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

- ONLINE DRUG SAFETY CONCERNS 1
- PRESCRIPTION ASSISTANCE..... 1
- NARCOLEPSY DRUG FOR FM..... 2
- FM CLINICAL DRUG TRIAL..... 2
- HEALTH CARE COVERAGE..... 2
- DISABILITY WARS..... 3
- FM: TIPS FOR FEELING BETTER..... 3
- FM: MUSCLE BLOOD FLOW..... 4
- JUNK FOOD ADDITIVES..... 4
- GENETICALLY ENGINEERED CORN..... 5
- ORGANIC FOOD CO-OP..... 5
- CFS & GENETICS..... 6
- PRESS BRIEFING..... 6
- CFS AD CAMPAIGN..... 7
- HOLDERMAN INTERVIEW..... 7
- CFS GENE EXPRESSION..... 7
- FAMILY RISK FOR CFS..... 7
- SHARP NEW PRACTICE OPENS..... 8
- HOUSING SUPPORT..... 9
- TISSUE/BLOOD BANK UPDATE.....10
- EMAIL PRAYER GROUP.....11
- UPCOMING MEETINGS.....11
- NCF RESEARCH GRANTS.....12

SAFETY CONCERNS ABOUT ORDERING DRUGS ONLINE

Jennifer Fix, a former leader of our support group, appeared last Fall as part of a panel on the McCuiston Program on KERA television. Jennifer is a pharmacist who owns the Medicine Shoppe in Haltom City. She is also a past President of the Texas Pharmacy Association.

This program can be viewed at www.McCuistonTV.com. Click on the November 20th show.

Also on the panel was Marv Shepherd, Ph.D., Director of Pharmacoeconomics at UT Austin. He stated that “drug thugs”, or felons from around the world, are operating numerous websites supposedly based in Canada, selling counterfeit drugs that contain little to no active ingredient.

Shepherd cited an FDA study in which 11,000 drug websites with “Canada” in their name were researched. They found that only 214

were actually located in Canada.

Shepherd stated that there is also concern about online firms actually based in Canada. According to Canadian law, Health Canada (the equivalent of our FDA) is not required to approve drugs that are imported into Canada for the purposes of exporting them out. Only drugs that are sold to Canadian citizens have to meet Health Canada standards.

Therefore, a customer in the US who orders from an online Canadian Pharmacy may very well be getting drugs that originated in China or Pakistan and are counterfeit.

Jennifer stated that the counterfeits are so good that even pharmacists can’t tell the difference. The pills look exactly like the real thing, as does the packaging and even the

continued on page 2

PARTNERSHIP FOR PRESCRIPTION ASSISTANCE

Many patients struggle to pay for their medications, but a free information clearinghouse can help them take advantage of numerous assistance programs covering more than 2,500 brand-name and generic drugs. The Partnership for Prescription Assistance (PPA) offers a simple way to access more than 475 public and private patient assistance programs, including those offered by compa-

nies belonging to the Pharmaceutical Research & Manufacturers of America (PhRMA).

The PPA is committed to increasing awareness of patient assistance programs and boosting enrollment of eligible patients who lack prescription drug coverage. Best of all, the clearinghouse is quick and easy to use: A short phone call or Internet session is all it takes. Patients can

simply fill out the application form online or call the toll-free number to have a trained specialist guide them through the steps. There is no charge for either service, and the average time to complete the process is only 10 minutes.

To find out more, patients and their caregivers can call toll-free 1-888-477-2669 or visit www.pparx.org

NARCOLEPSY DRUG HELPS FM PATIENTS

The results of a recent eight-week study show that Xyrem® (sodium oxybate) significantly reduces pain and improves sleep in Fibromyalgia patients. This research was presented at the annual meeting of the American College of Rheumatology in San Diego in November.

“These results are very exciting because - for the first time - we have results that provide evidence that a product which improves the quality of sleep during the night also has a dramatic effect on reducing pain,” said the study’s lead researcher, I. Jon Russell, M.D., Ph.D., an associate professor of medicine at the University of Texas Health Science Center in San Antonio.

Dr. Russell and his colleagues conducted a randomized, double-blind, placebo-controlled, multicenter clinical trial. They recruited 188 patients, of whom 147 [78%] completed the trial. Sixty-four patients received a placebo, 58 took 4.5 gms of oxybate a day, and 66 took 6gms of oxybate a day. They administered the drug orally twice a day during the eight-week trial.

In the study, the most commonly reported adverse events included nausea and dizziness and were dose-related [4.5g, 15% and 6.7%,

respectively; placebo, 9.2% and 1.5%].

Sodium oxybate, the active ingredient in Xyrem, is a sodium salt of gamma-hydroxybutyrate (GHB), a substance with a history of abuse when acquired illicitly and used illegally. Abuse of illicit GHB has been associated with adverse CNS events including seizures, respiratory depression and profound decreases in level of consciousness, with instances of coma and death. Xyrem is a central nervous system and respiratory depressant. Therefore, the use of other CNS depressants or alcohol is contraindicated in patients receiving Xyrem.

Xyrem is a Schedule III drug under the Controlled Substances Act and is only available through a restricted distribution system called the Xyrem Success Program.®

Xyrem, marketed by Orphan Medical, Inc., a subsidiary of Jazz Pharmaceuticals, was approved by the U.S. Food and Drug Administration (FDA) in October 2002 as the first and only treatment for cataplexy (sudden loss of muscle tone) in patients with narcolepsy.

For more information see fmaware.org/media.htm.

Online Drug Safety...continued from page 1

package inserts. Only lab testing can reveal whether a drug is real or fake.

Sixty percent of the counterfeit drugs sold online contain no active ingredient. The remaining may contain only a fraction.

Those who are able to physically go to Canada and buy from a pharmacy that sells to Canadian citizens can

be confident about the quality of the drugs they are getting.

But the chance of ordering from a Canadian website, that may or may not be in Canada, is a risky business.

FM CLINICAL DRUG TRIAL

Acurian, a company which prescreens applicants for clinical trials, is advertising a new study of an investigational drug for the pain caused by fibromyalgia. Although the advertisement was seen in the Sacramento, California, area, there are apparently doctors throughout the U.S. who are participating. No further information on what the drug is, or who and where the doctors are, is available from the company without a successful application.

The website is www.acurian.com, or call toll-free: 1-800-707-2650.

Since additional information on this study is currently unavailable, anyone interested should discuss it with their medical caregivers and/or contact the company.

Thanks to www.co-cure.org

HEALTH CARE COVERAGE OPTIONS

The National Association of Health Underwriters has created a database that provides information on health insurance options for low-income U.S. residents, people who change jobs and those who have pre-existing health conditions.

The Health Care Coverage Options Database provides a state-by-state list of public health insurance programs for low-income residents, such as Medicaid and the State Children’s Health Insurance Program (SCHIP). It also details 32 states that offer high-risk insurance pools for those with pre-existing health problems.

The database can be accessed at <http://www.nahu.org/consumer/healthcare/>

FINDING SUCCESS IN THE DISABILITY WARS

by Justin Frankel and Jason Newfield

This outstanding article can be found online at cfids.org. Click on archives, then Chronicle. It's in the 2004 Fall issue.

"The expert authors offer practical tips to guide you through the minefields laid by your insurer. Read this and you'll have a fighting chance of winning your long-term disability claim."

The authors describe the most common positions taken by insurance companies when denying claims. They go on to outline the most common claim requirements made by companies and how you can meet those requirements.

There is also a great section entitled "Five Common Long-Term Disability Claim Minefields . . . and what you can do to avoid them."

According to researchers at the Centers for Disease Control (CDC), 25 percent of Americans with CFIDS are unable to work due to the illness. The 2004 study also showed that those who continued to work lost one-third of their annual income to reduced hours and other factors related to CFIDS.

About the authors

Justin Frankel and Jason Newfield are the founders of Frankel & Newfield, P.C., a New York law firm focusing on disability insurance claims and litigation. They are the authors of *LTD Management*, a quarterly publication addressing various issues concerning disability claims. They have handled a multitude of disability insurance claims, appeals and litigation involving chronic conditions, including CFIDS and FM. They can be reached with any questions at 516-222-1600, or by e-mail at jcf@frankelnewfield.com or jan@frankelnewfield.com. Or visit longtermdisabilityclaim.com.

EXCERPT FROM "THE COMPLETE IDIOT'S GUIDE TO FIBROMYALGIA":

QUICK AND EASY TIPS FOR FEELING BETTER

by Lynne Matallana

When we deal with a big problem, we often feel that it will take a big solution to help resolve the problem. Luckily, this is not always the case. Many difficult symptoms of fibromyalgia can be dealt with via small lifestyle changes or easy, unsophisticated treatments.

PROBLEMS WITH COGNITION AND MEMORY

Tip: Slow down the pace of your life.

Explanation: Among the more common fibromyalgia symptoms are cognition and memory problems, affectionately referred to as fibro fog. Many memory problems result from doing too many things at one time or continuing to function even when you are overly fatigued. Slowing down and paying attention to the amount of thoughts and activities you are processing through your brain at one time can help reduce the symptoms of foggy memory. After you have reduced the amount of information you are processing, practice the following: Repeat things to yourself, write things down, and eliminate things in your environment (noise, interruptions, excessive light, bad smells, and so on) that distract or over-stimulate you. If you have to do something that requires a lot of concentration, try doing it at a time when you feel less fatigued.

SORE, STIFF MUSCLES

Tip: Soak in an herbal bath and lightly massage your muscles with an herb-filled washcloth.

Explanation: A warm or hot-water bath, filled with a mixture of soothing herbs, can calm sore muscles and relax your mind. Deep, moist heat can even calm your internal organs.

Take a small handful of each: valerian, lavender, linden, chamomile, hops, and burdock root; simmer the herbs for 15 minutes in two gallons of water. Strain the herbs from the infused water and place them in a soft cotton washcloth. Pour the infused water into your bath, adding enough warm water to fill the tub three-quarters of the way full. Soak in the herbal water for 20 to 30 minutes. (If you have dry skin, reduce the amount of time you spend in the water.) Use the herb-filled cloth to lightly massage areas of your skin or muscles that are particularly painful or tense.

FEELINGS OF STRESS, LONELINESS, AND FEAR

Tip: Adopt a pet.

Explanation: Research shows that pets have a therapeutic effect on their owners. They can actually reduce a person's blood pressure, muscle tension, and other physical stress responses. They also have a positive effect on their owner's mood. Studies have shown the pet owners live longer, healthier lives. Pick a pet that fits your interests, temperament, lifestyle, and environment. Anything from a tropical fish, dog, bunny rabbit, or even a horse will have that affect; a pet has the ability to divert your attention away from your pain and beyond yourself.

EXCESSIVE PAIN WHILE TRYING TO DO HOUSEHOLD CHORES

Tip: Pay attention to your back. Household chores can put extra strain on your spine and the muscles in your back.

continued on page 3

Explanation: Fibromyalgia pain can be exacerbated by simply doing the normal daily activities of caring for your home. To protect yourself from hurting your back or causing additional body strain, remember to practice the following:

--When you attempt to pick up a heavy object, always bend from the knees, not the waist. As you lift, hold the item as close to your body as possible.

--While talking on the phone, do not cradle the phone between your ear and shoulder. Always hold the phone with your hand, or better yet, use the speakerphone or headset.

--Store pots, pans, and bowls in cabinets that are at waist level. This eliminates the need to bend and lift these heavy objects.

--Eliminate reaching and bending by using long-handled dusters, mops, and cleaning brushes. Use a "grabber-device" to help pick up lightweight items or things out of your easy reach.

--When doing laundry, don't overload a laundry basket and carry it through your house or down your stairs. Instead, place a few clothes in a dirty towel or sheet. Make the bundle light enough to carry or drag the bundle behind you. There is no need to carry laundry down a staircase when you can drop it over a railing.

SORE FEET, BRUISES, AND STOMACH UPSET

Tip: Using earthy solutions can relieve pain, fatigue, and a variety of other symptoms.

Explanation: Earthy solutions include plants, herbs, and natural food products that can bring relief to health problems. Remember, however, that just because something is derived from a plant or is

called natural does not mean that it is always safe. Use common sense and always tell your health care professional what you are taking. Examples of earthy solutions include the following:

--Sore feet. Soak sore feet in peppermint and chamomile tea.

--Bruises. Rub in Arnica oil or cream. Arnica montana is a daisy-like mountain flower that seems to relieve bruising and swollen joints and muscles.

--Intestinal upset. Acidophilus changes the intestinal flora and reduces the chance of getting diarrhea, stomach aches, gas, and bloating.

--Fungus. Tea tree oil is helpful in eliminating fungal infections including athlete's foot.

--Stomach upset. Chamomile tea (made from the chamomile flower) can help relieve nausea and menstrual cramps, and promote sleep.

--Cut or insect bite. Lemon oil can act as an antibacterial antiseptic for minor cuts and insect bites. Lemon juice is a digestive stimulant that helps with digestion and constipation.

--Anxiety. Lavender tea possesses the ability to calm the nervous system and relax your mood. Even the smell of lavender can have a calming effect.

*Editor's note: The preceding five tips are excerpted from "The Complete Idiot's Guide to Fibromyalgia" by Lynne Matallana, reprinted with permission, and copyright © 2005 Lynne Matallana. There are 25 terrific tips in the chapter from which these 5 tips are taken. To buy the book, please click on the following link:
<http://www.immunesupport.com/shop/Books.cfm>*

ImmuneSupport.com 11/05

DECREASED MUSCLE BLOOD FLOW IN FM PATIENTS DURING EXERCISE

Investigators used contrast enhanced ultrasound imaging of muscles to monitor the blood flow of 10 FM patients and 10 controls during and after exercise.

The FM patients showed decreased muscle blood flow compared to controls during exercise. These results support the suggestion that muscle ischemia (deficient blood flow) can contribute to pain in FM, possibly by maintaining the central nervous changes such as central sensitization / disinhibition.

(See <http://www.wellcome.ac.uk/en/pain/microsite/science4.html>) for a helpful discussion about pain mechanisms and definitions of terms such as "central sensitization.")

*Eur J Pain. 2006 Feb;10(2):137-44.
Elvin A, Siosteen AK, Nilsson A, Kosek E.
PMID: 16310717 [PubMed - in process]*

Immunesupport.com 11/05

JUNK FOOD ADDITIVES STOP NERVE CELL GROWTH

Mixing the common additives aspartame an artificial sweetener and monosodium glutamate (MSG) causes nerve cell damage, say researchers at the University of Liverpool. The results from a two-year study were recently published in the journal Toxicological Sciences.

The researchers found the additives were much more potent in combination with each other than on their own. Mice were exposed to concentrations of MSG and aspartame relative to what a child would receive in an average snack and

continued on page 5

GENETICALLY ENGINEERED CORN PRODUCING HERBICIDES IN YOUR GUT?

Awidely cultivated variety of genetically engineered corn may be slowly poisoning American consumers.

Dupont's Pioneer Liberty Link corn was bioengineered to withstand high levels of the toxic herbicide glufosinate. Enzymes in the plant actually break down the herbicide, making it less toxic to the plant, thereby allowing farmers to apply higher levels of herbicides to the plant and surrounding weeds.

Scientists are now finding that enzymes in the human gut are likely "reactivating" the herbicide within our bodies. A recent study on rats found that 10% of the chemicals were reconverted back to the toxic herbicide within the digestive tract of the animal. Another study on goats found a full 30% of the herbicide was rebuilt in the gut.

Glufosinate is known to cause nerve damage and is a likely endocrine disruptor. Scientists are also concerned that by reactivating the toxic chemical in the digestive tract, it is likely killing off beneficial bacteria necessary for healthy digestion.

Learn more:
http://www.organicconsumers.org/2006/article_637.cfm

THE ORGANIC FOOD CO-OP: EAT WELL AND SAVE MONEY!

Deborah, a member of our support group, recently shared some information about her experience with a local organic food co-op. She gets organic produce at a lower price than conventional produce and says she has never eaten so well!

Your Health Source Co-op was formed to bring organic produce into our area at great prices with many convenient pick up locations throughout the Metroplex. They buy from organic suppliers and local suppliers and work to provide the finest and most interesting variety of produce available. Joining a co-op makes it possible to buy directly from farms without a middleman.

This Co-op offers a mixed produce variety basket, which is delivered twice a month. The Your Health Source email list will let you know what is included in each delivery. The amount of food varies between 15-30 pounds. The amounts of any one item are generally reasonable - one or two lettuces, 2 1/2 pounds of apples or bananas, etc.

A sample delivery: Braeburn apples, bananas, Marrs oranges, D'Anjou pears, tomatoes, green beans, broccoli, carrots, celery hearts, redleaf lettuce, white onions, russet potatoes, sweet potatoes, zucchini.

A full order is \$40 and feeds a family of 4 for 2 weeks. Small households may only want half an order, which feeds 2 people for 2 weeks. An additional fruit share is also available, as is a vegetable share.

There is a \$25 fee to join the co-op and it is suggested that you try the co-op for 3 delivery periods. If after the initial 6-week trial period, you find that the co-op is not for you, your \$25 check is returned to you.

Health Source also offers nutrition classes, as well as online food preparation guidelines and recipes through their e-group. For more information check out their website: www.yourhealthsource.org. You can also join an open discussion on health at HealthSourceGrp-subscribe@yahoogroups.com, or a recipe exchange at HealthSourceGrpRecipeExchange-subscribe@yahoogroups.com.

To join the co-op contact:
Monica Brown
2136 FM RD 51 N
Weatherford, TX 76085
817-793-3509
Monica@YourHealthSource.org

*Learn more and sample fresh produce!
see upcoming meetings on page 11*

Junk Food Additives...continued from page 4

drink. Researchers were surprised to see the additives interfered with nerve signaling systems and actually stopped the nerve cells from growing.

Aspartame is commonly found in diet drinks, candies and flavored

medicines, while MSG is frequently found in chips, processed cheese and many processed foods.

Learn more: <http://www.organicconsumers.org/toxic/msg010306.cfm>

CFS & GENETICS

In late April the Centers for Disease Control and Prevention (CDC) announced that CFS has a biological and genetic basis. CDC Director Julie Gerberding called the study “groundbreaking” and hailed its novel methodology.

CDC BACKGROUND

The lack of specific diagnostic criteria since CFS was first defined 20 years ago has led to debate over whether the cause could be an infectious agent, psychiatric, or something else--and made research funding for the disorder highly political. In 2000, a CDC division director lost his job after the agency diverted \$12.9 million that Congress had instructed CDC to spend on CFS research to other infectious disease studies. The agency agreed to restore the money over 4 years and launch a major study.

THE NEW STUDY

The new project, led by William Reeves, CDC’s lead CFS researcher (who had blown the whistle on the diverted funds), took an unusual approach. Instead of recruiting patients already diagnosed with CFS, the CDC surveyed one-quarter of the population of Wichita, Kansas by phone to find people suffering from severe fatigue. Several thousand then underwent screening at a clinic for CFS.

Out of this survey, 172 people, most of them white middle-aged women, were deemed to fit the criteria for CFS (58) or CFS-like illness (114). A total of 227 people, including 55 controls, then underwent an extensive 2-day battery of clinical measurements, including sleep studies, cognitive tests, autonomic nervous system function, biochemical analyses,

gene expression and gene mutation studies. This part of the study alone cost upward of \$2 million, says Reeves.

In another unusual step, the CDC’s Suzanne Vernon then handed this massive data set to four teams of outside epidemiologists, mathematicians, physicists, and other experts. Over a six-month period, the four teams independently examined the 500 clinical measures and 20,000 measures of gene expression. Some groups also looked for associations between CFS and almost 500 common mutations in nearly 50 genes involved in the hypothalamic-pituitary-adrenal (HPA) axis. (A great deal of previous research has shown this axis to be involved in CFS.)

THE RESULTS

Fourteen papers produced as a result of this study were published in the April 2006 issue of the journal *Pharmacogenomics*. The fruits of this study, the most detailed and comprehensive clinical study on CFS to date, have garnered a great deal of media attention.

Researchers found that the patterns of expression of about two dozen genes involved in immune function, cell signaling, and other roles are different in CFS patients, and provide what Harvard University CFS researcher Anthony Komaroff calls “solid evidence” for a biological basis of CFS. They dispel the notion that “this is a bunch of hysterical upper-class professional white women,” says Reeves.

Reeves also said that CFS patients consistently exhibited particular genetic sequence variations “in certain genes that are related to those parts of the brain activity that mediate

continued on page 8

PRESS BRIEFING HIGHLIGHTS

During the press briefing on this study, Dr. Reeves made the following statements:

- Only 16% of the CFS patients identified in the study had been previously diagnosed and treated.
- One-quarter of CFS patients are on disability or out of work.
- People with CFS are as impaired as people with Multiple Sclerosis, people with AIDS, or those undergoing chemotherapy. They’re not going to die, but they are as impaired.

Full press briefing:

www.immunesupport.com/library/show-article.cfm?id=7141&T=CFIDS_FM

Co-cure.org

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 (CFS) and fibromyalgia (FM). The CFS/FM Support Group of DFW is a clearinghouse for information about CFS & FM. 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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CFS PRINT ADS APPEAR IN NATIONAL MAGAZINES

As part of the CFS Public Awareness Campaign, a full-page color print ad about chronic fatigue syndrome appears in the July issues of Ladies' Home Journal and Better Homes and Gardens. These two magazines have a combined readership of more than 20 million, giving us the opportunity to elevate CFS in the minds of millions of Americans.

The ad depicts the impact of CFS and educates people about the symptoms of the illness. It carries both the CDC and the Department of Health and Human Services logos, clearly signaling that CFS is a public health concern. The ad points people to the CDC website where new content about symptoms, diagnosis and treatment are now available. The website is still under construction, and additional content will be added later this summer. Go to www.cdc.gov/cfs to view the content that has been posted so far.

The print ad also introduces the campaign slogan, "Get informed. Get diagnosed. Get help." This call to action will appear on all the public awareness materials distributed as part of the CFS public awareness campaign, including TV and radio PSAs and the traveling photo exhibit.

Look for the ad in Ladies Home Journal and Better Homes and Gardens on newsstands nationwide.

Eileen Holderman, a new Texas resident and a Trustee of the New Jersey Chronic Fatigue Syndrome Association (NJCFSA), recently did an interview about Lobbying and CFIDS advocacy. Hear the interview at the NJCFSA web site: www.njcfsa.org

GENE EXPRESSION: CAUSE OR EFFECT?

Lighthouse Editorial

CFS researcher and clinician Paul Cheney has pointed out to patients the difference between genotype and phenotype. Genotype consists of the genes one inherits at birth – the DNA code that basically does not change. Phenotype refers to the fact that one's genes may, at various times, be switched on or off. The switch is like a dimmer switch – the genes can be switched on high, moderate or low. Phenotype refers to which genes are "on" or "off", and to what degree they are "on".

"Genetic mutations" or "common genetic changes" typically refer to one's inherited genotype, which generally does not change throughout your life. "Gene expression" refers to one's phenotype, which is rather dynamic, shifting during one's lifetime.

Perhaps most importantly, long before this study came out, Dr. Cheney noted that not all - or even most -

changes in gene expression precede an illness. Many changes may be a response to the illness, not a cause. Therefore, differences in gene expression between healthy folks and CFS patients may say more about how the body responds to or compensates for CFS than about what causes CFS. (Of course one might be able to theorize about the cause(s) of an illness by looking at how the body compensates for it.)

The CDC study looked at both genetic mutations and gene expression, according to Dr. Vernon, and found that CFS patients differed from healthy controls in both. However, when reading all the various articles about this study, it can be difficult to determine whether genetic mutations or genetic expression are being referred to. And it would appear to matter since genetic mutations would presumably precede the illness, whereas gene expression might or might not.

WHAT IS YOUR FAMILY'S RISK FOR CFS?

Researchers surveyed CFS patients to determine how many family members also had CFS. They found the following incidence rates:

Children: 5.1%
Spouses/Partners: 3.2%
Parents & Siblings: 1.1%
2nd & 3rd Order Relatives: 0.8%

The occurrence rate of CFS in the general population is 0.42%.

A little math reveals that children of CFS patients have a risk factor of contracting CFS twelve times greater than the general population. Spouses/Partners have a 7.6 fold increased risk. Parents and siblings are just over two-and-a-half times more likely to have

CFS. And second and third order relatives are almost twice as likely to have CFS.

This would certainly seem to uphold recent research on correlations between genetics and CFS. The results concerning the spouses/partners of patients also suggest that there may be an infectious or contagious component. Nationally known CFS specialist Dr. Cheney stated years ago that any such period seemed to be limited to the first year of illness: he didn't really see others in the household of a patient becoming ill after the first year.

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Page Range: 3-13 [2006]

stress response." Those individuals with CFS "have different gene activity levels that are related to the body's ability to adapt to challenges and stresses that occur through life, such as injury and trauma," continued Dr. Reeves.

The genetic variations between those individuals with CFS and those without the disease occur in the hypothalamus-pituitary-adrenal axis (HPA), which affects the body's ability to withstand stresses such as injury and infection.

"Our working hypothesis is that the HPA axis and the brain is [sic] a plastic organ which changes its actual physical architecture, depending on how stress is accumulated over a lifetime," Dr. Reeves explained. "To some extent, genetics determine how you react to these stressors, and, more important, they actually determine your subsequent reaction to stress later during the life span."

Five common genetic mutations (or polymorphisms) found on three genes also clearly distinguished the CFS patients from the healthy controls. These inherited genetic variations also clearly fell into three distinct groups among the CFS patients. The CFS subgroups had genetic profiles that correlated with certain prominent symptoms. The first CFS subgroup was marked by particularly extreme fatigue. The second CFS subgroup was characterized by heart-rate variability, differences in cortisol, and sympathetic nervous system differences. The third subgroup was primarily menopausal women.

The three genes that distinguished between the healthy controls and the CFS patients encode information for (1) the glucocorticoid receptor, (2) serotonin, and (3) tryptophan hydroxylase.

IMPLICATIONS

The results of the study are good news for those dealing with CFS. The findings will increase the ability to predict who is susceptible to the disease. "Knowing the molecular damage involved will help us devise effective therapeutic intervention and control strategies," said Dr. Vernon. And will "help us identify better ways to more effectively diagnose the illness, and to come up with more effective treatments," continued Dr. Reeves.

FUTURE RESEARCH

Reeves stated, "One of our caveats is that it is a small study." Currently, a team of researchers is collecting data on CFS from a population sample of 30,000 people in Georgia. They plan to repeat the study with at least 100 more CFS patients. Vernon says her group is also validating the gene-expression results and will hold another computational exercise next month at Duke University in Durham, North Carolina, with a larger data set.

Later this spring, the CDC is launching a media and education campaign to promote CFS awareness. "There is no questions that chronic fatigue syndrome is a real condition," says Dr. Reeves. "It is a serious public health problem.

DONATIONS

Once again folks, you've been busy and we thank you for your efforts!

Donations since October 2005:

- iGive.com..... \$57.48
- Kroger \$354.88
- Safeway/Tom Thumb..... \$108.98

For questions or information about the shopping donations program, or if you would like to make a donation to our support group, contact Carol Sieverling (treasurer@dfwcfids.org).

THANK YOU FOR YOUR FAITHFUL SUPPORT!

DR. LARRY SHARP OPENS NEW PRACTICE

Dr. Larry Sharp's new practice, scheduled to open July 24, will provide a setting for him to utilize new treatment protocols he has learned while working the past 6 months with Dr. William Cowden, a nationally known doctor who treats a variety of conditions including Lyme Disease and CFS. Dr. Cowden will be returning to Fort Worth to work with Dr. Sharp on Fridays and/or Saturdays, one or more times a month, at Dr. Sharp's new office.

The new office is currently being renovated with materials, including paint and flooring, for those with environmental sensitivities.

continued on page 12

CFS/FM SUPPORT GROUP OF DFW

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(817) 886-9262

HOUSING & HEALING SUPPORT FOR PEOPLE WITH CFIDS & FIBROMYALGIA

ReCreation Community Housing Association is developing a Health and Wholeness Housing Community to help meet the needs of people with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) and Fibromyalgia. We are doing this because we believe that living in community, especially a community of peers, dramatically enhances one's life and reduces the sense of isolation which so often plagues those disabled with CFIDS and Fibromyalgia. Research has shown that living in a community which provides easy and regular social contact with others, especially those sharing similar issues, is highly beneficial.

ReCreation Community Housing Association is a not-for-profit organization founded by Dr Judy Warrington. After completing several years of research in the late 1980s the first Recreation Health and Wholeness Center was opened. The Center has provided guesthouse, retreat and respite facilities in Massachusetts for the last 16 years. Judy is currently in the process of expanding her Gloucester Harborfront Retreat to provide greater accessibility for her CFIDS/FMS guests. (cfidsretreat.com)

Through research, facilitation and involvement with support groups, counseling and hosting members of the CFIDS/FMS Community, and while living with their own disabilities, a small group recognized that there was a desperate need for permanent, affordable, accessible and highly supportive housing for people with CFIDS/FMS. It took a small band of brain-fogged PWCs a further 2 years to commit the vision to paper!

Here is what we have accomplished so far:

After careful consideration of needs and economics, we acquired land in Windsor, Aiken County, South

Carolina. The area offers relaxed un-pressured living a natural setting and warm climate. There are many walks, trails and gardens in the countryside and the historic city of Aiken. Aiken offers cultural advantages including the University of South Carolina; a major medical center and a clinic for alternative whole health practitioners. The area also offers relatively low construction costs because there is no need for basements, heavy insulation or powerful heating systems.

We are now planning the site and community facilities, researching energy saving measures, and designing the most cost-effective housing. We are able to assist qualified low-income buyers with applications for low interest federal loans. We are also seeking public and private funding to help reduce the cost of common facilities.

We are working with engineers, local authorities, lending institutions, governments, contractors and the medical community to ensure that the project is well-executed and well-integrated into the larger community. We are gathering data through a survey on our website about the needs and desires of people with CFIDS and Fibromyalgia so that we can bring all this awareness to bear on our planning.

We intend that the community will run on a cohousing model. Cohousing is a concept that originated in Scandinavia many years ago and is rapidly becoming a very popular way to live in this country. In cohousing, each individual or family owns their own house or apartment, which is fully equipped for private living. However there are also shared community spaces and equipment, which encourage both socialization and conservation of resources. For example, there might be craft rooms, a library, a den for meetings. The possibilities

are endless and are decided upon by residents to meet the needs of the community.

It is intended that the Recreation Health and Wholeness Community consist of individual residences, ranging from suites and apartments to small homes. These will be built around a "village center" which will feature a community building where residents can join together as they choose for meals and other activities. The idea behind this center is to provide opportunities for interaction in both casual and organized gatherings. The "village center" will also have a facility housing offices for mainstream and alternative practitioners, therapists and other skilled professionals who can provide support services in the community. All homes and facilities will be 100% handicapped accessible.

Cohousing communities are run by the residents, who decide by vote or by consensus how the community will operate and what its financial priorities will be in terms of maintaining and enhancing the facilities and in creating social opportunities.

Now we seek like-minded individuals to join our project!

We firmly believe that, no matter how disabled any of us is, we still have something to offer. There is an immense reservoir of talent and experience among those of us who may no longer be able to function at the level we once did. However we still have the knowledge, ability and interest to be able to contribute to a successful project.

We are not asking for money. We are asking that you consider the benefits of this project and learn more about it with the goal, we hope, of having

continued on page 10

you commit to join us in making it become a reality. To achieve that, we would hope you can share your talents when you are able.

By joining together and pooling our strengths we will make a difference! Together we can create reasonable cost housing and resources for people with CFIDS and Fibromyalgia, their families and those practitioners in the helping professions who seek the healthy and wholesome lifestyle we hope to create.

For more information about this

project and how you can participate, please visit our website at pwcco-housing.org. Pictures, sample plans, costs, financing assistance and pre-applications can also be found on the website.

If you would like to consider joining -- or simply want more information -- fill out and submit our Cohousing Survey. Even if you are not considering joining the cohousing community, we would be very grateful for your input because it will help us better meet the needs of our residents.

If you have expertise in any field that we jointly decide could help in the development of the community, we invite you to meet with us and enjoy a complimentary two-day stay at our Gloucester, MA retreat.

Please help spread this message to people who are seeking a better lifestyle. Telephone us at (978) 282 1505 or e-mail us at cfids@fibromyalgiacfids.com.

Dr. Judy Warrington

LIONS CLUB DONATES TO THE CASEY FERRO ME/CFS TISSUE & BLOOD BANK

(This update was posted to the co-cure.org list by Pat Fero, Casey's mother.)

On July 4, 2005, at the age of 23, Casey Fero died in his sleep. In September, a Madison forensic pathologist determined that Casey had Myocarditis, that is, viral infection of the heart muscle. Some medical researchers suggest that there is a link between cardiac problems and chronic fatigue syndrome (CFS).

Casey was diagnosed with CFS at age 9 and again at age 15. It caused him to feel weak, unable to think, and exhausted. He was plagued with headaches, stomach problems, and had major sleep disorder among a list of daily symptoms. Casey persevered and did not want people to know his condition. Early on, he knew that medical help was unavailable and furthermore, he was met with disbelief in the school and in the doctor's office.

As a lasting tribute to Casey, the Fero family, the Wisconsin Chronic Fatigue Syndrome Association, Inc., and Mothers against Myalgic Encephalomyelitis, Inc. (MAME) will create the first universal access

blood and tissue bank for ME-CFS patients.

Sound medical research is the key to understanding the cause of these disorders and to developing treatments that can help patients manage daily living. Many recognized illnesses, such as Alzheimer's, were poorly understood before the creation of tissue and blood banks. Precious gifts of tissue and blood benefit all individuals and families living with illness.

A universal access specimen bank means that any scientist can ask for samples provided that their study meets careful guidelines. The Institute for Viral Pathogenesis (IVP), a Medical Diagnostic Laboratory in Milwaukee, will house specimens. (www.ivpresearch.org) IVP follows government regulated procedures to care for donated tissue and blood.

Right now, we are fund raising to buy an additional freezer for storage at the facility. The cost is about \$10,000, and we're already about half way there! Will you help us make it to our goal? Your contribution is tax deductible through the Wisconsin CFS Association, Federal ID number 39-1614649. You can

send a check to the association at the address listed below. Please specify CASEY'S FUND. You can also donate online at www.wicfs-me.org. Contributions are dedicated to Casey and will not be used for any other purpose.

The Lake Tomahawk Wisconsin Lions Club recently donated \$500 to the fund. This is particularly amazing since Lake Tomahawk is a very small town with about 40 members in the Lions Club. One of the officers has offered to call other Lion's groups on our behalf. He tells me that many groups are very generous. Can you imagine if the fund had \$100 from every club in the county? (I think BIG.)

If you are a member of the Lions Club, or have a friend who is, might you help by getting me your information to pass on to our friend in Lake Tomahawk? I can also send you a copy of the Tissue & Blood Bank Flyer, or send snail mail copies if you plan to attend a Lions club meeting.

Wisconsin CFS Association
747 Lois Drive
Sun Prairie, WI 53590

EMAIL PRAYER GROUP FORMED

One of the losses many of us experience is the opportunity to be part of a faith community. Those who are disabled and largely homebound simply cannot get to church anymore, at least on any kind of regular basis. Too often the relationships that are part of the meaning and power of a faith community are lost. Even those who are managing to work are sometimes too exhausted to do more than rest on the weekends.

In early October a member asked me to pray for her and her 19-year-old son. He's been in Iraq since January. His sergeant from Arlington was killed in a roadside bomb right in front of her son. A week earlier her son was riding with the Sgt., and had he not been re-assigned he would have been killed as well. As it was, a female Air Force soldier was also killed. This moved me to finally act on this idea.

Our prayer concerns list allows members to share all sorts of prayer requests - not just those related to our own health. All are welcome to share their prayer concerns, and it's

good to hear the outcomes of the situations for which we are praying, whenever possible.

Of course you don't have to post requests. You can simply read those of others and pray for them. Prayer is one of the most powerful acts we can engage in. And directing our attention away from ourselves and focusing on the needs of others can be very healthy.

On other lists discussions about faith and beliefs tend to become very controversial and divisive. This is not the forum for such discussions, and the moderators will edit out any such comments. This is

UPCOMING MEETINGS

TUES., JULY 25 EAT WELL AND SAVE MONEY
7:00—9:00 p.m.

Monica Brown, Director of Your Health Source

Monica will teach us how to transition to a healthy organic diet at the lowest cost possible. Bring your taste buds as samples of fresh food from Your Health Source organic produce co-op will be available, plus some healthy snacks and home-made tortillas! Yum!

Location: East Room, Edwards Cancer Center

AUGUST/SEPTEMBER NEW INSIGHTS INTO CFS

Date/Time To Be Announced

Paul Cheney, M.D., Ph.D.

Dr. Cheney returns to update us on his latest research! Watch for further announcements as details are finalized.

SAT., OCTOBER 14 THE BODYTALK SYSTEM

2:00—4:00 p.m.

Lori Carey & Patti Goerdel, Certified BodyTalk Practitioners

The BodyTalk System is a healing modality that addresses the roots of chronic pain and chronic disease. It combines the wisdom of advanced yoga, the insights of modern physics and mathematics, the energy dynamics of acupuncture, the clinical findings of Applied Kinesiology, and western medical expertise. BodyTalk allows the body's energy systems to be re-synchronized so they can operate as nature intended.

Lori taught special education and 10 years ago became a massage therapist. Patti has a background as a surgical technician. They both have been BodyTalk Practitioners full time for the last 3 years.

Presentation will include treatment for a few volunteers selected from attendees.

Location: East Room, Edwards Cancer Center

FEBRUARY 2007 RESTORING LIFE THROUGH DETOXIFICATION

Sharon Price, Certified Nutritionist

Please Be Aware! Many members are quite chemically sensitive. Out of consideration, please try to avoid the most common offenders: fragrances, perfumes, smoke, dry cleaning fluids, household products &/or chemicals, or clothes exposed to these.

simply a place where we can join together in praying with and for one another, regardless of how we experience or define God or what specific beliefs we hold.

The list archives are private, accessible only to other members – just like our other email lists. The list is fully moderated to ensure that requests

are sincere (not spam or otherwise out-of-place).

To join, go to yahoogroups.com and sign up for CFS-FM-DFW-prayer.

Blessings.

Carol Sieverling, M.Div., M.A.C.E.

NCF FUNDS CFS RESEARCH

The National CFIDS Foundation (NCF) announced its latest grant recipients in October 2005. These newest NCF research grants total \$186,000.

Dr. Konstance Knox and Dr. Donald Carrigan are virologists with the Institute for Viral Pathogenesis in Milwaukee, Wisconsin. They are recipients of a \$159,000 NCF research grant titled "The Potential Role of New Infectious Agents in Chronic Fatigue Syndrome."

Dr. Yoshitsugi Hokama is the recipient of a \$25,000 NCF grant titled "Verification of the Site 5 Sodium Channel Effect of the Abnormal Lipid Found in Chronic Fatigue Syndrome Patient Sera."

Dr. Derek Enlander is the recipient of a \$2,000 NCF research grant for

his collaboration with Dr. Jonathan Kerr on a "RNA Gene Expression Study" for CFS/ME patients.

Since 2002, over \$325,000 directed to fund research concepts have originated from the NCF as part of their Research Grant Program.

All donations used for research have come directly from our CFIDS/ME community! A more detailed explanation of each research grant funded by The National CFIDS Foundation is in the winter edition of their quarterly newsletter, which is available on their web site.

National CFIDS Foundation, Inc.
103 Aletha Rd.
Needham, MA 02492-3931
781-449-3535
NCF-NET.org

NEW SUPPORT GROUP
INFORMATION LINE
(817) 886-9262

Get information about our support group, including meeting updates!

Sharp...continued from page 8

They plan to start seeing patients, or at least booking appointments, on Monday, July 24th.

Located just off Interstate 30 at Las Vegas Trail, the office address and phone number is:

8509 Western Hills Blvd, Suite #300
Fort Worth, TX
817-246-7676

CHENEY RETURNS
TO DALLAS/FT WORTH!
SEE INSIDE FOR MORE INFO

RETURN SERVICE REQUESTED

P.O. Box 433
Grapevine, Texas 76099-0433
(817) 886-9262

LIGHTHOUSE
The Newsletter of the Chronic Fatigue Syndrome &
Fibromyalgia Support Group of Dallas-Fort Worth
www.cfids.org

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