



The newsletter of the Chronic Fatigue Syndrome & Fibromyalgia Support Group of Dallas-Fort Worth

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POSSIBLE DIAGNOSTIC MARKER FOR CFS: OUR TAX DOLLARS AT WORK—FINALLY!

(aka The Saga Continues: CDC Use of CFS Research Funds)

Scientists at the Centers for Disease Control (CDC) are fine-tuning an exciting new technology that may eventually lead to a diagnostic marker for CFS. DNA microarrays, a recently developed technology, now allow researchers to detect and evaluate thousands of genes at once, offering a staggering amount of information and a host of possibilities for diagnosing and treating numerous illnesses.

The microarrays are not looking for inherited genetic abnormalities, as do the Genovations test panels (immune, detox, cardiac and osteo—see www.genovations.com). Instead, the microarrays look at normal genes to see which ones are turned “on,” (meaning active and expressing; sending out instructions) and

which ones are turned “off,” (inactive). This pattern of genes being turned on and off is largely the result of illness, not heredity. It also is very fluid, shifting as one’s clinical status changes. The goal of gene profiling using microarrays is to see if there are patterns of gene expression that are unique to certain illnesses. The answer appears to be, “Yes!”

CDC researchers, led by Dr. Suzanne Vernon, a molecular epidemiologist, completed an initial study last fall involving 22 people. They looked at 1794 genes and were able to correctly identify the five CFS patients based on a pattern of gene activation and inactivation unique to that subgroup. The genes that most often differed from the healthy controls were those implicating immune dysfunction.

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CFS/FM CONFERENCE SUMMARY (PART ONE)

by Larry Sharp, D.O.

The clinical and patient symposium for CFIDS and FM was held on 9/19/02 in Los Angeles. The conference was co-sponsored by: National Fibromyalgia Association; American Association for Chronic Fatigue Syndrome; Foundation for Care Management; and, The Healthy Foundation.

There were many excellent lectures and workshops directed to understanding the pathophysiology and treatment of these misunderstood illnesses. Each speaker was an outstanding researcher or practitioner in his or her field, and most had authored one or more books. Moving discussions with actress A.J. Langer and Olympic speed skater Amy Peterson covered the public relations field.

Most important of all, the mood was optimistic and hopeful. It is my pleasure to share my lecture notes and this brief synopsis

in hopes that the knowledge shared can light a candle in all our windows. Although this is in no way complete, it is a composite of what I felt were the most important lectures.



ENHANCING BIOLOGICAL METHYLATION TO MITIGATE SYMPTOMS OF FIBROMYALGIA

Todd Ovokaitys, M.D.

One of the bodies’ detoxification pathways involves METHYLATION. This involves adding a methyl group (CH3) to other molecules. This process takes place in every cell of the body. An example of defective methylation is increased homocysteine levels.

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Homocysteine is a toxic amino acid. Your body's methylation cycle converts it into methionine (an essential amino acid). Methionine then combines with an energy source in the body to form the natural antidepressant, S-ADENOSYLMETHIONINE (S-AMe).

Patients with CFIDS and FM (as well as heart patients) typically have high homocysteine levels in their blood and spinal fluid. This indicates defective methylation. Low S-AMe levels, due to this defect, are associated with the reduced serotonin and melatonin levels that explain depression and sleep cycle disorders. There are numerous other serious consequences to high homocysteine: lymphocyte dysfunction, Telomere shortening ("The new aging theory"), vascular endothelial damage (heart disease), and destruction of DNA, to name a few.

The good news is that one can lower homocysteine and raise S-AMe levels with an inexpensive supplement: Trimethylglycine, also known as Betaine. Trimethylglycine is an amino acid capable of donating three methyl groups. This compound crosses the blood-brain barrier better than S-AMe and is less expensive (dose 2 grams per day). It is most effective when supplemented with B6, B12, Folic Acid and Choline. Dr. Ovokaitys has further improved this with laser treated Betaine manufactured by his company Gematria Products, Inc. The laser treatment improves absorption.

EFFECTIVE TREATMENT OF CHRONIC FATIGUE SYNDROME AND FIBROMYALGIA

Jacob Teitelbaum, M.D.

Three lectures and workshops were given by this dynamic speaker. He presented impressive data concluding that treating hypothalamic dysfunction which produces poor sleep, low hormone levels and impaired immunity results in dramatic improvement in terms of pain and lifestyle complaints.

His treatment protocol includes addressing:

- ❖ Poor sleep, utilizing herbal or pharmaceutical interventions;
- ❖ Hypothalamic hormone dysfunction—low thyroid, adrenal, growth hormone, low ovarian and testicular function, and low vasopressin—measure levels and replace all, or portions of, these hormones;
- ❖ Effects of immune dysfunction—chronic infections, bowel infections, dysbiosis, viral infections;

- ❖ Gut dysfunction—recommends Great Smokies Lab Comprehensive Digestive Stool Analysis (CDSA); (www.gsdl.com)
- ❖ Mind/body/soul attention. I recommend reading his book "From Fatigued to Fantastic" or checking out his website www.endfatigue.com.

Dr. Teitelbaum concluded his workshop by describing his next book, tentatively titled "Three Steps to Happiness."

1. **Be honest with your feelings**—feel everything without the need to understand why. Feel this as long as it feels good, and then let it go by shifting attention to something else.
2. **Life is a no-blame system**—No blame, No fault, No guilt, No judgement, No comparisons, No expectations.
3. **Follow your bliss**—use feelings to guide you.

THE IMPORTANCE OF EMPHASIZING MAGNESIUM IN THE TREATMENT OF CFIDS AND FM

Nan Fuchs, Ph.D.

High calcium and insufficient magnesium diets are making people ill. Our S.A.D (Standard American Diet) is excessive in calcium and deficient in magnesium (among other deficiencies). Supplementing magnesium can reduce pain, cramping, heart disease, arthritis, hypertension, PMS and even osteoporosis. Magnesium is important for the production of cellular energy (ATP). It also reduces insulin resistance, corrects hypertension (it is a vasodilator), and improves arthritis (unabsorbed calcium can collect in the joints).

Magnesium helps calcium get into the bone and other tissues and it can reduce PMS. Dr. Fuchs mentioned an interesting side story: Dr. Robert Heaney studied 48 women in Nebraska in 1978. He estimated their daily calcium intake was 670mg per day. He concluded that women should double their intake, consuming 1,200–1,500mg per day of calcium. The U.S. dairy industry then used this single study of a very small sample to increase sales. Dr. Fuchs believes that high levels of calcium do not increase bone density, and in fact, high amounts can actually result in bone fragility.

Dr. Fuchs recommends a dose of 600–1,000mg magnesium glycinate or citrate with or without malic acid daily. If diarrhea occurs, reduce the dose. She has authored numerous booklets on the use of magnesium.

CFS IN THE SMITHSONIAN

The Smithsonian, a monthly, award-winning magazine featured an article on CFIDS, entitled, "Betting on Seabiscuit." Published in December 2002, the article reports on current CFS research, profiles best-selling author Laura Hillenbrand and details her personal experience with CFS.

Hillenbrand has recently been busy with the making of a Seabiscuit movie, slated to open July 25, 2003, starring Jeff Bridges and Tobey McGuire (recent star of Spiderman). "Here was a story I could get lost in," says Hillenbrand. "Writing it helped me redefine myself, to become Laura the author instead of Laura the sick person." When her book, *Seabiscuit: An American Legend*, became so successful, she happily championed the cause of CFS patients and became their spokesperson.

The Smithsonian article goes into some depth not only about Laura's story, but also about CFS research and theories about the possible cause or causes of the illness. While CFS was once known as, "the Yuppie flu," researchers now understand that the reality of CFS is far from this once commonly-held, negative stereotype and is, in fact, much more widespread than previously thought. Now researchers are trying to isolate the physical cause or causes of CFS.

The extreme difficulty in diagnosing the illness has complicated matters greatly for both sufferers of the disorder and for the medical community that attempts to treat them. This article discusses how it now looks hopeful that CDC researchers may have found a means of developing such a diagnostic test—and eventually new treatments. The theory the CDC researchers are working on involves exploring the genetic material to determine which genes are active, or "on" and which are inactive, or "off."

Analyzing this information yields a sort of genetic signature—a pattern from which researchers may one day be able to routinely diagnose the disorder and its' various subcategories. For more information, read the article about DNA microarrays in this issue of the DFW Lighthouse (Diagnostic Marker for CFS, p. 1); it is an intriguing theory.

Television station WNBC in New York also did a story (www.wnbc.com/drdauidmarks/1815900/detail.html) based on the Smithsonian article that featured a local person

It is worth noting that, with this technology, 1,794 genes are considered a small sample. Other CFS researchers plan to test the blood of CFS patients with microarrays that will evaluate 45,000 genes at once. In the near future, the CDC also intends to release various study results that examine both a larger group of patients and a larger group of genes.

In "Betting on Seabiscuit," published in the December 2002 *Smithsonian*, Dr. Vernon states, "CDC researchers may be on the verge of developing a [diagnostic] test, based on analyzing patients' genetic material." She also predicts that microarrays will someday routinely diagnose CFS—whatever the underlying cause.

"Most CFS experts would agree that there may be several subcategories of [the disorder]—due to an infectious agent or to stress and so forth," says Vernon. "I anticipate seeing an underlying gene-expression pattern common to all CFS patients but, in addition, some unique genes expressed that correspond to each subgroup."

See listserv.nodak.edu/scripts/wa.exe?A2=ind0211d&L=co-cure&F=&S=&P=3404 for the full article.

The CDC's first study was published in March 2002 in Disease Markers 18(4): 193-199. See www.iospress.nl/site/html/02780240.html; also, see www.gla.ac.uk:443/newsdesk/stories.cfm?PRID=1291

Thanks to www.co-cure.org (for more info, search the archives for "microarrays").

Smithsonian... continued from page 2

with CFIDS (PWC) Eileen Holderman and NY clinician Dr. Susan Levine. Says Dr. Levine, "The internist typically says, 'I did all your blood tests and everything looks fine here; we can't figure out what's wrong with you.'" "The doctor would say, 'you must be depressed, go out and get a job, [or] are you and your husband planning on having a baby, etcetera.'" This new test would eliminate this doubt and the difficulty doctors have in diagnosing this illness. Several other television stations aired coverage on the article as well.

To read the article in full, go to: www.smithsonianmag.si.edu/smithsonian/issues02/dec02/fatigue.html

Katzenstein, Larry. "Betting on Seabiscuit." Smithsonian, December 2002, p. 59. www.cfids.org; www.co-cure.org

THE ROLE OF CANDIDA IN FM

Michael McNett, M.D.

The pesky yeast, *Candida*, has been implicated in causing FM by:

- ❖ blocking thyroid receptor sites, which causes poor conversion of sugars to energy (ATP), raises fat production and causes fatigue, as well as
- ❖ inhibiting the production of substance P, which makes one more sensitive to pain.

Dr. McNett follows the candida diet, stresses probiotics, and uses anti-fungal medications. He is medical director, Paragon Clinic, Chicago.

NATURAL HIGHS: DEALING WITH MOOD CHANGES OF CFS & FM USING SPECIFIC BOTANICAL TREATMENTS

Hyla Cass, M.D.

Based on her book "Natural Highs," Dr. Cass explained the rationale and properties of several natural substances.

- ❖ St. Johns Wort is an uptake inhibitor of serotonin and dopamine, and thus is an antidepressant.
- ❖ Ginkgo Biloba, one of the oldest plants on the planet, is an antioxidant, blood thinner and improves memory and energy.
- ❖ S- Adenosyl-Methionine (SAME) is a methyl donor as described previously, enhancing production of neurotransmitters, fatty acids, phospholipids, proteins, nucleic acids and glutathione.
- ❖ Other herbs discussed were Kava, Valerian, Hops, and passionflower as relaxants.
- ❖ Finally, adaptogens were described.

Authors Note: Adaptogens are substances that have no toxicity or side effects at normal doses and that non-specifically increase the body's resistance to disease and to physical or chemical stresses. They assist the body in combating stress by maintaining its homeostatic balance and in recovering from the effects of adverse environment, emotions and disease influences. One product I have found particularly effective is ADRESET, made by Metagenics, Inc.

- ❖ The adaptogens included:
 - Ashwaganda**—stabilizes cortisol levels, enhances memory
 - Ginseng**—supports the adrenals, enhances the body's response to stress, gives immediate energy
 - Licorice**—prevents the breakdown of cortisol
 - Astragalus**—adrenal support and immune support, as well as anti-inflammatory

Many of these adaptogens are available in combinations commercially.

NUTRITIONAL IMMUNE MODULATION OF CFS

Michael Rosenbaum, M.D.

author, Solving the Puzzle of Chronic Fatigue Syndrome

Dr. Rosenbaum's talk included numerous original CFS research articles. His strategy is:

- ❖ Shift from Th-2 to Th-1 predominance
- ❖ Enhance NK cell activity
- ❖ Reduce pro-inflammatory cytokines
- ❖ Reduce herpes reactivation.

Dr. Rosenbaum's approach is multi-faceted: vitamins A, B's, Zinc, antioxidants; raise Glutathione with NAC; Whey extracts; and, alpha Lipoic acid.

Other supportive therapies include:

- ❖ Thymic Protein A—a potent stimulant of Th-1 cells, lowers RNA ase -L and 2, 5 A synthetase levels, improves sleep, anxiety and short-term memory
- ❖ Chlorella—binds heavy metals, increases NK cell function.
- ❖ Therapeutic mushrooms—improves Th1/Th2 balance.
- ❖ Arabinogalactans—increase NK activity, lowers TNF-alpha.
- ❖ Probiotics—influence TH cytokines.
- ❖ Colostrum—contain transfer factors.
- ❖ Echinacea and Astragalus—immune-stimulating herbs.
- ❖ DHEA—reduces pro-inflammatory cytokines.
- ❖ Omega-3 oils—reduces pro-inflammatory cytokines.

Unfortunately, this article cannot provide the detail in the lectures, however, the syllabus or individual audiotapes can be purchased from:

AMCT
2719 N. Parkside Ave.
Chicago, IL 60639
Info @ AdMedCon.com
800. NOW. TAPE

Dr. Sharp serves on the support group's Board of Directors. His wife and son have CFIDS and are patients of national CFIDS specialist Dr. Paul Cheney. Dr. Sharp practices in Fort Worth and can be reached at 817.732.2878.

NEUROTOXIN DISCOVERED IN CHRONIC FATIGUE SYNDROME

In November 2002, Dr. Yoshitsugi Hokama's research discovered ciguatera toxin, a potent neurotoxin, in the blood of CFS patients. He states, "Chronic ciguatera poisoning has already been suggested as a scientific model for Chronic Fatigue Syndrome." Ciguaterins are potent, heat-stable, non-protein, lipophilic sodium channel activator toxins and are recognized as some of the most potent biological toxins known. They produce dramatic neurological manifestations, such as peripheral sensory or motor symptoms (including paresthesias, pain, burning, tingling, numbness), central symptoms such as headache, autonomic dysfunction and also affect multiple body systems (gastrointestinal, immune, hepatic, cardiovascular) and the muscles. Many CFS patients in the study had higher toxin levels than patients with cancer, hepatitis or acute ciguatera poisoning.

The research is sponsored by the National CFIDS Foundation. Dr. Hokama is a Professor in the Department of Pathology at the John A. Burns School of Medicine at the University of Hawaii at Manoa. He is a world expert in the area of fish toxins. Additionally, he developed the Membrane Immunobead Assay test for patient sera, using specific monoclonal antibody for ciguatera toxin (Mab-CTX).

The ciguatera toxin is found in large reef fish, most commonly barracuda, grouper, red snapper, eel, amberjack, sea bass, and Spanish mackerel. These fish live in coral reef waters, commonly called the tropics, including the Caribbean, Hawaii, and coastal Central America. The toxins tend to concentrate in predator fish, such as the barracuda and other carnivorous reef fish, because they eat other fish that consume toxin-producing algae (dinoflagellates) living in coral reef waters. Harmless to fish, but poisonous to humans, the toxin is odorless, tasteless, and not destroyed by cooking. People are poisoned by the toxin after eating tropical or subtropical contaminated fish.

This begs the question, "If I don't eat much fish, why do I care?" The NCF is emphasizing that this is a ciguatera-like toxin. It may not be the same exact substance, especially since people with CFS seem to have so much more of it than anyone who gets this poisoning by eating fish that have it. The speculation is that it is so molecularly similar that the testing cannot yet distinguish the difference. Part of Dr. Richie C. Shoemaker's theory (see the October 2001 issue of the DFW Lighthouse;

also check out www.chronicneurotoxins.com or search on immunesupport.com for Dr. Shoemaker) is that something inside us (a virus, bacteria or some other pathogen) is producing a neurotoxin and it may just be incredibly similar to the fish toxin.

Time and research will tell. In the meantime, some other commonly asked questions (courtesy of The National CFIDS Foundation) include:

1. *Is this fish toxin?*

Ciguatera is a fish toxin but until all research is complete, we do not know if this is the exact same entity as ciguatera toxin. We do know that all tests for ciguatera toxin come up positive in those with CFS that we've heard from thus far and are far higher than those seen in acute ciguatera poisoning.

2. *Is testing available?*

Yes. Testing has been ongoing as announced and the protocol may be read at www.ncf-net.org.

3. *How much is testing?*

\$100.00 and patients will receive an invoice while the prescribing physician will receive the results.

4. *What treatment is recommended?*

There is currently no known, proven treatment for this and Cholestyramine will not help (Cholestyramine is a cholesterol-lowering agent that is also used to remove bile acids from the body by attaching to certain substances in the intestine and then passing, unabsorbed, out of the body.) It is hoped a proven treatment will be available sometime this year but more proven science is necessary first.

For further information:

- ❖ www.ncf-net.org (National CFIDS Foundation, Inc.)
- ❖ www.ncf-net.org/library/Okinawa.html for information on the presentation given by Dr. Hokama
- ❖ www.ncf-net.org/library/Hokama.html for Journal of Toxicology: Toxins Review (2003), "Chronic Phase Lipids" by Y. Hokama, et al.
- ❖ www.ncf-net.org/library/NeurotoxinJournalArticle.html Neurology of Ciguatera article by Dr. John Pearn
- ❖ www.immunesupport.com
Lab info and physician concerns:
808-956-5464 (voicemail)
808-956-8682 or 808-956-8282 (laboratory, no voicemail)

Information from www.immunesupport.com

UNUMPROVIDENT UNDER FIRE

UnumProvident, America's largest long-term disability (LTD) insurer, is under fire from multiple targets. Three recent developments people with CFIDS may find of interest follow.

DATeline NBC AIRS STORY

On October 13, 2002, DatelineNBC aired a program investigating whether UnumProvident, in reaction to 1993 financial reports showing a company loss of millions, launched an aggressive company-wide effort to cut costs and, as a direct result, is unfairly cutting off benefits to policyholders. To view a transcript of this program, go to archives at www.cocure.org. The show "60 Minutes" aired a similar story about UnumProvident on November 17, 2002.

FORMER EMPLOYEE FILES SUIT

Dr. Patrick Fergal McSharry, a former UnumProvident medical director, filed suit against the company "alleging that medical personnel were encouraged to deny disability claims."

Magistrate Bill Carter is quoted as saying in a court memorandum, "Apparently, there are a number of individuals across the country who have been denied benefits under a disability insurance policy purchased from UnumProvident or one of its affiliates and/or administered by UnumProvident who now have lawsuits pending against UnumProvident and/or its affiliates arising from the denial of disability benefits."

The suit says, in part, "Although defendant employed various medical doctors for the ostensible purpose of providing needed medical guidance in reaching benefit decisions, the medical personnel were not truly utilized for that purpose.

"It was defendant's primary purpose and policy to deny disability claims. The medical advisors were only to be used to provide language and conclusions supporting denial of claims."

For a complete transcript of this article, please see: www.chattanooga.com/articles/article_26192.asp

UNUMPROVIDENT CLASS ACTION SUIT

Jon Holder, Esq., a Maine attorney, has recently filed a class action lawsuit on behalf of persons who feel that UnumProvident has

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unfairly denied or terminated their long-term disability benefits. He is seeking witnesses who are willing to go public with their complaints against UnumProvident's claims review process. For more information, contact Jon Holder at 207.774.2899, fax 207.774.9562; email at jholder@maine.rr.com or mcaufield@maine.rr.com.

Note: One of our group members, Pat Owen (patohoo@yahoo.com), is working with an attorney who is preparing a Texas class action suit against UNUMProvident and is looking for anyone living in the Galveston/Houston areas who believes UNUMProvident Insurance Company has wrongfully terminated his or her long-term disability benefits, and would be interested in joining or discussing joining a class action suit against UNUMProvident. Pat has CFS/FM, but does not believe the individual(s) she is seeking in Galveston/Houston must have the same disability.

www.co-cure.org

VISION PROBLEMS IN CFS

Many questions have surfaced about vision problems associated with CFIDS. The Padula Institute of Vision (PIV), located in Connecticut (www.padulainstitute.com), provides many services including Behavioral Vision care, Low Vision Rehabilitation, Glare Sensitivity, Neuro-Optometric Rehabilitation, as well as assisting those with neurological problems such as those associated with CFIDS.

Behavioral Vision consists of re-learning visual processing such as the ability to concentrate and become oriented with what the eye sees. With certain accidents or illnesses, we sometimes must re-learn what was initially given to us at birth.

Neuro-Optometric Rehabilitation helps those with problems resulting from a trauma, such as a head injury, eye injury, or associated illness.

Low Vision Rehabilitation assists patients with balance and posture issues while using tools to aid those with blind spots, vision impairment or cataracts.

Glare Sensitivity patients have a sensitivity to light, either sunlight, specific indoor lighting, etc. Although Glare Sensitivity can be serious, it may also be treatable with using corrective eyeglasses or contact lenses.

SMALLPOX VACCINE: HAZARDOUS OR HELPFUL?

Well, for certain groups of people, the jury is still out. Decide for yourself.

Smallpox is a serious, highly contagious, and sometimes fatal infectious disease. According to the CDC, it kills up to 30% of the people who are infected with it. A virus called variola, which spreads from person to person through close contact, causes it.

There is no specific treatment for smallpox disease, and the only prevention is vaccination. The smallpox vaccine does not contain smallpox virus and cannot spread or cause smallpox. The smallpox vaccination provides full immunity for 3 to 5 years and decreasing immunity thereafter.

However, the vaccine is made from a "pox"-type virus related to, but less harmful than, the smallpox virus. The smallpox vaccine contains the "live" vaccinia virus (it is not a dead virus like many of the other vaccines). Because the virus is live, the vaccination site must be cared for properly or the virus can spread to other body parts or to other people.

In certain individuals, smallpox vaccination can result in adverse reactions. Most reactions are totally benign, but may be alarming in appearance. Some are serious, but treatable. A few rarely-occurring reactions are serious, life threatening, and can be fatal.

Monitoring by the CDC of recent vaccinations given have suggested that the vaccine may cause heart inflammation, inflammation of the membrane covering the heart, and/or a combination of these problems. Heart pain (angina) and heart attack have also occurred following vaccination; however, it is not clear whether the vaccine caused these problems.

Experts continue their investigations in this issue. In the meantime, the recommendation (www.bt.cdc.gov/agent/smallpox/vaccination/heartproblems.asp) is that if you have had a doctor diagnose you as having a heart condition (with or without symptoms), you should NOT get the vaccine at this time.

Additionally, the recommendation is that you should NOT get the vaccine if you have three or more of the following risk factors:

- ❖ High blood pressure
- ❖ High blood cholesterol
- ❖ A doctor has told you that you have diabetes or high blood sugar.

- ❖ You have a first-degree relative (mother, father, brother, sister, etc.) who had a heart condition before the age of 50.
- ❖ You smoke cigarettes now.

The CDC is in the process of gathering more information and investigating these problems so these exclusions certainly may change. Simply check with the CDC or your health care provider for the most current information.

The following groups of people are at greater risk of developing a serious adverse reaction resulting from unchecked replication of the vaccine virus (progressive vaccinia):

- ❖ Expectant mothers
- ❖ People with certain skin conditions such as eczema or atopic dermatitis
- ❖ People being treated for cancer
- ❖ People who have had an organ transplant
- ❖ People who have solid organ or stem cell transplant
- ❖ People with conditions that weaken the immune systems such as HIV/AIDS
- ❖ People who have malignancy, leukemia, lymphoma, agammaglobulinemia, or autoimmune disease
- ❖ People with an evolving central nervous system disorder
- ❖ People who are undergoing treatment with radiation, antimetabolites, alkylating agents, corticosteroids, chemotherapy agents

It is noted on the CDC website, however, that anyone who has been directly exposed to the smallpox virus SHOULD get the vaccine, regardless of their health status.

The full report is available at The International Society for Infectious Diseases website:

www.promedmail.org/pls/askus/f?p=2400:1001:449057::NO::F2400_P1001_BACK_PAGE,F2400_P1001_PUB_MAIL_ID:1010,19803

In addition, the CDC (phone: 888.246.2675) has a detailed web page with a multitude of information at www.bt.cdc.gov/agent/smallpox/index.asp

www.co-cure.org

Note: NONE of this information should be considered advice. For advice on your health, consult with your healthcare provider.

MILNACIPRAN: FIRST DRUG IN NEW CLASS OF AGENTS (NSRIs) SHOWS PROMISE AND HOPE

Cypress Bioscience, Inc., a commercial company in San Diego, CA, has proven to be a leader in developing products for the diagnosis and treatment of Fibromyalgia (FMS), and other related chronic pain and central nervous system disorders. In October 2002, the National Fibromyalgia Research Association held a meeting, "Neurology and New Treatment Modalities in Fibromyalgia." They invited Cypress' CEO, Jay Kranzler, MD, Ph.D., to present their research on a newly developed drug called Milnacipran. A leader in clinical research of fibromyalgia, Cypress was the only industry representative invited to share its research amongst other presenters including leading academicians in neurology, pain, and rheumatology.

Cypress' presentation included a description of their new drug, Milnacipran, as a potential treatment for FMS, and the novel pain assessment tools used in their double-blind placebo controlled study with 200 patients. One of the tools, an Applied Pain Threshold Tester (APT2) allowed participants to more accurately record factors such as pain, fatigue, sleep quality and quality of life information. Milnacipran, a chemically novel drug, is the first of a new class of agents known as Norepinephrine Serotonin Reuptake Inhibitors

(NSRIs). NSRIs have a preference for norepinephrine over serotonin in the treatment of chronic pain. While NSRIs share the same pharmacological profile with the Tricyclic Antidepressants (TCAs) in reducing chronic pain, they appear to lack the side effects common in TCAs. Historically, TCAs have consistently demonstrated superior efficacy in the treatment of pain reduction in chronic pain disorders which have similar symptomology, such as Fibromyalgia, IBS and tension headaches, compared to other drug classes (i.e.: SSRIs, NSAIDs, and non-opiate pain medications). Many patients, however, are unable to tolerate TCAs due to the common side effects.

For this reason, Cypress has made it their goal to be committed as an innovator in discovering new agents, such as Milnacipran, which has a similar effect of pain control through its norepinephrine reuptake action but lacks the undesirable side effects common in TCAs. In early 2003, Cypress expects to announce their Phase II trial test results on the drug efficacy and safety of Milnacipran.

For more information, go to www.cypressbio.com, Thanks to www.FMSresource.com.

UNIVERSITY OF MIAMI PROCIT STUDY

The University of Miami Procrit Study is a clinical trial funded by the National Institutes of Health (NIH), National Heart Lung and Blood Institute. This five-year study is designed to determine whether persons with CFS, who have diminished red blood cell volume, will experience clinical improvement through treatment with Procrit.

A federally-approved medicine, Procrit stimulates the body to use its own mechanisms to increase red blood cell production. The treatment intervention lasts about 4 months. Because the red blood cell transports the needed oxygen and blood sugar to the cells, the study hypothesis is that increasing red blood cell volume will act to decrease fatigue and other CFS symptomology and improve circulatory control. The role of the immune and circulatory systems in the treatment outcomes is also being assessed. The study is a placebo-controlled design but if those with low

red blood cell volume are initially randomized to placebo treatment they will be offered an opportunity to receive the Procrit treatment in a follow-up study phase.

A panel of scientists at the NIH reviewed evidence such as previous pilot studies which indicated that there was compelling evidence to support potentially using Procrit to treat CFS patients with diminished red blood cell volume. They resoundingly agreed that such a study should be conducted. Hence, the University of Miami received funding to do this study in the fall of 2000.

The web page and brochure describing the study are at: www.bmrc.miami.edu/research/niaid/procrit.asp. For questions regarding the study, contact AlexGonzalez@miami.edu.

POTENTIAL IBS RELIEF

Recent investigations have shown that bacterial overgrowth of the small intestine is associated with a number of functional somatic disorders including irritable bowel syndrome (IBS), fibromyalgia, and chronic fatigue syndrome. A case study by Doctors Logan and Beaulne at the CFS-FM Integrative Care Centre in Toronto, Ontario, published in the October 2002 issue of the *Alternative Medicine Review*, suggests that enteric-coated peppermint oil (ECPO) may be beneficial in treating IBS. In this case, a patient with small intestinal bacterial overgrowth (SIBO) reported marked relief from IBS-like symptoms after treatment with ECPO. Hydrogen production was also significantly reduced after treatment.

Although a number of controlled studies have shown ECPO of benefit in IBS treatment, showing strong evidence of anti-microbial activity, ECPO has not been specifically investigated for its effect on SIBO. Continued research is necessary to decrease the subjectivity of IBS symptoms and to better understand the effects of ECPO on a larger population.

While further investigation is necessary, these results suggest one of the mechanisms by which ECPO improves IBS symptoms is anti-microbial activity in the small intestine.

For further information, visit www.co-cure.org. Logan, A.C. & Beaulne, T.M. (2002). The treatment of small intestinal bacterial overgrowth with enteric-coated peppermint oil: A case report.

BOOK REVIEW: "PARTING THE FOG: THE PERSONAL SIDE OF FM/CFS"

Through prose and poetry, the author, Sue Jones, "gets to the heart of the FMS/CFS experience" in this candid account of dealing with the reality of being an FMS/CFS sufferer. The book includes chapters on each of the major symptoms; one devoted to "other" symptoms of FMS/CFS; a letter to supportive people; and, a "Don't Ask/Do Ask" list for "Normals." Humor mixes with hardship and the pages are sprinkled with hope. The book could be the answer for those of us longing for understanding rather than yearning for a miraculous cure.

This helpful book is available through Amazon.com and www.partingthefog.com.

GYNECOLOGICAL CONCERNS IN CFS

By Rosemary Underhill

Women suffering from CFS commonly have a bewildering array of symptoms that can affect every body system, including the reproductive system. Diagnostic confusion sometimes occurs because some symptoms are common to both CFS and gynecological conditions such as premenstrual syndrome or menopause. These common gynecological conditions can also cause an exacerbation of CFS symptoms. The female reproductive hormone system might also play a part in the causation and persistence of CFS, since the illness occurs twice as often in women as men.

Although scientific studies are limited, a number of gynecological conditions have been found to occur more frequently in women with CFS. These conditions are usually associated with abnormal reproductive hormone levels, immune dysfunction and/or pain. Some of these conditions may even pre-date the onset of the CFS. Endocrine and/or immunological changes may possibly be present in some CFS patients before the full-blown syndrome becomes manifest.

Find the complete article at: www.cfids.org/archives/2002rr/2002-rr3-article03.asp
Rosemary Underhill, MB, BS, MRCOG, United Kingdom is a physician who specializes in obstetrics and gynecology. Dr. Underhill served as a medical consultant for the New Jersey consensus manual for the primary care of CFS.
www.cfids.org

CFS/FMS IN THE NEWS

The Chicago Tribune, November 17 issue featured an article, "Hope for the Exhausted," that reports on a DePaul University study exploring therapies to combat the drain of CFIDS. "We're evaluating new therapies, and we're very optimistic about the outcome," Leonard Jason, a clinical psychologist and principal investigator of the study.

BioPeople, a magazine that covers the business of biotechnology, featured an article in its Autumn 2002 issue highlighting the lack of treatment available to CFIDS and FM sufferers and how biotech companies are gearing up to meet this unmet need. BioPeople's readership is comprised 7,700+ decision makers.

PREGABALIN: PROMISING NEW DRUG BEING STUDIED FOR FMS

Pregabalin, a follow-up compound to its GABA agonist gabapentin, is being developed by Pfizer and has been shown to provide improvement of pain in patients with fibromyalgia according to data presented on October 26, 2002 at the annual meeting of the American College of Rheumatology. It also was shown to improve sleep and fatigue levels.

The study involved 529 patients diagnosed with FMS, randomized to receive placebo or pregabalin for eight weeks. Patients characterized and recorded their pain on a daily basis in detailed diaries. Pregabalin-treated patients (450 mg/day) showed statistically significant improvements in pain compared to those who received placebo. Further, 29% of pregabalin-treated patients reported at least a 50% reduction in pain, compared with a reduction of 13% for patients who received placebo, a difference that was statistically significant. In addition, pregabalin significantly improved sleep quality and fatigue.

"To demonstrate improvements in the core symptoms of FMS—pain, sleep, and fatigue—represents an important advance..." said Dr. Leslie Crofford, lead investigator and associate professor of internal medicine, Division of Rheumatology, at the University of Michigan in Ann Arbor. "FMS is highly debilitating for patients and difficult to treat; we are in need of new treatment options that are both effective

and well-tolerated," Dr. Crofford said. "These data are highly encouraging because pregabalin was shown to provide significant relief from the most troublesome symptoms for patients." The most common dose-related side effects reported by patients were dizziness and drowsiness. Most adverse events were mild to moderate in intensity, and many resolved during the study. Seventy-eight percent of all patients completed the study.

Developed by Pfizer.com, Pregabalin has been studied in an extensive clinical program involving over 8,000 patients worldwide. The company has completed pivotal studies to support the filing of a New Drug Application for pregabalin for the treatment of several central nervous system disorders including neuropathic pain, generalized anxiety disorder and as an add-on therapy for epilepsy. It is not known at this time when the drug may be available for prescription. Pfizer Neuroscience is committed to pioneering innovative therapies for neurologic and psychiatric disorders and has helped bring leading medicines to market for treatment of these disorders.

Thanks to www.immunesupport.com for this information. The full text of their article can be read at www.immunesupport.com/library/bulletinarticle.cfm?ID=4041.

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. The CFS/FM Support Group of DFW is 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 medical advice, consult your healthcare provider.

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WHAT WORKS FOR MANAGING CFIDS AND FIBROMYALGIA: MINIMIZING RELAPSES

By Bruce Campbell

The CFIDS/FM Self-Help organization, (www.cfidsselfhelp.org), is a non-profit group that offers resources and low-cost self-help courses over the Internet and in person since 1998 for people with CFIDS, fibromyalgia and related illnesses. We focus on empowering patients through teaching scientifically-proven coping strategies in a structured, supportive setting.

Relapses, sometimes called setbacks or flares, are an inevitable and often demoralizing part of chronic illness. One strategy for preventing relapses is to have a set of your own personal guidelines for managing chronic illness, a few rules that focus your efforts to live successfully with chronic illness. We will look first at techniques used by students to reduce the frequency and severity of setbacks, then strategies for limiting them.

PREVENTING RELAPSES

MAKING MENTAL ADJUSTMENTS

Many of the coping techniques in this section involve new habits and behaviors, but their foundation lies in having new expectations for oneself based on acceptance of the limits imposed by illness.

PACING

Pacing is a favorite strategy for bringing stability to life and preventing setbacks. Pacing

involves a variety of strategies, such as reducing activity, shifting among different activities, having short activity periods and living according to a schedule.

REST

Rest can be used regularly to prevent relapses. Extra rest can help avoid setbacks when there are special events or a secondary illness.

CONTROL STRESS

CFIDS and FM are very stress-sensitive, so minimizing stress can prevent relapses.

HONOR THE BODY'S SIGNALS

There is a strong temptation to respond to the onset of symptoms by "pushing through." Listening to the body's signals at such times can prevent symptoms.

TAKE CARE OF SECONDARY ILLNESSES

Having other health problems besides CFIDS and fibromyalgia can make symptoms worse. Treating other conditions and acknowledging that they intensify symptoms can be helpful.

BE ASSERTIVE

Standing up for oneself can help you meet your needs, reduce stress and thereby prevent relapses.

SOLITUDE

Time alone can reduce stress and allow for recharging of batteries.

continued on page 9

SUPPORT GROUP INFO

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Operational Fund: \$3960.67

RESOURCES

The following resources are available. View the resources online at www.virtualhometown.com/dfwcfids/resources.html. Make checks payable to the CFS/FM Support Group of DFW. Mail to Carol Sieverling, 513 Janann St, Euless, TX 76039. Please note the resource being ordered.

Items shipped outside the US require an additional \$5, and payment must be in US cash or a check drawn on an American bank (no money orders or postal orders from other countries—they incur significant fees).

- ❖ Paul Cheney, MD, Ph.D.: "New Insights into the Pathophysiology and Treatment of CFS." (video, October 2001, \$15)
- ❖ A 36-page packet including information transcribed from visits with Dr. Cheney is also available for \$4. (includes all "Cheney" newsletter articles from the last two years.)
- ❖ Les Simpson, Ph.D.: "Abnormal Red Blood Cell Morphology in CFS/FM/GWS/MS." (video, September '01, \$15)
- ❖ A CD containing Dr. Simpson's PowerPoint presentation and lecture notes from September 2001 is available for \$3.
- ❖ Myra Preston, Ph.D.: "Cognitive Dysfunction in CFS & its Treatment." (video, April '00, \$15)

Additionally, cassette tape copies of the November 19th meeting on Oral Health & Chronic Illness presented by Alan Sprinkle, DDS (Arlington) are now available for \$3 each. Send checks made out to the CFS/FM Support Group to Carol Sieverling.

Editorial Note: To answer several member inquiries: national CFS specialist Paul Cheney advocates an extended protocol using chlorella to remove mercury in the body before removing amalgams, and also believes that providing a protected air supply during amalgam removal is of the highest priority. This involves a dam across the throat and breathing air only through the nose that has no contact with air in the room.

DRUG SOURCES

Two more drug sources to add to the list appearing in the Oct. '02 issue:

- ❖ www.rxbenefits.com
- ❖ Rx Power 877-797-6937

Both are discount cards, about 20% savings, minimal annual fee, free for seniors.

MAKING TIME FOR PLEASURE

Chronic illness often means pain and frustration. Having pleasurable activities helps to reduce frustration and thereby makes it easier to live within limits.

IDENTIFYING RELAPSE CAUSES

Last, relapses can be prevented by identifying and avoiding their causes.

LIMITING SEVERITY OF SETBACKS

TAKE EXTRA REST

The most common strategy for overcoming setbacks is to take extra rest, continuing it until the flare subsides.

ACT IMMEDIATELY

Reduce the impact of relapses by taking action as soon as symptoms begin.

POSTPONE, DELEGATE OR ELIMINATE TASKS

Reducing activity by postponing tasks, asking for help or even letting go of something as unnecessary can help speed the end of a flare.

SEEK CONSOLATION AND SUPPORT

Students report being helped by saying consoling words to themselves and by making contact with other people.

PREPARE

Having things handy and in place helps reduce the crash anxiety and makes it easier to weather.

Full article at:

www.cfidselfhelp.org/artcl_what_works_8_relapses.htm

Our program was created by Bruce Campbell, Ph.D., a recovered CFIDS patient who before becoming ill was a consultant to self-help programs for chronic illness at Stanford University.

CUTTING DRUG COSTS

Is your medication too expensive for your budget? If so, information in this article, "Top 17 Ways to Cut Your Prescription Drug Cost," might help. The Cost Containment Research Institute in Washington, DC has just published some information on how and where to get low-cost prescription drugs.

Cost-cutting examples given include: qualifying for a free drug program; using a generic when possible; getting a free pharmacy card; getting a 90-day instead of a 30-day supply; and, using a pill splitter.

To view this valuable information, go to: www.fmare.org/newsletter/cutyourdrugcost.htm.



UPCOMING MEETINGS

APRIL 19 MUSCLE WORK IN CFS/FM
2:30 – 4:30 P.M.
STEPHEN S. RODRIGUES, M.D.

Dr. Stephen Rodrigues has been in private practice for two years and has had additional training in acupuncture, intramuscular stimulation and trigger point therapy.

MAY 17 NATUROPATHIC MEDICINE & CFS
SAT., 1:30 – 4:30 P.M.
BRAZOS MINSHEW, M.SC, N.D., L.A.C.

An acupuncturist, naturopath, and psychophysicologist, Brazos Minshew combines his extensive background in medical science, naturopathy and alternative treatments to create lifestyle and nutritional solutions to prevalent health challenges. A gifted educator, Dr. Minshew enjoys teaching the principles of healthy living to both medical professionals and anyone interested in getting and staying healthy. Brazos Minshew is a highly respected naturopathic doctor who has helped train other naturopathic doctors. Join us for an exciting PowerPoint presentation on his approach to understanding and treating CFS and FM. (www.TienaHealth.com)

Note: This meeting will be held in West 1 and 2, first rooms on your left after entering the ECC—Edwards Cancer Center.

JUNE 17 ASK THE EXPERTS
TUES., 7 – 9 P.M.
LARRY SHARP, D.O.; JENNIFER FIX, R.PH.

Come join us for a Q & A session with two of our board members: Dr. Larry Sharp and pharmacist Jennifer Fix. Both know these illnesses professionally and personally: Dr. Sharp's wife and son have CFS, and Jennifer's husband Bob is disabled with CFS. Jennifer recently attended a three-day seminar on Hormone Replacement Therapy, and will be happy to address that topic, as well as any related to the use of pharmaceuticals in CFS/FM. Dr. Sharp attended a national CFS/FM conference last fall, and has just recently had the opportunity to spend some time with Dr. Cheney. He will be happy to discuss recent developments in CFS/FM research and treatment.

MEETING INFORMATION

Unless otherwise stated, we meet on the first (top) floor of the Edwards Cancer Center in the East Conference Room of Harris Methodist HEB Hospital in Bedford.

To get to the hospital from Fort Worth, take the Central Drive exit off 183 and stay on the access road. From Dallas, take 183 (or 635 then 121 S to 183 W) to the Central Drive exit and do a U-turn under the freeway.

NOTE: Many members are extremely chemically sensitive. Please do not wear perfume, cologne, or clothes that have been exposed to smoke, dry cleaning fluids, or other chemicals to the meetings. Also, remember that many common household products contain very strong chemicals. Thank you.

SARS

Because of the interest in Severe Acute Respiratory Syndrome, Lois Randall, of the website, InfoMIN, (www2.rpa.net/~lrandall/sars.html), has collected and put up links to SARS information. She's collected this information from such sources as the CDC and WHO along with some informative articles. Topics include

symptoms, FAQ's, WHO daily updates, fact sheet, etc.

You can find additional information at pediatrics.about.com/cs/inthenews/a/children_sars.htm along with a multitude of other helpful links.

PBS WANTS TO HEAR FROM YOU

What are your experiences with chronic illness? Are you stricken with a chronic condition or are you caring for someone who is? Perhaps you have a relative or friend who wrestles with the day-to-day problems and dilemmas posed by these vexing diseases. If so, we want to invite you to share your experiences with the readers of this website. What are your struggles living day-to-day with chronic illness? How has the health care system met—or NOT met—your needs? What has worked for you in your community? Send your story to us and we will post it in “Your Stories.” www.pbs.org/fredfriendly/whocares/your_stories/your_stories.html



DISCOVERED I ALWAYS HAVE CHOICES AND SOMETIMES IT’S ONLY A CHOICE OF ATTITUDE.

—Abraham Lincoln

SHOPPING DONATIONS

Way to go shoppers! This quarter you earned \$159.37 for our group by using your Kroger Share Cards. (Contact Carol if you’d like a card.) We also received \$28.01 from Tom Thumb, thanks to those of you who went to their Customer Service and linked your current Tom Thumb card to group #9807. You shop, they donate, and our group receives funds that help pay for educational material that benefit both our members and the public.

For those of you who shop online: don’t forget about shopping via iGive.com Just go to www.iGive.com, sign up for their program and select this group as your “cause.” When you’re ready to make your purchase, sign in at iGive, connect through their “mall” to the place you want to shop (places such as Amazon.com, Sears, JCPenney, Walmart, ProFlowers.com, etc.). After you make your purchase, the place you just shopped at will donate a percentage of your total purchase to the cause you choose. This is an easy way to help the group pay for education & doesn’t cost *you* any extra money so it’s a win-win situation!

MANY THANKS!

Thanks again to those “Amazing Graces” at Emmanuel Presbyterian Church. Still, they continue to willingly fold, seal, and label this newsletter. With almost 800 copies of this newsletter going out to subscribers, this is a major chore! So many of our members are not even able to leave the house; time and energy is a most precious commodity. And it is a commodity of which we, collectively, have very little.

This issue was also made possible by the diligent efforts of our many other contributors, both named and unnamed. Because of the effects of this illness on your editors, this has truly been a “group effort.”

It is just so fantastic that we have this group of willing and able people to help us get this newsletter “out the door.” We are very grateful for all your hard work on our behalf and we cherish your giving spirits. Words are cheap but you must know, your support is greatly appreciated. Without you all, this publication would simply not be possible!

RETURN SERVICE REQUESTED

c/o Carol Steverling
513 Janann Street
Euless, Texas 76039

The Newsletter of the Chronic Fatigue Syndrome & Fibromyalgia Support Group of Dallas-Fort Worth
www.virtuallhomeown.com/dfyfids



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