

THE CFIDS CHRONICLE

Advocacy,
information, research
and encouragement
for the CFIDS
community

WINTER 2004 ■ VOLUME 17 ISSUE 1

Sleep and CFIDS

Poor sleep affects nearly every person with CFIDS

Unrefreshing sleep was found to be the most common of the eight official chronic fatigue syndrome (CFS) symptoms in a recent U.S. Centers for Disease Control and Prevention (CDC) study, affecting 95 percent of people with chronic fatigue and immune dysfunction syndrome (CFIDS). Eighty-one percent complained of problems getting to sleep or waking up early in the morning, making it the most common “non-case definition” symptom.¹

By Vicki
Walker and
the National
Sleep
Foundation

Primary sleep disorder is also an important rule-out condition as the doctor and patient consider CFIDS as a possible diagnosis. The likelihood of experiencing a sleep disorder also increases with age and weight gain.

According to the Royal Australasian College of Physicians, “[CFIDS] patients usually report a longer time to fall asleep, an increased time in bed awake, and a broken and restless sleep pattern.”²

However, the reasons for these sleep problems are not understood. Research results have been variable: for example, some studies have found unusual brain wave patterns during sleep, while others have not. Since poor sleep is known to cause memory and concentration problems and pain



in other conditions, some wonder whether these symptoms in CFIDS patients could also be perpetuated by sleep problems. Even healthy people can feel sick when deprived of normal sleep.

If your physician suspects you have a sleep disorder, he or she may refer you to a specialist for polysomnographic testing, also known as a sleep study. The article on page 3, reprinted with permission from the National Sleep Foundation, describes a typical sleep study.

Your sleep specialist may suggest you spend two nights in the sleep lab, because of a new study that suggests CFIDS patients suffer from a “first-night” habituation effect in the sleep lab. This causes the first night’s

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THE CFIDS CHRONICLE

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The CFIDS Association of America, Inc.

PO Box 220398, Charlotte NC 28222-0398

Information Line: 800-44-CFIDS
(800-442-3437)
(available 24 hours a day)
Resource Line: 704-365-2343
Fax: 704-365-9755
E-mail: cfids@cfids.org
Web site: www.cfids.org

Publisher: The CFIDS Association
of America
Managing Editor: K. Kimberly Kenney
Guest Editor: Vicki Walker
Circulation Director: Kristina P. Hopkins
Production Staff: Kasia Faryna
Marcia Harmon
Gloria Smith

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about CFIDS to all who inquire. Individual contributions are the Association's greatest source of support, and contributions are tax deductible to the fullest extent allowed by law. The CFIDS Association of America, Inc. serves as a clearinghouse for information about chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS), myalgic encephalomyelitis (ME) and other names. The Association does not endorse products or services, and the ideas expressed in the *Chronicle* are strictly those of the authors or quoted individuals. The CFIDS Association of America, Inc., and the *Chronicle* assume no liability for any medical treatment or other activity undertaken by readers. For medical advice, consult your personal health care provider.

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In Florida; "A copy of the official registration and financial information may be obtained from the Division of Consumer Services by calling toll-free, within the state 1-800-435-7352." In Maryland; "Documents and information filed under the Maryland charitable organizations laws can be obtained from the secretary of state for the cost of postage and copies." In Mississippi; "The official registration and financial information of the organization may be obtained from the Mississippi Secretary of State's office by calling 1-888-236-6167." In New Jersey; "Information filed with the attorney general concerning this charitable solicitation may be obtained from the attorney general of the state of New Jersey by calling 201-504-6215." In New York; "A copy of the latest annual report may be obtained from the organization or from the Charities Bureau, Department of Law, 120 Broadway, New York, NY 10271." In North Carolina; "Financial information about this organization and a copy of its license are available from the State Solicitation Licensing Branch at 888-830-4989." In Pennsylvania; "The official registration and financial information of The CFIDS Association of America may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 800-732-0999." In Virginia; "Financial statements are available from the State Division of Consumer Affairs." In Washington; "Secretary of State 1-800-332-4483." In West Virginia; "West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305." Registration does not imply endorsement.

For more information on chronic fatigue and immune dysfunction syndrome (CFIDS) or to view a copy of our IRS 990 form, visit our Web site, www.cfids.org. Contributions to The CFIDS Association are deductible for federal income tax purposes to the full extent allowed by law.

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MESSAGE TO MEMBERS

What if a simple case of the flu lasted for years?

Anthrax. West Nile Virus. SARS. Flu. Health topics that ignite fear and panic. Newspaper headlines and popular TV shows fuel the public's worries about being healthy one minute and seriously ill the next. However, anthrax poisoning, West Nile and SARS are relatively rare and somewhat exotic, making it easier to feel comfortably distant and safe from their effects. But flu is everywhere; it even has its own season.

An average of 114,000 Americans are hospitalized and 36,000 die every year from the flu. Experts warn that we're overdue for a flu pandemic, in which a new strain emerges to which no one is immune. In 1918 a flu pandemic took 20 million lives worldwide. Public health officials admit there is no

game plan to respond if a new strain evolved today.

This year's particularly virulent strain, an unprecedented shortage of vaccine and media focus on children's deaths have intensified public concern about flu. Nobody wants to get it. Nobody has "time" to be sick for a week or two. Imagine how people would panic if this year's strain caused an illness that lasted for months or years?

Yet, isn't that what CFIDS is, in its simplest form? A vicious flu that doesn't subside, that wreaks havoc on most major body systems and upsets subtle chemical pathways. A flu that turns a couple days of sick leave into short-term, then long-term disability. A flu that saps stamina, intellect, bank accounts and hope. A flu

that steals lives rather than ending them. A pandemic the experts haven't recognized yet.

In this new year we are testing novel ways to get the public's attention on CFIDS. We're focusing more resources than ever on educating health care providers about diagnosing and managing CFIDS. We are intensifying efforts to expand CFIDS research and strengthen public health measures.

In 2004 we intend to make important progress on all these fronts. We hope you will continue to support The CFIDS Association in these critical efforts.



K. Kimberly Kenney
President & CEO



Kim Kenney

Correspondence with the Chronicle editor



In the Fall 2003 issue, the Chronicle asked readers to respond to this Hot Topic question: “Besides a cure, what do you hope the new year will bring the CFIDS community?”

It is my ardent wish that the CFIDS community will learn all about the St. Amand guaifenesin/salicylate-free program for the treatment of FM and CFIDS. As a CFIDS patient who has been horribly ill since 1991 and who has tried most everything within reason to no avail, I found significant relief of my symptoms with this program. I have been on it now for over two years and have seen the wonder of what this protocol is doing for me and others.

Annette Perry, California

(Editor’s note: For more information about this treatment, see www.guaidoc.com)

Before a cure, we need to get rid of the humiliating, degrading “F” word. This “F” word does not describe our severe disease. Until we change it, little serious research will take place and most of the research that is done will be about “fatiguing illnesses.” Most people think we are lazy or crazy or both upon hearing the name of our illness. What does fatigue mean, anyway? I can’t even relate to that term, yet I have been deathly ill with a “diagnosis” of chronic fatigue syndrome for over 13 years.

Anita Burgess, Florida

We need to come together

In the late 1980s a CFIDS newsletter published a cartoon of an elephant being examined by five blindfolded doctors, each concentrating on a different part of its anatomy. This reflected the turmoil CFIDS was in. No one could draw a

clear-cut consensus for ailment or treatment — or even define it with a specific name.

I believe that the cartoon would be just as relevant today. CFIDS doctors, researchers, advocates and PWCs have not come together as a working team. While *individual* efforts have produced much knowledge and should be appreciated, the problem is that they are individual efforts. We have grants and research dollars scattered in all areas and none bears dynamic effect in the prevailing race.

The CFIDS battle has become a power play. We have two or three national advocacy groups contending for first place. Researcher is competing with researcher for fame and recognition rather than pooling his or her findings together with others’. Support groups relay information from doctors and national advocacy groups, taking a stand for one or another. Very few newly diagnosed PWCs have continued where long-time advocates have left off.

Until we join hands across the country and allow what we do know to amalgamate into a steadfast purpose, the problem will always remain an enigma — at the elephant’s expense.

Estelle Rouleau, California

**THE CHRONICLE HOT TOPIC:
YOUR TURN TO SPEAK OUT**

Each issue, *The CFIDS Chronicle* gives readers a chance to respond to a question concerning CFIDS. Here’s the Hot Topic for this issue:

“What is the one thing you’d tell a newly diagnosed PWC that you wish you’d known at the beginning of your illness?”

Send your responses to The CFIDS Association, PO Box 220398, Charlotte, NC 28222-0398, Attention: Hot Topic. Letters may need to be edited to meet our style and space guidelines. You can also send responses online to chronicle@cfids.org.

Sleep and CFIDS

(continued from front cover)

measurements to be unreliable, so the researchers suggest sleep measurements should only be used from the second night of testing.³

What Goes on in a Sleep Lab?

Are you scheduled to participate in a sleep study? Do you want to know what to expect? Here's a brief preview, with some suggestions on how to prepare for a successful sleep study.

If you have a sleep problem or disorder, your primary care physician may refer you to a sleep lab or clinic where you will participate in a sleep study. A sleep study (also called a polysomnogram) is a test that records your physical state during various stages of sleep and wakefulness. It provides data that are essential in evaluating sleep and sleep-related complaints, such as identifying sleep stages, body position, blood oxygen levels, respiratory events, muscle tone, heart rate, amount of snoring and general sleep behavior.

Usually you will make an appointment for your visit, which will take place at night. The sleep center may send you forms requesting your medical and sleep history prior to your appointment with the doctor. The form may ask for your bed partner's responses to some of these questions, since you may not be aware that you snore, stop breathing (sleep apnea) or kick your legs when you sleep. It also may provide tips and some special instructions for your sleep test.

Before your sleep test, you may meet with a physician or sleep specialist, who will go over your medical and sleep history. You may participate in a "split-night" test, in which half the night will be used to diagnose your sleep problem, and the other half will be used to treat the problem. This is sometimes done with patients who are being tested for sleep apnea.

After you arrive at the sleep center, you may be asked to complete a questionnaire on your sleep the night before. Many sleep centers offer a video or other information about the sleep study or specific disorders such as sleep

STRATEGIES FOR IMPROVING SLEEP

- **Establish a regular bedtime routine; go to bed only when sleepy and wake at the same time every day. If you don't fall asleep within 15 minutes, get up and try again when you are sleepy.**
- **Only use your bedroom for sleeping or sex; don't read or watch TV in bed.**
- **Avoid napping, if possible, or limit naps to 30 minutes.**
- **Use sleep medications judiciously. Some things that have helped include: over-the-counter medications like diphenhydramine (in Benadryl and Tylenol PM), prescription drugs such as tricyclic antidepressants and hypnotics, and nutritional supplements like melatonin and valerian.**
- **Relieve pain to the greatest extent possible, since pain interferes with sleep.**
- **Exercise within your limits — gentle exercise and stretching can improve sleep — but don't do strenuous exercise within six hours of bedtime.**
- **Avoid caffeine, alcohol and tobacco. Limit fluids, spicy foods and heavy meals in the evening, but consider a light snack before bedtime.**
- **Control noise, light and temperature in your bedroom.**

Tips courtesy of the Royal Australasian College of Physicians and the National Sleep Foundation.

apnea, since a significant percentage of those who have sleep tests are suspected to have sleep apnea. The video may also address what you should expect during the sleep test to ease any fears you may have. Then you will be asked to change into nightclothes.

After changing, someone called a polysomnographic technician will connect you to the electrodes that will record your brain waves and muscle movements throughout the night. The electrodes are placed in specific areas and applied with water-soluble glue and tape. The electrodes record brain waves, muscle movement, rapid eye movement (REM), air intake and periodic limb movement. A microphone attached to your neck records snoring, and two belt-like straps around the chest and lower abdomen monitor muscle movement during

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Sleep and CFIDS

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breathing. Despite all of the equipment, most people say it doesn't disrupt their sleep.

After settling into bed, your technician may go to a monitoring room and ask you over an intercom to perform certain tasks that will show the electrodes are recording properly. You will be observed on a television monitor during the night, but that is to allow the technician to note your body movements during sleep.

When everything is working properly, the lights will be turned off and you can go to sleep. Many patients are so chronically tired that they have no problem falling asleep. While you are sleeping, your brain waves will be recorded to determine when you are awake or in Stage 1, 2, 3, 4 or REM sleep. You will be awakened in the morning and the electrodes will be removed. Since they are applied with water-soluble glue or tape, removal isn't painful. You will need to make an appointment with a sleep specialist to review the results of your study. You might be asked to complete a questionnaire concerning your sleep the previous night, and then you can go home.

Based on the results of your sleep study, you may be given treatment for a specific sleep disorder. For example, patients with sleep apnea may be prescribed continuous positive airway pressure or CPAP, which is a device that gently blows air into your nasal passages to keep the airway open while you are asleep.

Here is a checklist of items to bring for your sleep test (this may vary according to the sleep center):

- Nightgown, pajamas or any comfortable sleepwear, preferably with a button-down front.
- Your favorite pillow or blanket. Sleep centers provide bedding, including sheets, blankets and pillows, but yours may help you sleep better.
- Toiletries such as a toothbrush, toothpaste, hairbrush or comb.

- Clothes for the following day.
- Any needed medications.
- A book or other reading material.

Here is a list of things to do the day of your test:

1. Wash and dry your hair on the day of your sleep test. Try not to use any hair products, such as gels, hairsprays or heavy conditioners because they may prevent the electrodes from sticking to your scalp.
2. Remove nail polish and/or artificial nails from at least two fingers. The oximeter that is placed on your finger to monitor blood oxygen levels reads this information through the nail, so any polish or acrylic will inhibit an accurate reading.
3. Do not wear makeup. Some electrodes are on the face, so this area must be clean in order to get a good connection.
4. Obtain a normal night's sleep before the test, unless instructed otherwise by your doctor. Continue to take your regular medications and limit caffeine intake the day of your test.

This article was reprinted with permission from the National Sleep Foundation. For more information about sleep (including a free sleep diary to keep track of your sleeping patterns), visit the National Sleep Foundation Web site at www.sleepfoundation.org. ■

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1. Nisenbaum R, Jones JF, Unger ER, Reyes M, Reeves WC. A population-based study of the clinical course of chronic fatigue syndrome. *Health and Quality of Life Outcomes* 2003;1:49.
2. Working Group of the Royal Australasian College of Physicians. Chronic fatigue syndrome. Clinical practice guidelines — 2002. *Med J Aust* 2002;176 Suppl:S23–56.
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Big Picture of CFIDS Emerges

Wichita study's breadth alters government and scientific view of illness

Even after more than 20 years of study, the “big picture” of chronic fatigue and immune dysfunction syndrome (CFIDS) has been absent from research, as scientists have narrowly focused on one or two hypotheses at a time.

The main reason is financial: research dollars for CFIDS have been paltry and comprehensive studies are extremely expensive. Ironically, the 1999 federal inquiry into mis-spending of CFIDS funds at the U.S. Centers for Disease Control and Prevention (CDC), and the subsequent restoration of \$12.9 million to the agency's CFIDS program, made it possible for CDC to launch the most expansive study yet.

In 1997, CDC began calling 56,154 residents of Wichita, Kan., asking if any household member was experiencing fatigue or tiredness lasting more than one month. Those who responded affirmatively underwent an extensive screening questionnaire. People who seemed likely to have CFIDS (and a group of healthy controls) saw a study doctor for an extensive medical workup. Those who met the case definition for chronic fatigue syndrome (CFS) and a sample of healthy controls were invited back to the clinic annually to provide data on the course of CFIDS.

This study has produced a vast amount of information that has improved understanding of CFIDS. Most important, it involves people who are not generally part of CFIDS research. Since most had not been previously diagnosed with CFIDS, they would never have been studied otherwise. Most prior research has used patients in CFIDS specialty clinics, who are likely sicker and more affluent than people with CFIDS in the general population.

CDC's previously published results from the Wichita study include improved estimates of the prevalence of CFIDS — which rose from early guesses of four to eight per 100,000

to CDC's current 235 per 100,000 (nearly half a million American adults) — and the disturbing fact that only 16 percent of people who have CFIDS are diagnosed.

In the past four months, CDC has published four papers presenting findings from the Wichita study. All of the articles summarized below are available in “open access” journals, meaning that anyone can read the entire paper on the Web. URLs for each article are provided at the end of each summary. CDC researchers chose to publish in these journals to expedite the release of this data; conventional journals often take a year or more to publish findings.

Relapses and remissions are common

While CFIDS has long been considered a fluctuating illness, little hard data to back this up has been available. At each annual follow-up visit the CDC researchers classified each subject as having: a) CFS (meets all 1994 CFS criteria); b) partial remission (absence of fatigue, rest improves fatigue, fatigue doesn't interfere with activities, or fewer than four of eight case-defining symptoms); c) total remission (none of the case-defining criteria); or d) an exclusionary condition (permanent or temporary condition that precludes a CFS diagnosis).

Of the 65 CFS subjects who participated, 56.9 percent were classified in the total or partial remission categories at one or more follow-up visits, but only 22.5 percent sustained partial and 10 percent total remission over two or more study periods. At any follow-up visit only 20–33 percent remained in the CFS state and only 7.5 percent remained in the CFS state at two consecutive evaluation visits. Those who had been ill fewer than two years or who had fewer symptoms at the initial evaluation were slightly more likely to have remissions.

By Vicki Walker

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Big Picture of CFIDS Emerges

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These data clearly show that people with CFS cycle in and out of the “CFS state” (as outlined in the 1994 case definition) at irregular intervals. More than half of those who said they had a reduction in fatigue since their last evaluation stated they had at least six periods of remission in the last year. No particular treatment seemed to be associated with remission.

One weakness of the study is that the only people who were included were those who met research definition criteria at the initial clinical evaluation; people who were in a temporary remission at the first clinic visit were not part of the study. The investigators also point out that clinicians likely wouldn’t use such conservative criteria to diagnose CFS; most of the people probably would have continued to have a CFS diagnosis through their periods of remission.

Other interesting findings were that 31 percent had been previously diagnosed with depression, but only 17 percent tested positive for a lifetime major depressive disorder. Twenty-three percent were later diagnosed with exclusionary conditions — mainly sleep disorders, major depression with melancholia and inflammatory bowel disease. The most common symptoms were sleep-related (unrefreshing sleep and problems falling asleep). More than 60 percent were unemployed, but only 17 percent attributed unemployment to their fatiguing illness.



Drs. William Reeves and Suzanne Vernon are two of the CDC researchers investigating CFS.

Reference: Nisenbaum R, Jones JF, Unger ER, Reyes M, Reeves WC. A population-based study of the clinical course of chronic fatigue syndrome. *Health and Quality of Life Outcomes* 2003,1:49. www.hqlo.com/content/1/1/49

CFS as serious as other medical conditions

People with CFS are as impaired as people with medical conditions such as cancer, multiple sclerosis and AIDS.

Fatigued people in Wichita were classified into various categories, based upon their symptoms and medical history. One of the categories — “explained syndromic fatigue” — included people who would have met the full CFS criteria, except they had a medical or psychiatric condition which precluded the diagnosis. These included cancer within five years, emphysema, AIDS, lupus, multiple sclerosis, cardiovascular disease within two years, chronic hepatitis, major surgery within the past year, schizophrenia and substance abuse within five years of onset.

People with CFS and explained syndromic fatigue had similar levels of impairment in physical, social and recreational functioning, underscoring the fact that people with CFS are as impaired as people with better-known and -accepted conditions.

One difference between these groups was in employment: 40 percent of explained syndromic fatigue subjects reported being unemployed due to their illness, while only 15 percent of CFS subjects reported the same.

(The 15 percent figure differs from the 17 percent in the previous study because only 43 CFS subjects’ data were included in this paper, compared to 65 in the previous one.) The investigators believe this difference may be due to the relative difficulty of securing disability benefits for CFS compared to better-accepted conditions. The CFS subjects

may continue working because they do not believe there is an alternative. Also, since most of the CFS subjects had not been previously diagnosed, they likely did not have a basis for applying for disability benefits.

Reference: Solomon L, Nisenbaum R, Reyes M, Papanicolaou DA, Reeves WC. *Functional status of persons with chronic fatigue syndrome in the Wichita, Kansas, population.* Health and Quality of Life Outcomes 2003;1:48. www.hqlo.com/content/1/1/48

PWCs use more medications

People with CFS (PWCs) use more medications and nutritional supplements than healthy people. Pain relievers and vitamins/supplements were the most common types of drugs used by both groups, but the CFS subjects used more of them. The 90 CFS subjects (the majority of whom were not diagnosed before they were contacted for the study) used a median of five drugs each, while the 63 healthy controls used a median of two drugs each.

The CFS subjects were more likely than the healthy controls to use pain relievers, supplements/vitamins, hormones, antidepressants, gastrointestinal agents, central nervous system drugs and benzodiazepines.

The researchers did not ask why each product was used, so they could not explain the reasons for increased medication and supplement use. However, it does underscore CFS patients' greater need for symptom relief.

Reference: Jones JF, Nisenbaum R, Reeves WC. *Medication use by persons with chronic fatigue syndrome: results of a randomized telephone survey in Wichita, Kansas.* Health and Quality of Life Outcomes 2003,1:74. www.hqlo.com/content/1/1/74

Genes differ in sudden and gradual onset PWCs

Female CFS subjects with sudden onset (developing within one week) have a different genetic profile than those with gradual onset

(developing over more than a month). The CDC researchers examined 3,800 genes in 23 female CFS patients and found that the sudden onset group had 117 genes that were expressed differently from those with gradual onset. The main differences were in metabolism and RNA processing genes.

The researchers did not compare the CFS subjects with healthy controls, so it is unknown which group most differs from normal.

This study supports prior research suggesting that onset type may be an important clue to the heterogeneity of the CFS population. DeLuca, et al, reported that sudden onset CFS was more likely to develop following a viral or bacterial infection and Mawle, et al, reported that gradual onset CFS was associated with a greater number of stressful life events in the year prior to onset.

Reference: Whistler T, Unger ER, Nisenbaum R, Vernon SD. *Integration of gene expression, clinical and epidemiologic data to characterize chronic fatigue syndrome.* Journal of Translational Medicine 2003,1:10. www.translational-medicine.com/content/1/1/10

Tip of the iceberg

The information CDC has published to date is only a small portion of the data collected from the multiyear study. CDC is starting to analyze data from the most intensive segment of the study: a two-day hospital stay which included neuroendocrine, immune and autonomic nervous system tests; sleep studies; memory and information processing tests; and stress and psychological tests.

Approximately 400 people with CFS, severe chronic fatigue, explained syndromic fatigue or no fatigue were invited to participate in this comprehensive testing battery. Once analysis is completed, this portion of the study should provide a wealth of information about the biology of CFS. (For more on the CDC research, see the Winter 2003 *Chronicle* article on the subject at www.cfids.org/archives/2003/2003-1-article01.asp) ■

Q&A: Mark VanNess, PhD, & Chris Snell, PhD

Working to understand why activity causes relapse in CFIDS

By Vicki Walker

Mark VanNess, PhD, and Chris Snell, PhD, are among the few exercise physiologists studying CFIDS. They, and their colleague Staci Stevens (a member of the federal CFS Advisory Committee and a person with CFIDS), use their knowledge of energy production and utilization to better understand why CFIDS patients feel so much worse after activity. Dr. VanNess is an assistant professor and Dr. Snell a professor in the Department of Sport Sciences at the University of the Pacific.

Q: What is exercise physiology?

VanNess: I break exercise physiology into two parts, the first being the acute responses to exercise, looking at changes in muscle contraction, energy delivery, heart rate, blood flow and processes like these when you exercise. The second part is teaching athletes or people with health conditions to operate at a higher level of efficiency and higher work output as a result of training. We're studying the acute response to exertion in our CFIDS research.

Q: What exercise testing do you do with your CFIDS subjects?

Snell: We use either a treadmill or a cycle ergometer that is manufactured to work at different outputs.

VanNess: We do a cardiopulmonary analysis where we collect the expired air for analysis of oxygen utilization and carbon dioxide production, and we also measure blood pressure and heart rate response to exercise. With those variables you can look at the patients' resting levels and then, as they start doing exercise, look at the acute responses — the responses that provide energy during exercise.

With the maximal exercise test, you take subjects all the way up to their peak exertion, so you're able to measure their peak oxygen utilization and carbon dioxide production, and how well they're able to activate their heart to bring heart rate up and increase systolic blood pressure.

Snell: As you increase your effort you're no longer able to supply sufficient oxygen to active muscles to completely metabolize the energy. So you go into a secondary energy system, called the anaerobic energy system, which is quite deviously designed to allow you to continue to work even though you're not using oxygen to produce the energy. In anaerobic metabolism the byproducts of exertion are not completely metabolized, so you end up with lactic acid building up in the bloodstream, eventually compromising your ability to continue working. You enter a condition called "oxygen debt." It's like being overdrawn at the bank — you have to pay it back before you can start spending again.

VanNess: Our research is unique in that we have looked at determination of anaerobic threshold in CFIDS. In order to determine anaerobic threshold you have to do an incremental exercise test to peak effort.

Q: Your research has also shown that CFIDS patients have a lower anaerobic threshold than healthy sedentary controls. What does that mean?

VanNess: If athletes spend too much time above their anaerobic threshold, they become exhausted and have to rest. We think the same applies to CFIDS patients. If their aerobic metabolism is lower than expected, then they'd spend more time above that

anaerobic threshold doing their regular activities. That may be producing prolonged recovery time and more exhaustion after activities of daily living.

Snell: In real terms, anaerobic threshold is the point at which you should stop working if you expect to recover in a reasonable amount of time. We can establish that very accurately with an exercise test and match that to a specific heart rate. A heart rate monitor can be used by the patient as a biofeedback mechanism to determine the point where they need to stop activity if they want to be able to function the next day. So it's becoming a useful, practical way people can monitor output during the day to allow them to stay within their energy envelope.

Q: What else have you learned about CFIDS?

Snell: We have access to the baseline data for 189 Phase III Ampligen treatment trial subjects. So we have a large subject pool of what we think have been consistently diagnosed CFIDS patients. We've found that those who have abnormal RNase-L activity (an indication of immune activation) are lower functioning than those who don't.

VanNess: The maximal exercise test is a very good measure of a patient's functional capacity. If you look at the results of an exercise test and you're not familiar with CFIDS, the patient's function (but not the Oxygen and carbon dioxide exchange measures) looks like that of a patient with cardiovascular or pulmonary disease. The exercise test can be used to rule out these other causes of fatigue when making a CFIDS diagnosis.

Q: Does your data compare with the findings of orthostatic intolerance in CFIDS?

VanNess: We've looked at the systolic blood pressure response to exercise. And, interestingly enough, it is blunted quite profoundly in patients with CFIDS. I think it's two ways of looking at the same thing: orthostatic intolerance is an inability to regulate blood pressure within normal parameters. I think the same thing occurs during exercise when you'd normally see a large rise in systolic blood pressure to provide blood flow during exercise. Patients with CFIDS don't activate that system well, so they may have a failure to perfuse (send blood to) muscle tissues during exercise.

Q: What CFIDS research studies are you planning?

Snell: We have two other ideas that we're pursuing on a small scale. One of them is the idea of doing two exercise tests separated by 24 hours. In a healthy individual when you do two exercise tests a day apart, the results are about the same. In a CFIDS patient, because of the post-exertional malaise, peak oxygen consumption is dramatically less on the second exercise test. We'd like to get funding to examine that a little more closely and not just describe the phenomenon, but try to determine why it's so much less the second day.

The second idea is trying to use the exercise test as a standardized stressor to look at post-exertional malaise. We'll look at some of the immune and hormonal responses and neurocognitive effects after exercise. So, we want to truly describe what post-exertional malaise entails in a CFIDS patient. ■



CFS Advisory Committee meets again

On Dec. 8, just 40 days after the Department of Health and Human Services (DHHS) convened the Chronic Fatigue Syndrome Advisory Committee (CFSAC) for the first time, the new committee again met. The 11-member group heard updates from the five federal health agencies that report to it. Chairman Dr. David Bell led discussions on the mission and priorities for the committee, research funding priorities, provider education, public awareness and the name change. Members of the public were given an hour to deliver public testimony. Jon Sterling, the Association's chairman, represented the Association at this meeting.

A list of 32 National Institutes of Health (NIH)-funded CFS-related research projects was circulated by Dr. Nahid Mohaghehpour, one of the researchers appointed to the committee. She presented an analysis of the research, expressing concerns about the quality of some of the listed studies and the potential loss of promising projects that are in jeopardy due to NIH's decision not to continue support for CFS cooperative research centers, which have been in existence since 1993. Another committee member, Dr. Charles Lapp, questioned whether

certain projects were relevant to CFS. Dr. Mohaghehpour suggested that priority should be given to multicenter studies and those that seek to identify the primary cause of CFS or to find animal models to study the disease. She also highlighted the need for more standardized methods to improve comparability between studies.

When asked by committee members for NIH-supported research project summaries and their respective funding levels, the NIH representative to the committee, Dr. Eleanor Hanna, stated that this information was not available to her. She noted that only two of the 32 projects listed relate to new grants and that total funding for 2004 was likely to drop to \$6 million from \$7.7 million, but none of the committee members questioned the reason for the 22 percent decline. Dr. Hanna also reported that a draft of a new research announcement soliciting CFS studies would be completed by the end of January. Dr. Bell stated that in order for the committee to advise DHHS about federally sponsored research, it is essential that more information about funded studies be made available to CFSAC members.

Committee member Dr. Roberto Patarca reviewed health care provider education

activities conducted by various organizations and agencies. He focused most heavily on efforts supported by the Centers for Disease Control (CDC) and carried out by The CFIDS Association. He shared his disappointment that the number of participants was not greater, although Dr. Lapp, a member of the faculty for this project, recommended that first year results be seen as a starting point. The committee discussed ways to extend outreach and encourage more doctors to learn about CFS.

The most highly anticipated discussion of the day came late in the afternoon. The Name Change Working Group, formed by DHHS to explore changing the name "chronic fatigue syndrome" to another term, had submitted its recommendations to the CFSAC at the committee's first meeting on September 29, 2003. The proposal suggested identification of a condition somewhat broader than CFS called neuroendocrine-immune dysfunction syndrome (NDS) with numerous subgroups (including myalgic encephalomyelitis (ME) and "Fukuda criteria," which refers to the 1994 CFS case definition) fitting under this larger umbrella term. These recommendations were based on three years of deliberation by

By
K. Kimberly
Kenney

the working group, including assessment of several surveys and consultation with researchers, clinicians and patient advocates.

Dr. Bell read a draft statement he had prepared with committee input in response to the proposal. He summarized, stating “the CFSAC agrees that the name ‘chronic fatigue syndrome’ is a poor name. However, we feel that a change of this name to another name should occur only when there is a better understanding of the pathophysiology of the illness.” (The full statement can be viewed at www.cfids.org/advocacy/cfsac-statement.asp.) A vote was taken to approve the statement; it passed unanimously, with Dr. Lapp abstaining due to his participation on the Name Change Working Group. Several observers who had championed the proposal appeared stunned by the swift decision and offered objections. Dr. Bell moved on to new business and the hour of public testimony that concluded the day.

The committee plans to hold its next meeting in March 2004. DHHS staff are working to establish a CFSAC Web site and listserv to facilitate communication with the public and among committee members.

Board considers name change

The CFSAC’s decision to decline recommendations made by the Name Change Working Group was explained in a statement approved at the Dec. 8 meeting (see above). The Association’s Board met on Dec. 10 to review and discuss the statement and to formulate a response. Because of the importance of this issue to the CFIDS community, since 1998 the Board has maintained authority for setting and communicating Association policy on the name change.

In its statement released on Dec. 11, the Board reaffirmed its position that “a name change is necessary” and urged the CFSAC to “serve the CFS community and the public by propelling research and public policy issues forward so that answers are found that would satisfy its requirements to recommend a name change.” The Board’s statement can be viewed at www.cfids.org/advocacy/c-act_12112003.asp.*

Appropriations update

As this issue of the *Chronicle* goes to press, Congress will return to Washington to complete work on the 2004 funding bills that support thousands of federal programs, including health

NIH SPENDING QUESTIONED

Some members of Congress are concerned that generous budget increases provided to the National Institutes of Health (NIH) in recent years have not been used in ways that will accelerate medical advances and improve the nation’s health. Two Congressional committees have held hearings about NIH, inviting advocacy groups and researchers to voice their concerns about funding policies and priorities.

The CFIDS Association is sharing its concerns about funding for CFIDS research with NIH staff, Congressional committees and other advocacy organizations and coalitions. This year, NIH will be an intense focus of our public policy activities.

and biomedical research. The CFIDS Association’s requests for increased funding of CFIDS research and direction to various health agencies have been shared with key legislators continuously by individual advocates, The Sheridan Group (the Association’s lobby firm) and Association staff. These bills move sluggishly through Congress due to political battles over big programs with huge budgets. Still, it’s important that we carefully follow the health bill’s progress to ensure that our provisions are not lost as language and numbers change to reflect the latest political compromises. Watch the Web site (www.cfids.org)

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JOIN C-ACT FOR THE LATEST NEWS

CFIDS Activist (C-ACT) members receive the latest news on events in the CFIDS community, such as CFSAC meeting dates, opportunities to participate in advocacy activities and tools to interact more effectively with government officials.

Membership is free, so join today! Send an e-mail message with your name, mailing address, telephone and e-mail address to: C-ACTMembership@cfids.org or call the Resource Line at 704-365-2343. For more information, visit us on the Web at www.cfids.org/advocacy/cfids-activists.asp.

for updates, or join our C-ACT listserv by sending your name and e-mail address to C-ACTMembership@cfids.org.

Election year opportunities

In November all members of the House of Representatives, one-third of the Senate and the President will be elected. The vast majority of these legislators is seeking re-election and will spend weekends and session breaks campaigning in their districts and states. New candidates for office will be highly visible as well. Now is an excellent time to attend town hall meetings and other public appearances where you might be able to talk briefly with the candidate or submit a question about CFIDS research funding. Advocates with lots of energy and time might consider volunteering in a campaign. The contacts made there can prove beneficial if the person is elected now, or at some time in the future.

Access to presidential candidates is much more

limited, although unique opportunities do exist. Watch for online chats, call-in radio and TV programs and other ways to pose CFIDS-related questions to presidential hopefuls. You never know where people may end up!

Lobby day postponed

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

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

burden of asking people to physically travel to Capitol Hill to lobby.

With this being a major election year, the possibility exists for considerable turnover among members and staff after Nov. 2. If leadership of the House or Senate changes parties, committee assignments will change dramatically too.

These circumstances call for a major CFIDS education campaign in 2005. In 2004, we'll be asking you to write more letters and make more phone calls — and providing you with improved tools to do so. We'll also begin planning for a large-scale 2005 lobby day. Join C-ACT today to ensure that details of all advocacy activities reach you first!

** If you do not have Internet access, send a self-addressed, stamped envelope to the Association at the address on the inside front cover of this issue and ask for "Name Change Statements." ■*



Photo: Steve Sorensen, PWC

Snapshots OF CFIDS

A SPECIAL SUPPLEMENT TO THE CFIDS CHRONICLE • WINTER 2004

Whatever Doesn't Kill You Makes You Stranger

By Kate Franklin

I stood outside, blinking as my eyes adjusted to the bright sunlight. Behind me sat a squat nondescript building marked with only its address, 6700-B, and inside, a windowless room, darkened for slides and crudely drawn overhead projections. As I stood waiting for a cab to take me back to the hotel, exhaustion set in. I had held it at bay during the morning with sugar and caffeine, but now I could feel it settling into my bones. I looked for a place to sit, but there wasn't a bench or even a ledge. Across a concrete expanse I could see only 6700-A, the companion, mirror image of the building behind me.

The fatigue was familiar, expected. Ten years before, I had come down with what I thought was the flu. I never recovered. Ultimately I was diagnosed with chronic fatigue syndrome, a baffling condition with a constellation of symptoms including profound exhaustion, joint and muscle pain, headaches and the like. I had come here, to the National Institutes of Health, for a "State of the Science" meeting — invited by the scientists to convey the patients' perspective on the illness, to "put a human face on it" for researchers, many of whom had never before encountered an actual patient. I was anecdotal evidence at best, just one story, uncontrolled for all of life's uncontrollable variables, a single data point for the scientists to ponder.

I had written a speech and practiced it, but knew I hadn't captured the essence of the illness. How to describe the feeling of chronic unwellness

to those blessed with health? The speaker before me, a prominent researcher in the field, gave me a clue. "Scientists don't know the cause of many symptoms," he said, "fatigue for example." He talked of lying in bed, feverish, with muscles aching and that deep sense of exhaustion that accompanies the flu. We don't yet have the science to explain what intricate processes are at work, what chemicals or enzymes are producing that profound weariness, he said. We just know, he went on, that if we stay in bed resting a few days, and let the virus run its course, we can pick ourselves up and go on with our lives.

"Imagine," I said, as I rose to speak, "that you have the flu, not for days, but for months, or even years — that you lie in bed for weeks on end — that you feel as tired when you wake up as when you finally drift off to sleep again. That's what it feels like," I told them. "Imagine."

I told them how the illness had divided my life into "before" and "after." How I was just living my life until that one day 10 years ago when I got the flu and didn't get better. How I was just living my life until that one day when I wasn't, couldn't anymore. Couldn't work, couldn't bike, ski, swim. Couldn't do anything really except lay in bed or on the couch, resting — waiting for the fog of fatigue to lift.

I spoke for myself and other patients I knew — how we went from doctor to doctor in search of answers and found none. How we turned in desperation to vitamins and herbs, then bee pollen,

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Whatever Doesn't Kill You...

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shark cartilage, evening primrose oil, then magnets, crystals, then faith healers. How we combed through Internet sites of patients' accounts of the illness for a lead to that one magic substance that would return us to our former lives.

Was I depressed? one scientist wanted to know.

"Chronic illness is depressing," I said. "It brings with it so many losses, loss of our careers, hobbies, relationships, and with those losses too, a loss of our former identities, our former selves."

"Imagine," I said to them, this distinguished panel, gathered at the epicenter of biomedical research, "that you could no longer pursue your career, that you were no longer the accomplished scientist, the expert in your field that you are here today."

Imagine, I thought, that your biggest achievement was coping, getting through life, day after day, navigating through pain and loss, the twin shoals of unceasing illness.

"What do patients want most?" another of the scientists asked.

I knew that many patients had been lobbying for a name change, "chronic fatigue syndrome" sounding so insubstantial, so trivial so as to subject its sufferers to ridicule. In England it's called "myalgic encephalomyelitis," a much more impressive-sounding illness. It was a subject of some debate on the Internet. One patient's sly suggestion was "living death syndrome," and another, my favorite, "the disease formerly known as chronic fatigue syndrome," accompanied by a cryptic symbol.

For me though, I didn't really care what it was called — I just wanted not to have it anymore.

"We want a cure," I said without hesitation. We'd often fantasized about it at meetings and support groups and told each other what we'd do if it happened. A big party, I'd always said, one that lasted for days. We'd drink and dance and revel in our wellness.

"You'll all be invited," I told the scientists. "We'll carry you through the streets on our shoulders." They laughed, the tension finally broken.

Afterward the scientists approached, some to thank me for my candor, others to ask additional

questions, musing over my answers as if they might hold the key to the mystery of the illness. Patients surrounded me too. Some pressed their cards or handwritten notes into my hands. One had just a hug. "You told my story too," he said.

This morning I had come to hear the scientists' perspective on the illness. We sat at the conference table together — 12 researchers and one patient — around us the room filled with other scientists and patients observing. I didn't speak but sat silently at the table — a reminder to the scientists that their findings in the lab somehow translated into a real toll on real lives. I sat as they talked about double-blind, controlled experiments, of "robust" science, "elegant" studies — as they marveled over unexpected, puzzling, "interesting" results.

Perhaps a "stealth virus," one suggested with concurrence from the others — arriving unheralded, wreaking its havoc with the immune system and then vanishing, undetected. Maybe some environmental trauma that triggers a disruption of the neuroendocrine system, another mused, referring to that complex web of chemical messengers and nerve receptors that control our breathing, our heart rate, everything that our bodies do without our conscious direction.

"No party for you," the scientists joked with one another, echoing my comment of the day before, as each confessed his or her bewilderment over some aspect of the disease.

As I listened, I was heartened and disheartened. Smart, dedicated people were working on the problem, but the cause of the illness remained elusive, what we didn't know about it seemingly overwhelming what we did.

I left at the lunch break when fatigue finally won out over my determination to stay and witness. As I stood outside, a scientist from the panel approached me and thanked me for my presentation.

"Most patients are so angry, so strident. They're their own worst enemies," he scowled. "Don't they know we're doing all we can. If this were an easy problem to solve, we'd have solved it years ago."

Patients were angry. Many had been told for years that there was nothing wrong with them, that their all too physical symptoms were "all in their

heads,” the result of stress, of their inability to cope with their emotions or the demands of a normal life. The medical establishment, doctors and the government agencies responsible for the public health had been seemingly slow to respond — so slow, so painfully and infuriatingly slow as those stricken lay in bed, resting, waiting — and was just now, after a decade or two of apparent indifference to lobbying by patients and their families, rousing itself, shaking itself from its torpor to confront the problem.

“You have to understand,” I said. “Many patients have suffered a long time.”

As he turned to go back into the building, I saw Robert, one of the angry, strident patients, loping up the walk, pushing off his cane with every other step. I thought of my own folded cane in my bag, now used mainly as a prop when I needed to look as disabled as I felt.

Robert came and stood beside me. I cocked my head toward the building behind me. “What did you think?” I asked.

“There’s an old Chinese curse,” he said, “‘May you live in interesting times.’ In our case, he said, the curse is ‘May you have an interesting disease.’”

I laughed and offered up my own illnesses, perversions of meaningless adages that the well heap upon the sick. “When one door closes, a thousand others slam in your face,” I said, and then my favorite, “Whatever doesn’t kill you most likely maims you horribly and ruins your life forever.”

Robert smiled and said, “That reminds me of an e-mail I got from someone. I have no idea if this guy meant it or if it was just a typo. It said ‘Whatever doesn’t kill you makes you stranger.’”

I started laughing again, at both the absurdity and the truth of it. Robert joined me and we laughed for a long time together, giddy in the bright sunshine, relieved at our temporary escape from the dreary room inside. I wiped tears of laughter from eyes.

“Well, there’s no question about that,” I said as my cab finally pulled up. Robert waved goodbye and turned back toward the building. I got in, closed my eyes and leaned back into the seat, surrendering finally to the fatigue, feeling it close around me.

As I flew back to Boston from D.C. later that week, my speech to the scientists went around the world, leapfrogging from computer to server to computer on the World Wide Web, posted there by one of the angry-patient-activist groups. I arrived home to a full inbox of e-mail messages from patients and their families. Some had questions; others offered just their thanks and encouragement.

A patient from Germany wrote of the illness as “a grey shapeless fog hanging over me,” but added, “I have learned to accept it and adapt myself, my life, my habit of daily things to this given rhythm. I would even say that I appreciate beautiful things better than before. This state of illness, it goes up and down like a wave and I try to enjoy every peak consciously and to tolerate every down.”

He apologized for his occasionally awkward English, needlessly I thought. I understood perfectly and recognized him as a fellow traveler, as one who goes through life, day by day, with chronic illness his companion.

Yes, I thought. You’ve told my story too.

The author became ill with CFIDS in 1990 and is currently working toward her master of fine arts degree in creative writing at Emerson College. Kate Franklin is her pen name. ■

Preparedness

By Liz Burlingame

I pull on my shoes and tie them tight.

When I first became sick with CFIDS, I could scarcely believe what was happening to me. For the first time in my life I was totally debilitated, forced to stay in bed, quit school and ultimately resign from my job. The nausea, headaches and overwhelming exhaustion kept me in bed for days and even weeks at a time. Despite my obvious ill health, some corner of my brain kept believing I was not sick. It was this autopilot segment of my thinking that kept saying, “When you wake up in the morning, it’s time to get dressed and prepare for the day.” Never mind that the day will almost certainly be spent in bed; if it’s morning, it’s time to get up. So on my worst days, it is not at all

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Preparedness

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uncommon for me to get dressed (often lying down) and pull on my shoes.

My thinking is that there exists the possibility, however remote, that I might recover (even spontaneously) at any given moment. And if I should spontaneously recover (it could happen), my shoes are tied and I'm ready to go. Hypothetically, I'm prepared to walk directly outdoors with not a moment wasted. My ambition far outweighs my abilities.

I keep my bedroom window open so that when I emerge turtle-like from beneath my pillow, I can hear the bustle of humanity in the distance. I hear the cacophony of activity and dream of getting out of bed, shirking off this maddening disease and rushing back into living. I picture masses of people going about their daily lives and the one commonality I see in each and every person is this: they're all dressed. Nobody's wearing pajamas and few people are barefooted. When I'm dressed I'm involved with them. I live vicariously through them. To steal a line from Jack Kerouac, I am prepared "... to get up in the morning to walk proudly on the sidewalks of life"... at least in theory.

The downside is that I have spent entire days nestled under blankets with my head on the pillow, fully clothed with my shoes tied. I should confess that in 12 years I do not recall a single day in which this scheme has panned out. However I am unwilling to scrap the routine while the possibility for recovery still exists. I might yet completely recover, and I am most unwilling to relinquish that fact ... or my shoes. ■



First Winter of My Illness

Mary Anne Mitchell

Snowflakes, dancing in the wind,
land with a delicate touch
on my outstretched tongue.

The first tentative flakes
meander through the air,
swirling and twirling,
head over heels,
giddy with delight
like children in a playground.

Soon enough,
the snow takes on a serious quality,
heavy with purpose,
cold to the touch,
landing silently
until the ground is covered
with a blanket of shimmering crystals.

Across the street
a man is already shoveling the first layer.
The snow is lifted from its resting place
and tossed aside in a jumbled heap.

My neighbor's son races outdoors
shrieking with pent-up laughter.

Twirling, arms flung wide
he falls backward,
creating a snow angel with muddy boots.

I can feel the icy shiver up my spine
as snow seeps into his collar.

He lies as if dead
— boy and snow —

then opens his mouth to
welcome the newest arrivals.

Slowly, I turn from the mailbox,
letters in hand,
my cane

bearing the weight
of trembling limbs.

I take a ragged breath
and drag in puffs of icy air,
willing my heart
to slow

its relentless pace
as my immune system
kicks into overdrive.

Winter claims my frozen view
and settles in my bones.

The author wrote this poem in 2001, during her first winter of being ill. She says, "it expresses the desolation and separateness I felt on that day."

Keeping you up to date on recent events across the nation and around the world

Medical education news

The CFS health care provider education project, a collaborative effort of The CFIDS Association and the Centers for Disease Control and Prevention, unveiled a new exhibit at the American Public Health Conference. The display reminds health care professionals that they can “help the person behind the symptoms” and offers information about CFS and continuing education opportunities. The exhibit also traveled to the American College of Nurse Practitioners annual meeting and will be used at national conferences over the next year. Also on tap for 2004 is a DVD presentation of the CFS continuing education seminar, which will be handed out for free at future conferences.

The CFS continuing education seminar was recently presented to nurse practitioners in Arkansas and physician assistant students in New Jersey. Other events are being scheduled around the country, as are “Grand Rounds” education sessions at some of the nation’s leading medical and public health schools.

Feedback from both patients and health care professionals was central to the redesign of a print advertisement promoting the CFS provider education project. The ad will be placed in

medical and health care journals including the *Journal of Family Practice* and *New England Journal of Medicine*.

To view images of the new display and the promotional ad, visit the Association’s Web site at www.cfids.org/about/provider-ed.asp.

Japanese to study CFIDS

A consortium of Japanese university researchers, drug makers, food companies and a government agency have joined forces to better understand the nature of fatigue and CFIDS.

Top Japanese CFIDS research experts are central participants in the consortium. The group’s goals are to find biomarkers for fatigue, develop foods and drugs to combat the symptom and find ways of preventing overwork. According to the *Japan Times*, the project’s initial phase, scheduled to conclude in September 2005, will focus on developing fatigue assessment tools and biomarkers.

Skloot wins book award

Author Floyd Skloot won the 2003 Oregon Book Award for Creative Nonfiction for his collection of CFIDS-inspired essays, *In the Shadow of Memory* (University of Nebraska Press).

Nearly two decades ago, CFIDS seized sudden control over Skloot’s body and mind.

Although he had a knowledgeable and understanding physician, treatment failed to restore his health. It took years to craft a new life from what was left of the old one. He began writing to make sense of the painful, isolating experience of being chronically ill.

Reviews of *In the Shadow of Memory* and more about Skloot’s other publications can be found at home.earthlink.net/~skloot.

Hillenbrand continues to make an impact

Laura Hillenbrand, author of *Seabiscuit, An American Legend*, was selected as one of *Vogue* magazine’s Heroines of 2003. Her story is featured in the December issue. Hillenbrand was also honored by *Glamour* magazine in its December issue, as one of its 12 Women of the Year.

Iraqi schoolchildren will receive free copies of *Seabiscuit*, thanks to Hillenbrand and Lt. Col. Sherman McGrew, an army reservist in Iraq. McGrew wrote to Hillenbrand of the positive impact her book made on him and a group of schoolgirls he met while delivering medical aid. Hillenbrand, touched by McGrew’s story, is purchasing 500 copies of the Arabic translation of *Seabiscuit* for the students. ■



The latest information on research, treatment and diagnosis of CFIDS and related disorders



By Vicki Walker

Terms in bold type appear in the CFIDS Glossary box.

Serotonin gene abnormality in CFS

Japanese scientists have found an aberration in some CFS patients' serotonin gene and hypothesize that it may be related to the **pathophysiology** of the condition. Serotonin is a brain chemical that regulates sleep, appetite, pain, mood, emotion and inflammation.

CFS patients were more likely to have rare forms of the serotonin transporter gene compared to controls. The so-called longer gene variants were seen in 40 of 156 genes from CFS patients, and only 12 of 100 genes from controls. This genetic alteration may result in a person having lower levels of active serotonin and may also increase susceptibility to CFS, according to the researchers. Serotonin interfaces with the hypothalamic-pituitary-adrenal (HPA) axis and may play a role in the **endocrine** abnormalities that have been found in CFS. The study was published in *Biochemical and Biophysical Research Communication* in November.

Serotonin inhibitor may alleviate CFS

Four out of five patients treated with granisetron, a serotonin **agonist**, saw marked improvements in fatigue and

function within two weeks of starting therapy, according to an article in the September 2003 issue of *Netherlands Journal of Medicine*. The positive results faded two weeks after discontinuing treatment.

The promising results have led to the initiation of a placebo-controlled, blinded study. Although the present study was open-label and a placebo effect can't be ruled out, there is a strong rationale behind the study. Increasing evidence points to an upregulation of serotonin in the pathogenesis of CFS, which would explain why serotonin agonists might be effective, and why antidepressants in the selective serotonin reuptake inhibitor (SSRI) category, such as Prozac, have not worked as well.

Editor's note: Contradictory research findings, such as appear in the above two studies, may reflect variable study methodologies, such as different patient selection criteria or ways of interpreting findings. The only way to clear up these and other mysteries of CFIDS is through research studies which involve large numbers of patients and use proven study methodologies and techniques.

Milnacipran treats FM pain

Results of a Phase II study showed that milnacipran is effective in treating fibromyalgia pain and that its impact on

pain is distinct from its antidepressant properties. The drug worked equally well in depressed and nondepressed FM patients, but the placebo response was stronger in depressed patients. This "suggests that the pain experienced by these patients is not directly related to their mood," according to Jay D. Kranzler, MD, PhD, of Cypress Bioscience, the sponsor of the study.

Milnacipran is a new class of drug that acts on two key neurotransmitters, norepinephrine and serotonin. It is available in 22 countries, but not yet in the U.S. Cypress Bioscience launched a Phase III clinical trial of the drug as an FM treatment in October.

CFS research, diagnosis clarified

An international group of CFS researchers offers long-needed clarification of the 1994 CFS case definition in the December 31 issue of *BMC Health Services Research*. The authors make a particular effort to explain "exclusionary conditions," which is a key part of the 1994 case definition, but has been difficult to interpret and apply.

Exclusionary conditions are medical or psychiatric conditions that could plausibly cause CFS symptoms, such as multiple sclerosis or chemotherapy treatment. Because the biology of CFS is not

understood, researchers must screen potential subjects for exclusionary conditions to rule out the possibility that their findings could be attributed to another condition (or set of conditions) present in the subjects.

Although the 1994 definition was written only for research settings, it was adopted by physicians to diagnose their patients because no alternative clinical guidelines existed. The new paper's authors acknowledge that the concept of exclusionary conditions may have less importance in clinical practice. They state, "In the clinical setting, patients with exclusionary conditions may be diagnosed and managed as having CFS on the basis of the physician's medical opinion as to whether the exclusionary condition is likely to be a major contributor to the patient's fatigue." While this change seems to broaden the definition of CFS, it likely reflects how the illness is actually diagnosed by doctors.

The paper clarifies other ambiguities in the original case definition. For example, the case definition concept that "rest should not substantially alleviate fatigue" has sometimes been misinterpreted to suggest that if you feel better after resting, you do not have CFS. The authors explain that this statement was intended to distin-

guish CFS from the "fatigue associated with overwork that resolves when the excessive demands end."

The article also makes a concerted effort to standardize research instruments by recommending specific instruments to measure particular symptoms. One major problem in CFS research has been the use of vastly different tests to assess the same symptom (such as cognitive impairment), making it nearly impossible to compare one study's results to another's. If adopted by researchers, these recommendations should greatly improve comparability of research.

The full text of this article is available at www.biomedcentral.com/1472-6963/3/25.

Progesterone elevated in women with CFS

In a small Canadian study, women with CFS had significantly higher levels of progesterone and its **metabolite** isopregnanolone compared to healthy controls. These differences could not be attributed to medications or depression — further evidence, say the researchers, that CFS differs from depression.

The authors, writing in the February 2004 issue of *Psychoneuroendocrinology*, suggest this progesterone elevation may explain the com-

mon finding that cortisol, another hormone, is low in CFS. Progesterone influences cortisol production, but cortisol can be inhibited if progesterone metabolism is diverted toward the production of the ring-A metabolites, particularly isopregnanolone, which was significantly elevated in the CFS group. ■

CFIDS GLOSSARY: TERMS YOU NEED TO KNOW

Agonist: A drug or chemical that combines with a cell receptor to produce a physiologic reaction typical of a naturally occurring substance. A serotonin agonist is able to mimic the effects of serotonin by stimulating activity at the brain's serotonin receptors.

Endocrine: Glands (or the system of glands) that secrete hormones directly into the circulatory system. Hormones regulate many organs in the body, and because they have such widespread effects, many of the leading theories about CFS involve abnormalities in the endocrine system.

Metabolite: A substance produced by metabolism or by a metabolic process. Metabolism is the sum of the physical and chemical processes in the body and the process which makes energy available to an organism.

Pathophysiology: The functional changes associated with or resulting from disease or injury, as opposed to structural defects. The pathology of CFS would set the disease in motion, while the pathophysiology would explain the effects of the disease in the body.

Sources: *Dictionary.com* and *Pharma-Lexicon.com*

Activities and opportunities from The CFIDS Association of America**Almost \$300,000 raised in Annual Fund drive**

More than 1,100 CFIDS Association friends contributed to the 2003 Annual Fund, raising a total of \$291,834 to help meet the ongoing need for flexible, unrestricted income in the fight to end CFIDS.

The Annual Fund drives vital programs in CFIDS awareness, education, public policy and research. These are valuable efforts important to people with CFIDS and those who care about them.

Thanks to Association volunteers and donors who helped make the 2003 Annual Fund a success. Special thanks to **Beverly Horton**, whose \$60,000 matching gift inspired so many others to give as generously as possible.

Complete financial results will be available in the Association's 2003 Annual Report due out in May.

Association staffing changes

Mark Giuliucci resigned from the Association's staff this fall due to family needs. Mark had served as editor of *The CFIDS Chronicle* and *The CFS Research Review* since 2001. Public Relations Coordinator **Leah Moseley**, also a member of the Association's team since 2001, recently relocated to the Washington, D.C., area,

where she was offered a position with DeVry University. We are sorry to see the departure of these two valued staff members.

We are pleased to welcome **Marcia Harmon** as the Association's Director of Publications. Marcia's wealth of experience will be a strong asset to the Association's publications, including the *Chronicle* and *CFS Research Review*, which she will edit. **Vicki Walker**, a member of the Association's staff from 1993-2003, is serving as guest editor of this issue of *The CFIDS Chronicle*.

Welcoming new Board members & officers

New directors and officers were elected by The CFIDS Association's Board of Directors this fall. Officers for the 2004 Board will be: Chairman **Jonathan Sterling**; Vice Chairman **Joseph Lane**; Treasurer **Jane Perlmutter**; and Secretary **Barbara Comerford**.

The Board regrettably accepted the resignation of director **Beth Levine**, due to health reasons. Beth had served on the Board since 2001. Two new directors were elected:

Susan L. Jacobs, Esq. is a partner at a general practice law firm and is actively involved in her community of Providence, R.I. She is

president of the Attleboro Area Bar Association and has served on the boards of several organizations, including the Attleboro Museum, the Brown Hillel Foundation and Big Sister Association of Greater Boston, where she was awarded "Big Sister of the Year" in 1994. Ms. Jacobs' interest in CFIDS stems from her long-standing friendship with a person with CFIDS.

Lynn Holaday Royster, PhD, JD, is a professor at DePaul University, where she serves as mediator and trainer in the Center for Conflict Resolution. Her interests include creating equal educational opportunities for college students with disabilities such as CFIDS. She was instrumental in piloting a distance learning bachelor's degree program for disabled students at DePaul University's School for New Learning. Dr. Royster's 29-year-old son Patrick has suffered from CFIDS for more than half his life.

CFIDSLink grows in popularity

CFIDSLink, the Association's free monthly e-mail newsletter, currently has nearly 16,000 subscribers and the list continues to grow. To sign up, visit www.cfids.org/subscribe.asp or call the Resource Line at 704-365-2343. ■

Tips, strategies, ideas and helpful thoughts about CFIDS

Explaining CFIDS to others

I've been sick for 16 years. I live in a small town and when I bump into former colleagues or neighbors, they assume I'm cured because I "really look great."

I reply, "If I weren't doing pretty well today, you wouldn't have seen me. I'd be in bed."

Others ask, "What exactly is wrong with you?"

I say, "I have CFIDS/ME."
"What's that?"

"Doctors aren't sure. Something is the matter with my immune system. I feel like I've got a terrible case of the flu all the time, and maybe I do. I've also got a ton of allergies I never had before."

If they keep asking, I keep answering with the latest research efforts. When the encounter is ending, I say, "Oh, some people call this disease chronic fatigue syndrome."

That always startles them. "I've heard of that. I never realized how bad it can be."

That, of course, is the outcome all people with CFIDS want: an informed and concerned public.

Kathleen T. Choi
Hawaii

Music can boost energy

As a long-term CFIDS patient and an Alzheimer's caregiver for my mother, each day presents challenges. The hardest part is getting my

"If you aren't working, make sure to follow disability application deadlines."



mother up, fed, medicated, bathed and dressed, which usually takes just over an hour. Energy is always at a premium and on days of extreme exhaustion, I sometimes wonder if I can make it through all the steps.

To help me get through all the tasks, I've found a certain type of music quite helpful. While most contemporary music is not for me, I've discovered the powerful and beautiful voice of Clay Aiken from *American Idol*. I taped his performances and listen to them every day during my mom's bath time.

The songs energize me as I complete the work, and then I know I can rest. Especially on days when my CFIDS symptoms are at their worst, the music really helps get me through it all, and my mom seems to enjoy the songs too.

Since I'm not a particularly auditory person, I've been surprised by the power of this music to give me a critical boost during the most physically exhausting part of my day. I'd strongly encourage others to explore music as an option to help counter the debilitating effects of CFIDS.

Name withheld at writer's request

Keep abreast of deadlines

If you are not working because of CFIDS, but haven't yet applied for disability benefits, make sure to learn about and follow application deadlines.

Because I was off work for three years before my doctors agreed to sign my state disability benefits application, I missed the deadline to apply and did not qualify for benefits.

Since I wasn't aware of any deadline, I didn't start fighting to get my doctors' signatures until it was too late. Since different disability benefits programs have different requirements, find out early what federal, state or private benefits you might qualify for, and learn their individual requirements.

Karen M. Campbell
California

Have a One to One tip you'd like to share? Send it to the Chronicle at The CFIDS Association of America, P.O. Box 220398, Charlotte, NC, 28222-0398. You can also send them by e-mail to chronicle@cfids.org.

Deficiencies You Can Deal With

Studies show CFIDS and FM patients are likely to be low in several important vitamins, minerals or amino acids, but smart supplementation can help.

By Patti Schmidt

Our bodies need a steady supply of micro-nutrients — vitamins, minerals and essential amino acids — to operate properly. If you have chronic fatigue and immune dysfunction syndrome (CFIDS) or fibromyalgia (FM), you're prone to nutritional deficiencies.

"It's likely that marginal deficiencies not only contribute to clinical manifestations of CFIDS, but also are detrimental to the healing processes," explains physician Melvin R. Werbach.¹

Enlist your doctor and a nutritionist to help you discover your nutritional needs and how best to meet them. Have a pharmacist look periodically for potential interactions between the herbs, supplements and prescription or over-the-counter medications you take.

Which supplements to take?

Werbach's study suggests people with CFIDS (PWCs) are low in the B vitamins, vitamin C, magnesium, sodium, zinc, L-tryptophan, L-carnitine, coenzyme Q10 and essential fatty acids "primarily due to the illness process rather than to inadequate diets."¹

Research also shows PWCs have a problem with oxidative stress: one study recommended glutathione, N-acetylcysteine, alpha-lipoic acid, oligomeric proanthocyanidins, ginkgo biloba and bilberry.² Other studies have reported growth hormone and NADH deficiencies.

Werbach suggests identifying deficiencies with objective testing when possible, treating them effectively and retesting after treatment to ensure success. But when testing is impossible, he suggests supplementing for a trial period since "it's often difficult to rule out marginal deficiencies, because serious adverse reactions are rare and because nutritional supplements offer a therapeutic benefit."

In other words, it probably won't hurt and it may help.

How much to take?

Sensitivity is a problem for many, so start with $\frac{1}{8}$ – $\frac{1}{4}$ of a normal dose and work up to the dose your body can tolerate without side effects.

Begin one new thing at a time and write down when you began taking it. (If you begin three things at once, how will you know which is helping or hurting if you experience new symptoms or side effects?) By noting symptoms, you may see patterns or trends.

Vitamins

Vitamins are nutrients in foods that assist essential biochemical reactions within your body. There are 13 vitamins. Your body can store up to four months' worth of the four that are fat-soluble — A, D, E and K; and enough of the other nine water-soluble ones — C (ascorbic acid) and the B-complex vitamins (B-1, B-2, B-3 B-5, B-6, B-12, folic acid and biotin) — to last for several weeks.

B-complex vitamins

One study found preliminary evidence of reduced functional B vitamin levels, particularly pyridoxine (B-6), in CFIDS patients.³ Even people who aren't B-12 deficient have more energy after vitamin B-12 shots, so many physicians urge fatigued patients to try B-12.

In one preliminary trial, 2,500–5,000 mcg. of vitamin B-12 given by injection every two to three days led to improvement in 50–80 percent of a group of PWCs; most improvement appeared after several weeks.⁴ Oral or sublingual B-12 supplements are unlikely to provide the same results as injectable B-12 because the body cannot absorb large amounts orally.³

Recommendation: The B vitamins work synergistically, so take a B-complex vitamin or other multivitamin supplement that contains at least the U.S. RDA of each of the B-complex vitamins. Although B-12 shots are most effective,

sublingual lozenges help. Take either a shot of 1,000–5,000 mcg. hydroxycobalamin (which some patients say stings) or cyanocobalamin, or one sublingual dose of 1,000 mcg. B-12 per day.

Vitamin C

Studies show people respond well to 1–6 grams daily of vitamin C — their risk of heart disease and cancer decreases, they manage chronic illness better and they live longer. A 1996 Japanese study showed CFIDS patients improved after taking intravenous infusions of vitamin C and DHEA.⁵ In Dr. Jesse Stoff's study of 1,357 patients, which he treated using 1,000 mg. of vitamin C three times daily and Biomune OSF, an immune-modulating substance, he claimed 88 percent of those who had one detected viral infection improved within one year. Those with multiple infections improved at roughly half that rate.

Recommendation: Take 1–6 grams of vitamin C daily, broken into even doses throughout the day.

Vitamin E

A 1993 study found vitamin E reduces stroke and heart attack risk by 57 percent and 52 percent, respectively. A survey of American Heart Association members showed more than 62 percent are taking vitamin E. With recent research showing that CFIDS patients may have a higher risk of heart disease,⁶ vitamin E is a potent antioxidant that should be in every PWC's regimen.

Recommendation: Take 400–800 IU of vitamin E daily.

Minerals

Minerals are often overlooked, but they shouldn't be. Without minerals, vitamins are useless. In their dissolved state, minerals create and maintain a healthy internal environment which allows other nutrients to do their jobs.

Magnesium

Magnesium deficiency can cause immune and autonomic nervous system dysregulation. Experimental magnesium deficiency produces

fatigue, depression, poor exercise tolerance and decreased resistance to psychological stress.

In a randomized, double-blind, placebo-controlled study, investigators described the efficacy of intramuscular magnesium in 20 PWCs who had lower red cell magnesium levels than 20 healthy controls.⁷

In 1990 Dr. Carol Jessop reported that low magnesium levels are common and can be detected with a 24-hour urine sample. She instructs the patient to take 400–500 mcg. magnesium for three days and then repeats the test to determine how much the body retained. "If they retained greater than 50 percent, it's significant because magnesium is very important in muscle relaxation. Many of my fibromyalgia patients improve by adding magnesium to their diet," she said.⁸

Magnesium supplements don't always work because they're alkaline and can neutralize the stomach's hydrochloric acid, which is why nutritionist Adelle Davis notes people with digestive problems shouldn't take magnesium supplements.

Dr. Zoltan P. Rona believes magnesium deficiency is common in FM despite a high magnesium intake. He attributes that to leaky gut syndrome, which creates mineral deficiencies because gastrointestinal proteins that transport minerals to the blood are damaged by inflammation. He says if the carrier protein for magnesium is damaged, magnesium deficiency develops and muscle pain and spasms occur.⁹

Recommendation: 250 mg. magnesium three times daily has produced good results in FM patients, especially when combined with 1,200–2,400 mg. malic acid daily. Dr. Jacob Teitelbaum's CFIDS/FM treatment protocol calls for two tablets of Pro Energy (a magnesium/malic acid supplement) three times a day for eight months, then two tablets a day (less if diarrhea is a problem).¹⁰ He recommends starting with one or two a day and slowly working up. Taking it with food may lessen diarrhea. Pro Energy is available from www.immunesupport.com or at 800-366-6056.

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Sodium

In several controlled studies, PWCs had a higher rate of orthostatic intolerance (OI), an autonomic nervous system condition where blood pools in your legs when you stand, denying your brain the blood and oxygen it needs to operate normally. Sodium helps regulate blood pressure and water balance and it can elevate blood pressure. If you have OI, eating extra salt and drinking two to three quarts of water a day can naturally improve the condition.

Dr. Nancy Klimas suggested that increased salt and water intake can make the kidneys efficient at getting rid of the extra sodium after a few weeks. When that happens, Klimas prescribes fludrocortisone (Florinef). Another route is to prescribe alpha-1 agonists, such as midodrine (ProAmatine).

Recommendation: If you have OI, buy buffered salt tablets available at a pharmacy and follow your physician's directions concerning dosage. Also increase your water intake. If these don't help, you may need a prescription medication.

Zinc

Zinc is important in the activity of enzymes needed for cell division, growth and repair (wound healing, for example) and immune system functioning. Zinc also plays a role in taste and smell, carbohydrate metabolism and DNA replication.

Dr. Stephen Davies, editor of the *Journal of Nutrition in Medicine*, noted, "CFS patients are nearly always deficient in magnesium ... [and] frequently deficient in zinc and copper, too."

Dr. Carol Jessop stated, "Low zinc levels are common, although only 32 percent of patients show this on blood tests ... But many patients either have poor wound healing or leukonychia (white spots on the fingernails), which are signs of zinc deficiency" she said.⁸

Recommendation: Take a 15–25 mg. zinc supplement every day.

Final advice

Sometimes science can help you determine which supplements you need. For

example, your physician can test how much iron is circulating in your blood; if you're low, he can prescribe iron supplements. After you take them for a while, he can measure how you're doing with another blood test. This isn't always the case, though.

In your search for a balanced supplement regimen, take this advice from Jack Challem, *The Nutrition Reporter*TM: "Vitamin supplements have their place, but they're additions to a sound diet, not replacements for it. Instead of trying to compensate for what you do wrong, strive for balance. Eat a wholesome diet as consistently as possible, and then add supplements."

This is an edited version of a longer article that was published at www.immunesupport.com/library/showarticle.cfm/ID/3554 in 2002. ■

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CFIDS and the Muse

By Steve
Sorensen

The Muse is medicine.

I learned this early in my journey towards recovery from CFIDS. Over these years I've come to understand that sustaining our creative spirit is as important as proper diet, rest and exercise. Developing ways to maintain our artistic activities is a crucial part of keeping in touch with our humanity and a vital aspect of any healing process.

Despite the fact that our physical and emotional energy is diminished, we can still lead creative lives if we match activities to our situation. We don't have to feel trapped by our illness. In fact, we can use it as an opportunity to explore new creative outlets we may not have tried otherwise.

Keeping my own Muse alive despite CFIDS has become a crucial part of my recovery over these past 11 years. Prior to CFIDS, I enjoyed climbing high into Colorado's Rocky Mountains to explore its amazing backcountry and bring back photographs of my travels to share with others. Although an engineer by trade, it's my photography that defines a large part of who I am.

Of course you can imagine how CFIDS impacted me. Not only was I unable to hike, it left me with little energy or will to take photographs at all. Almost overnight I lost a large part of who I was. After that initial period of self-pity we all go through, I realized my situation wasn't going to change soon. I was just going to have to deal with it.

Because art and creativity played such a major role in my life prior to CFIDS, I knew I had to figure out a way to incorporate them into my healing. Over time I developed an approach to keeping my Muse alive that I call the Artistic Pyramid. Each level of this pyramid's three layers describes a different way of participating in the creative process and the amount of energy required. Thinking about it this way allows me to match my activities to the amount of energy I have at any particular time.

My Artistic Pyramid's layers are (bottom to top): Enjoying Art, Creating Art and Sharing Art.

Enjoying Art

Enjoying others' artwork is the easiest way to sustain your creative spirit. As the base of the Artistic Pyramid, it forms the majority of the activities we do. Examples include listening to music, reading a book or watching a movie. Exposure to others' works keeps our creative side active without draining away too much energy.

For the first several years of CFIDS, I didn't have the physical or emotional energy to create my own artwork, so I immersed myself in other artists' work. I used it as a time to explore new reading topics, listen to my increasingly diverse music collection and watch old movie classics. Now I have more energy for artistic activities, but I still take time to seek inspiration from the artwork of others.

Some *Enjoying Art* ideas you might try include:

- List a half-dozen books you've always meant to read and use this time to read them.
- Explore new music genres. Browse local or online music stores or the library and pick out some CDs that catch your eye. Try out radio stations you've never listened to before.
- Pick an actor or director and watch five to 10 of his or her films in chronological order to see how his or her artistic styles have evolved.

Enjoying others' artwork will inspire you to create your own, which leads to the next layer of the pyramid.

Creating Art

Creating art is the act of making something for the sheer joy of it. You don't have to worry about showing it to anyone; you're simply making art for its own sake. Although it takes

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Photo: Steve Sorensen

more energy to create art yourself, the pleasure of the act is worth it. This is especially true if you're expanding your creative skills or learning a new art form.

After about five years of CFIDS I'd recovered enough to begin photography again. Spending time in a local rental darkroom was out, but I discovered I could assemble a digital darkroom on my home computer. This allows me to work on photographs at my own pace. I even began experimenting with new digital imaging techniques that combine painterly effects with photos, something I never could have done in the traditional darkroom.

Creating Art examples you might try:

- Make a "Day in the Life" book by taking photos over the course of a day and describing them in your own words.
- Learn a new instrument. The recorder or penny whistle are fun, simple ones to pick up.
- If your energy permits, take a short art class at a local community center or college.

Over time, once you're creating art freely, you may find yourself with the interest and energy for the top layer of the pyramid.

Sharing Art

This is the most energy-consuming level of the Artistic Pyramid, but also the most rewarding. Sharing your art allows others to enjoy the results of your creative activities. It

doesn't matter whether this takes place among family and friends, or in a more public forum. The key is you're able to share your creative expressions with other people, and maybe even inspire them to create works of their own!

With my new digital darkroom, I began sharing my photographs again with family and friends by incorporating the images into hand-made greeting cards. I expanded into making larger prints and eventually worked up the nerve to apply for (and win) a one-man show at a local bookstore. This success inspired me to begin selling my photos through nearby stores, art fairs and online. The importance to me is not the sales themselves, but the opportunity to share my favorite images with those who enjoy them.

Sharing Art ideas you can try:

- Create and mail out a family newsletter.
- Put some of your artwork (stories, photos, drawings, etc.) up on a Web page.
- Make someone a handmade gift.

I find the only danger with the *Sharing Art* layer of the pyramid is that it can be extremely addictive, so remember to pace yourself.

The point of all this is that we don't have to let CFIDS kill our creative spirit. Keeping art in our lives reminds us of our connection with the rest of humanity, no matter how crummy we might feel at times. There are easy ways for us to match our artistic activities to our energy levels if we approach it properly. The Artistic Pyramid is my way of thinking about this, but you can devise other methods that work in your own situation. You may even discover, as I did, that you're heading down new artistic paths you never would have imagined!

Just remember, the Muse is medicine.

*Steve Sorensen is an engineer and photographer living in Boulder, Colo. You can see his images at www.bannertree.com. He is now starting on a book titled *Creative Sanity: 101 Ways to Keep Your Muse from Going Stir-Crazy!* ■*

Your guide to published resources

Fixing Frannie

By Frannie Rose
2003, GMA Publishing.
\$16.00, 269 pp.
Review by Kerry Ryan-Kuhn

With openness and humor, Frannie Rose shares her journey with chronic illness and offers her insights and experiences as a guide for others on a similar journey.

“I have written this book as my gift to you. My purpose was to tell you what I learned about the medical system in the most creative way I could, by sharing my feelings.”



In her simple and humorous style, she takes readers with her into places seldom discussed: the exam room, conversations with her doctor, parenting with chronic illness, abandonment by loved ones. In doing so, she shines light on the whole picture of the chronic illness experience.

In this second edition, Rose adds a chapter about her triumphs and challenges over the past six years since her diagnosis of a rare disease, subsequent treatment and return to health. Again, Rose confidently steps into a difficult topic, the aftermath of living with chronic illness.

Frannie Rose inspires her readers to never give up on themselves or finding the medical care they deserve.

I'd Rather Be Working: A Step-by-Step Guide to Financial Self-Support for People with Chronic Illnesses
By Gayle Backstrom
2002, AMACOM,
\$14.95. 252 pp.

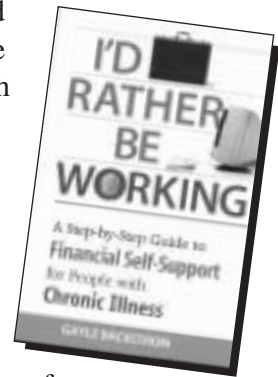
Gayle Backstrom has had fibromyalgia since childhood, so she brings a tremendous amount of personal experience, combined with research and realistic guidance, to the topic of earning money when you have a chronic, unpredictable illness, such as CFIDS.

There are few topics more emotion-laden to Americans than employment and financial security. Many people primarily identify themselves by their function in the workplace (it's more common to hear, “I'm an accountant” rather than “I'm a wife” when asking a person to describe herself). When chronic illness tears away at their ability to work, many people find that their self-worth declines too. This book tries to help individuals fill that void.

Backstrom opens the book with a series of self-evaluation exercises designed to help readers clarify their individual

abilities and limitations, resources and liabilities. Part II covers government employment resources, including a thorough discussion of the Americans with Disabilities Act and its pros and cons. Part III helps readers find information about education, training and financial aid and gives advice on the job search process specifically relevant to people with chronic illness.

The wealth of data is supplemented by real-life stories of people with a variety of chronic illnesses, describing their individual pathways to seeking employment. Some are success stories — either in finding employment or starting small businesses — while others are not. This section, like the core of *I'd Rather Be Working*, is a realistic, informative and, above all, personal look at a difficult problem facing millions of Americans. ■



Interested in writing book reviews for the Chronicle? Contact the editor at The CFIDS Association of America, P.O. Box 220398, Charlotte, NC 28222-0398, or online at chronicle@cfids.org.

Information, resources and opportunities for people with CFIDS (PWCs)



Bulletin Board space is provided at no cost to individuals or groups who conduct non-profit or volunteer activities for the CFIDS community. The CFIDS Association of America assumes no responsibility for content. Send notices to The CFIDS Chronicle at chronicle@cfids.org or mail to PO Box 220398, Charlotte, NC 28222-0398, Attn: Chronicle.

RESOURCES

The Cost Containment Research Institute has published a revised edition of its booklet, "Free and Low-Cost Prescription Drugs," to help consumers find patient assistance programs provided by the major drug companies. To receive a copy, send a check for \$6 to Institute Fulfillment Center, Booklet #PD-75, PO Box 210, Dallas, PA 18612-0210. For information, see www.institutedc.org.

Medicare is another source of information about free and reduced-priced medications. The telephone number 1-800-MEDICARE acts as a clearinghouse for information on drug companies' patient assistance programs, which offer discount programs for select drugs.

Singles with CFIDS or fibromyalgia are invited to find friends, sharing, bonding or possibly even romance at the Internet group CFIDS

and Fibro Singles. For more information, visit health.groups.yahoo.com/group/CfidsandFMSingles/

People disabled by chronic illnesses have a new opportunity to earn a college degree through self-paced distance education through DePaul University's School for New Learning. For details, visit www.snlonline.net or call 1-866-SNLFORU.

FUND RAISERS

The Long Island CFIDS Society is selling 2004 *Entertainment* discount books to raise funds for The CFIDS Association of America's research program. Books for many areas of the U.S. are available. Visit www.cfids.org/community/shop-give.asp for a link to order your book today.

CONFERENCES

Frontiers of Knowledge in Sleep & Sleep Disorders: Opportunities for Improving Health and Quality of Life will be held March 29-30 on the National Institutes of Health campus in Bethesda, Md. Registration is free and open to all who preregister. For more information visit www.sleeptranslation.com or call 301-435-0193.

Advances in Understanding and Treating Chronic Fatigue Syndrome and

Fibromyalgia will be held at the Salt Lake Sheraton in Salt Lake City. A health care provider conference will be on May 14, and a patient conference on May 15. For more information visit <http://cme.ihc.com> or call 801-408-1976.

Identifying the Causes & Exploring the Newest Treatment Options for Fibromyalgia and Chronic Fatigue Syndrome will be held May 14-15 at the Marriott Hotel in Overland Park, Kan. For further information call Yvonne Keeny at 913-384-4673 or visit www.fibrocoalition.org.

Myopain '04, the sixth World Congress on Myofascial Pain and Fibromyalgia, will be held July 18-22 in Munich, Germany. For more information, visit www.myopain.org or call 210-567-4661 (in the U.S.).

The American Association for Chronic Fatigue Syndrome will hold its seventh international conference on CFS, fibromyalgia and related illnesses October 8-10 in Madison, Wisc. The Wisconsin CFS Association is hosting this meeting, which includes clinical, research and patient sections. For more information, visit www.aacfs.org/html/meetingstoc.htm. ■

WHAT IS CFIDS?

Chronic fatigue and immune dysfunction syndrome (CFIDS) is a serious and complex illness that affects many different body systems. The cause has not yet been identified. It is characterized by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), neurological problems and numerous other symptoms. CFIDS can be severely debilitating and can last for many years. CFIDS is often misdiagnosed because it is frequently unrecognized and can resemble other disorders including mononucleosis, multiple sclerosis (MS), fibromyalgia (FM), Lyme disease, post-polio syndrome and autoimmune diseases such as lupus. CFIDS is also known by the names chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME).

HOW IS CFIDS DIAGNOSED?

Despite more than a decade of research, there is still no definitive diagnostic test for CFIDS.

According to the CFS case definition published in the Dec. 15, 1994, issue of the *Annals of Internal Medicine*, diagnosing CFIDS requires a thorough medical history, physical and mental status examinations and laboratory tests to identify underlying or contributing conditions that require treatment. Clinically evaluated, unexplained chronic fatigue can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social or personal activities.

2. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have pre-dated the fatigue.

HOW IS CFIDS TREATED?

Treatment for CFIDS is intended primarily to relieve specific symptoms. It must be carefully tailored to meet the needs of each patient. Sleep disorders, pain, gastrointestinal difficulties, allergies and depression are

some of the symptoms which can be relieved through the use of prescription drugs, over-the-counter medications and other interventions such as physical therapy. People with this illness may have unusual responses to medications, so extremely low dosages should be tried first and gradually increased as appropriate.

Lifestyle changes, including increased rest, reduced stress, dietary restrictions, nutritional supplementation and minimal exercise, are recommended frequently. Supportive therapy, such as counseling, can help to identify and develop effective coping strategies.

WHO GETS CFIDS?

CFIDS strikes people of all age, ethnic and socioeconomic groups. Most cases in the United States are women between the ages of 40 and 49, but CFIDS afflicts men, women and children of all ages.

Carefully designed studies have yielded estimates that more than 800,000 adults in the U.S. have CFIDS. In women, CFIDS is more common than multiple sclerosis, lupus, HIV infection, lung cancer and many other well-known illnesses.

DO PWCs GET BETTER?

The course of this illness varies greatly. Some people recover, some cycle between periods of relatively good health and illness, and some gradually worsen over time. Others neither get worse nor better, while some improve gradually but never fully recover.

The CDC is conducting a long-term study of PWCs to learn more about the course of illness. CDC investigators have reported that the greatest chance of recovery appears to be within the first five years of illness, although individuals may recover at any stage of illness. Investigators have also found an apparent difference in recovery rate based upon type of onset. PWCs with sudden onset reported recovery nearly twice as often as those with gradual onset. This study is ongoing and observations about the course of illness are likely to change as more data is collected.

This document is adapted from "Introducing CFIDS," a pamphlet about CFIDS published by The CFIDS Association of America. Single copies are free of charge; multiple copies may be ordered by calling the Resource Line at 704-365-2343.

E-MAIL ADDRESSES FOR THE ASSOCIATION

Visit our Web site to request information by e-mail
www.cfids.org

To join the Association, subscribe to the *Chronicle* or change your address
membership@cfids.org

Submitting articles or letters to the *Chronicle*
chronicle@cfids.org

General questions
cfids@cfids.org

Jon Sterling,
Chairman
chairman@cfids.org

Kim Kenney,
President & CEO
kkenney@cfids.org

Board of Directors
board@cfids.org

Kristina Hopkins,
Controller
kphopkins@cfids.org

Jamie Davis,
Development
development@cfids.org

Marcia Harmon,
Publications
mharmon@cfids.org

Nova Bouknight,
CFIDS Support Network
nbouknight@cfids.org

MISSION

The Mission of The CFIDS Association of America is to conquer CFIDS. The Association works toward its mission by:

- **Building recognition of CFIDS as a serious widespread medical disorder,**
- **Securing a meaningful response to CFIDS from the federal government,**
- **Stimulating high quality CFIDS research,**
- **Improving health care providers' abilities to detect, diagnose and manage CFIDS and**
- **Providing information to persons with CFIDS and enabling the CFIDS community to speak with a collective voice**

Advocacy, Information, Research and Encouragement for the CFIDS Community