techniques), she feels better than she has in ten years. Her hypnotherapist, Edward Joseph, can be reached at 827.589.7407.



Another 100% free internet service is now available. Just go to FreeI.net, www.freei.com. Seems to be a pretty nice system they have set up and pretty easy to use!



CFIDS STUDY SHATTERS MYTHS

Working under an NIH grant, DePaul University researchers discovered some shocking truths about CFS. Researchers randomly surveyed over 28,000 people and determined that as many as 800,000 people suffer from CFIDS, twice the number previously estimated by the CDC. The rate for women is 522 per 100,000; for men, 291. CFIDS in women is 15 times more common than lung cancer (33/100,000) or breast cancer (26/100,000), and 40 times more common than AIDS. Latinos (726/100,000) and African Americans (377/100,000) are at greater risk than Caucasians (310/100,000).

CFIDS prevalence was highest among skilled craftsmen/women, clerical, and sales workers; second highest among unskilled laborers, machine operators, and semiskilled workers; and lowest among professionals. Before the onset of CFIDS, 59.3% of the CFIDS patients had never experienced a psychiatric illness—including depression. Only 10% of the CFIDS patients identified by the study had been previously diagnosed. This study shattered many stereotypes about CFIDS patients, establishing that CFIDS sweeps across all

boundaries of race, gender and class, is not "all in your head," and goes largely undiagnosed.

A brochure is available at www.cinda.org/support/supportive/pamphlets/pamphlets.html, includes a quote from a 1995 Congressional CFS Briefing by specialist Mark Loveless, MD. He states that a person with CFS is "as ill as an AIDS patient in the final two months of life." The brochure also includes the oft-quoted information that CFIDS can leave patients more functionally impaired than congestive heart failure, multiple sclerosis, and end-stage renal disease. While valid, remember that the range of severity for CFIDS patients goes from quite severe to mild to moderately ill. Such quotes are not meant to frighten or discourage people, but to validate those who are seriously ill and meet with disbelief from family, friends and the medical community.

The results are published in a breakthrough study in the Archives of Internal Medicine, October issue.



SUPPORT GROUP INFO

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To volunteer, contact Carol—every little bit helps! Possibilities include, but aren't limited to, a social gatherings coordinator, a librarian, a compiler of social services/resources, and someone to handle tape orders. If you would like to nominate yourself for someone else for the Advisory Board, contact Carol.

Financial Report: current balance is \$836.49 (including \$150 earmarked for 501c3).

QUICK CALENDAR

- Jan. 22 CFS/FM Treatment
Sat., 2:30 p.m.; hospital
- Jan. 30 Spiritual Journeys
Sun., 3 p.m.; hospital
- Feb. 5 Intro to Yoga
Sat., 3 p.m.; hospital
- Feb. 15 Helpful Solutions
Tues., 7 p.m.; hospital
- Feb. 26 Macro Broccoli Restaurant
Sat., 5 p.m.; Richardson
- Mar. 12 Spiritual Journeys
Sun 3 p.m.; hospital
- Mar. 21 Nutrition & Water,
Tues., 7 p.m.; hospital
- Apr. 8 Tour—Whole Foods & Dinner
Sat., 4 p.m.; Arlington

NAVIGATING THE BODY: EXPRESSING INVISIBLE PAIN THROUGH ART

This amazing website, www.Navigatingthebody.com, is not to be missed! If you are not online, it's worth seeing at a friend's or a library. Share it with family members and friends; they may catch a glimpse of what living with chronic pain and illness is like. It consists of three pages rendered by a talented graphic artist. Each wonderfully unique page depicts a different woman's experience of FM or CFS/FM. The words and imagery are incredibly beautiful and moving. Donimo's section incorporates x-rays, representing "all the medical stuff, the ways in which docs look inside us and limit us to images and tests. X-rays are harsh images, though beautiful. There is a dualism in this. I am fascinated by the results and images of tests, but I hate how I end up feeling like my body is an 'it' or something." Rose's page seems to express lost intimacy and disconnect-edness.

This site also addresses the feeling of invisibility experienced by so many, and the difficulty of validating something we can't see or hear.

Susan, the site creator, says, "Folks with chronic pain have to fight to be understood and believed. More belief equals greater freedom of movement, whether in our personal relationships or with society at large." Donimo echoes these sentiments, saying, "I think there is a certain ease that comes with being understood. I find that with friends or lovers, the more they understand what I live with and how it affects my life, the easier it is for me to just 'be.' It is the quest for ease in my own psyche that often drives me to help others understand. Bringing the inside out is about moving in the world and in our bodies with as much fluidity and ease as possible. I know that it is hard with FM or other chronic pain. But I do think that honesty and telling the hard truths really does help in the long run."

This is a truly powerful work. Check it out and then be sure to share it with others. A transcript of the WebMD chat is available at my.webmd.com/member/532422.

DIAGNOSING CFS/FM: WHY "MEDICAL VS. PSYCHOLOGICAL" IS IMPORTANT

Written by Mary Schweitzer, Ph.D. the following article was posted to the news service at www.co-cure.org. Mary has constructed a wonderful website titled, "The CFIDS/M.E. Information Page," www.cfids-me.org.

The antipathy within the CFS/M.E. population to being diagnosed as having a primary psychiatric disorder has nothing to do with whether as individuals we have any prejudices about primary psychiatric disorders. It stems, rather, from the more obvious problem of getting the correct diagnosis and the correct treatment.

If a patient with a broken leg is diagnosed as having primary melancholic depression (because he doesn't go anywhere) and given Prozac—that is the wrong diagnosis and the wrong prescription. That is the point. Wrong diagnosis, wrong prescription.

Let me suggest the work of DeLuca, et al on measuring mood disorders in CFS/M.E. patients. They found that CFS/M.E. patients neither tested like "normals" on standard tests of major mood disorders, nor did they test like patients with primary melancholic depression.

Rather, they tested almost precisely like MS (Multiple Sclerosis) patients.

Fewer than half of diagnosed CFS/M.E. patients have secondary depression. Of course, those with secondary depression need to be treated—but after being treated for secondary depression, they continue to have their CFS/M.E. symptoms. Coping techniques can help, of course, but again, the main problem—CFS/M.E.—remains.

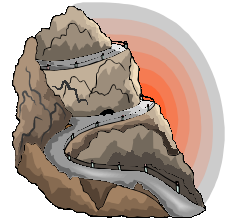
THIS, then, is the issue. What is the appropriate diagnosis, and what is the appropriate treatment? It's really very simple. Primary psychological disorders are the wrong diagnoses for CFS/ME patients, and psychological treatment the wrong protocol—unless of course one thinks the best way to treat someone with a broken leg is with Prozac, psychotherapy, and Cognitive Behavioral Therapy.



SPIRITUAL JOURNEYS

Spiritual journeys.

This illness can be a rough road at times. While many people find that chronic illness challenges their faith and rocks their world, it also potentially becomes a time of tremendous growth.



This group will explore the various spiritual aspects of living with chronic illness. During our first January 30 meeting, we'll share our stories and expectations, and then decide what format we'd like for our future meetings.

The diversity of our religious backgrounds will be both a challenge and a tremendous resource. The group's goal is to welcome a variety of faith perspectives and honor each person's particular journey and belief system.

Let's make this a wonderfully loving and supportive group in which we share our struggles, joys, and insights. Together let's discover spiritual resources that can bring added meaning, power, reconciliation, and hope to our lives.

WE WON AGAIN!

For the second year in a row, our support group received an award from the CFIDS Association of America for our Awareness Day activities. The award includes a certificate for \$150 of educational materials in recognition of many of our activities.

These activities include: efforts to get a resolution passed declaring May 12 to be Awareness Day from the Texas House of Representatives and the cities of Fort Worth, Arlington, Irving and Grand Prairie; information tables at two area hospitals and 19 local libraries; Dr. Cheney's seminar; and, the CFS stories that aired on the Irving cable channel and a Spanish language TV station.

Many thanks from the group to all who participated in these activities; your efforts are greatly appreciated!

NEED FREELANCE WORK?

Many people with chronic illness need temporary and/or flexible employment opportunities. JobSwarm, www.JobSwarm.com/13921307, is a comprehensive, fast-growing service that matches businesses with freelancers. The process is beneficial to both parties and free of charge. Freelancers can submit bids on project proposals in a variety of fields, including computer programming, graphics design, marketing and translation services.

Thanks to Sheryl Jefferies for posting this notice through Co-Cure.

SOCIAL SECURITY DISABILITY NEWSLETTER

Stan Denman, a local lawyer specializing in social security disability, has begun publishing a newsletter on social security disability for clients, former clients, or anyone interested in SSDI. Topics include information on the assessment process, improving your chances, changes within the SSA that may affect your continued eligibility, the review process, and return-to-work issues. To receive complimentary issues, contact Stanley Denman & Associates at 214.219.7288.

HISTORY OF MEDICINE

- 2000 BC - - - "Here, eat this root!"
- 1000 AD - - - "That root is heathen. Here, say this prayer!"
- 1500 AD - - - "That Prayer is superstition. Here, drink this potion!"
- 1940 AD - - - "That potion is snake oil. Here, swallow this pill!"
- 1985 AD - - - "This pill is ineffective, take this antibiotic!"
- 2000 AD - - - "That antibiotic doesn't work anymore. Here, eat this root!"



JAN. 22 REGULAR MEETING: "CFS/FM TREATMENT"

Dr. Howard Lang; Sat., 2:30 p.m.

Dr. Lang has been practicing medicine for over 20 years and was one of the first physicians in the area to acknowledge and treat CFS and FM. Over the years he has seen hundreds of CFS and FM patients. At this Saturday afternoon meeting, he will discuss his testing procedures and treatment protocols. Don't miss this opportunity to hear one of the most experienced CFS/FM doctors in the metroplex. *Note that this is a Saturday afternoon meeting*

JAN. 30 SPIRITUAL JOURNEYS: SUN., 3 P.M.

While many people find that chronic illness challenges their spirituality, it can also be a time of tremendous growth. During this initial meeting we'll share our stories and expectations, and decide what format we want these meetings to take. The diversity of our religious backgrounds will be both a challenge and a tremendous resource. The hope is that this will be a group that welcomes a variety of faith perspectives and honors each person's particular journey. Let's focus on what we have in common, and share with each other spiritual resources that provide connection, meaning, reconciliation, power and hope.

FEB. 5 SPECIAL MEETING: INTRO TO YOGA: SUZANNA SHANK: SAT., 3 P.M.

You may have heard that yoga is particularly beneficial for those with CFS/FM. Here's your chance to find out what yoga is and if it's for you. Suzanna will be conducting sessions to introduce the benefits of yoga, which include increased flexibility and strength, detoxification and relaxation. She will focus on proper approach, form and breathing, and will begin with gentle, basic poses geared to the needs of those with chronic illnesses. Try not to eat at least an hour before class. Wear comfortable clothing and bring a large towel or an exercise mat. *Please be sure to not wear any scented products to this meeting.*

FEB. 15 REGULAR MEETING: "HELPFUL SOLUTIONS: A GROUP DISCUSSION OF WHAT WORKS:" TUES., 7 P.M.

Come and share what has worked for you and learn what has helped others. While what helps one person may not help another, we can learn a great deal from one another. Come and share which tests, drugs, supplements, herbs, mediations, coping mechanisms, etc. have helped you. Time may run short, so if you'd like to summarize your information on paper, please bring 20 to 40 copies.

(Note: The support group is not to be used as a sales forum. If you are a distributor please speak only of your own personal experience with a product and very briefly mention how to obtain it. Anything further would be inappropriate.)

FEB. 26 SOCIAL GATHERING: MACRO BROCCOLI: SAT., 5 P.M.

This cozy Richardson macrobiotic restaurant serves healthy, primarily organic, meals that are sugar- and dairy-free. A wide variety of dishes will be available many gluten-free. Sugar-free desserts made with rice or maple syrup, both less hazardous than refined sugar, will also be served. Expect to pay around \$10 per person.

Reservations are essential. Please call Carol by Feb. 23 if you plan to attend.



MAR. 12 SPIRITUAL JOURNEYS: SUN., 3 P.M.

MAR. 21 REGULAR MEETING: TIRED & TOXIC-SHARON PRICE; WATER & OXYGEN ... THE VITAL BASICS-LORI LOVING: TUES., 7 P.M.

Are you tired and toxic? The symptoms of CFS and FM can be the direct result of insufficient nutrients and/or the build up of toxins. Come learn about the elimination pathways of the body and the importance of internal cleansing from Sharon Price, a Certified Nutritionist, herbalist, and kinesiologist who is completing her masters and pursuing her Ph.D. in Natural Health Science. Lori Loving will help us rediscover the simple yet critical nature of proper hydration and oxygenation-the foundation for health and well being. Lori has been involved in preventive health care for thirteen years.

APR. 8 SOCIAL GATHERING: TOUR OF WHOLE FOODS (ARLINGTON) AND DINNER IN THE CAFÉ; SAT., 4 P.M.

Look for more information in the next newsletter.

TEITELBAUM COMING!

Nationally renowned clinician, researcher, and author Jacob Teitelbaum, MD will present a three-hour seminar on Saturday, May 6 from 2 p.m. to 5 p.m. (location TBA) on the effective treatment of FM and CFS. Harris Methodist Hospital-HEB and the City of Irving will jointly sponsor the event.

Earlier in the day Dr. Teitelbaum will present a separate lecture and discussion specifically for health-care professionals. We're pursuing the possibility of continuing education credit for this lecture.

Dr. Teitelbaum will present the results of double blind, placebo-controlled study he recently completed on the treatment of CFS & FM that will be published later this year. In this study, 85% of the treated patients improved; 50% improved significantly.

Look for more details in the next newsletter!

CHRONIC FATIGUE SYNDROME & FIBROMYALGIA SUPPORT GROUP OF DFW

If you find any listing in this newsletter that says to contact Carol, it references our group leader, Carol Sieverling; see the credits for further information about contacting her. Please note that this newsletter will also be available online at: members.xoom.com/dfwnews/.

The CFS/FM Support Group of DFW meets from 7:00–8:30 p.m., the third Tuesday of each month at Harris Methodist HEB Hospital, located at Hwy 183 and Hospital Parkway in Bedford. We meet on the first floor of the Edwards Cancer Center; signs will direct you to the room. There will be an additional monthly meeting alternating between social and spiritual gatherings.

Some patients are affected by chemical odors. We ask for your thoughtful consideration of others—don't wear perfume, cologne or clothes exposed to smoke to the meeting. Remember that common household agents frequently have heavy chemical odors also.

THANKS AGAIN!

Many thanks to the amazing women at Emmanuel Presbyterian Church who so willingly take care of the folding, licking, sticking, and other mailing and distribution-related needs for us.

Also, many thanks to the HEB Hospital and their staff for their donation of printing and mailing services.

Without you all, this publication would not be possible.



8617
Sponsored by Harris Methodist HEB Hospital
c/o Carol Sieverling
513 Janann Street
Eulless, Texas 76039

LIGHTHOUSE

The Newsletter of the Chronic Fatigue Syndrome & Fibromyalgia Support Group of Dallas-Fort Worth
www.virtualhometown.com/dfw/cfs

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