



The newsletter of the
 Chronic Fatigue Syndrome &
 Fibromyalgia Support Group of
 Dallas-Fort Worth
 Volume 6, No. 4, October 2004

View the DFW Lighthouse online at:
www.virtualhometown.com/dfwcfids/news/index.html

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THE LATEST RESEARCH & TREATMENT FOR CFIDS & FM 2004 ANNUAL SEMINAR SATURDAY, NOVEMBER 6, 2004; 2-5 P.M.

Three doctors associated with the Fibro & Fatigue Centers will present cutting-edge information on CFIDS and FM at this year's annual seminar. Leading off with an overview of the latest research, Dr. Kent Holtorf will discuss treatment options for CFIDS and FM and share his patients' responses. He will also explain the role of bio-identical hormones in an aggressive treatment plan.

Next, Drs. Larry Sharp and Ken Kippels will discuss the identification and treatment of potentially unique etiologies in these conditions, including heavy

metal toxicity, neurotoxins, and coagulation defects. Common issues in CFS and FM range from immune dysfunction and low thyroid problems to adrenal insufficiency and growth hormone deficiency. Treatment has six basic components that must be addressed: pain and sleep disturbances; promote energy; balance hormones; enhance immunity and treat underlying viral infections; address unique etiologies; and, provide a maintenance program.

Dr. Holtorf will conclude the seminar by looking at patient outcomes in a session titled, **"There is nothing more**

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A HUSBAND'S STORY: AFTER NINE LONG YEARS, MY WIFE RECOVERED FROM FM

by Mark Kidder

My wife suffered with debilitating fibromyalgia (FM), experiencing nine long years of chronic pain with virtually no relief. I want to share the good news that, thanks to a wonderful doctor, she has found relief from debilitating, disabling pain.

I write this as an extremely appreciative husband who is so happy and grateful to have his wife back! With newfound success, I feel a deep obligation to tell as many FM sufferers as I can reach. Thankfully, this is not a story of unending pain and misery but of hope and recovery!

Jackie, my wife, was a very active and physically fit woman who loved life. She

worked, ate healthy, did not smoke, and took no medication at all. She was unstoppable! On July 23, 1995 while shopping, she lifted up her head and "saw stars." She was in so much pain, she had to sit on the floor in the store for about 15 minutes. She barely made it home. Our lives were instantly changed forever.

Jackie had a horrific case of FM, encompassing virtually all its associated symptoms. The pain became so excruciating at times that it caused her to throw up uncontrollably. Certain muscles were in a constant state of spasm. She had

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important than how YOU feel.” He will elaborate on the latest methods available that quantify and clearly demonstrate positive outcome tracking. This critical issue in healthcare is a necessary component in any treatment program.

SPEAKERS

Dr. Holtorf is the Chief Medical Officer of Fibromyalgia & Fatigue Centers, Inc. While in medical school, his CFS symptoms emerged; he spent the early part of his medical career searching for the causes and cure for this little known condition. In 1994, Dr. Holtorf used this knowledge to begin a family practice specializing in natural hormone replacement and optimization, chronic fatigue syndrome, fibromyalgia, and hypothyroidism. In 2001, he established a center in Los Angeles specializing in the care of fibromyalgia and chronic fatigue syndrome patients. Since then, he has had extraordinary success in significantly reducing the pain and increasing the energy levels for the majority of his 3,500+ patients. Last year, Dr. Holtorf joined with one of his FM patients, Bob Baurys, to found the Fibromyalgia & Fatigue Centers, Inc. (FFC). By training FFC physicians and staff, Dr. Holtorf and his proven medical protocol now give hope and help to millions of FM and CFS patients.

Dr. Kippels is a board certified Obstetrician and Gynecologist and the Staff Physician at the Dallas FFC. He has been practicing medicine in Plano, Texas for twenty-two years. While serving in the U.S. Army, Dr. Kippels served as an Assistant Professor at Baylor University in San Antonio where he was an instructor in the Army Physician's Assistance School. Joining the Fibromyalgia and Fatigue Center in January 2004, with the opening of the first center, Dr. Kippels brings his vast knowledge of the endocrine system, hormones, and their effect on each system of the body. Combining this experience with the clinical training provided by Dr. Kent Holtorf, Dr.

Kippels is well qualified to address the intricacies of FM and CFS.

Dr. Larry Sharp is a board certified Family Practitioner and the Staff Physician at the Fort Worth FFC. He has been practicing medicine since 1985. He first became aware of CFIDS in 1987 when his wife got ill after a ski trip to Lake Tahoe. His first son became ill with CFIDS shortly thereafter at the age of two. As an AACFS member—an international professional CFIDS organization for clinicians and researchers—Dr. Sharp follows current research in the field. He is also a member of the CFIDS Association of America and the National CFIDS Foundation. Additionally, Dr. Sharp has served on the Board of Directors of the CFS/FM Support Group of DFW (virtualhometown.com/dfwcfids) for the last several years. Dr. Sharp is an Associate Clinical Professor at UNTHSC/TCOM. His research positions include: sub-clinical investigator, MDS Harris; Department of Endocrinology, Henry Ford Hospital; and, Department of Infectious Disease, Baylor College of Medicine.

There are currently six FFC locations nationwide, with the Fort Worth office being the seventh. Opening soon will be offices in Pittsburg, Salt Lake City, Philadelphia, and Detroit. For more information on Fibro & Fatigue Centers (FFC), visit fibroandfatigue.com or call (toll free) 866.443.4276. Contact information for the individual centers may be found at fibroandfatigue.com/center_location.htm.

DETAILS & DIRECTIONS

The seminar will be held at the Irving Civic Center Complex (825 West Irving Blvd.) in the Irving City Council Chambers. The Chambers, which are to the left of the lobby area, seat 200 people. Questions about the 2004 Annual Seminar may be directed to Carol, the City of Irving (Carole Lawrence, 972.721.3623), or the FFC. From 183, take the Irving Blvd. exit. Take Irving Blvd. south to the Irving Civic Center Complex. Look for the flagpoles and park in front. If you go too far, there is a huge fountain and the Irving Library. Irving City Hall is before/next to the library. There is also a parking garage behind city hall on Rock Island Road.

terrible migraines about twice a month and developed restless leg syndrome.

Initially we followed a traditional path, seeing a neurosurgeon, a rheumatologist, three neurologists, an internist, and an endocrinologist. She was given stronger and stronger pain medication. None of the treatments provided any relief.

Jackie's pain began getting worse and she was put on a Duragesic (Morphine) patch normally reserved for cancer patients. It barely took the edge off. She was completely debilitated. We pursued other avenues, including a chiropractor, an acupuncturist, an osteopath, yoga, light therapy, nutrition, and supplements.

With her daily pain at 9.5 on a scale of 10, a pain management specialist recommended an extreme procedure, once a week for three weeks. Jackie was hospitalized and placed under general anesthesia. They threaded a catheter into her cervical spinal column and injected the most expensive cutting edge drug. She risked paralysis and we spent \$30,000—only to have the pain return 10 days after the last surgery.

The third neurologist that Jackie saw put her on Elavil, Xanax, Lortab, Celebrex, and Soma, and took her off the Duragesic patch, which involved horrible withdrawal symptoms. By now, the summer of 2000, five years into our journey with FM, we had spent over \$100,000 seeking pain relief. Jackie's pain was now tolerable, but unfortunately, she was a zombie!

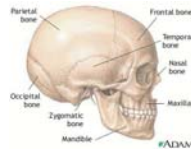
In March 2004, she woke up with incredible pain in her neck and upper back. The neurologist increased all her doses by 50% and added a high dose of Neurontin to “the cocktail.” Despite the added medication, Jackie was still in great pain. She slept only a couple hours each night sitting in her recliner.

Desperate, I searched the web to find something that could help Jackie. After

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hours of searching, I found a little known treatment called Bio Cranial Therapy, and one of the teachers of this technique, Dr. Stuart Marmorstein, happened to be nearby in the Houston, Texas area. I made an appointment to take Jackie there the next morning.

At his office, he explained the Bio Cranial Therapy program. This technique involves relieving pressures of the “mater” system along the spinal column. The dura mater is the very tough, fibrous membrane covering the brain and the spinal cord. The mater continues downward through the base of the skull throughout all parts of the spinal column. This same protective sheath connects to the vertebrae, the discs, and the muscles that surround the spinal column. All of this mater is connected, but in different areas, it is termed either the dura, pia, or arachnoid mater. This “mater” actually wraps around, protects the “nerve roots” that come out of each side of the spine, and goes to all parts of the body.



behind her head. Based on the structure of Jackie’s skull, he positioned the fingers of his right hand a certain way at the base of her skull. He then put his left hand firmly down on top of her shoulder. He then brought her head forward a bit and placed his chin on top of her head. He then proceeded to slowly and gradually push Jackie’s head further and further forward towards her chest while simultaneously and gently twisting her head towards the right. With his chin, he was able to sense how hard he could comfortably push her head forward. After about 60 seconds, he gently released her from this “stretch” and let her lay her head flat again for about a minute in a relaxed position. He then switched hands and did the same exacting technique, pushing her head forward and twisting it to the left.

Like many doctors, Dr. Marmorstein does not take insurance directly. He will, however, give you the paperwork to file for reimbursement. The first visit was \$130.00; subsequent visits are \$65.00.

As we left, I was afraid we’d wasted the time and money. Jackie said she felt disoriented and lightheaded. After the treatment and into the afternoon, she was abnormally quiet. About 5:30 PM she looked at me and said, “I don’t want to jinx this, and I’m almost afraid to say it, but I don’t have any pain.” I about fell out of my chair! She was so happy she started to cry, and so did I.

Her current regimen of meds included eight Lortab (pain) pills a day, tranquilizers, Neurontin, antidepressants, etc. She had taken her morning dose, but felt no need for any after her treatment. At 7:30 p.m. she said, “Hon, I’m so sleepy. I’m going to bed.” She hadn’t been able to sleep in the bed for months. But, she went to bed and slept for 15½ hours. She said she hadn’t slept that well in years.

She felt some soreness in her neck and upper back, but not much more than that. She said “Let’s go out for lunch, and then go shopping.” For the last eight

weeks, it was all she could do to get from her recliner to the toilet and back!

We had a wonderful, pain-free weekend. Early the following week, she had a little pain return just like Dr. Marmorstein had predicted, but nothing like before, and she went in for another treatment. Each week the pain-free time lasted longer, and when the pain returned days later it was always at a lower level than the previous week.

Her migraines stopped immediately after her first treatment. After two weeks, feeling returned to her fingers. She continues to see Dr. Marmorstein about once a week. It’s been about two months since our first visit and I have my wife back! She hasn’t felt this good since 1995! She has no pain, takes no medication, and has no migraines!

It’s amazing how life has changed for us. Since then, we have been very active and we’re playing catch-up. Jackie joined the local fitness club and is working out 5 days per week with weights, and has resumed aerobics and jogging!

I am so thankful for this gift. The cloud of continual illness and pain has been lifted. We are so grateful to God and Dr. Marmorstein for this restoration. I hope many others with FM try this. If you get only a fraction of the relief that Jackie has been blessed with, even that is worth more than gold itself!

Feel free to email Dr. Stuart Marmorstein (www.drstuart.net) or call him. He is very patient, very smart; you can sense he really wants to help people get better. Email me directly at markkidd@cox-internet.com.

Editorial Note: more info can be found at biocranial.com, including a list of practitioners that includes Dean Shepherd, DC in Carrollton; Turner Johnson, DC in Flower Mound; Iva Lim Peck LAc, RN, LMT in Plano; and Jud Kendall, DC, Jerrod Wright, DC, and Hunt Whitehead, DC, all in Southlake. Drs. Kendall and Wright, trained in this technique, will be the speakers at our October 19 meeting.

During the treatment, Jackie laid flat on her back with Dr. Marmorstein standing

NEW PAINKILLER PRODUCES FEWER SIDE EFFECTS

by Amanda Gardner, HealthDay Reporter

Lumiracoxib (Prexige), a new COX-2 inhibitor painkiller, appears to be as safe as certain other drugs when it comes to cardiac effects. Moreover, it's safer than other drugs that can cause gastrointestinal complications, new research contends. The FDA has not yet approved the drug, but these research results will form the basis of a claim for approval by Novartis, the drug's maker.

The trial involved 18,325 patients aged 50 or older, all of whom had osteoarthritis. The participants were randomly chosen to receive either 400 mg of lumiracoxib once a day; 500 mg of naproxen (an NSAID with some anti-clotting properties) twice a day; or 800 mg of ibuprofen (an NSAID that is relatively inert) three times a day.

Some participants also had coronary disease. Fifty percent had hypertension, 20 percent high cholesterol, and 10 percent had had an event in the past. Participants with heart disease were not

sought out, but they were not excluded. Some participants were taking low doses of aspirin for its heart-protecting effects.

In the study, those taking the new drug were not at any greater risk for a cardiovascular event than those taking the other two drugs. The exciting news was an 80 percent reduction in the risk of gastrointestinal complications—such as bleeding, perforation or obstruction—in the lumiracoxib group versus the other groups. However, this benefit was lost when patients took aspirin along with the new drug.

healthfinder.gov/news/newsstory.asp?docID=520771 Copyright © 2004 ScoutNews, LLC. All rights reserved. Lancet. 2004 Aug 21;364(9435):675-84. Comparison of lumiracoxib with naproxen and ibuprofen in the Therapeutic Arthritis Research and Gastrointestinal Event Trial (TARGET), cardiovascular outcomes: randomised controlled trial. Farkouh ME, Kirshner H, Harrington RA, et al. Co-cure.org

ENZYME SETS CLOCK

by Robert Preidt

According to University of Illinois researchers, the activation of an enzyme called PKG-II triggers biochemical reactions that may be critical in helping our biological clock distinguish between night and day.

When scientists blocked the enzyme's action in experiments, circadian rhythms seemed stuck in the "late night" phase. "Activation of PKG-II may serve as a critical checkpoint," the authors wrote, allowing our internal clocks to "align with dawn in the solar cycle."

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FM PAIN—NOT JUST IN YOUR MUSCLES

Many people think fibromyalgia (FM) just involves a problem within their muscles, but recent FM research shows, "evidence of central nervous system hyperexcitability related to central sensitization."

This means FM patients experience an increased sensitivity to, and magnification of, sensory input. The lightest touch is amplified; pain is amplified. The brain simply does not process signals correctly. FM is, in large part, a pain processing disorder that originates in the central nervous system.

Pain. 2004 Aug;110(3):689-96. *Maintenance of windup of second pain requires less frequent stimulation in fibromyalgia patients compared to normal controls*. Staud R, Price DD, Robinson ME, Mauderli AP, Vierck CJ. PMID: 15288410 [PubMed—in process]

KUTAPRESSIN BACK

Kutapressin, a potent anti-viral and immune-modulating drug, went out of production over a year ago. Marc Share, Executive Director of the NIDS Parent Coalition (*Neuro Immune Dysfunction Syndromes, nids.net*), announced on August 31 that, "Schwarz has completed the transfer of the production and distribution licensing rights to a new Pharma. All legal obstacles have been resolved and the production issues and agreements with the previous suppliers have been resolved. Production has begun and Kutapressin, re-branded under a new name due to legal and liability issues, will be available by the beginning of 2005 and perhaps sooner."

FM DIAGNOSTIC TEST

Corgenix Medical Corporation (*corgenix.com*) has developed an Anti-Polymer Antibodies (APA) ELISA test kit for diagnosing fibromyalgia (FM). It is expected to enter FDA clinical trials in the United States this September, and will subsequently be available if the FDA grants regulatory clearance.

"Current data suggests that APA-positive FM patients comprise the majority of fibromyalgia patients," said Luis Lopez, MD, Chairman and CEO of Corgenix. "This test is intended for use as an aid in the diagnosis of patients presenting with the symptoms and signs of FM syndrome, as an aid in differentiating fibromyalgia patients from patients with other autoimmune diseases, and to aid in determining which fibromyalgia patients have an immune response that is associated with their symptoms."

The APA Assay is the first laboratory test for objectively identifying FM patients. The test detects IgG anti-polymer antibodies in human blood. Research has shown that the antibody titers correlate with the severity of symptoms. (The more antibodies one has, the worse the symptoms.)

© Pr Newswire; August 19, 2004

LARRY SHARP, D.O. TO HEAD NEW FORT WORTH FIBRO & FATIGUE CENTER

LIGHTHOUSE: What attracted you to the Fibromyalgia & Fatigue Center, Inc. (FFC) organization?

DR. SHARP: Many things! Their system allows me to expand treatment options for patients, while reducing the overall cost of office visits. A Quest Lab is part of every FFC facility, which is efficient and most insurance covers the testing.

They have a treatment protocol that is very comprehensive, yet also individualized. Before coming in, new patients fill out a 24-page Health History that helps pinpoint their specific issues and determine which tests are needed and which treatments will be most effective. Such a streamlined system really helps make the most of our time with patients.

It's an outstanding organization with knowledgeable, committed people who understand these illnesses. Dr. Kent Holtorf, the Chief Medical Officer, struggled with CFIDS, and Robert S. Baurys, the CEO, was diagnosed with FM five years ago. When he became one of Dr. Holtorf's 3,500+ patients and had a great outcome, they combined their skills and FFC was born. I think it's significant that both know these conditions personally, not just professionally. The same is true for me, since my wife and oldest son have CFIDS.

One of the most professionally exciting aspects to this organization is the opportunity for a great deal of interaction with other doctors treating CFIDS and/or FM. The physicians in every FFC location train intensively with Dr. Holtorf. After a new FFC location opens, Dr. Holtorf personally visits the center and works for several days with the staff physician with their patients. In addition, weekly phone conferences are held with all the FFC doctors across the country. We share new research, discuss new protocols, ask for input on difficult cases, etc. Being part of such a large team enriches all of us.

LIGHTHOUSE: Are you able to incorporate your own insights, and those you gain from doctors outside the FFC network, into your practice?

DR. SHARP: I certainly am. I believe that's one of the contributions I bring to the FFC. Over the last several years, I've had access to numerous consultations with Dr. Paul Cheney, a nationally-known CFIDS specialist. I am thrilled he is back in practice after a serious health crisis. I've had two consultations with him in the last few months and am working with Dr. Holtorf to determine how to best incorporate some of Dr. Cheney's newest protocols into the FFC algorithm of care.

LIGHTHOUSE: What are some of the treatment options offered to CFIDS and/or FM patients?

DR. SHARP: That depends of course on the patients needs. However, some of the most common treatments within this comprehensive and integrated approach are:

- ◆ Finely tuned endocrine testing and treatment
- ◆ Numerous types of IV treatments and injection therapy
- ◆ A large array of nutraceuticals and supplements to customize each treatment to each patient
- ◆ Bio-identical hormone balancing
- ◆ Mitochondria enhancements to promote energy
- ◆ Integration of alternative therapies

Of course, once the conditions are under control, we work with the patient to develop an individualized maintenance program with minimally necessary medications and supplements to assure absence of symptoms.

Located at 451 South Hulen Street in Fort Worth, the newest FFC is scheduled to open October 25. Patients can start booking now through the central toll free number (866.443.4276). For more details about the FFC centers, visit fibroandfatigue.com.

E NEWS!

If you are able and willing to receive the newsletter via email link (to the pdf file), it will save time, energy, and money! You can either print off the newsletter or read it online. The notices are sent out to the newsletter mailing list (DFW_Newsletter at yahogroups.com) when each issue is ready. There is no discussion on this list, just newsletter announcements. If you wish to switch to the e-version, contact Carol so she can make sure you do not also receive the hardcopy. She can send you an invitation to any of the yahogroups if necessary or you don't understand the process..

SPEAKER/TOPIC INPUT

We traditionally meet in November to brainstorm speakers and topics for the coming year. Then, we rank the results according to interest level.

Attendance at the meetings over the last few years has dropped to two or three people, so, we will be discontinuing these meetings. Since most input comes from emails or phone calls anyway, we're asking anyone with speaker and/or topic suggestions to simply give them to Carol by email or phone (dfwcfids58@comcast.net; 817.283.1115).

NEW CHENEY INFO

Dr. Paul Cheney began seeing patients in July. Carol Sieverling recently had an appointment with him. Look for exciting new treatment information from Dr. Cheney in our next issue!

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IRRITABLE BOWEL SYNDROME: A TEAM APPROACH

By Stevan Cordas, D.O., Nelle Cotton, D.O., Nancy Didriksen, Ph.D.

Many FM and CFS patients also have irritable bowel syndrome (IBS), one of the most common chronic gastrointestinal disorder in the United States. IBS is the second leading cause of missed workdays due to the gastrointestinal pain and change in bowel movement status. The direct and indirect costs in this country are \$25 billion.

DIAGNOSIS BY EXCLUSION

A common disorder, IBS must be diagnosed after a number of other disorders or factors are eliminated, including: Celiac disease; parasitic, bacterial, viral or opportunistic infections; hypothyroidism, hyperthyroidism; Diabetes; Addison's disease; use of laxatives or constipating medications; rare endocrine tumors; colorectal carcinoma; intestinal pseudo-obstruction; scleroderma; lactose intolerance; and, psychiatric disorders. Since they affect approximately 1 million Americans, Crohn's disease and Ulcerative Colitis are two of the more common serious problems to also exclude.

ALARM SIGNS

Important to recognize, alarm signs include:

- ◆ blood in the stool
- ◆ fever
- ◆ weight loss
- ◆ nighttime symptoms
- ◆ anemia

If any of these symptoms are present or the patient begins to have problems after age 40, a complete gastrointestinal evaluation is warranted, including a colonoscopy. These signs and symptoms are not generally present in IBS patients, though severe cases can have night symptoms.

WHAT IS IBS?

The 1992 Rome II criteria include at least 12 weeks (not necessarily consecutive) of abdominal pain or discomfort that is: relieved with defecation; associated with a change in frequency of

stools; or, associated with a change in appearance of stools (at least two of the three must be true).

Supportive symptoms (from the Rome I criteria) may also include:

- ◆ Fewer than three bowel movements per week
- ◆ More than three bowel movements per day
- ◆ Hard or lumpy stools
- ◆ Loose (mushy) or watery stools
- ◆ Straining during a bowel movement
- ◆ Urgency (having to rush to the bathroom)
- ◆ Feeling of incomplete evacuation
- ◆ Passing mucus (white material) during a bowel movement
- ◆ Abdominal fullness, bloating, or swelling

PATHOPHYSIOLOGY OF IBS

Experts consider this disorder a brain-gut dysfunction. When the IBS abdominal pain is present, portions of the IBS brain do not activate the same as they do in healthy patients. Experts hypothesize that central sensitization and a chronic pain memory syndrome (in part due to neural remodeling) is present, resulting in hyperesthesia (unusual sensitivity of the skin) and allodynia (pain from stimuli which are not normally painful). For FM patients, this scenario sounds familiar. Both FM & IBS involve serotonin dysfunction. Since most serotonin in humans is found in the gastrointestinal tract and platelets, (with only 10 to 15% in the brain), it is curious that all FM patients do not have IBS. Familial clusters have been identified and genetics are involved although the exact mechanism is not clearly understood.

To summarize, the pain-information processing within the central nervous system varies radically between normal individuals and those with IBS; the

result for IBS sufferers is painful GI contractions. The interactions between their brain, central nervous system, and GI system are just not functioning properly. Their colon reacts to stimuli that does not affect a normal colon, and that reaction is much more severe. On a positive note, IBS produces no harm to the lining of the colon, and does not lead to cancer or other intestinal disorders.

TRADITIONAL TREATMENT

The traditional treatment of IBS depends on first categorizing patients into four groups:

- ◆ Those who have acquired the disorder over age 50. Those in this group need a colonoscopy and special attention to eliminate organic disease. It is rare for IBS symptoms to appear for the first time in the elderly.
- ◆ Those with predominately diarrhea symptoms
- ◆ Those with predominately constipation symptoms
- ◆ Those with predominately abdominal pain, nausea, or gas symptoms

The patients are then categorized into mild, moderate, or severe and treated accordingly:

- ◆ Mild: manage stress and make dietary and lifestyle changes
- ◆ Moderate: As per Mild + fiber supplements utilizing over-the-counter (OTC), anticholinergic, or psychotropic medications (i.e. imipramine or trazadone) that have anticholinergic activity
- ◆ Severe: As per Moderate + tricyclic or SSRI antidepressants, or 5-HT₃ or 5-HT₄ medication

The drugs used include: belladonna and its derivatives (anticholinergics—used to relieve spasm and pain); antidepressants and axiolytics; 5 H₃ agonists—Lotronex (*alosetron*)—for diarrhea and pain in women (withdrawn for a time due to ischemic colitis complications); 5 H₄



agonists—Zelnorm/Zelmac (*tegaserod*)—for constipation-related IBS. In Europe, they are using a Kappa-opioid agonist (fedotozine).

OUR METHOD

Regarding drugs, I have not been happy with the H3 or H4 agonists (helpers) used in traditional treatment methods, so I reserve these for unusual cases. Our method uses the same subclass separation as mentioned above. Older patients need a more in-depth evaluation. Those younger than 50 should have a TSH, or free T3 or 4, sigmoidoscopic examination, CBC, sed rate, stool for parasite evaluation and digestion capability, and, an ordinary chemistry panel to help exclude other problems. Addressing the main triggers of IBS is critical to both calm the disorder and keep it quiet. These triggers are: diet, structure, emotions, and sensitivities.

DIET

The primary dietary triggers of IBS include: alcohol, carbonated drinks, whole grains, intestinal irritants such as coffee (even decaffeinated), chocolate, tea, onions, artificial sweeteners (Stevia is satisfactory), and, especially fat.



There are many other dietary suggestions that will help calm IBS symptoms.

Avoid red meat, processed meats, egg yolk, and dairy products. Eliminate fried foods. Be aware that the fruits and vegetables cabbage, beans, broccoli, cauliflower, onions, prunes, and apples all produce gas.

Introduce fruits, vegetables, beans, and lentils carefully in small amounts as tolerated (the skins are insoluble, with the interior flesh being soluble). Raw vegetables, seeds, whole wheat, bran, nuts, and popcorn contain insoluble fiber and may increase diarrhea.

A common mistake is to follow the older medical advice to eat increasing amounts of wheat bran. However, doing this only aggravates the problem. *Plantago majorum* (psyllium) is an acceptable soluble fiber. Others are polycarbophil and metylcellulose.

Preferably, the diet's foundation utilizes plant foods with soluble fiber. Brown rice, oatmeal, buckwheat (soba) noodles, corn meal (polenta), quinoa, and barley are the whole grains that are safest for IBS. Root vegetable staples are best—for their soluble fiber—instead of higher glycemic index foods like white rice, sweets, white flour, or potatoes. IBS sufferers should add healthy fats (olive, canola, flax, avocado, nuts, fatty fish like salmon and tuna, etc.) and safe proteins (fish, skinless chicken breasts, egg whites, soy, etc.) to their soluble fiber dietary staples.

A general list of soluble fiber foods include: rice, pasta and noodles, oatmeal, barley, fresh white breads such as french or sourdough (not whole wheat or whole grain), rice cereals, flour tortillas, soy, quinoa, and corn meal. Other soluble fibers include: potatoes, carrots, yams, sweet potatoes, turnips, rutabagas, parsnips, beets, squash, pumpkins, mushrooms, chestnuts, avocados



(though they do have some fat), bananas, applesauce, mangoes and papayas. Papaya is also a digestive aid that can relieve gas and indigestion.

In summary, avoid: sweets and alcohol; fried foods; animal fats in excess as they stimulate the gut too much; intestinal irritants; carbonated products; insoluble fibers like raw vegetables, raw fruits, and whole wheat; excessive amounts of analgesics such as ibuprofen, aspirin etc. (IBS is correlated with a higher amount of analgesic use than seen in the general population.)

General recommendations include the following: use soluble fibers from plant sources, safe fats; reintroduce small amounts of fruits and vegetables as the body permits; use psyllium to supplement soluble fiber; and, drink 6 to 8 glasses of water per day.

The following supplements can also help: peppermint, ginger, fennel, and digestive enzymes (however, be aware that peppermint can increase reflux problems or GERD). Probiotics are the main products we use, based on AK testing. There is some evidence that IBS is aggravated by increased hydrogen intestinal-gas from fermentation.

Other helpful products are: chamomile, aloe mucilaginous polysaccharides, fo ti root, comfrey, slippery elm, L-glutamine, valerian root, acupuncture, lobelia, spascupreel, and cayenne fruit.

There are general principles that are important when eating. Eat slowly. Chew

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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your food properly; don't gulp it down. Try to be happy or at least neutral at a meal. A negative mindset contributes to a disordered bowel.

STRUCTURE

As an osteopathic physician, I was trained over thirty years ago in the importance of the connections between the intestinal tract and the spinal nerves. Chronic intestinal problems affect the ninth thoracic spinal area and the sacral region. This causes a reflex from the gut to the spine. Eventually, the nervous system changes. Negative feedback occurs causing the spine and higher centers to send an incorrect message to the intestine resulting in IBS. The fault lies in how the colon functions.

Advanced osteopathic methods permit restoration of the tissues and bones of the spinal region to their normal state. Some of this viscous cycle is thus broken. At times, altered posture or traumatic events cause tissue changes, thus, binding muscles, organs, nerves, or blood vessels. Later, these altered signals cause a short circuit (abnormal feedback) to the intestine. Scoliosis (spine curvature), short leg, and degenerative spinal disorders are common examples of structural problems that modify or worsen IBS. We advise our IBS patients to undertake osteopathic treatments. Other body-type therapists, acupuncturists, and chiropractic physicians can also serve in this role depending upon their skills. Covering this area is the second member of our team, Dr. Nelle Cotton, a manipulative specialist.

EMOTIONS

In recent years, more emphasis has been placed on IBS being a physical rather than an emotional disorder. Studies indicate, however, that 60% of IBS patients have one or more emotional problems so this must be considered and addressed properly.

Several areas of treatment that have proven valuable in this disorder include: yoga, a specialized type of hypnosis,

biofeedback, and cognitive therapy. Though not studied as well as the others, energy psychology methods can be helpful and permit faster results in certain cases. We advise our IBS patients to perform a MMPI II or other psychometric testing to see if there is a problem in this area. Remember that emotional problems can trigger or aggravate IBS, not cause it. Our third team member handles this area, Nancy Didriksen, a clinical health psychologist.



I utilize the Hinz method to restore the brain and peripheral serotonin levels, as well as the catecholamines (dopamine, norepinephrine, and epinephrine). The Hinz method is a safe and effective protocol utilizing concentrated neurotransmitter precursor amino acids. A timed urine study then is used to adjust the amino acid therapy by measuring serotonin, dopamine, norepinephrine and epinephrine levels. In other words, we raise the brain and peripheral neural hormones without drugs or side effects so that, once balanced, there is improvement in the intestinal utilization of the neurotransmitters.

We do not use this method in milder cases or in those that respond to dietary and natural supplementation. However, for more severe cases or those that have problems with medications from other

doctors, the Hinz program can be a blessing. It is also used if major depression, migraine, or FM is also present.

SENSITIVITIES

Though controversial, many reports indicate that a high percentage of IBS patients report that individual foods aggravate their problem. Though some are allergic, most food problems do not have associated allergic symptoms. It is often helpful to eliminate foods that are detrimental to the individual.

An elimination diet can help determine which foods are problematic. Standard food allergy testing correlates poorly. The A LEAP (or SAGE) test is currently recommended and is sometimes covered by insurance. This test correlates with IBS symptoms in 40 to 60% of cases, in my experience. These tests study mediator release from the blood elements, when the patient's blood is mixed with a food or food additive that can result in destruction of the patient's red blood cells in the tube.

SUMMARY

By changing the structural relationship, changing the diet, restoring better colon flora, improving digestive capability, improving emotional stress when required, and restoring serotonin levels to a more healthy amount, a vast majority of IBS patients can expect to have control over their IBS.

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Operational Fund: \$1773.11

NIH FUNDING: ALARMING!

CDC Researchers report that, “Lost productivity due to chronic fatigue syndrome (CFS) was substantial both on an individual basis and relative to national estimates for other major illnesses....continued research to determine the cause and potential therapies for CFS could provide substantial benefit both for individual patients and for the nation.”

The steep decline in NIH funding for CFS research was the topic of a presentation and report delivered to the DHHS CFS Advisory Committee by the CFIDS Association’s (CAA) Kim McCleary. Ms. McCleary conducted a detailed analysis of funding information provided by the NIH budget office for CFS research from FY 1999-2003.

Although the total, five-year CFS research funding reported by NIH was \$31.6 million, the numbers indicate vastly overstated NIH support for CFS research. The discrepancy is caused by the inclusion of 17 misclassified projects. After appropriate adjustments, NIH’s support for CFS research dropped to \$25.8 million for the past five years and less than \$4 million for FY2003. The FY2003 figure is little more than the amount spent on CFS research by NIH in **1992**. Over this same time period, the overall NIH budget increased a **whopping 76%**.

The CAA’s report calls for NIH to, “take immediate steps to reverse the shocking decline in CFS research and to build a robust program commensurate with the magnitude of the illness.” Specific recommendations contained in the 45-page CAA report were presented by Ms. McCleary to key Congressional staff.

*Click on the Capitol Building icon at cfids.org do your part. “Tell A Friend” to generate even more support for these requests. It’s easy to do! For a copy of the report in its entirety, send an e-mail message to NIHreport@cfids.org. A summary of the findings is available on the “What’s New” section of the CAA website. CDC information referenced: the online journal *Cost Effectiveness and Resource Allocation*.*

IONCLEANSE: SAFE & EFFECTIVE DETOX SPECIAL DISCOUNT OFFER

Many in our support group became interested in IonCleanse detoxification after seeing several members receive free treatment sessions during a meeting. It was amazing to see what came out of their bodies!

One member who responds poorly to even the gentlest detox supplements found this to be an effective treatment with no adverse side effects. Several members discussed purchasing a machine together but it soon became obvious this would be both financially and logistically impossible.

SPECIAL OFFER

Pete Allen, the owner of Super Value Pharmacy, has agreed to purchase a machine and give the first 25 people who commit to five sessions a lifetime price of \$20 a session. (The typical price per session is \$50.) This is quite a deal considering the machine costs approximately \$2500 and has \$60 plates that require frequent changes. The savings could potentially represent hundreds of dollars per person! Additionally, Super Value Pharmacy has a nutritionist on staff, carries supplements and herbs, and has an outstanding compounding pharmacy. They are located 3/4 of a mile north of Airport Freeway on Industrial Blvd. in Euless.

HOW THE IONCLEANSE WORKS

The IonCleanse and an earlier generation unit have been in use for twenty years. Several area doctors, chiropractors, and nutritionists use them in their practice. The small unit sits in a small tub of water and uses electricity to break apart the water molecules, generating both positive and negative ions. Clients sit with their feet in the water, and the ions quickly travel through the body, attaching themselves to many different toxic substances, neutralizing them.

The neutralized particles extracted from the body through osmosis (the move-

ment of particles from an area of higher concentration to an area of lower concentration) move from your body into the tub. Many objects and colors appear in the water during these sessions. The colors produced in the water are a reaction between many things, such as: toxins, salt added to the water, metals in the array, the acidity/alkalinity of the person, etc. The colors seen in members who have had the treatment ranged from orange and brown to green. There was also sometimes foamy, mucous-like stuff, some black flecks, and some white particles.

THE NEED

We are exposed daily to a heavy, unending toxic load. Ongoing periodic detoxification is essential to restore or maintain good health. The human body acts like a giant magnet that attracts and holds toxins. Heavy metals, partially oxidized fats, unassimilated proteins, cholesterol deposits, uric acid, lactic acid, and the vast array of chemicals that pervade our water, air, and food attach themselves (in ionized form) to joints, organs, arteries, nerves, and tissues, disrupting their function and creating an environment hospitable to disease, allergies, and immune system breakdowns.

PART OF THE SOLUTION

The IonCleanse provides a thorough and efficient way to detoxify the body more effectively and faster than any herbal or fasting protocols, with little or no stress to patients. Used properly, the IonCleanse provides a comfortable and relaxing way to rid the body of toxins **without causing a healing crisis.**

WHO BENEFITS?

While everyone can benefit from IonCleanse footbaths, significant benefits are often seen in patients with edema, inflammation, gout, osteoarthritis, heavy metal toxicity, chemical sensitivities or toxicity, ADD/ADHD,

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NEW APPROACH MAKES IT EASIER TO DIAGNOSIS CFS

by Jennifer Warner, WebMD Medical News

The long sought-after physical evidence of chronic fatigue syndrome (CFS) may be found in the skin, according to a new research study. The study suggests that differences in skin temperature and electrical activity may provide a new way to identify the disorder. CFS causes a variety of common symptoms which makes it hard to distinguish from other ailments. Researchers estimate that CFS affects between 0.5% and 3% of the population, but diagnosing the condition is difficult and somewhat controversial. "There are a number of medical professionals who don't believe CFS exists in the first place," says researcher Hannah Pazderka-Robinson, of the University of Alberta. "The problem is both CFS and depression are characterized by very similar profiles. Imagine a patient who approaches a doctor and

tells him they feel depressed and tired all the time."

Researchers say their study, which appears in the August issue of the *International Journal of Psychophysiology*, is the first to use electrodermal activity and skin temperature to look at differences between people with chronic fatigue syndrome, those with major depression, and healthy individuals. Electrodermal activity measures the electrical activity within the skin and was measured by placing electrodes on each hand. The study showed that people with CFS scored much lower on measures of how well electricity passes through the skin compared with those with depression or healthy individuals. Skin temperatures were also much higher among those with chronic fatigue syndrome than in the other two groups.

Researchers believe the results suggest that despite sharing similar symptoms with depression, people with CFS can be identified by physiological measures: skin temperature and electrical activity within the skin. The authors also say this study adds to the growing body of evidence that demonstrates that CFS and depression are distinct disorders with distinct neurobiological profiles, consistent with different disease profiles.

"New Approach May Make It Easier to Diagnose Complicated Disorder" by Jennifer Warner at WebMD.com, "Skin Offers Clues to Chronic Fatigue Syndrome" at ImmuneSupport.com. Int J Psychophysiol. 2004. Aug;53(3): 171-82. *Electrodermal dissociation of chronic fatigue and depression: evidence for distinct physiological mechanisms.* Pazderka-Robinson H, Morrison JW, Flor-Henry P. PMID: 15246671.

IonCleanse... continued from page 9

autism, allergies, respiratory disorders, joint or muscular pain, circulatory disorders, headaches, and lactic acid toxicity (common in CFS and FM). Check with your health-care professional if you have any concerns about this treatment.

CONTRAINDICATIONS

The following should not use the IonCleanse system:

- ◆ Anyone who has a pacemaker or any other battery-operated or electrical implant
- ◆ Anyone on heartbeat-regulating medication
- ◆ Anyone who has had an organ transplant
- ◆ Anyone taking a medication the absence of which would mentally or physically *incapacitate* them (e.g., psychotic episodes, seizures, etc.).
- ◆ Pregnant and lactating women. They should not use the IonCleanse because it pulls toxins out of tissues and fat. These toxins *could* impair

fetal development and *will* become part of the milk fed to an infant.

RECOMMENDATIONS

- ◆ Clients with low blood sugar should eat before an IonCleanse session. The IonCleanse tends to lower blood sugar in diabetics and may do so with those who are hypoglycemic.
- ◆ Clients should take certain medications after an IonCleanse session. Many medications must maintain a certain blood level to be effective, such as blood pressure medication. Schedule an IonCleanse session just before taking such medication so proper blood levels are maintained.
- ◆ Do not take supplements two hours before an IonCleanse—take them afterward.
- ◆ Most clients on dialysis, taking insulin, or experiencing congestive heart failure are able to use the IonCleanse. This gentle detoxification will help the body eliminate

toxins which the kidney and heart cannot eliminate on their own, but will not interfere with medications or deplete insulin levels.

- ◆ Most clients who have a metal joint implant are able to use the IonCleanse, but some have found the exposure to an electromagnetic field to be uncomfortable. If you feel uncomfortable, stop the treatment immediately.
- ◆ One or two 30-minute sessions a week is typical. Some patients under a doctor's supervision do three a week for two weeks and then take a three-week break. The number of sessions needed varies greatly among clients. The company says that 10 to 14 sessions are often needed to relieve symptoms; then, maintenance sessions are done less frequently.

Please contact Carol if you are interested and invite family and friends to participate in this special offer. (dfwfid58@comcast.net or 817.283.1115)

SHOPPING DONATIONS

Way to go shoppers! Our shopping totals this time around are:
iGIVE.COM \$65.35

If you shop online, please join *iGive.com*. Many popular merchants participate in their program, each donating to our group with **no added cost to you!** *iGive.com* does not sell any personally identifiable information. To join, go to: *iGive.com/CFMofDFW*. After you've joined, just sign-in at *iGive.com* to shop.

KROGERS \$89.18
TOM THUMB \$28.45

Our Tom Thumb number (9807) is now good at any Safeway-owned store in the country, including Vons, Randalls, Pavilions, Carrs, Dominicks, and Genuardi's. Our group number is the same for all stores, so if you have friends or family in another part of the country who shop at one of these stores, ask them to put our number (9807) on their card at the Customer Service counter. Our group will reap the benefits. For questions or information about the shopping donations program, please contact Carol.

Thank you for your faithful support!

HOPE FOR FM PATIENTS

When pain specialist Dr. David Johnson (812.425.2662) tested his FM patients for viruses, the results showed they were each testing at abnormal levels for three to nine viruses out of 17 checked.

He's using anti-virals to try to suppress the viruses, which can take years. In the meantime, Johnson says, "I want to get the word out to physicians to test for the virus, use the anti-virals, and let's have some input and see if we can eradicate this condition." The treatment is also helping CFS & IBS sufferers.

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UPCOMING MEETINGS

OCTOBER 19 BIO CRANIAL, ACUPUNCTURE, & BRT
TUES., 7:00–9:00 P.M.

JERROD WRIGHT, D.C. & JUD KENDALL, D.C.

Dr. Wright and Dr. Kendall are trained in the Bio Cranial technique mentioned in the story on FM recovery on page one. Join us to learn more about this treatment and their experience with it.



They also employ other treatment options depending on a person's needs. Working with all three communication pathways of the body, they either remove interference from or stimulate each pathway as needed using chiropractic for nervous system, BRT for the endocrine system, and acupuncture for the meridian system. This brings balance and healing so the body can heal itself.

The Body Restoration Technique (BRT) gets at the core of hormone imbalances and resistive hormone syndromes without using supplements or pills. It is a bio-energetic, non-invasive method of "cracking the case" of weight problems, thyroid-related conditions, and many other hormone imbalances. (*wrightwellness.com*, 817.488.4186)

NOVEMBER 6 FM & CFS: RESEARCH & TREATMENT
SAT., 2:00–5:00 P.M.

KENT HOLTORF, M.D., KENNETH KIPPELS, M.D., & LARRY SHARP, D.O.

Join us to hear about the latest in innovative research and treatment options for CFS and FM from Fibromyalgia and Fatigue Center doctors. The use of bio-identical hormones to address endocrine issues will be presented. There will also be a discussion of underlying issues, such as heavy metal toxicity, neurotoxins, and coagulation defects (see article on page one for details).

NOVEMBER 16 HELPFUL SOLUTIONS
TUES., 7:00–9:00 P.M.

GROUP FACILITATOR

There have been requests for more meetings where members share what's working for them to improve their health and help them cope. We'll have one "Helpful Solutions" meeting each quarter, either in addition to the regular monthly meeting or as the actual monthly meeting. Four members have been recruited to take turns facilitating these meetings using a "Toast Masters" technique to ensure that no one dominates and that all who wish to speak will have an opportunity. Join us for this informal format, get to know each other, and learn what's working for others!

DECEMBER 11 HOLIDAY STRESS BUSTER – GENTLE R & R
SAT., 3:00–4:00 P.M.

GENTLE R & R COORDINATOR, SUZANNA

Ease into the holidays with a "Gentle R & R" session led by group member, Suzanna. Take the edge off your holiday season demands as she leads us through healing techniques for the mind and body. The self-help relaxation routine will include some gentle stretching, breathing exercises, and guided meditation. Bring an exercise mat (or large towel), a neck support pillow, if needed, a long strap, and a bottle of water. Please RSVP to Suzanna (Suzannaflex@msn.com), our Gentle R & R Coordinator.

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. 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!

TOP LYME BOOK—HALF PRICE

The outstanding new book, *Beating Lyme Disease: Using Alternative Medicine and God-Designed Living*, by Dr. David Jernigan is available to our members for \$19 plus shipping. This 410-page hardcover sells for \$39.95 on amazon.com. Reviewers give it five out of five possible stars. Dr. JoAnn Whittaker of Bowen Labs states, "This book is fantastic! It covers so many important issues that I have been trying to tell people for years." You can read more about this book at amazon.com. Contact Carol to order this book.

PFIZER DRUG DISCOUNTS FOR UNINSURED

Pfizer allows uninsured U.S. residents to buy prescription drugs manufactured by the company at a 15% to 37% discount. Individuals without prescription drug coverage who make less than \$31,000 annually and families that make less than \$45,000 qualify for average discounts of 37%. Medicare beneficiaries who have exhausted their \$600 subsidy qualify to pay a flat fee of \$15 per prescription. Enroll by phone (toll-free 866.776.3700) or online at pfizerhelpfulanswers.com. (Find this article at: www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=25341).

MAILING LIST UPDATE

With over 800 folks receiving the newsletter, it's time to clean up the membership list again! We need to verify that those receiving the newsletter wish to receive it! To continue receiving the newsletter, you must contact Carol (dfwcfids58@comcast.net, 817.283.1115).

Once you have been "renewed," a star will appear by your name on the mailing label; new members should already see a star on their label. Anyone who has not renewed by April 1, 2005 will be dropped from the mailing list. Even if you're receiving the e-version, please go ahead and contact Carol. We want to keep our list accurate, particularly for rare, special mailings.

Our quarterly newsletter is free although donations of \$5 or \$10 a year (or more) are always welcome to cover expenses. (Make checks out to CFS/FM Support Group, 513 Janann St, Euless TX 76039.) All donations are tax-deductible.

Don't Forget - Renew Your Subscription Today!



RETURN SERVICE REQUESTED

c/o Carol Stevering
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Euless, Texas 76039

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