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

Volume 6, No. 2, April 2004

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Treating Chronic Fatigue Syndrome & Fibromyalgia: An Interview with Kent Holtorf, M.D.

The following is an interview by ImmuneSupport.com with Dr. Kent Holtorf who is the Medical Director of the Fibromyalgia and Fatigue Center. Their newest clinic recently opened in Dallas (fibroandfatigue.com;972.980.2300). Dr. Holtorf is also the new guide for the CFS and FM section at About.com (chronicfatigue.about.com). Dr. Holtorf will be coming from California to speak at our April 20 support group meeting.

ImmuneSupport

In your article on the effective treatment of chronic fatigue syndrome and fibromyalgia (in the library at *immunesupport.com*), you state that "individuals with these syndromes have measurable hypothalamic, pituitary, immune and coagulation dysfunction. These abnormalities result in a cascade of further abnormalities, in which stress plays a role." Could you discuss how you approach treating the following problems in CFS and FM patients:

Dr. Holtorf

Immune dysfunction

If a complete immune panel is done on chronic fatigue syndrome (CFS) and fibromyalgia (FM) patients, almost all have immune dysfunction, which often includes poor natural killer cell function. These cells are very important in killing viruses and bacteria. It is very difficult to eradicate chronic infections when these cells are not functioning well. Antibiotics and antivirals do not work well and are often infective if the immune system is not stimulated as well. You are never able to kill all the infectious agents unless the body is able to clean up the residual left by the antibiotic or antiviral. This is very similar to the situation with AIDS patients.

There are a number of methods to do this. What I use depends on the infection present, but in general, I like Transfer Factor, Pro Boost, Maitake Mushroom, whey protein, astragalus, NK Stim, and beta-glucan combinations with natural and pharmaceutical antivirals or antibiotics. Growth Hormone, thyroid and cortisol are also very good immune enhancers. Yes, I said cortisol—low doses of cortisol for people who have adrenal insufficiency act as an

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Neurontin for Pain Relief: Dr. Charles Shepherd

by Charles Shepherd, M.D.; Medical Advisor for the UK ME Association; Co-Cure.org

Patients with ME/CFS (ME—myalgic encephalitis) commonly experience varying degrees of pain. The pain can affect the muscles, joints, and/or be neuropathic in quality (i.e. it has a burning, stabbing, or piercing quality and may be associated with areas of numbness or tingling/paraesthesiae). Patients find it difficult to satisfactorily control persistent pain with over-the-counter analgesics such as aspirin, paracetamol, or NSAIDs (e.g. ibuprofen).

When the pain becomes more severe, prescription-only analgesics are often only partially effective—although a low dose of a sedating tricyclic antidepressant drug such as amitriptyline (start with 10mg or 25mg at night) is worth a try. However, this approach can cause daytime drowsiness and other unpleasant side effects in some patients.

An additional management approach for moderate to severe pain in ME/CFS, especially that of a neuropathic quality, is to consider the use of the anticonvulsant drug gabapentin (trade name: Neurontin). Unlike amitriptyline, gabapentin now has a UK product license for the symptomatic treatment of all forms of neuropathic pain. It has been used as an anticonvulsant since 1994, has a low incidence

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Dr. Holtorf... continued from page 1

immune enhancer. Large doses are immune suppressors. Your body normally increases cortisol in times of infection. Oxidative therapies, can be very powerful; I customize the specific treatment for the patient.

Coagulation Problems

This is diagnosed with a specialized laboratory test that includes soluble fibrin monomer, fragment 1 +2, and thrombin/antithrombin complex. Defects are treated with heparin to stop the excessive production of soluble fibrin monomers and vascular digestive enzymes to help clean up the fibrin already laid down.

Low Thyroid

CFS and FM patients will often have a number of thyroid abnormalities including a low free T3, a high reverse T3, and a low TSH. These abnormal ratios are not usually discovered using the standard laboratory interpretation of hypothyroidism. When CFS and FM patients are treated with thyroid, they are almost always under-dosed because their pituitary dysfunction results in their TSH becoming quickly suppressed, which normally indicates too much thyroid. Because these patients have pituitary dysfunction, one must forget about the TSH and not treat based on this parameter. These patients can also have a thyroid resistance syndrome. This has not been a well-accepted concept by general mainstream medicine and many refuse to believe it exists because the exact mechanism has not been elucidated, but this a real phenomenon.

In fact, in this week's *International Journal of Medical Research*, a major peer-reviewed medical journal, a patient was described that required 10 times the normal dose of thyroid intravenously before her symptoms would resolve. This resistance usually improves as the patient gets better and thus, they need less thyroid.

Adrenal Insufficiency

To diagnose, I typically use symptoms and a combination of blood sugar, free cortisol, and HgA1C%. One must have a high clinical suspicion, not just think in terms of normal and abnormal. These normal levels are determined for healthy individuals, not the chronically ill, so the cortisol levels should be higher with this illness. Saliva and 24-hour urine tests can be done, but can also result in false positive and false negative results. Some doctors who treat these disorders have reported that cortisol is not helpful; this is totally opposite to my experience. I have found adrenal hormone to be very helpful.

Growth Hormone Deficiency

Many CFS and FM patients are low in growth hormone. This hormone is produced in the pituitary so it is expected with these illnesses. Treatment can sometimes make a tremendous impact but because of the cost, it is not used on most patients. IGF-1 is the best indication for growth hormone levels.

IS: Once you've determined which problems a CFS or FM patient has, do you prescribe both traditional and alternative treatments, or do you focus on a single method at a time?

Dr. H: One must use both traditional and so-called "alternative treatments." In order to treat these diseases adequately, I use many treatments simultaneously. If one treatment were used at a time, it would take many years before the patient feels better. I use many treatments at the same time, but I remove a treatment every two weeks when the patient is feeling good for a period of time.

IS: Tell us a little bit about the Hormone and Longevity Medical Center where you practice.

Dr. H: I started the Hormone and Longevity Center to concentrate on the treatment of hormone deficiencies with hormonal optimization. Eighty percent of our practice is for patients complaining of fatigue, with CFS and FM probably being the biggest part of the practice. This was also the case when I ran the Thyroid Optimization Center.

IS: What are the biggest challenges you face with treating CFS and FM patients?

Dr. H: Although we have good success with CFS and FM, these are challenging cases that require doctors to spend significant time with the patient. It cannot be accomplished with seven-minute office visits.

IS: What are the biggest successes you've experienced with treating CFS and FM?

Dr. H: Many of these patients are very sick and have given up. It is so gratifying to get these patients back to having a life. They are just so grateful. Many have been unable to work and/or have been on disability and now, following treatment, are happy, functional, and productive.

IS: Are you working on any promising new treatments at this time—either through research or a trial-and-error process with your patients?

Dr. H: I am working on new treatments every day in practice. I have recently found that oxidative therapy can be immensely effective. This involves the administration of intravenous hydrogen peroxide. This is a very safe treatment backed by decades of studies. It is popular in Europe for a number of disease states and conditions and has been advocated by the International Oxidative Medicine Association in this country. Hydrogen peroxide is naturally produced in our bodies and has wide-ranging effects: it activates the immune system; kills viruses, bacteria, and parasites; increases oxygen delivery to the cells; and, activates the mitochondria (energy factory of the cell). This appears to be a perfect treatment for CFS and FM patients. I am very excited about the results with this therapy, especially in conjunction with the therapies described above. I am going to launch a study involving this combination therapy.

I have been asked by companies to conduct drug trials for FDA approval. I have been declining to do so because, at this time, I do not feel they are worthwhile, although I am sure they will eventually get approval. The drugs seem to be somewhat effective but are generally unspectacular.

IS: What are the most exciting developments you've seen recently in treating CFS and FM?

Dr. H: Recent developments are taking place in a stepwise manner, but I do not believe it will be through the so-called "mainstream medicine one-drug cures." I think these are very treatable conditions; advances will continue to improve treatment. I do believe, however, that incidences of CFS and FM will significantly increase in number and at some point will be considered an epidemic—they are very poorly-treated through the standard health care delivery system.

ImmuneSupport.com; 06-15-2003.

Kuibitang for CFS

Kuibitang (KBT) is clinically used to treat patients suffering from chronic fatigue syndrome (CFS) in South Korea. However, its effect has not been investigated experimentally. Recent reports have shown that CFS patients display an altered cytokine production. We examined the effect of KBT on lipopolysaccharide (LPS)-induced various cytokines production in peripheral blood mononuclear cells (PBMC) of CFS

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Kuibitang... continued from page 2

patients and healthy controls. KBT (1 mg/ml) significantly inhibited LPS-induced tumor necrosis factor-alpha, interleukin-10, and transforming growth factor-beta1 production in PBMC of CFS patients. However, LPS-induced interferon-gamma production was significantly increased by KBT (0.01 mg/ml). These results provide evidence of a novel activity of the KBT that regulate cytokines production related to CFS.

J Ethnopharmacol. 2004 Feb;90(2-3):253-9. *Effect of Kuibitang on lipopolysaccharide-induced cytokine production in peripheral blood mononuclear cells of chronic fatigue syndrome patients.* (Shin HY, An NH, Cha YJ, Shin EJ, Shin TY, Baek SH, Kim CH, Lyu YS, Lee EJ, Kim HM). Department of Pharmacology, College of Oriental Medicine, Kyung Hee University, Seoul, South Korea. PMID: 15013189.0

Duloxetine for FM?

Researchers at the March 4 American Academy of Pain Medicine 20th Annual Meeting in Orlando, FL discussed their conclusions that duloxetine, a drug being studied for depression, may be a safe and effective treatment for fibromyalgia symptoms, particularly in women, and regardless of whether or not major depressive disorder (MDD) coexists.

"We found that duloxetine has a direct effect on pain, which is not merely associated with treatment for depression," said Madelaine Wohlreich, MD, Clinical Research Physician, Eli Lilly and Company, Indianapolis, IN.

"Depression is very frequently accompanied by painful symptoms. By showing we can affect painful symptoms with or without depression, it adds credibility to the fact that this drug might in fact offer something to depressed patients in particular."

Dr. Wohlreich and her associates concluded that duloxetine is an effective and safe treatment for many of the symptoms associated with fibromyalgia—particularly for women, who are the majority of this group. Unfortunately, men did not show any improvement on any efficacy measures.

ImmuneSupport.com; 03-10-2004. Duloxetine May Be Effective for Treatment of Fibromyalgia Symptoms (Jerry Ingram).

A Double-blind Trial Comparing Duloxetine to Placebo in the Treatment of Fibromyalgia with or without Major Depressive Disorder. Poster 166. DGDispatch. Doctor's Guide © 1995-2004.

Neurontin... continued from page 1

of side effects, and is generally well-tolerated by this group of patients.

Mode Of Action

The precise way in which gabapentin reduces pain remains uncertain, but probably involves a 'dampening down' of pain perception in both the central (i.e. brain) and peripheral nervous systems. It probably also affects the chemical transmitters which help modify pain responses—one in particular being GABA (gamma-aminobutyric acid).

Clinical Trials

Several clinical trials have demonstrated significant benefits in reducing neuropathic pain in conditions such as diabetes, shingles (post-herpetic neuralgia), and trigeminal neuralgia. In these trials, gabapentin improved general mood and overall quality of life as well. Although no clinical trials involving ME/CFS patients have been conducted, gabapentin has been effective in relieving muscle cramps.

There is also a report suggesting gabapentin can also help relieve moderate to severe nausea (*Effect of gabapentin on nausea induced by chemotherapy in patients with breast cancer.* Lancet (2003); 361,1703-1704).

Side-Effects

Gabapentin appears to have a good safety record with a low incidence of side effects—even when used at quite high doses. Side effects sometimes reported (i.e. from 8%–24%) in the clinical trials included dizziness, somnolence, headache, diarrhea, confusion/disorientation, and nausea. More serious side effects appear to be unusual but do occasionally occur. Gabapentin should be used with caution in people with liver, kidney, or mental health problems as it has been reported to cause jaundice and psychosis. Gabapentin should not be used during pregnancy or when breast-feeding.

Drug Interactions

Be cautious with antacids containing aluminum or magnesium as these can slow the absorption of gabapentin. It should be taken two hours after taking such an antacid.

Personal Experience

I normally recommend starting with a very low dose (either 100mg or 300mg) and increasing very gradually over a period of a few weeks—according to patient response and problems with side effects. The UK product license for pain relief is up to a maximum dose of 1800mg but some of my colleagues are willing to go higher (up to 3600mg) than this.

The feedback I have from carefully selected ME/CFS patients who have used gabapentin (mainly for neuropathic pain) has generally been very positive. A significant number report that their sleep pattern is much better as well and some say their cognitive function has improved. However, others report that they feel less "with it" than normal, possibly due to the sedation, but this problem can diminish as time goes on. About 15% find they cannot tolerate the drug due to side effects. I also have a few reports of gabapentin relieving nausea—in line with the findings reported in the Lancet paper.

Editorial note: Neurontin, along with Klonopin, was prescribed by national CFS specialist Paul Cheney. Both address excitatory neurotoxicity. See the article on our website in the Cheney section, "Klonopin: Protecting the Brain'" (virtualhometown.com/dfwcfids/medical/klonopin.html).

No Lobby Day 2004!

For the first time in 13 years, we have decided not to schedule a lobby day for 2004. Instead, we will be focusing on helping people who are concerned about CFIDS participate in CFIDS advocacy efforts, without the financial, medical, and personal burden of traveling to Washington, DC.

Having people with CFIDS demonstrate strong support for the Association's policy initiatives has always been key to our success on Capital Hill. Historically, this has largely occurred on lobby day. However, new tools make it easier than ever for citizens to interact with officials without ever leaving home, eliminating the burden of physically traveling to Capital Hill.

With this being a major election year, there may be considerable turnover among members and staff. If leadership of the House or Senate changes parties, committee assignments will change dramatically too.

This calls for a major education campaign in 2005. In 2004, we'll be asking you to write more letters and make more phone calls—and providing you with better tools to do so. We'll also begin planning for a large-scale 2005 CFIDS Lobby Day.

K. Kimberly (Kenney) McCleary,
President & CEO, The CFIDS Association of America, Inc. (*cfids.org*). *ImmuneSupport.com.*

The Ultimate Solution to Disease

by Sherry Rogers, M.D.

Dr. Sherry Rogers is board certified by the American Board of Environmental Medicine, the American Board of Family Practice, and is a Fellow of the American College of Nutrition and a Fellow of the American College of Allergy, Asthma, and Immunology. A leading environmental medicine authority for more than 26 years, prominent author, and national speaker, Dr. Rogers has her private practice in Syracuse, New York where she sees patients from around the world. She has taught over 100 physician courses in six countries, has written more than a dozen books, scientific papers, textbook chapters and a newsletter, and is a frequent radio and tv guest.

Despite the fact that many of my patients have become excellent students of environmental medicine, some are still not completely well. What is preventing their recovery? The major demons are heavy metals (mercury leads the list), pesticides, detox deficiencies, and Candida. Studies now confirm that environmental chemicals cause 95% of cancers. We are all a cesspool of the lifetime accumulation of chemicals from our air, food, and water. U.S. EPA studies of chemicals stored in the fat of humans show that 100% of people had dioxins, PCBs, dichlorobenzene, and xylene while another analysis of the exhaled breath of humans showed carcinogenic benzene in 89% and perchloroethylene in 93%.

What is the ultimate mercury removal? The best way to rid the body of heavy metals, pesticides, and hydrocarbon residues? The Infrared Sauna. It has been known for decades that sweating is an effective way of eliminating stored chemicals, including heavy metals. In fact, sauna is one of the detoxification procedures used in environmental units in Dallas (Dr. William Rea) and North Carolina (Dr. Alan Lieberman—where the sickest of folks go to heal). However, many people, me included, cannot tolerate a sauna. We feel weak, sick, dizzy, faint, and may have an increased heart rate and headache. However, thanks to improved technology, many tolerate the infrared sauna much better. This is because it utilizes a heat energy that penetrates the tissues more effectively and allows use of an overall lower temperature.

Another of my concerns related to the use of a sauna, even for the few brief moments I could tolerate one, was the fact that my eyeballs burned so badly. I couldn't believe that the heat on my corneas was good for them, and feared this might even trigger cataracts. (There have been no studies done on this.) Regardless, I don't experience that type of eye pain when in the infrared sauna, only profuse sweating—just the effect you do want in order to release many toxins from storage areas in the body.

Our bodies eliminate stored mercury through stool, urine, or sweat—sweat being the most efficient. I used to hesitate recommending something so expensive. However, when you realize the lifelong incapacity and expense of disease, such as heart disease, fibromyalgia, chemical sensitivity, chronic fatigue syndrome, chronic pain syndromes, migraines, Alzheimer's, or any illness caused by chemical or metal toxicity, a sauna is worth the expense and is a household necessity.

A sauna used to be thought of as a luxury but may, in fact, be a primary solution to the problem. I think this is so important that I am going to show you, in future issues of my newsletter, *Total Wellness Newsletter*, how you might be able to obtain insurance reimbursement, and how to create a program with the right minerals and protocol so that you don't sweat yourself into a cardiac arrest by depleting your good minerals along with your heavy metals, pesticides, and other pollutants.

The majority of folks with insurmountable medical problems have stored chemicals (pesticides and heavy metals top the list) poisoning their recovery system. Going to an environmental unit is a luxury. My search led me to a very reputable company, High Tech Health. (You know how reluctant I am about recommending anything before I investigate it.)

Sweating is a God-given mechanism, but must be done properly and safely in order to be successful. The infrared sauna is something that you would use for a lifetime, for the world will never run out of ways to poison us. It can become a major tool in your anti-aging program. Since it is a major expense, you may want to find a way to put your sauna in a garage, basement, game room patio, lanai, or porch and share the cost with neighbors.

The pollution of the world is not going away. To unload the body enough so that it can heal itself infrared sauna is my preferred tool. And to maintain good health once you reach your goal, the sauna should become a weekly routine. Sauna, in and of itself, is not the "magic bullet," but for now, I think this is exceedingly neat that we can treat with heat.

Reprinted with permission, from: *The Ultimate Solution to Disease*, by Sherry Rogers, M.D. This article originally appeared in the May 2000 issue of Dr. Rogers' *Total Wellness Newsletter*. To subscribe, call Prestige Publishing (800.846.6687) or visit *prestigepublishing.com*. This article also appeared in NEEDS February 2003 newsletter, *Natural Health Connection*. A free subscription can be obtained by calling 800.634.1380 or visiting *needs.com*.

For more information about the infrared sauna from High Tech Health, call 800.794.5355 or visit *hightechhealth.com*.

Infrared Sauna—Hot Online Topic

For many months now, many members of the email/online list CFSFMExperimental at *yahoogroups.com* have been sharing their experiences with infrared sauna. Many report significant benefits.

The High Tech Health infrared sauna is built with the needs of the chemically sensitive in mind. The wood is poplar, which does not outgas like cedar or other materials. It's important to drink plenty of fluids, replenish electrolytes, and take additional minerals (particularly magnesium and zinc) to avoid problems. Many suggest starting out with ten-minute sessions and advancing to no more than twenty minutes.

Individual FAR infrared ceramic heaters are available for purchase, and some are placing them in small rooms (i.e. bathrooms) for a sauna-like effect. One expert cautions though, that these infrared heaters will accelerate outgassing from materials in the room. Most bathroom cabinets outgas formaldehyde for years! Please don't inadvertently expose yourself to more toxins as you attempt to detox!

It may be possible to locate these saunas in your local area at clinics or health clubs. Or perhaps members may wish to connect through our announcement list to explore purchasing one together with others in your area.

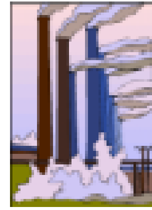
See the excerpt from a related article by Jill Neimark and Byron White on the next page.

Sauna: A Powerful Therapy for Home Healing

Excerpted from, "Healing Chronic Illness at Home: Oxygen, Ozone, Sauna, and Detoxification for Lyme Disease, Fibromyalgia, Chronic Fatigue Syndrome, and MCS," by Jill Neimark and Byron White, N.D. Jill Neimark is an author and journalist who writes frequently on health and science for national publications. She is also a lyme patient. Byron White, N.D., is a naturopath who suffers from lyme disease and employs a variety of home-based therapies to successfully manage chronic illness.

Says Jill, "A very powerful modality that can be carried out at home is sauna therapy. Human exposure to toxins has dramatically increased in the last century. Their residues can be reduced through sauna therapy. In addition, sauna increases circulation and improves lymph flow. By allowing the body to eliminate toxins through the skin, sauna therapy helps the liver, kidneys, and bowel. As you sit in the sauna, your body temperature goes up, mimicking the natural fever response—which boosts the immune system.

"Sauna therapy can be done at home. Dr. White has a top of the line Healthmate Far Infrared Sauna, while I have a very inexpensive near infrared bulb sauna designed by naturopath Larry Wilson. Others use far infrared heat lamps. Although there is much debate about the benefits of different types of saunas and the depth that various forms of infrared penetrate into the body, we feel that most forms of sauna, used carefully, are helpful. Infrared saunas are easier to tolerate because they tend to heat the body and not the air, allowing people to tolerate much longer sauna time and achieve the same results.



"The length of time spent in the sauna varies with each individual. Most chronically ill individuals should start with about 10 minutes, and see how that impacts them over the next 24-48 hours. I overdid my sauna therapy in the beginning, staying in for 45 minutes and experienced an increase in muscle pain as a result. After Dr. Wilson performed hair mineral analysis on me he advised me to reduce my sauna to 20 minutes every other day."

"It is important to fit the treatment to the person and not the person to the treatment," explains Dr. White. Each person's body goes through a natural building and detoxification cycle as it heals."

Read more at: *ImmuneSupport.com/library/bulletinarticle.cfm?ID=5187&PROD=N0134; (11-21-2003).* ©2004 Pro Health, Inc. For Far Infrared Lamps information, see: *ycyhealth.com/tdp_index.shtml*

For Infrared Bulb Sauna information: email Dr. Larry Wilson,(*Larry@drlwilson.com*) or call 928.445.7690. Dr. Wilson also sells a very useful book, *Manual of Sauna Therapy* (*drlwilson.com*). His site also has a lot of useful information about saunas, hair analysis, detoxing, etc.

New Tests for Lyme Disease

Given the great number of overlapping symptoms, many CFIDS patients and doctors are now testing for Lyme Disease. Igenex, the current leader in the field of Lyme testing, offers a great deal of information on Lyme disease at *igenex.com*. With Lyme Disease and the test being so controversial, it is prudent to be tested by more than one lab if you can afford it. New tests for Lyme have recently been developed by Immunetics and Immunosciences. It is likely that the new C6 Immunetics test will soon be included on the new panel at Immunosciences.

Immunetics

Immunetics Lab of Cambridge, MA (*immunetics.com*; 800.227.4765), has produced a new test for Lyme Disease that won Food and Drug Administration (FDA) approval. It was funded by the National Institute of Allergy and Infectious Diseases (NIAID, *niaid.nih.gov*).

"The C6 test is the result of years of collaboration in an ongoing effort to improve our ability to diagnose Lyme Disease," explains microbiologist Phillip Baker, Ph.D., NIAID's Lyme Disease Program Officer. "This new approach is an important first step in that direction."

It is the first diagnostic tool to use a synthetic product called C6. C6 is a hybrid chemical-marker based on components derived from the tick-borne bacterium that causes Lyme Disease. The C6 test is sensitive only to antibodies generated during an active infection.

The C6 approach resulted in a high rate of sensitivity (97%) to antibodies from both the early and late stages of Lyme Disease. This ELISA test also has a high rate of specificity (98%) and results in fewer false positive readings when compared with current screening methods. Significantly, no false positive readings were obtained when the kit was used to test people who had previously received LYMErix (TM), the Lyme Disease vaccine. The test also detects antibodies specific to both U.S. and European strains of Borrelia.

Immunosciences

Dr. Aristo Vojdani, head of the Immunosciences Lab (*immunosciencelab.com*, 800.950.4686), has developed and is offering six new Lyme Disease tests, in addition to the standard PCR test.

The first two tests are for IgG and IgM antibodies for Lyme, peptides 1 to 7. This test determines whether the B-lymphocytes have produced these antibodies. The next two tests look for Lyme-specific T-helper cells by testing whether the T-helper cells from a blood sample respond to two antigens from the Borrellia spirochete. The final two tests look for Lyme-induced cytokine production from immune cells, by provoking a blood sample with Lyme antigens, including both TNF-alpha and IL-10.

CFSFMExperimental list (yahoogroups.com); Co-Cure.org.

PWC Blake Edwards Wins Oscar!

On Sunday, February 29, the Academy of Motion Picture Arts and Sciences awarded a Lifetime Achievement Oscar to writer, director, and PWC (person with CFIDS) Blake Edwards. Best known for creating the Pink Panther series. other noteworthy films by him include *Victor/Victoria, S.O.B, 10, The Great Race, Breakfast at Tiffany's*, and *The Days of Wine and Roses.*

Edward's 1986 film, *That's Life!* is said to be about his struggles with CFIDS. The movie stars Jack Lemmon as a wealthy Southern California architect and Julie Andrews, (to whom Edwards has been married for thirty+ years), as his wife.

Other highlights included four Oscar nominations for *Seabiscuit*, the movie based on the book by PWC Laura Hillenbrand.
Co-Cure.org.

Exiled By Multiple Chemical Sensitivity (MCS): A Survivor's Perspective

Reverend Linda Reinhardt is a published author and the Pastor/Director of The Jeremiah Project. Her work in the field of MCS has received nationwide recognition. She also appears in ***Who's Who in Medicine, 2003****. Based on an article by Janine Ridings (aromaofchrist.com).*

The Reverend Linda Reinhardt's personal journey is truly amazing. One night in 1987, she was poisoned by aerial spraying of the pesticide malathion as she slept by an open window. She went into anaphylactic shock, was hospitalized, and almost died. Her lungs and immune system were severely damaged and she became chemically sensitive.

She eventually recovered enough to attend seminary in Austin. Upon her graduation in 1995, she and her husband moved to five acres in Canyon Lake, Texas since she could not tolerate the pollution of a city. While they were building a "safe" home, she lived in a gutted Airstream trailer formerly owned by another MCS patient. She was ordained by the Presbyterian Church to a ministry with MCS patients and established a newsletter, educational outreach, and outdoor worship services.

Unfortunately, in 1998 a neighbor placed two 500-gallon tanks of diesel fuel just 300 yards from Linda's trailer, and she eventually became very ill and collapsed. She spent the summer of 1999 camping on a neighbor's property, but with the onset of winter she returned to the trailer on her property. Her health worsened.

By February of 2000 she was vomiting every forty minutes and had lost 60 pounds. Numerous doctors said her case was hopeless and many gave her a death sentence. Her extremely poor health and quality of life led to a loss of will to live. Wanting to die, she thought that Easter would be a special day to go home to be with the Lord. Easter came and went, however, and Linda realized it wasn't her time to go! God had other plans for her.

One nutritionist was willing to treat her if she moved off the property. She and her husband now reside on five acres of a large Presbyterian camp. Linda lives outdoors without electricity or running water. During winter, ice sometimes forms inside her trailer. On hot, 100-degree Texas summer days Linda's only recourse is to rest on a cot under a tarp. A simple car ride requires months of recovery. Because she cannot tolerate the compounds and chemicals in modern technology or products, she cannot watch TV, talk on the phone, listen to the radio, or use a computer. She cannot read or write—touching paper makes her vomit. (They've tried over 20 different organic or "safe" brands.)

She is writing a book (in her head) about God's unconditional love, and hopes to someday have it published. Linda also spends time in prayer for the needs of others. She keeps going by keeping life in perspective. She believes we live in a culture of excess and that the way many Americans spend money is obscene.

Linda points out that in a world of 6 billion people, about 4.8 billion live in substandard conditions, often without running water or electricity, and many have little or no shelter. Knowing that many of those people don't even have food, clean water, or access to medical care, she is thankful her conditions are not as bad. One of Linda's keys to perseverance is having a thankful heart.

Another coping skill is her ability and willingness to be honest with God. Linda gets angry at her circumstances and tells God about it. "When will this end? How much more sensitive will I get? How much longer can I keep putting my husband through this? Since we have no money how will we ever buy property? How are we ever going to leave this place?"

Linda says there seems to be no solution to her problems, so all she can do is trust God. She realizes she must make the best of each day, asking God to give her the grace to make it through. She says God always does.

New CFS Ads!

A collaborative effort between The CFIDS Association of America and the CDC has produced new ads and displays promoting the CFS Provider Education Project. Targeting a multidisciplinary audience, the ads will be placed in several professional journals such as the *New England Journal of Medicine.* The displays will be used in numerous conferences and patient meetings.

Comments may be sent to both the CDC's Dr. William Reeves (*wcr1@cdc.gov*) and to the CFIDS Association of America *(cfids@cfids.org)*.

For more information or to view these ads, go to: *cfids.org/about/provider-ed.asp.*

MCS Resource

After counseling more the 2500 individuals suffering from chemical injury (MCS), Reverend Linda Reinhardt observed that the pain of the resulting illness is often not as severe as the woundedness of skepticism. Family and friends find it difficult to believe MCS is a real illness and do not understand the illness' effects. Just when the sufferer needs support most, he/she is often not given the respect and dignity offered those suffering more familiar illnesses.

Author, Pastor/Director of *The Jeremiah Project*, and also an MCS sufferer, Reverend Reinhardt has published a forty-page booklet about MCS entitled, *"We Can't Have It Both Ways."* This wonderful booklet takes the reader, concisely and simply, through a progression of logical articles aimed at gently yet methodically dispelling the doubts and skepticism in a non-medical context.

It provides practical suggestions for accommodation and lifestyle changes. Get one for yourself and your family! To order, send a $10 donation to the address below. Available in bulk: 3 for $25, 10 for $75.

The Jeremiah Project
222 Soft Wind #2
Canyon Lake, TX 78133

Reverend Linda Reinhardt is a published author and the Pastor/Director of *The Jeremiah Project*. Her work in the field of MCS has received nationwide recognition. She also appears in ***Who's Who in Medicine, 2003****.* Contact Linda through her husband at either 830.935.4618 or *i_am_jeremiah78209@yahoo.com.*

The newsletter is available via email or regular mail and donations to *The Jeremiah Project* are welcome. From the newsletter, *I Am Jeremiah*, summer 2003.

I am Jeremiah.

I am the canary in the mine.
My song has been silenced
But the miners do not heed.

I am the window into the future.
The view is clear
But no one wants to see.

I am Jeremiah,
Weeping not for myself
But for a world
That does not understand.

Linda C. Reinhardt '93

NIH Research Grant

Dr. Yoshitsugi Hokama tested numerous CFS patients and found high levels of a neurotoxin resembling Ciguatera in most participants (see the April 2003 *DFW Lighthouse* newsletter—*virtualhometown.com/dfwcfids/archive/cfs0203.pdf*).

On March 5, the University of Hawaii's Pacific Research Center for Marine Biomedicine received a National Institute of Environmental Health Sciences grant for $5 million. Dr. Hokama will try to determine whether chronic exposure to ciguatoxin may be associated with enigmatic health conditions, such as CFS.

Dr. Hokama announced his findings about CFS at the International Symposium on Toxins and Natural Products in Okinawa, Japan, 2002. Since then, he has also published his research in the *Journal of Toxicology* and the *Journal of Clinical Laboratory Analysis* (2003).

For more information, go to: *ncf-net.org/library/neurotoxinPR.html or Co-Cure.org (archives); March 6.*

AACFS Conference

The Seventh International AACFS Conference on Chronic Fatigue Syndrome, Fibromyalgia, and other Related Illnesses will be held October 8-10, 2004, in Madison, Wisconsin. The program is divided into three segments: research, clinical, and patients' topics.

The conference will be held in the Alliant Energy Center. Hotels providing accommodations include the Clarion Suites and the Sheraton Madison. See *aacfs.org*.

CFS, Orthostatic Hypotension, & Midodrine

This piece is from a CFSFMExperimental list post (yahoogroups.com) by Rich Van Konynenburg, Ph.D. Rich made some very insightful comments about a paper posted on Co-Cure.org ("Dysautonomia In Chronic Fatigue Syndrome: Facts, Hypotheses, Implications," Naschitz, et al; Journal of Medical Hypotheses (2004 Feb;62(2):203-6). cfids-cab.org/rc/Naschitz-1.pdf).

Rich wrote, "The main thrust of this paper is that measurements of cardiovascular reactivity might be helpful in the diagnosis of CFS. However, the paper also reports on a small study of the use of midodrine (Pro-amatine) in CFS. This drug is an alpha-1 adrenergic agonist, and as such, it acts as norepinephrine would to cause constriction of blood vessels, thus remedying orthostatic hypotension in some people.

"As regular readers may recall, I have suggested in the past that PWCs with orthostatic hypotension may have a shortage of norepinephrine in the sympathetic nerves that serve the veins of the lower body, thus allowing blood pooling there when they stand up (based on the low blood volume work the late Dr. David Streeten did with Dr. Bell).

"I have theorized that this shortage of norepinephrine results from the large, continuous demand on tyrosine, the amino acid precursor of norepinephrine, by sympathetic nerves serving the arterioles in the skin.

"Because of the low metabolic rate in CFS, which I suggest is caused by partial blockades in the Krebs cycles of the red, slow-twitch skeletal muscle cells resulting from peroxynitrite elevation (the latter theorized by Prof. Martin Pall: *molecular.biosciences.wsu.edu/Faculty/pall.html*), (secondary to glutathione depletion there), the sympathetic nervous system decreases blood flow to the skin to decrease the heat loss and conserve body heat.

"This paper supports this model. These researchers find that using midodrine helps the orthostatic hypotension problem as well as improving fatigue. I think that the use of midodrine probably improves the blood flow to the brain by constricting the veins in the lower body. Perhaps it also relieves some of the demand on tyrosine and on glutathione—which is needed to detoxify some of the products of excessive norepinephrine production. This could explain the improvement in fatigue.

"The success of FIR heater or sauna treatment also figures into this. I think it warms the tissues, raises the metabolic rate, and relieves the demand on norepinephrine, tyrosine, and glutathione, as does the use of midodrine.

"I do want to caution people that midodrine can cause elevation of blood pressure in the supine position (lying on one's back) in some people. However, it may be helpful as part of a treatment program for some PWCs. Of course, consult your doctor or medical professional about using it in your particular situation."

Disclaimer: I am an unlicensed, independent researcher with a background in the physical sciences and engineering. I have been studying chronic fatigue syndrome (CFS) as an avocation for more than seven years. I am not a clinician or a practitioner and do not accept remuneration from clinicians, patients, or vendors of the products mentioned herein.

A disclosure statement in keeping with the spirit of the California Business and Professions Code that pertains to complementary and alternative health care services can be found at the end of the post at listserv.nodak.edu/scripts/wa.exe?A2=ind0403a&L=co-cure&F=&S=&P=207

CFSAC News

The Chronic Fatigue Syndrome Advisory Committee (CFSAC), has recently launched a new website, *hhs.gov/advcomcfs*. The site provides CFSAC-related information and useful links. This important committee coordinates all CFS-related activities of all government agencies

The e-mail address given at "Contact Us" (*cfsac@osophs.dhhs.gov*) provides a valuable opportunity for input from the public. You may also sign up to receive email from the CFSAC. To join the ADVCOMCFS list, go to: *list.nih.gov/archives/advcomcfs.html*.

For more information, see *cfids.org*.

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. 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* staff assume no liability for any medical treatment or other activity undertaken by readers. For medical advice, consult your healthcare provider.

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Neuropsych Deficits

The degree of neuropsychological dysfunction across multiple domains was examined in individuals suffering from chronic fatigue syndrome (CFS).

In this descriptive study, a similar series of neuropsychological tests was administered to a group of CFS patients and healthy participants. CFS patients (n = 141) and 76 healthy control participants were tested on memory, attention (concentration), speed of information processing, motor speed, and executive functioning.

On the 18 measures administered, the results indicated that CFS patients were more likely than healthy controls to fail at least one test in each of the following domains: attention, speed of information processing, and motor speed, but not on measures of memory and executive functioning. Overall, CFS patients demonstrated a greater total number of tests failed across domains.

J Int Neuropsychol Soc. 2004 Mar;10(2):278-85. *Neuropsychological deficits in patients with chronic fatigue syndrome.* (Busichio K, Tiersky LA, Deluca J, Natelson BH). Chronic Fatigue Syndrome Center, Newark, New Jersey. PMID: 15012848, indexed for Medline, *www.nlm.nih.gov*.

FM & the Family

This study assessed both familial aggregation of fibromyalgia (FM) and tenderness and pain measures, and also, familial co-aggregation of FM and major mood disorder (major depressive disorder or bipolar disorder).

Study participants either had the FM criteria of the American College of Rheumatology or were control rheumatoid arthritis (RA) patients with no lifetime diagnosis of FM.

Information was collected for 533 relatives of 78 FM participants and 272 relatives of 40 RA participants. The researchers concluded that FM and reduced pressure pain thresholds aggregate in families. They also found that FM co-aggregates with major mood disorder in families. This study indicates that genetic factors are involved in FM etiology and in pain sensitivity. They also believe mood disorders and FM may share these inherited factors.

Arthritis Rheum. 2004 Mar;50(3):944-52. *Family study of fibromyalgia.* (Arnold LM, Hudson JI, Hess EV, Ware AE, Fritz DA, Auchenbach MB, Starck LO, Keck PE Jr.). University of Cincinnati College of Medicine, (*Lesley.Arnold@uc.edu*). PMID: 15022338. *Co-Cure.org.*

New Approach to Pain

We know that pain perception can be altered by mood, attention and cognition, or by direct stimulation of the cerebral cortex but we know little of the neural mechanisms underlying cortical pain modulation.

One of the few cortical areas consistently activated by painful stimuli is the RAIC (rostral agranular insular cortex) where, as in other parts of the cortex, the neurotransmitter gamma-aminobutyric acid (GABA) robustly inhibits neuronal activity.

Here we show that changes in GABA neurotransmission in the RAIC can raise or lower the pain threshold—producing analgesia or hyperalgesia, respectively. Locally increasing GABA, by using an enzyme inhibitor or gene transfer mediated by a viral vector, produces lasting analgesia by enhancing the descending inhibition of spinal nociceptive neurons.

Selectively activating GABA(B)-receptor-bearing RAIC neurons produces hyperalgesia through projections to the amygdala, an area involved in pain and fear.

Most current therapies work "from the bottom up," focusing on peripheral areas where pain is experienced. This research approaches pain "from the top down"; that is, blocking signals from the brain to the peripheral areas.

Also, see *Brain Pathway Shows Potential Therapy for Chronic Pain Including Fibromyalgia,* at *ImmuneSupport.com, 02-11-04.*

Nature. 2003 Jul 17; 424 (6946): 316-20. *Analgesia and hyperalgesia from GABA-mediated modulation of the cerebral cortex.* (Jasmin L, Rabkin SD, Granato A, Boudah A, Ohara PT). Department of Neurological Surgery, (*ucpain@itsa.ucsf.edu*), University of California, San Francisco. PMID: 12867983.

Speaker Resources

The following resources are currently available. You may view available resources at *virtualhometown.com/dfwcfids/resources.html.*

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

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 or include this form.

- Joe Brewer, M.D.: "Viral Infections, Hypercoaguable Syndrome, and Their Treatment"
  - ❑ video, September '03, $18
- Paul Cheney, M.D., 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.
  - ❑ all "Cheney" newsletter articles, $4
- Myra Preston, Ph.D.: "Cognitive Dysfunction in CFS & its Treatment."
  - ❑ video, April '00, $15

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Operational Fund: $851.65

CFS & Pregnancy

Many women with CFS are concerned how pregnancy may affect their health, and, if their illness could harm their unborn child. Drs. Schacterle and Komaroff of Harvard Medical School surveyed 86 women about their 252 pregnancies, both before and after the onset of chronic fatigue syndrome.

Regarding CFS symptoms during pregnancy: 41% reported no change, 30% reported improvement, and 29% felt worse.

After pregnancy: 30% reported no change in CFS symptoms, 20% reported an improvement, and 50% reported feeling worse.

The rates of most pregnancy complications were similar in pregnancies occurring both before and after the onset of CFS. However, more miscarriages occurred in women after the onset of CFS (30% vs. 8%). Developmental delays or learning disabilties also occurred more often in these children (21% vs. 8%).

The researchers believe these higher rates could be explained by the difference in the mothers' ages between pregnancies that occurred before and after the onset of CFS. (The CFS pregnancies occurred when they were older.) Pregnancy did not consistently worsen CFS.

Arch Intern Med. 2004;164:401-404. *A Comparison of Pregnancies That Occur Before and After the Onset of Chronic Fatigue Syndrome.* (Schacterle, RS, Komaroff, AL). *Co-Cure.org.*

Shopping Donations

Way to go shoppers! This six-month period, you earned $10.28 for our group shopping at Tom Thumb while Kroger shopping donations were $185.96. If you need a Kroger card, contact Carol. For Tom Thumb cards, ask their Customer Service to link your current Tom Thumb card to group #9807.

To shop online, go to *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 and connect through their "mall" to the place you want to shop. You shop, they donate, and our group receives funds that pay for educational material.

Thank you for your faithful support!

Upcoming Meetings

Apr. 20 Treating CFS & FM
Sat., 2:30 – 4:30 p.m.
Kent Holtorf, M.D.

An expert and pioneer in treating CFS and FM, Kent Holtorf has treated over 3000 CFS and FM patients at his Los Angeles clinic. Dr. Holtorf's practice also focuses on hypothyroidism, natural hormone replacement and the treatment of endocrine disorders. Recently named Medical Director of the Fibromyalgia and Fatigue Centers, the newest of which just opened in Dallas and, having suffered from CFS himself, Dr. Holtorf is committed to sharing breakthrough medical information and proven treatment protocols with others (see the interview with him featured in this issue on page one). He is currently writing a book on CFS and FM. For more information, go to *fibroandfatigue.com*.

May 22 Treating CFS and FM with the QXCI
Sat., 2:30 – 4:30 p.m.
Jonathan E. Walker, M.D.

Neurologist Jonathan Walker is a clinical professor at Dallas' Southwestern Medical School and has studied and worked locally with Dr. Lee Cowden. Dr. Walker began treating CFS and FM patients in 1984. Among other modalities, he employees neurokinesiology and, most recently, the Quantum Xrroid Consciousness Interface (QXCI), a form of bioenergetic testing. The QXCI scans the body for over 8000 substances (nutrients, toxins, pathogens, allergens, etc).

In this method, factors contributing to illness or preventing healing are identified, and a corrective electromagnetic pulse is then administered to restore balance. A typical course of treatment is a one-hour session once a week for three weeks. He has treated 30 long-term FM patients. About ten have had dramatic improvement and no longer need pain medicine. Another ten have had significant improvement. Treatment is covered by most private insurance and Medicare but not Medicaid. Join us for a fascinating presentation and a demonstration with a volunteer! (Dr. Walker is located in Dallas. You may reach him at 972.991.1153 or *neurotherapy@sbcglobal.net*.)

June 15 Helpful Solutions & Practical Tips
Tues., 7 – 9 p.m.

The collective wisdom of our members is featured at this month's meeting. Come share your knowledge, whatever it may be: healthy food that's easy to prepare; treatment protocols you can do at home (like epsom salt baths, special breathing techniques, or heat socks); how to travel with injectibles that need refrigeration; social services for which you may be eligible; tests and treatments that have helped the most; etc.

If you are able to, please write it down and bring 25 copies or so. Sometimes, time (and energy) run short. Come join us as we learn valuable methods for coping from each other!

Meeting Information

Unless othewise 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. Out of consideration for others, please avoid wearing to the meetings fragrances or clothes that have been exposed to smoke, dry cleaning fluids, or other chemicals. Remember also that many common household products contain fragrances and other very strong chemicals.

Thank You!

Many Thanks!

Thanks again to Julie Quinn's third-period business class at Trinity High School for folding, sealing, and labeling this newsletter. With almost 800 copies

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