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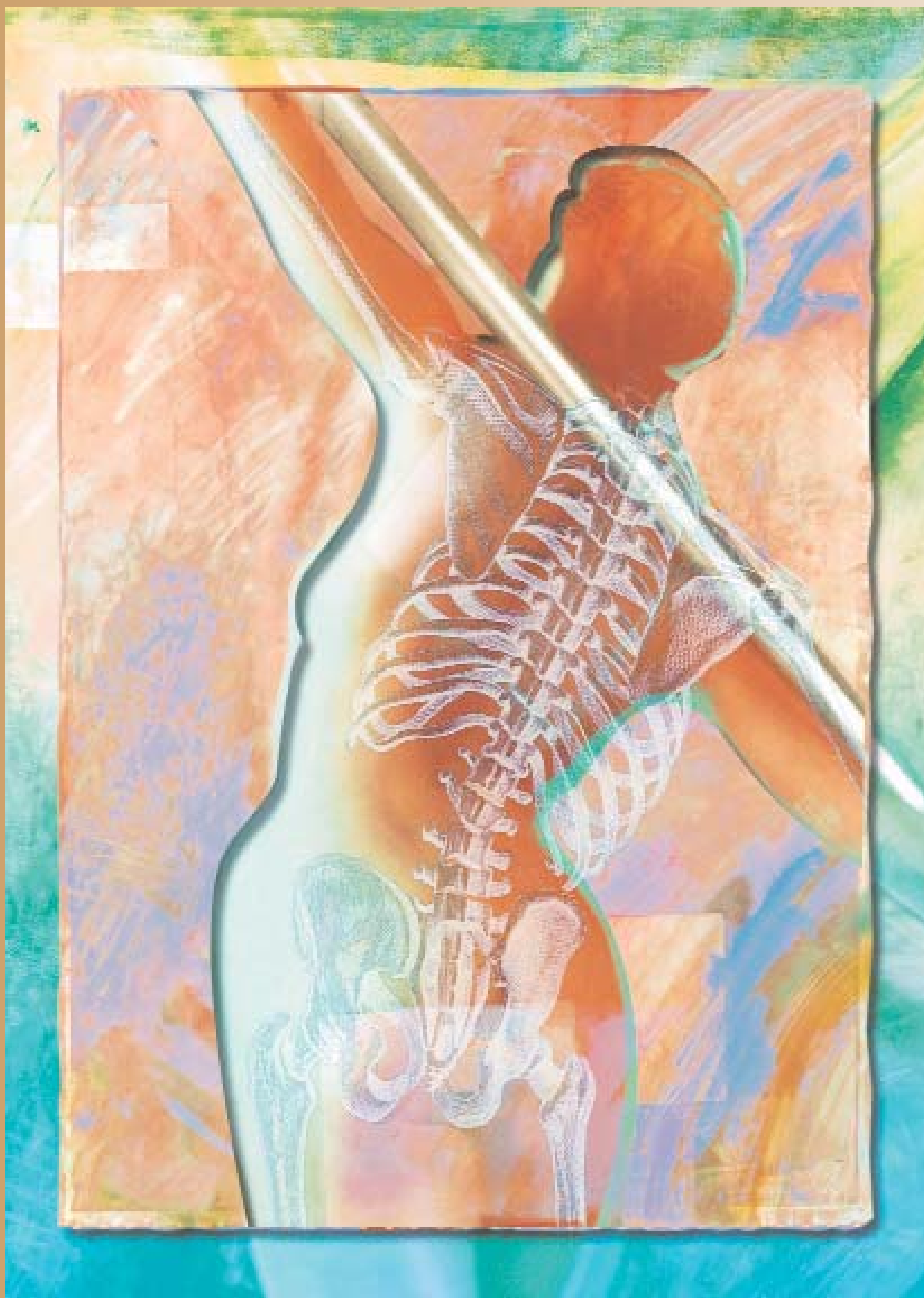
THE CFIDS ASSOCIATION OF AMERICA

THE CFIDS CHRONICLE

Advocacy, information, research and encouragement for the CFIDS community

A QUARTERLY PUBLICATION OF THE CFIDS ASSOCIATION OF AMERICA ▪ SUMMER 2004



Wish you could stretch and walk, even exercise, without paying for it the next day?

CFIDS is an exercise enigma. The exercise that is so beneficial in managing most chronic illnesses can actually make CFIDS symptoms worse. Find out how new research and approaches are helping many CFIDS patients solve this exercise dilemma.

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Message to Members

In recent months, as we have met with and heard from members of the CFIDS community, the CFIDS Association Board of Directors has been asked to clarify the Association's position on the name change issue. Some people have asked if we have given up the fight.

We believe the name *chronic fatigue syndrome* is inadequate, misleading and problematic. The term contributes to the lack of understanding of the serious and complex nature of the disease. Our position on these two points remains unchanged from 1994, when we first joined others working to change the name.

Over the decade since then, the CFIDS Association has invested time, money and energy to garner support for a name change. We funded Dr. Leonard Jason's research on the name and its attributions; we sponsored several different name change groups, including providing financial support for activities of the federal name change working group that reported its recommendations last fall; and we conducted multiple surveys of patients, providers and others on this hot-button issue. We have reported on it regularly in the *CFIDS Chronicle* and our other publications. Considerable board and staff resources have fueled these important efforts.

On December 8, 2003, the government's CFS Advisory Committee (CFSAC) declined to recommend a name change, saying, "We feel that a change of the name to another name should occur only when there is a better understanding of the pathophysiology of the illness."

Our board immediately convened by phone to discuss the CFSAC's position and determine how to proceed. What compelled us most was the realization that not one of the appointed members of the CFSAC—each one knowledgeable about CFIDS, its complexity and its devastating impact—was persuaded to recommend a name change, even with their combined understanding of the history of the issue and the passion it has generated in the patient community. In the face of this, how could we expect to persuade the larger medical community and the general public to use a new name not endorsed by experts in the field? The CFSAC's decision means that efforts to pursue a name change stand little chance right now of succeeding beyond the patient community.

We have viewed the name change as one strategy to accomplish important goals—greater public awareness, expanded research, informed and compassionate medical care and more responsive government and social services. We're working harder than ever to achieve these ends by other means, until the name change issue can be vigorously reengaged at a time when success is more likely. Some of these activities are described elsewhere in this issue; others are in the planning stages.

We're also pushing harder than ever to get results from NIH and CDC—results that translate into better understanding of the pathophysiology of CFIDS so a name change, firmly rooted in science, is widely supported.

Let there be no mistake: we have not abandoned the fight. We will continue to report progress on other fronts, and we will be ready to act on opportunities to change the name.

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ABOUT OUR ORGANIZATION: The CFIDS Association of America, Inc., is a public, nonprofit, charitable organization. In addition to publishing the *CFIDS Chronicle* and the *CFS Research Review,* the Association directly funds CFIDS research and advocacy efforts and provides free information 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 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 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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OUR 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**
- **Providing information to persons with CFIDS and enabling the CFIDS community to speak with a collective voice**

Expressing gratitude

I am a PWC. In 1997 I boarded a plane from Reno, Nevada, to Washington, D.C., to help lobby for CFIDS. It was there I had the pleasure of meeting Kim Kenney, Tom Sheridan, Dr. Robert Suhadolnik and many other incredible people. My trip was one of my biggest victories since CFIDS hit my life 17 years ago.

I felt compelled to write and tell you what a highly efficient and effective community you are—and we are! I am always so moved by your *Chronicle.* Your articles are always right on the money. I am so utterly impressed with your consistently accurate information and your fine ability to present it.

I would revel in a cure so I can pursue a vocal career rich with stamina and endurance. I know the CFIDS Association is doing everything it possibly can to give me my life back, setting me free to live without such horrific restraints. I want you to know that we know you are fighting for us! I dream of the day I am able to fly back to D.C. and perform for all of you to say thank you for all you do. From the bottom of my heart and with abundant gratitude,

Kelly Jeffery Mooneyham

Anger article was welcome

I want to congratulate you on your new format for the *CFIDS Chronicle* and the relevancy of the subject matter. I have kept up to date on CFIDS and FM literature for more than 10 years, and I think the article on anger and its relationship to health is the most cogent I have read to date.

I would like to expand on the thought of anger being recognized as a relapse trigger. I have found that inappropriate anger is a very sharp warning signal to pay attention to what is going on. Also, some medications impact my emotions. Prednisone is a very potent anger trigger for me. I can't even take a taper dose because it leads to rage and depression. Another unexpected trigger for me was Biaxin, a common antibiotic. Always check out prescriptions for potential side effects.

Jill Mouat

The economy of debate

I was recently sent a CFIDS/FM newsletter written by members of a CFIDS support group. I was floored by the biased, angry tone of the articles. Commentaries about the CFS Advisory Committee conference held last September cast certain key activists and doctors in a most unflattering and even offensive light. I couldn't imagine what profit could possibly be gained by vilifying hardworking members of the CFIDS community.

I feel no need to cast blame on people working toward awareness, treatment and cures for CFIDS. Even if these same people address the issues in ways I would not, I still appreciate their effort, and I still respect the difficulty of their task. There is room for debate—for candid and open discussion devoid of insult. The more we talk, the closer we come to an understanding. The more we yell, the further isolated we become. What's more, I could not decipher what, if anything, was gained by the attitude of those angry activists at the meeting. No point was driven home by the anger with which it was presented. The same idea could have easily been conveyed in a civil tone, and possibly with great success.

In the recent, often heated debate over the proposed name change, I've been heartened to hear thoughtful reasoning on both sides. I've been equally saddened when the debate degenerates into pointless attacks on the character of the debaters. Kim Kenney has worked for years with the CFIDS Association, always striving for greater public awareness of CFIDS and writing intelligent commentary. In my own experience, I met Dr. William Reeves several years ago when he came to speak at our local CFIDS support group. I left that meeting feeling that the CFIDS community has no better friend than Dr. Reeves. Frankly, if I cannot have a cure for CFS, then an understanding, empathetic doctor is the next best thing, and Dr. Reeves is just that kind of man.

As a disabled PWC of 13 years, I adamantly refuse to be counted among the mudslingers of CFIDS activism. If a PWC is angry about being incurably sick, I share that frustration; but when that anger is channeled into mudslinging and blame, then count me out. I am too weary and too sick to be involved in anything but intelligent, constructive dialogue.

Liz Burlingame

Best issue ever!

I am a support/contact person in Oregon. I'm requesting extra copies of the spring 2004 *CFIDS Chronicle* because I have many people who could benefit from reading and keeping this issue. In my opinion, it is the best issue you have ever put out.

Barbara Eborall

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CFS costly to U.S. economy

CFS costs the U.S. economy $9.1 billion per year in lost workplace and household productivity, according to researchers at the U.S. Centers for Disease Control and Prevention (CDC). The study found that, on average, CFS costs a patient $20,000 per year, or approximately half of his or her annual workplace and household productivity.

Approximately 25 percent of people with CFS in the study were unemployed due to the illness. Even those who continued to work saw, on average, a one-third decline in income due to reduced hours and productivity.

The $9.1 billion estimate is likely low, report the study authors. First, the study only included people who met the full CFS case criteria on the day they were evaluated and excluded anyone in a temporary remission. Therefore, the researchers state, the study is "likely to underestimate the number of individuals affected by CFS" and, as a result, also underestimates the total cost to the U.S. economy. Second, the figure reflects lost labor force and household productivity only, and does not include health care costs, payment of disability benefits or declines in quality of life. Finally, because CFS is a chronic illness, the economic losses have a "substantial long-term impact on the standard of living of individuals with CFS and their family members."

According to the study authors, "The extent of the burden indicates that continued research to determine the cause of and potential therapies for CFS could provide substantial benefit both for individual patients and for the nation."

Reynolds KJ, Vernon SD, Bouchery E, Reeves WC. The economic impact of chronic fatigue syndrome. Cost Eff Resour Alloc. *2004;2(1):4.* The full text of the article is available at: http://www.resource-allocation.com/cotent/2/1/4.

Factors related to employment unknown

A study commissioned by the Social Security Administration (SSA) found that unemployment is high among people with CFS, but no patient characteristics seem to predict the ability to return to work.

The study analyzed 53 CFS research studies published between 1988 and 2001 to answer the following questions: (1) What is the evidence that some individuals with CFS have discrete impairments that are associated with disability? (2) What is the evidence that in the CFS population, current neuropsychological tests reliably detect cognitive or affective impairments associated with decreased ability to work? (3) What is the evidence that in individuals with CFS, treatments are effective in restoring the ability to work? (4) What are the patient characteristics that best define improvement or positive outcomes in the CFS population such that they experience improvement in functioning? Where it occurs, how is this improvement in functioning related to the ability to engage in work activity?

The researchers found that impairments in physical and mental performance are not consistent among people with CFS or unique to CFS, but CFS can be disabling according to SSA criteria. Two assessment instruments—the Medical Outcomes Study Short Form Health Survey (MOS SF-36) physical and mental functions and the Profile of Mood States (POMS) confusion, fatigue and depression scales—seemed to provide the best evidence of impairment in people with CFS. Functional capacity evaluations should be useful in defining a person's ability to work, reported the authors.

No specific treatment or intervention was effective in restoring the ability to work, although individual rehabilitation programs, cognitive behavior therapy and exercise therapy were associated with increased employment at follow-up.

The study authors were limited in their analysis by the low number of relevant CFS studies; the wide variety of study designs, which limited comparability across studies; and the nonavailability of standardized assessment tools for CFS.

Important needs in CFS disability research, according to the authors, are development of validated and reliable measures of impairment specifically for CFS, analysis of other factors or characteristics that might relate to disability, and longitudinal studies of interventions to find those that are effective in restoring the ability to work.

Ross SD, Estok RP, Frame D, Stone LR, Ludensky V, Levine CB. Disability and chronic fatigue syndrome: a focus on function. Arch Intern Med. *2004;164(10):1098-107.*

Exercise studies analyzed

Exercise therapy improves CFS patients' fatigue, sleep, quality of life and work capacity, but the treatment may be less acceptable to patients than other management approaches, such as pacing and rest. This was the conclusion of a Cochrane Collaboration report on research on exercise therapy for CFS.

The study's authors were limited in making conclusions by the small number of studies on exercise and CFS. Only five studies met inclusion criteria; three were conducted in the United Kingdom, one in Australia and one in New Zealand. The United Kingdom studies used the Oxford definition of CFS, while the others used the Fukuda (CDC) criteria.

Low-intensity exercise seemed to be more effective than high-intensity, which was used in only one study. Participants in the high-intensity study were more likely to drop out of the study and less likely to improve. Exercise combined with an antidepressant medication was more effective than exercise alone, but adding an intensive patient education program to exercise delivered no additional benefit.

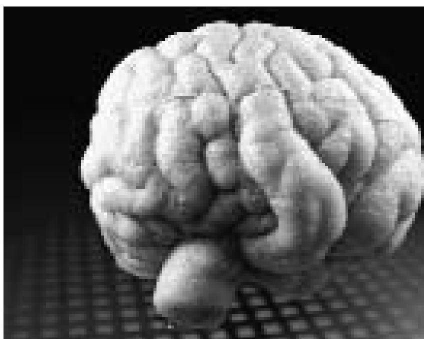
Because there were so few studies available, the researchers suggest that a single study could substantially alter their conclusions. However, the researchers said, "There is encouraging evidence that some patients may benefit from exercise therapy . . . Patients with CFS who are similar to those in these trials should be offered exercise therapy, and their progress monitored."

Edmonds M, McGuire H, Price J. Exercise therapy for chronic fatigue syndrome. Cochrane Database Syst Rev. *2004;(3): CD003200.*

Cognitive performance slow in CFS

A recent study suggests a new explanation for the memory and concentration problems common in CFS. Prior research has pinned the blame on general problems with complex information processing, but the new research suggests that the cause may be a specific impairment in the brain's ability to plan a response to stimuli.

The researchers used functional MRI (fMRI) to examine brain activity and cognitive performance in 16 nondepressed CFS patients and 16 matched healthy controls. While both groups had similar rates of errors on timed visual and motor imagery tasks, the CFS patients were considerably slower to respond and had more missed responses. The CFS patients used visual processes on nonvisual tasks to a greater degree than healthy controls, suggesting that the brain was trying to compensate for problems in motor performance. Finally, when they made errors, the CFS group was nonresponsive in the part of the brain responsible for assessing the accuracy of emotional/motivational information and regulation of emotional responses.



The researchers propose that impaired motor planning could also be responsible for CFS patients' low levels of physical activity, since this area is also responsible for the brain's ability to plan movement. They also suggest that disturbances in the motivational area of the brain are a central aspect of the CFS pathophysiology.

De Lange FP, Kalkman JS, Bleijenberg G, Hagoort P, Vd Werf SP, Van Der Meer JW, Toni I.

CFIDS GLOSSARY

Cochrane Collaboration: **An international, independent organization that aims to help people make well-informed decisions about health care. It specializes in "evidence reports," which are analyses of medical research on treatments for a wide variety of conditions. See www.cochrane.org for more information.**

Functional Capacity Evaluation: **A systematic process of assessing an individual's physical capacities and functional abilities to establish the physical level of work he or she can perform. (American Occupational Therapy Association)**

Functional MRI: **fMRI is a brain imaging tool that shows which parts of the brain are activated by various stimuli. A traditional MRI shows the brain's structure, but not its function.**

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The idea that if you'll just exercise, eat right and take better care of yourself, your health will improve is **firmly planted in the American psyche.** After all, it works for chronic illnesses like type 2 diabetes and heart disease. It should work for CFIDS. But it doesn't. CFIDS is an **exercise enigma.** What should patients and their doctors do in the face of this enigma? Read on.

BY DR. CHRISTOPHER R. SNELL, DR. J. MARK VANNESS AND STACI R. STEVENS, GUEST CONTRIBUTORS

When Working Out Doesn't Work Out

It is somewhat ironic that for an illness where patients are often diagnosed as deconditioned and characterized as lazy, exercise exacerbates symptoms rather than relieving them. Well-meaning health care professionals often recommend aerobic exercise as a cure-all for the symptoms of CFIDS without fully understanding the potential consequences of their prescriptions. As anyone with CFIDS who has attempted to "get fit" using traditional approaches to exercise knows, the results can be devastating.

Improved fitness is generally achieved by progressively taxing the heart, lungs and circulatory system through increases in duration and intensity of activity, for instance, running faster and for longer periods of time. This is often called graded aerobic exercise, and it has shown some success for treatment of CFIDS. However, this success may not accurately portray the exercise experience for a vast majority of people with CFIDS (PWCs). Typically, graded exercise studies employ some form of exercise stress test as a baseline measure for assessing improvements in physical functioning. Given the trauma such tests can engender, it seems reasonable that many potential participants choose not to continue with the study after the initial exercise test. One patient, for instance, told us the exercise stress test "was as bad as the worst days I ever had in six years of illness." Therefore, positive results from graded aerobic exercise studies may

only reflect outcomes for a high-functioning and relatively small percentage of the CFIDS population. Contrary to the popular mantra "no pain, no gain," the reality of exercise for many PWCs is "no gain, much pain!"

The oxygen debt roller coaster

By attempting to exercise on their good days, PWCs often become trapped in a cycle of overwork and collapse. The consequences of symptom exacerbation, postexertional malaise and even collapse can ultimately lead to activity avoidance. In addition to the primary effects of their illness, patients are now trapped in a downward spiral of deconditioning, with all its attendant problems. It is a cruel irony. They cannot exercise because it makes them ill, and because they are unable to exercise they become sicker still.

The situation is further complicated by the fact that physical inactivity imposed by chronic illness can exacerbate already limited physical abilities and lead to greater risk of heart disease, obesity, diabetes, osteoporosis and injury. However, all may not be lost. The solution perhaps lies in understanding how the body uses energy.

It is painfully obvious that many PWCs don't recover well from continuous aerobic activity: "I always thought that exercise meant aerobic activity—swimming, running, biking," said one patient. "Every time I do something aerobic I pay for it." This may be because, for PWCs, the activity is not aerobic.

The aerobic energy system depends on a constant supply of oxygen being delivered to active muscles. There is evidence to suggest that this process may be impaired in CFIDS, with a possible link to immune dysfunction. In the absence of an adequate supply of oxygen, energy production shifts to anaerobic (without oxygen) processes. These systems are very effective at producing high levels of energy for short periods of time, but not without a cost. That cost is oxygen debt, which is the difference between oxygen required for activity and oxygen supplied and used.

To picture what oxygen debt looks like, imagine athletes doubled over, or prostrate on the ground, unable to speak and gasping for air following a 100-meter sprint. Oxygen debt equals fatigue and, before normalcy can return, it must be repaid. While this oxygen debt roller coaster is not unique to CFIDS, interest rates on the payback may be significantly higher. "I felt fatigued, like I had walked a hundred miles the day before," said one PWC following exercise. "I felt very tired and slept most of the day" is another usual response.

Did You Know?

If aerobic exercise is causing you to crash and burn, it may be because the way your body processes oxygen during aerobic activity is impaired. There is evidence to suggest that there may not be an adequate supply of oxygen during exercise for people with CFIDS, shifting energy production from aerobic to anaerobic processes. The resulting oxygen debt could be contributing to the roller-coaster effect CFIDS patients feel following exercise. The good news is there are ways to overcome this deficit.

"... physical inactivity imposed by chronic illness can exacerbate already limited physical abilities and lead to greater risk of heart disease, obesity, diabetes, osteoporosis and injury."

Redefining exercise

It is our experience that if physical activity is to become a positive in the lives of CFIDS patients, they must forget the traditional approaches to training that so often fail. It's not how much effort you put out, but rather how well you recover from the effort that is important. Patients need to recognize that it's okay to exercise for a very short time and rest. The

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Author Staci Stevens works with PWCs to help them redefine their notion of exercise and set activity at appropriate levels to avoid relapse. A PWC herself, Stevens knows all about postexertional malaise and crushing fatigue following exercise and activity.

activity should be restorative, or analeptic, serving to relieve, not exacerbate, symptoms. Redefining exercise in this way acknowledges that a cookie-cutter approach to exercise therapy for CFIDS will not work because one size does not fit all. To be successful, any exercise program should be tailored to match the individual patient's functionality and symptom fluctuations. As a prelude to engaging in exercise, patients should ask themselves: What activities do I already do? How do I feel immediately after and the following day? Do I experience post-activity relapse? What are my exercise goals?

Analeptic exercise

It should be noted that we are not recommending exercise as a cure for CFIDS. Analeptic exercise is intended to restore functionality lost through inactivity, give patients a sense of control over their illness and, hopefully, improve the quality of their lives. Some patients also report symptom relief, in particular a reduction in muscle and joint soreness and improved cognitive functioning. One patient told us: "I really see exercise as a plus for reducing muscle and joint pain. I feel like I am getting blood circulation. I feel I can think better."

To this end, activities are designed to train the short-term, or anaerobic, energy system to increase range of motion and improve functional strength—the strength necessary to successfully and comfortably perform normal activities of daily living. Two key elements are matching program and function by setting activity levels at appropriate intensities and for reasonable durations.

To find an appropriate baseline for activity, we propose that initial durations should not exceed 30 seconds, about the length of a typical television commercial. As for intensity levels, it is essential that patients recover in a reasonable time. To this end, rest is a critical component of analeptic exercise therapy. We suggest that rest periods be at least three times, and up to six times, longer than exercise bouts. It's also likely that patients will need to reschedule or discontinue another daily activity to make time and reserve energy for exercise.

When exercise does work out

1 A typical analeptic exercise program progresses through four stages. Patients should begin with stretching and strengthening exercises. These might include focused breathing exercises, step-ups, wall push-ups, modified chair dips and toe raises. Stretching can be done between strengthening exercises. An exercise progression goal would be increasing from one set of four repetitions to two sets of eight.

2 For stage two, as strength improves, resistance in the form of Thera-Bands or light weights can be added to the workout. Over time patients should, as one expressed it, "feel stronger, more flexible and able to get around better."

3 Stage three of the program comprises dose-controlled interval training—exercising large muscle groups for a specific length of time interspersed with periods of rest. This could involve walking up and down stairs with a chair situated on the landing to permit resting between intervals. Success of this stage is dependent on patients learning to monitor heart rate so they avoid pushing too hard and triggering relapse. A functional goal would be for the patient to engage in activities of daily living without precipitating post-exertional malaise.

4 Finally comes the maintenance stage. To ensure patients transition from chronic fatigue to chronic exercise, it's important that they perceive improvements in functionality. Setting realistic, functional goals and keeping an activity diary can provide motivation. Positive feedback and support from family, friends and care providers is essential to success.

Exercise *can* work out and the enigma *can* be resolved when PWCs are empowered to get off the roller coaster and off the couch, take control of their illness and experience enhanced quality of life. As one PWC recently shared, "It gives me a feeling of being empowered because it's something that I'm doing. I'm not sitting in a chair feeling victimized." ■

Authors Snell, Stevens and VanNess

Christopher Snell, Ph.D., and J. Mark VanNess, Ph.D., are professors in the Sport Sciences Department at the University of the Pacific. They have been involved in CFIDS research for the past six years and have published widely on CFIDS-related topics. Staci Stevens, M.A., is an exercise physiologist and PWC who has designed rehabilitation programs for CFIDS patients for the last 15 years. She is the chair of the Workwell Foundation, which is dedicated to research and improving quality of life for PWCs. Staci is presently serving as a member of the government's CFS Advisory Committee.

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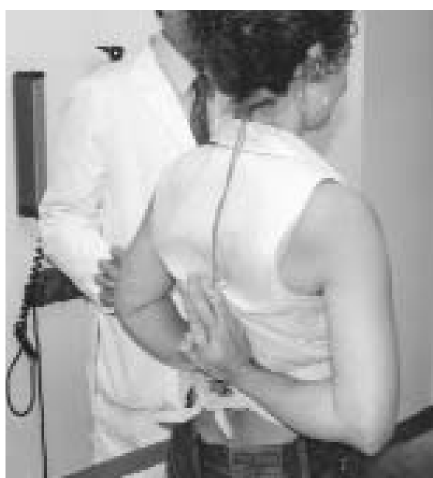
"The activity should be restorative, or analeptic, serving to relieve, not exacerbate, symptoms. Redefining exercise in this way acknowledges that a cookie-cutter approach to exercise therapy for CFIDS will not work because one size does not fit all. To be successful, any exercise program should be tailored to match the individual patient's functionality and symptom fluctuations."

Joint Hypermobility & the Link with CFIDS

Are you one of many CFIDS patients who have hypermobile joints? If so, you will be especially interested in this article, which explores **joint hypermobility** as a possible **predisposing factor** to developing CFIDS.



All photos in this article by David Love

Being able to amuse friends and family with tricks like these may be fun when hypermobile individuals are young, but the condition can lead to many unwelcome physical symptoms as people age.

By Dr. Alan Pocinki, Guest Contributor

Many people have joints that are unusually flexible, or hypermobile. Often the degree of hypermobility is mild, and they don't even realize they are more flexible than others. In more extreme cases, individuals can amuse their friends by putting their feet behind their head or popping their thumbs out of joint.

I see many patients in my general medical practice with varying degrees of hypermobility, but in studying CFIDS patients since 1987 I have been struck by the presence of joint hypermobility in almost every one. To substantiate this clinical impression, I recently gave a survey about hypermobility-related symptoms to 20 consecutive patients seen in my office who met the 1994 CDC diagnostic criteria for CFIDS, and I examined their joints for hypermobility.

The prevalence of hypermobility-associated symptoms in these 20 consecutive CFIDS patients and age- and sex-matched controls (seen for unrelated medical conditions, such as asthma) is shown in the chart on the next page. The chart also includes each patient's Beighton score, a measure of the severity of joint hypermobility. The Beighton scale assigns one point each (right and left) for the ability to: pull back the fifth finger beyond 90 degrees; touch the thumb to the underside of the forearm; hyperextend the knees beyond 190 degrees; hyperextend the elbows beyond 190 degrees; plus a ninth possible point for the ability to put both palms flat on the floor while bent at the waist (without bending the knees).

One thing worth noting is that only 8 of the 20 patients had previously been told by a physician that their joints were unusually flexible. I recently saw a patient who is one of seven siblings who all developed CFIDS. They were studied at NIH in the 1980s in an unsuccessful attempt to find a CFIDS marker. He is now 50 and walks with a cane because of severe osteoarthritis and multiple spinal operations, yet when I explained the apparent association of hypermobility with CFIDS, his eyes bugged out and he exclaimed, "You

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mean could I like put my foot behind my head before I got sick? Of course I could. We all could!"

What is joint hypermobility?

Hypermobility syndrome is a condition in which the joints are so flexible that they cause symptoms such as joint or muscle pain. Because of the looseness of the joints, there is increased strain on the surrounding soft tissues to stabilize the joints. These soft tissues are themselves often overly lax and, between their laxity and the increased strain on them, they are prone to tearing and spasm, leading to pain and stiffness around joints. (Many such painful sites correspond to the characteristic tender points of fibromyalgia, so it's not surprising that hypermobility has also been associated with the development of fibromyalgia.)

The term hypermobility syndrome usually also suggests the presence of other symptoms beyond just joint and soft-tissue problems. Lax joints are often associated with increased tissue elasticity elsewhere, most prominently in the blood vessels. Overly stretchy veins dilate like balloons, filling up with too much blood, a condition known as venous pooling. Because much of their blood is "pooling" instead of circulating, individuals with this condition typically have cold hands and feet, low or low-normal blood pressure and lightheadedness on standing quickly.

Overly elastic vessels may also explain the predisposition hypermobile individuals have to varicose veins, hemorrhoids and migraine headaches. Problems with anxiety and disturbed sleep also appear more likely. The decreased rigidity of subcutaneous tissues offers diminished protection to the blood vessels underneath, so these patients usually report bruising easily.

PREVALENCE OF HYPERMOBILITY-RELATED SYMPTOMS

SYMPTOMS	NUMBER OF CFIDS PATIENTS	NUMBER OF CONTROL PATIENTS
Ever diagnosed with CFS	20	0
Ever diagnosed with fibromyalgia	15	0
Ever dislocated a joint	7	0
Often get lightheaded on standing quickly	17	1
Bruise easily	17	6
Tend to have cold hands and/or feet	20	4
Often feel cold when others don't	17	7
Neck often feels stiff	18	6
Joints often feel stiff, click, creak or grind	20	6
Ever diagnosed with migraine	13	3
Ever had varicose veins	9	4
Ever had hemorrhoids	12	3
Often crave salty foods	14	2
Diagnosed with mitral valve prolapse	7	0
Average Beighton score (up to 9 points)	6.3	0.5

The prevalence of features of joint hypermobility syndrome in my random sample of patients with CFIDS is quite high, suggesting the possibility of a pathophysiologic relationship between the two conditions. In fact, Peter Rowe and his colleagues at Johns Hopkins first described the association of CFIDS, orthostatic intolerance and hypermobility in 1999. David Goldstein has documented the extent of autonomic dysfunction in CFIDS patients studied at NIH, and others have described autonomic dysfunction in otherwise healthy patients with hypermobility. The combination of hypermobility and autonomic dysfunction appears not only to predispose certain individuals to develop CFIDS, but also accounts for most of its characteristic symptoms.

The link to CFIDS symptoms

How might joint hypermobility and associated autonomic dysfunction account for the development of the symptoms of CFIDS? As mentioned above, pain in muscles and joints, without swelling or redness, may develop from the excessive strain that unstable joints put on the muscles around them. Venous pooling not only explains the orthostatic intolerance seen in many CFIDS patients, but diminished blood flow to the head and neck may contribute to sore throat by affecting blood flow to neck muscles, and it's probably a major contributor to cognitive dysfunction—the "brain fog" many CFIDS patients describe.

Hypermobility patients are predisposed to at least three different types of headaches. Not only do they often suffer from migraines, but they get tension headaches from

Dr. Alan Pocinki examines 23-year-old CFIDS patient Megan Gurney Lavedas, a former dancer and gymnast who has had CFIDS since she was 17. She is unusually flexible, with a Beighton score of 9 out of a possible 9 points. When Dr. Pocinki first saw her six years ago, her blood pressure was 70/40 and she could barely sit up without passing out. Today, thanks to intravenous fluids administered several times a week and medications, Megan has graduated from college and is teaching a dance class once a week.

chronic strain of overtaxed neck muscles, which are trying to compensate for the laxity of ligaments supporting the head. They also are prone to dehydration- or hangover-type headaches from lack of blood flow to the brain.

To compensate for their poor vascular tone and increased venous pooling, most hypermobility patients appear to have increased adrenergic (or noradrenergic) tone. In other words, they make more of the body's "fight or flight" stimulating hormones, called catecholamines (or they may overrespond to normal amounts). Increased circulating catecholamines typically make these patients—when healthy—high-achieving, always-on-the-go individuals, just as so many CFIDS patients were before getting sick.

Sickness, pain or other stress can further raise catecholamine levels. With high levels to start, any physical or psychological stress that triggers a further increase makes levels way too high, leaving patients, as one recently said to me, "tired but wired." They may feel jittery and appear anxious.

Similarly, when they try to fall asleep, the stimulating effect of the extra adrenaline may keep them awake. If they are able to fall asleep, patients may continue to make increased catecholamines overnight, giving them a shallow, dream-filled sleep, so they are easily wakened overnight and then feel unrefreshed.

Often patients will describe waking abruptly an hour or two after falling asleep, like they're "running a race," with their heart pounding and feeling "wide awake," with great difficulty getting back to sleep. Such episodes are often misdiagnosed as panic or anxiety attacks, when in fact their etiology is physiologic, not psychological. With the normal decline in blood pressure during sleep, some patients may actually become hypotensive enough to trigger a reflex catecholamine surge, waking them with a jolt. A drop in blood sugar can also be such a trigger. When I described this phenomenon to one patient treated unsuccessfully for years for panic and anxiety, he exclaimed, "That's exactly how I feel!"

In addition to problems with joints and circulation, hypermobile patients tend to have increased elasticity of other tissues, including the gastrointestinal, genitourinary and respiratory tracts. Pain from stretch receptors that are too easily stimulated may well be the cause of many of the symptoms of irritable bowel syndrome, interstitial cystitis and vulvodynia. Increased pulmonary elasticity may cause airway collapse, triggering the reflex dyspnea—deep and/or rapid breathing and the sensation of not being able to get a full breath—that many CFIDS patients describe.

Thus, hypermobility and the physical features and dysautonomia often associated with it not only account for virtually all of the diagnostic features of CFIDS, but also explain some of the other symptoms often associated with the illness (including orthostatic intolerance), as well as some of the physiologic traits of patients before they got sick.

Symptom improvement

If this model is valid, then correction of some of the underlying pathophysiology should result in improvement of symptoms. Although it's impossible to correct

entirely the problem of venous pooling, David Streeten found a decade ago that MAST trousers (like a giant blood pressure cuff) inflated around the lower extremities and abdomen to force pooled fluid back into circulation dramatically eliminated pain and cognitive dysfunction. More simply, administration of intravenous fluids, to temporarily increase circulating volume, also greatly relieves symptoms in many patients. Typical patient responses I hear are, "I feel so much better after the fluid" and "The difference between before and after the fluid is like night and day." I have been struck, as have many of my patients, by their observation that receiving fluids not only improves their fatigue, lightheadedness and overall sense of well-being, but their brain fog and muscle and joint pain diminish as well.

These observations suggest that other measures aimed at improving circulation may also help relieve some of the symptoms of CFIDS. In fact, many patients even find simple measures like wearing support hose and keeping their feet elevated whenever possible are helpful. An increased intake of salt and fluid, and avoidance of medications and foods that are dehydrating, such as alcohol and caffeine, help many patients feel better. Also valuable to some patients is the use of pharmacologic measures, such as fludrocortisone or nondeglycerized licorice, which increase salt and fluid retention.

The consensus of the 2003 NIH Workshop, "Neuro-Immune Mechanisms and Chronic Fatigue Syndrome," was that there is a "vulnerable population" at risk for CFIDS. It appears that patients with joint hypermobility syndrome are just such a vulnerable group. These individuals normally compensate for many of their physiologic problems, for instance with increased adrenergic tone to compensate for low blood pressure and venous pooling. When confronted with certain triggers, however, such as acute physical illness, major emotional stress or even specific environmental exposures, this compensation may be lost, and the symptoms of CFIDS may develop.

Hypermobility, and the physical features and dysautonomia often associated with it, account for virtually all of the diagnostic features of CFIDS and also explain some of the other symptoms often associated with the illness.

This model is an observational and therefore simplistic one. What exactly causes the disruption of the previous balance to precipitate the onset of CFIDS is unknown. Although this model predicts an essential role for autonomic and/or hormonal (neuroendocrine) dysfunction, the precise cause must be elucidated by future research. ■

Dr. Pocinki began studying CFIDS at the National Institutes of Health in 1987, and he continues to see CFIDS patients as a significant part of his general internal medicine practice in Washington, D.C., where he is an Assistant Clinical Professor of Medicine at George Washington University. He received a CFIDS ACTION Champion award in 2000 and last year was honored with the D.C. Medical Society's Distinguished Service Award.

TIPS FOR IMPROVING YOUR SYMPTOMS

- **Wearing support hose and keeping your feet elevated whenever possible may sound like simple measures, but they can provide real benefits.**
- **Your doctor can administer intravenous fluids. Although it's a temporary fix, this does increase circulating volume and relieve symptoms in some patients.**
- **Many patients with hypermobile joints get relief simply by increasing their daily intake of fluids and salt.**
- **Cut back on foods that are dehydrating, such as alcohol and caffeine, or avoid them.**
- **Consider pharmacologic interventions like fludrocortisone, which increases salt and fluid retention.**
- **To alleviate venous pooling, try prescription high-pressure hose. Waist-high ones are the closest thing to MAST trousers, which are not widely available.**
- **While standing in line at the grocery store, frequently shift weight from leg to leg.**
- **Small doses of stimulating medications, such as pseudoephedrine and phentermine, can raise blood pressure and heart rate and improve circulation and energy.**

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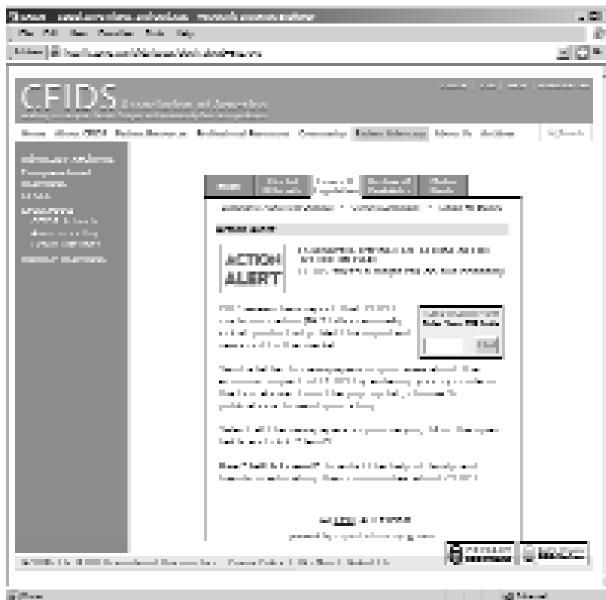

Advocacy Made Easy

THE GRASSROOTS ACTION CENTER MIGHT EVEN BE CALLED "ADVOCACY FOR DUMMIES." IT WILL DRAMATICALLY INCREASE OUR CRUCIAL AWARENESS EFFORTS.

BY MEGHAN BRAWLEY, SUMMER INTERN

The Grassroots Action Center is a new and exciting online tool that makes reaching lawmakers, public health officials and the media with timely information about CFIDS easier than ever. This time- and energy-saving tool was added to the CFIDS Association of America's advocacy arsenal in April 2004. We encourage all Association members and readers to subscribe to the Grassroots Action Center listserv and help us generate a groundswell of support for increased research, awareness and understanding of CFIDS.

Through the Grassroots Action Center, we send Action Alerts to listserv subscribers when new CFIDS information is available and at times when influencing legislators can make a critical difference. Subscribers can immediately respond to these Action Alerts by sending ready-made messages to their legislators or to other influential policymakers via e-mail. We have already written letters for you, but there is space for you to add paragraphs to customize each e-mail. Adding something about your personal experience with CFIDS to these messages provides compelling evidence that CFIDS warrants more attention.

The Grassroots Action Center also allows individuals to create custom e-mails on any topic at any time, so you don't have to wait for an Action Alert to write to your local media or state representatives.

The Grassroots Action Center debuted April 16, 2004, and the first five Action Alerts were sent weekly to support CFIDS Awareness Day on May 12. The first alert targeted members of Congress who make funding decisions for medical research and social services. In all, more than 1,300 letters were sent to Capitol Hill.

The second Action Alert enabled individuals all over the country to contact their local media to generate CFIDS coverage in their hometowns. The online directory of local and national press people allows anyone easy access to media outlets nationwide. Because the editorial page of local newspapers is widely read by people in the community, including lawmakers and other opinion leaders who want to know what's important to area residents, this alert was directed to editorial pages. Almost 2,800 letters were sent to papers across the country, resulting in quite a few articles.

Following the third alert, advocates sent more than 3,000 letters to Secretary of Health Tommy Thompson and key members of his staff. Thompson heads the Department of Health and Human Services (DHHS) and provides leadership for the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and several other health agencies. These letters focused attention on the shrinking support of CFIDS research by the NIH, reinforced the need for more staff for the CDC's research program and thanked Thompson for creating the CFS Advisory Committee of the DHHS, an important forum for moving research and education efforts forward.

The fourth Action Alert was directed to Dr. Zerhouni, director of the NIH and an important decision maker concerning research funds. Over the four-year period from 1999 to 2003, the NIH has reported support of CFIDS research totaling

"I want to commend the CFIDS Association for bringing to PWCs and their families the Grassroots Action Center and awareness campaign. Those of us who serve as advocates have never had such a wonderfully useful tool! I just can't say enough about it. I have enjoyed participating in the campaign. You have made it so very easy! Thank you!"

—Kim Weaver

$31.6 million out of a total budget of $27 billion. This amount is hardly adequate for a disease that affects more than 800,000 Americans, costs the U.S. economy more than $9 billion a year and remains challenging to diagnose and treat. The 1,013 letters sent to Dr. Zerhouni implored the NIH to increase its efforts to find the cause of CFIDS, as well as biomarkers and effective treatments.

The final Action Alert in support of Awareness Day was sent to members of Congress, but took a different approach than the first letter. More than 1,000 letters were generated asking members of Congress to write the heads of committees that make health funding decisions.

PWCs who want to participate in lobbying activities on Capitol Hill, but who are not physically or financially able to do so, are finding the Grassroots Action Center a valuable tool that gets results. It provides a consistent, collective voice for PWCs and other concerned individuals, while still allowing messages to be personalized to describe the effects of CFIDS on the patient and his or her family.

It has never been easier to be heard. Carol Sieverling, of the Dallas-Fort Worth support group, used the Grassroots Action Center to contact her local radio stations. Her letter prompted a KRLD producer to call Carol. She helped set up an interview with Larry Sharp, a local doctor who has a wife and son with CFIDS and who treats many CFIDS patients himself. The show aired on May 9.

During this introductory campaign to launch the Grassroots Action Center, almost 10,000 messages have been sent to senators, representatives, other members of the federal government and the media. Because the program is still in its infancy, the Association is thrilled with this response. But imagine the impact the CFIDS community could have on policymaking and CFIDS awareness if every Association member and every subscriber to the CFIDS*Link* joined the Grassroots Action Center and sent messages in response to Action Alerts! The real power of the tool will be apparent when Action Alerts activate large numbers of people to deliver a very specific message within a short time frame.

The Grassroots Action Center listserv replaces the CFIDS-Activist (C-ACT) advocacy listserv. Members of the C-ACT listserv have been automatically included in the new Grassroots Action Center listserv and will continue receiving Action Alerts.

If you would like to join in the grassroots effort to promote CFIDS as a national health priority, you can subscribe to the Grassroots Action Center listserv by visiting http://capwiz.com/cfids/mlm/. You can also subscribe by following the steps outlined in the box on this page. ■

IT'S SO EASY! JUST FOLLOW THESE STEPS!

1 **Visit www.cfids.org. Click on the Capitol building icon located on the left navigational bar. You will be directed to the Grassroots Action Center homepage featuring Action Alerts. Click on any of them. (You can always go back and choose another topic later.)**

2 **Click "Go" in the "Take action now" box. (To send letters to local media or to your state representatives, you need to enter your ZIP code in the box. The next page will ask you to select up to five message recipients from a list based on your ZIP code. After choosing your message recipients, click on the "Compose message" box.)**

NOTE: Follow these instructions if there is not a "Take action now" box on the page after you have clicked an Action Alert link. Scroll down the page to find links that say "Click here" to send a letter, to contact the media or to use the "Tell a friend" feature. Choose one option. On the next page you will see a "Take action now" box that does not require a ZIP code. Click "Go" to be taken to the message composition page.

3 **Personalize the ready-made message in the space provided.**

4 **Make sure to sign your name in the text box provided at the bottom of the page. This system requires your name and contact information. This information will not be used for any purpose other than to identify you to the recipient. To avoid retyping in your contact information each time you submit a message, click the "Remember me" box. If you'd like to receive a copy of the message you send, click the "Send me a copy" box.**

5 **Click on the box that says "Sign me up for the Grassroots Action Center Listserv" to receive Action Alerts.**

6 **Click the "Send message" box.**

7 **You will be directed to a confirmation page thanking you for using the Grassroots Action Center. You may opt to use the "Tell a friend" feature here by entering the e-mail addresses of up to four friends. Click the "Send now" box to ask them to send their own messages. (The CFIDS Association will not contact your friends unless they join the GAC listserv on their own.)**

People with CFIDS are just hypochondriacs.

CFIDS is another word for a breakdown.

It's hard to believe it's all in your head. Why would someone want to live like that?

Changing public perceptions about CFIDS—and the patients who suffer from the illness—is a top priority for the CFIDS Association. To help us acheive this goal, we commissioned research to **"map" current public attitudes** and **identify key messages** that can change hearts and minds.

By Marcia Harmon, Director of Communications

Perception vs. Reality

What does the general public really think about chronic fatigue syndrome? Do men and women view the illness the same way? Are the myths that were so prevalent a decade ago still impacting the way CFIDS patients are viewed? Is the name a barrier that can't be overcome? How can we change the public's attitudes about this devastating disease?

Every CFIDS patient knows that these questions are more than rhetorical. Perceptions about this illness color their lives on a daily basis. Perceptions impact the quality of health care and the level of support patients receive from family, friends, co-workers—almost everyone they come into contact with. Perceptions have power, for good or bad.

Since its inception in 1987 the CFIDS Association has worked to help shape these perceptions by educating the general public and health care providers about this illness. Given the fact that the illness was only recognized in the mid-1980s by the Centers for Disease Control and Prevention, it is still relatively "new" to the mainstream American consciousness. The CFIDS Association itself, although the largest and oldest organization of its kind, is very new when compared to voluntary health organizations like the American Cancer Society, founded in 1913, the American Heart Association, established in 1924, or even the National Multiple Sclerosis Society, founded in 1946.

Although we have come a long way in less than two decades, and we have many victories to be proud of, efforts to increase public awareness and shape public policy are being hampered. The lack of scientific concensus on the cause or treatment of CFIDS, the scarcity of resources for research and education on the scale needed, tensions within the patient community, and the lack of a visible spokesperson have all worked against acceptance of CFIDS as a serious and legitimate public health concern.

We have a lot of anecdotal evidence, much of it from the patient community, about attitudes, but the Association decided to take a more formal measure of public and provider attitudes about CFIDS. Last fall we commissioned the Winston Group, a highly regarded firm with expertise that matched our needs, to conduct research to give us concrete information to guide future decisions about how to

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best use limited resources to effect attitudinal shifts that will positively impact the lives of CFIDS patients.

Research methodology

The Winston Group conducted a mix of qualitative and quantitative research to discover the beliefs and feelings people hold about CFIDS. Focus groups (qualitative research) were used to determine how key audiences feel about the illness. Two focus groups were held in Alexandria, Virginia, with primary care physicians. Two were held in Fairfax, Virginia, among the general public, with one group of men and one of women. And two focus groups were conducted in Philadelphia, Pennsylvania, with women between the ages of 30 and 50.

Following the focus groups, omnibus questions were designed to quantify the research findings. A telephone survey of 1,000 registered voters who are demographically representative of the general population was conducted to ensure that what we learned from the focus groups was representative of the general public and to quantify the key messages generated by the focus group results.

Research compiled by the Winston Group allowed them to create "perceptual maps" of the existing belief and value systems held by two target audiences: the general public and primary care physicians. Understanding the perceptions that form these audiences' conclusions about CFIDS is vital to identifying the underlying beliefs and assumptions we need to change to shift our target audiences from their original conclusions to perceptions and attitudes that more closely match the reality of this disease. Determining how to create this attitudinal shift is vital to the success of any future public or provider education and awareness efforts.

In the spring issue of the *CFS Research Review* we published the first article in a two-part series on the results of the research with primary care physicians. The second article will appear in the fall issue of that publication. Here, we will limit our coverage to the perceptions of the general public that were revealed by the research.

Physical vs. psychological

The research was geared to assess basic knowledge about CFIDS. In the absence of concrete knowledge about the cause of the illness, there was a lot of debate over whether CFIDS is physiological or psychological in origin. The men were evenly split on this point; they were also confused as to whether a mental condition causes CFIDS, or if the illness leads to psychological symptoms. Women were more likely to believe that CFIDS is a physiological illness that may result in psychological problems. Here are some views expressed on the topic:

- CFIDS is basically depression.
- People with CFIDS are just hypochondriacs.
- Some people don't think it exists.
- CFIDS is another word for a breakdown.
- Because nothing can be found physically, it must be a mental thing.
- I believe it is primarily physiological, then leads to psychological problems.
- I associate CFIDS with depression and dysfunction.
- It's hard to believe it's all in your head. Why would someone want to live like that?
- The symptoms can be serious, but CFS can't be proved.
- It starts out physical, but then becomes psychological.
- It is not in your head.

Assigning motives and blame

Skepticism about whether CFIDS is physical or mental in origin affected the way the general public perceives not only the illness itself, but the patients who have it. People were more likely to assign blame to patients and to look for underlying motives for those identifying themselves as having CFIDS:

- It's an attention-getting disorder.
- A CFIDS diagnosis gives people the right to quit their job and collect disability.
- CFIDS is more of a choice, not an accident.
- Problems associated with CFIDS stem more from being overweight, unhealthy and having a bad marriage.
- It is caused by stress and our rush, rush lifestyles.
- I think of young women who are depressed and unhappy.
- Because it gets you out of things, I think of lazy people when I think of CFIDS.

A CFIDS diagnosis gives people the right to quit their job and collect disability.

A CFIDS patient seeks sympathy with a "woe is me" attitude.

- A CFIDS patient seeks sympathy with a "woe is me" attitude.
- CFIDS began because somebody thought they were tired and made up a disease for it.

There was strong conflict between viewing CFIDS patients as lazy malingerers and seeing them as sympathetic victims of a mysterious illness. Some participants were

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> What concerns me is that we don't know how to prevent it.

> Since doctors can't categorize it physically, they want to assign it to a mental problem.

> CFIDS is a serious and real disease.

> With CFIDS cases, the doctors are at a loss, which is frustrating and confusing.

unsure whether to be skeptical or sympathetic in the face of varying opinions among focus group participants, and some vacillated back and forth. Without knowledge, people were easily swayed by misinformation supplied by others.

Fear and empathy

In spite of some harsh attitudes, the research findings also show the general public is concerned about the illness. Discussion about CFIDS among participants and the sharing of both facts and opinions led respondents to sympathize with patients and imagine what it would be like to have CFIDS, whether or not the symptoms are physical or mental in origin. Most expressed both fear and empathy:

- I fear what it might do to my life if I really did have CFIDS.
- I wouldn't be able to have a career.
- How would I support my family?
- I would be frustrated if I had it because my husband would not support me or buy the diagnosis.
- It would be debilitating.
- Others don't believe you, and you may lose friends.
- It would be hard to care for my children.
- CFIDS leads to extremely low energy levels. I would have no creativity or desires.
- Would people have sympathy for me, or blame me?
- There is a stigma attached to CFIDS.
- You stigmatize yourself because you think you're going crazy.

Health care system lacks answers

The research also included an assessment of the general public's perception of the overall health care system with regard to CFIDS. Participants were asked about the treatment of acute illnesses compared to chronic ones, how the health care system responds to a CFIDS diagnosis and what patients with CFIDS can expect.

Both men and women agreed that the health care system is more adequately geared toward treating acute illnesses than chronic illnesses. They were divided on the question of whether an acute or a chronic illness would be worse, but both men and women indicated a slight preference for the view that a chronic illness would be worse, even though some acute illnesses can be fatal.

Other key perceptions related to how the health care system responds to CFIDS include:

- CFIDS is so misunderstood.
- No one knows what causes it or why you get it.
- I am concerned about CFIDS because there is so much we don't know about it.
- Because there is no treatment, I would feel helpless.
- With CFIDS cases, the doctors are at a loss, which is frustrating and confusing.
- There is only so much the system can do for you.
- What concerns me is that we don't know how to prevent it.
- It's often misdiagnosed.
- The treatment and cure for CFIDS is vague and uncertain. There is no course of meds to take.
- Since doctors can't categorize it physically, they want to assign it to a mental problem.

Affirmation

While the research validated many of the complaints from the patient community about public perceptions of CFIDS, there is some encouraging data. The old stereotypes about CFIDS being the "yuppie flu," with sufferers labeled as hypochondriacs still exist, but they are waning. Some participants held to these old myths, but most did not. Some people's perceptions had been changed beforehand by knowing someone with the illness; other attitudes were changed favorably by facts shared at the focus groups. Some pertinent comments were:

- I am somewhat familiar with chronic fatigue syndrome, and I believe it would be debilitating.
- Before my husband's experience, I thought it was all bunk.
- Knowing someone with the disease made me regard it as more serious.
- CFIDS is a serious and real illness.

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- Anyone who has to spend their life in bed has a serious illness.
- I guess it is a real disease.
- Even exercise doesn't work, and exercise is usually the cure-all.

What's in a name?

In the general public research, respondents pointed to problems with the name *chronic fatigue syndrome.* The general population of women felt the word *fatigue* misrepresents the disease; the men honed in on the word *syndrome,* saying it doesn't sound as serious as the word *disease.*

However, respondents stated that "a name is what you make of it" and suggested that any new name would be stigmatized too unless public awareness about CFIDS is raised. Researchers concluded that while the name is problematic, it's not a significant stumbling block to increasing public awareness of CFIDS and support for patients. While the Association still endorses an ultimate name change, the research supports the conclusion that we can move ahead with new public education and awareness initiatives even without a name change. The name doesn't define the disease; the lack of information defines the disease.

Changing attitudes with specific messages

This research shows that the general public is relatively uninformed about CFIDS, confused about whether or not it's a legitimate disease and unsure if it's a psychological or a physiological illness. The level of stigmatization patients endure is high. Because of societal attitudes, patients are often denied the vital support system from their family, friends, employers and physicians that is essential to combat a chronic illness. That's the bad news.

The good news is that the quantitative research conducted by the Winston Group showed that once people are given even a few basic facts about CFIDS, the number of Americans who reported they believe it's a serious disease rose 9 percent, from 64 to 73 percent. Perceptions change favorably with knowledge.

Some key messages were identified during the research as the most persuasive in changing attitudes. Many focus group participants were stunned that exercise doesn't improve CFIDS and could actually make it worse. Respondents took CFIDS more seriously when faced with facts that suggest that even when patients take "positive actions" such as exercising or resting, they may not get better. The fact that physical or mental activity may lead to postexertional malaise and an exacerbation of symptoms is a powerful persuader that "it's not the patient's fault."

Another specific message that changed respondents' attitudes was the sense that the clock is ticking on the possibility of a good outcome for CFIDS patients. The fact that CDC studies indicate that the greatest statistical likelihood for recovery occurs in the first five years of illness—and that delays in diagnosis and symptom management are linked with poorer long-term outcomes—clearly alarmed research participants. They were more likely to understand and support the need for early diagnosis and effective treatments to increase the chances of recovery.

Another key motivator for changing attitudes was the fact that in spite of thousands of research studies on CFIDS, no one knows what causes the disease or how or why people get it. This led participants to the conclusion that the illness is mysterious and misunderstood and that we need to unlock those mysteries.

Once people are given even a few basic facts about CFIDS, the number of Americans who reported they believe it's a serious illness rose 9 percent, from 64 to 73 percent.

It's clear that present attitudes about CFIDS contribute to the low rate of diagnosis, lack of or delayed access to appropriate health care services, the withholding of support and validation from those who traditionally form a patient's support system, and a sense of hopelessness among CFIDS patients and their providers. These perceptions can't be shifted without broadening our existing outreach to the general public.

More efforts must be made to educate the public about CFIDS to improve recognition of the characteristic symptom pattern, encourage those whose symptoms fit this pattern to seek care early in the course of the illness, and improve the support system (including appropriate medical services) for the patient to maximize function and quality of life until research yields more effective treatment and prevention strategies. Improving the social context for CFIDS is likely to have important therapeutic benefits for patients and families who consistently report that the stigma associated with CFIDS is as damaging as the condition itself.

In the coming months the Association will be vigorously preparing for major educational initiatives targeting the general public, and pursuing the financial resources needed for this ambitious goal. Stay tuned to both the *CFIDS Chronicle* and the *CFIDSLink* for more information. ■

Spotlight
on Board Leadership

The CFIDS Association is fortunate to have the services of a **dedicated board.** In the last issue, six board members weighed in on a few hot topics. Here, the remainder share their **perspectives.**

"We know that the energy envelope of a PWC on any given day can vary drastically. But on good days, one of the most vital acts you can perform is to gather information to help you in ways that make a real difference in your life. The CFIDS Association wants to be your partner in this endeavor. Toward that end, we provide practical information that can empower you as you seek medical care, employment accommodations, Social Security disability benefits, social services or support from family and friends. I encourage you to use all the resources the Associa-tion has to offer. We have brochures, thousands of pages of information on the website, an e-newsletter, the *CFIDS Chronicle,* the *CFS Research Review* and a phone resource line to help you navigate your way through this illness."

—Susan Jacobs,
Attorney

"I believe one of the true tests of leadership is the ability to do the right thing, even when it's not the popular choice. It's true if you are a high school club officer who has to stand up and protest risky, out-of-bounds activities of fellow members at a club social event. It's true if you are the CEO of a large corporation who has to stand firm and push through a much-needed but much-opposed corporate restructuring. And it's true of CFIDS Association board members who must focus on activities that have the best chance of accomplishing the Association's mission, rather than getting bogged down in issues that are not propelling our cause forward."

—Rick Baldwin,
Information technology manager

"The CFIDS community faces many challenges during the coming decade as we marshal our human and financial resources to conquer this disease. If we are to be a force to be reckoned with, we need to speak with a common voice and a reasoned tone. We don't want to make it too easy for policy-makers, those in the government and private sectors who appropriate funds for research, or health care professionals to dismiss us as angry attention-seekers or emotionally unstable individuals—something that has happened far too often in the past. This doesn't mean we cannot disagree, but our debates on issues such as the name change should be respectful and include appreciation for the efforts everyone is making. Sarcasm, innuendo and personal attacks cast a negative light on us all."

—Lynn Royster,
Professor at DePaul University

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“During my 13 years with the CFIDS Association, I’ve been struck by a consistent refrain I hear from members: “Thank you for being there to carry on the fight when I’m too sick to do my part.” CFIDS imposes very real limits on energy and activity. We understand that these limitations can mean having to choose between taking a shower or having dinner with the family as the main activity for the day. So we’re very grateful for those who can manage from time to time to write to their state representative or inform a local health reporter about CFIDS. But on the days when that level of personal advocacy simply isn’t possible, the Association will be there, to educate and advocate, to speed progress in the fight to conquer CFIDS. For me, it’s a great honor to contribute to that constancy of purpose, always mindful of the women, men and kids who count on us to do what they cannot.”

—Kim (Kenney) McCleary,
President & CEO of the CFIDS Association

“One of the most valuable lessons I’ve learned as a board member of the CFIDS Association has been the importance of advocacy. Whether you lend your time or support to a grassroots letter-writing campaign or you visit legislators on Capitol Hill, every effort has the potential to change hearts and minds, forever altering the way this disease is viewed in the public eye, in your doctor’s office and in the halls of Congress. Granted, this is not an easy road, and each leap forward is hard won. But without the advocacy efforts of Association members and leaders, we never would have won the Social Security ruling that has made it easier for thousands of PWCs to win disability benefits. We never would have recovered the $12.9 million in misdirected reasearch funds at the CDC. And we never would have made educating health care providers about CFIDS the government priority that it is today. Advocacy translates into very tangible benefits for people with this disease.”

—Adrianne Ryan,
Former director/producer for ABC News and ESPN

BOARD DIRECTOR ESTABLISHES SCHOLARSHIP

Lynn Holaday Royster knows how CFIDS can impact the educational pursuits of young PWCS. Her personal journey with her son, Patrick, who has had CFIDS for the past 18 years, led her to pilot the Chronic Illness Initiative at the School for New Learning at DePaul University, where she works. This program is designed to help individuals with chronic illnesses complete their undergraduate degree.

Students with fatiguing illnesses like CFIDS, rheumatoid arthritis, MS, fibromyalgia and lupus often find it difficult, if not impossible, to meet the requirements of a conventional college program. The Chronic Illness Initiative gives such students the option of completing all degree requirements online and offers flexible time requirements to complete coursework. A special advisor is assigned to each student to help them plan and execute their studies.

Until this year, the program has only been accepting students over the age of 24. Now it is also open to chronically ill students between the ages of 18 and 23 through the Inside Track option. This special track provides additional guidance to younger students, many of whom may not have the life experience and self-directed perspective of older students.

Also new is the Chronic Illness Scholarship Award, an endowed scholarship established this year by Lynn Royster to honor her son. The scholarship is open to students who are enrolled, or are in the process of enrolling, in DePaul’s School for New Learning. Applicants must have a disabling chronic illness and demonstrate financial need.

The scholarship is especially meaningful to Lynn. “When you see what kind of effort ill students—many of whom are financially devastated because of their illness—are willing to put out to get an education, it makes you want to do everything you can to help them.”

For more information about the scholarship and specific requirements for applying, go to http//:www.snlonline.net. Follow the link to “Prospective Students” and “How to Apply.” The deadline for applying is August 1 of each year.

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Leadership in Action

Betty McConnell never imagined herself **becoming an advocate** for anything. But when her son became ill with CFIDS, everything changed. Today, Betty heads the Youth Education Committee of the NJCFSA, where advocacy leads to action.

Betty McConnell is a positive and inspiring force for both children and adults with CFIDS.

Since its formation in 1995, the New Jersey Chronic Fatigue Syndrome Association (NJCFSA) has worked hard to improve the lives of children and adults afflicted with CFIDS. Toward that end, the Youth Education Committee was established by NJCFSA vice president Betty McConnell.

As one of the founding members of NJCFSA, she was the only board member at the time who not only had CFIDS herself, but was raising a child with the illness. "I became an advocate for my son Scott in 1987, so it was only natural that I would become an advocate for all children with CFIDS in New Jersey," says Betty.

Betty is most proud of establishing the NJCFSA Scholarship. The $1,000 scholarship is awarded to graduating high school seniors with CFIDS in New Jersey who are continuing their education at a college or technical school. The scholarship mailing to every high school in New Jersey has become an outstanding awareness project in itself, but it's only one part of the NJCFSA's varied programs for youth.

Betty has been instrumental in targeting organizations and events that can have a significant impact on increasing awareness and understanding of CFIDS in kids. She was kind enough to grant this interview on the activities of the Youth Education Committee.

Q *What is the Youth Education Committee?*

A The committee is comprised of NJCFSA members who are advocates for children with CFIDS. Our main purpose is to offer support to parents and their CFIDS-diagnosed child or adolescent and to provide them with educational materials on pediatric CFIDS. Our committee is also dedicated to increasing awareness of CFIDS in children and disseminating reliable information to schools, pediatricians and the general public on the seriousness of chronic fatigue and immune dysfunction syndrome in young people.

Q *How does the NJCFSA Youth Education Committee help parents and children with CFIDS?*

A Our committee has put together a pediatric education package that contains numerous articles on pediatric CFIDS. The package includes a reading list of books, a resource list of websites and newsletters about CFIDS, a checklist for school nurses, medical journal articles on pediatric CFIDS and a collection of newspaper articles that have featured children and adolescents with the illness. We have also included many articles on coping skills for both parents and children. Additionally, NJCFSA maintains a physician referral list.

Q *What programs has the Youth Education Committee participated in?*

A Since 1998 we have participated in many pediatric education conferences and conventions. We have exhibited at the National Association of School Nurses

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Convention. We regularly exhibit at the New Jersey Education Association's (NJEA) annual convention. Twice we have conducted a workshop for school administrators, school nurses, teachers and child study team members at the NJEA Convention. We have also exhibited at the New Jersey Pediatric Nurse Practitioners Association conference, the New Jersey Nurses Association, the New Jersey League of Nursing Association's annual conferences and, most recently, at the New Jersey School Counselors annual conference. These conventions and conferences allow us to reach a wide range of medical providers and educators whose decisions impact the daily lives of kids with CFIDS.

Q *What other activities does the Youth Education Committee participate in?*

A For CFIDS Awareness Day 2003, we mailed pediatric education packages to Dr. William Librera, the Commissioner of Education for the state of New Jersey, to the superintendent of schools for each county in the state, to members of the New Jersey State Special Education Advisory Council and to the five catholic dioceses in New Jersey. As a result of this mailing, we received many inquiries for speakers and exhibitions.

Q *What did the Youth Education Committee do for Awareness Day 2004?*

A Our main goal for 2004 was to educate the state's pediatricians. Utilizing the website for the New Jersey chapter of the American Academy of Pediatrics, we found the names and addresses of the counselors and members of its Executive Council, Standing Committee, Advisory Committee and task forces. We assembled 60 pediatric education packages and sent them to this select group. Our package includes copies of *A Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome,* published by the New Jersey Department of Health and Senior Services, the Academy of Medicine of New Jersey and the University of Medicine and Dentistry of New Jersey. We hope leading pediatricians will share this information with their colleagues.

Q *Who are the other members of the Youth Education Committee?*

A Committee member Peg Walk has been an advocate for pediatric CFIDS since 1990. Before becoming ill with CFS, she was a computer programmer and elementary school math teacher with a master's degree in mathematics. Her interest in pediatric CFIDS came as a result of having a child with the illness. (Her daughter Sharon started the first newsletter and pen pal club for children with CFIDS in 1990.) Peg has been the support group leader for Morris County for many years and can be seen manning our exhibit tables at spring and fall conferences. NJCFSA recently elected Peg to its board of trustees.

Committee member Jon Sterling has been an advocate for children with CFIDS since 1992. As one of the founding members of NJCFSA and our first president, his interest in pediatric CFIDS was a natural consequence of his career as a school principal. Jon is a talented speaker and has given many lectures on behalf of children with this illness. Twice he traveled to Atlantic City to speak at the NJEA Convention. He recently exhibited at the New Jersey School Counselors Convention and gave a talk to teachers at a school in Passaic County, New Jersey. His understanding of the educational system and the accommodations necessary for an appropriate education for the CFIDS child is exceptional. In the past, Jon has served as support group leader for Bergen County, as president of NJCFSA and as treasurer of NJCFSA. He currently serves as a consultant to the CFS Advisory Committee to the U.S. Secretary of Health and is chairman of the Board of Directors for the CFIDS Association of America.

Q *Which other NJCFSA members and organizations have helped your committee?*

A Other NJCFSA members who have assisted with projects and exhibits are Ted Nilson, Jackie Niederle, Laura and Beth Warren, Stephanie Habermann, Teresa Johnson, Sheila Rosen, Janice Frank, James Glenn, Sharon Walk and Lorraine Steefel.

Our committee is also grateful to the CFIDS Association of America for providing educational materials for each project. We also acknowledge the assistance of the Pediatric Network website founded by Rebecca Moore and Mary Robinson for the many educational articles they feature on their site. This website (http//:www.pediatricnetwork.org) is invaluable to children with CFIDS.

Q *What is the most gratifying aspect of the work of the Youth Education Committee?*

A If all the exhibiting, education packages, scholarship programs and speaking engagements make the lives of children with chronic fatigue and immune dysfunction syndrome and their families easier, then we have accomplished our goal. ■

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"That was your old life."

BY MARIE TYBUREC, PWC

The words hit me like a physical blow. "That was your old life," Jewel told me.

I had been explaining to Jewel, one of seven siblings, that I wasn't ready to give up. I still intended to sing professionally, to work again, as I did before that day in 1998 when I was diagnosed with CFIDS and fibromyalgia. I was telling her my plans and hopes.

But before I go on, I must first back up to the summer of 1992. I was working as a typesetter at a newspaper. I enjoyed the work. I was very accurate. I could type 71 words per minute for eight hours and make almost no mistakes. I was also a proofreader.

That summer, due to balance problems and dizziness, I went to see a neurologist on the advice of my physician. He found pain wherever he pressed and told me, "You have fibromyalgia." I had never heard of it. When he explained what it was, I wasn't impressed. I had been in chronic pain since a 1969 fall from a horse that had twisted my pelvis and pushed my neck out of alignment.

Then in 1996 odd symptoms began one by one. My ribs hurt. I had to hold my arms around myself as I drove the 30 minutes to work every day. I began to have trouble concentrating. I experienced numbness in my skin and odd headaches that came and went. The bottom of my feet burned in bed. I learned to wear a TENS (Transcutaneous Electrical Nerve Stimulation) unit all day at work. When I unhooked it at night, I was so exhausted, I couldn't rise out of my chair.

Marie Tyburec is pictured here (left) with a self-portrait at a 1993 show. The adjacent painting is also a self-portrait. She wishes family and friends would realize that the talented and creative person who painted these still exists, waiting to be freed from the constraints imposed by CFIDS.

Fatigue was becoming constant.

I went through a battery of tests. An all-body bone scan, chest X rays, an EKG, a CAT scan of my lungs, an ultrasound of my abdomen, an MRI of my brain (due to an unexplained episode of severe head pain in one spot). I also had periodic lab tests, the standard ones, and came to believe the standard lab tests aren't sensitive enough to be useful with PWCs. My doctor believed me when I told him my symptoms, but the day came when he gave up and said, "I won't be the one able to help you." I appreciated his honesty.

The neurologist who finally diagnosed my CFIDS in 1998 told me the onset of the illness occurred much earlier. I now believe I had a combination gradual/sudden onset. A traumatic incident occurred at work shortly before I became ill. I was working as a temp in a difficult situation that culminated in a heated argument with my supervisor. I ended up screaming at her and giving my notice for that Friday. (I don't normally scream at people.) That Friday—May 22, 1998—I went home, not knowing it was the last day of my working life.

The next day was my birthday. I turned 43. The following week, I struggled to rise from my chair. I managed to go to a few job interviews that month. I would have a good day and think, "I'm going to be okay." The next day I would be so weak it was terrifying.

I applied for Social Security disability on June 3, 1998. The process began with a telephone interview. When he asked for my Social Security number, I broke down. The reality hit me. It would take 13 months, two failed attempts and a hearing before a judge to be approved for SSDI. I don't think I could have won my case without an attorney to represent me. I was too

sick to think straight.

The hardest blow for me was—and is—the profound cognitive impairment that began, for the most part, that summer. I no longer could find words. I mixed up word order and substituted the wrong word unintentionally. My brain felt foggy, confused. My short-term memory seemed gone. I could not rely on my mind anymore; I wrote everything down. For an aspiring writer, with 17 published poems to her credit, who had been working on a long manuscript, this was devastating. My first thought was: Will it ever come back—my ease with words, my dexterity of mind? To date, it has not.

Then there was the social fallout of dealing with an "invisible" illness. I remember talking to a staff person at the doctor's clinic. I told her I had CFIDS. She responded, "I wish I had time to be sick." A friend of mine laughed and said, "I have that all the time!"

The word *devastating* doesn't describe how completely your life is overturned by CFIDS. Since most of the damage is interior, people can be excused at first for not realizing you're functioning abnormally. What I resent deeply is that after explaining the illness and its invisible nature to people, even family, they don't believe me, or they forget what I told them.

God has been my anchor through all the devastation. I have grown closer to God. This is the only redeeming thing that has come out of being sick for six years. My only social outlet is church. I am too sick to volunteer, and too sick and too broke to do the things I enjoy, like listening to live music or dancing. I have not had a date in 10 years.

Activities that once gave me such joy—singing, dancing, writing poetry and oil painting—are now a great struggle. The triumphs, though rare, are priceless now. Last fall I was able to sing two solos at church and to paint two oil paintings that were up to my pre-CFIDS ability.

Through my physical therapist, I found a doctor who is now my best hope. He is a both a medical doctor and a naturopath, and I've been on his treatment protocol since 2000. He doesn't take insurance, and the treatment is expensive, but he works with me to keep the prices lower. He has an extensive knowledge of fatiguing illnesses and is always learning more.

As I write this, I count the cost of CFIDS. I am single and 49 years old. I have not improved except for brief periods, after which I return to my previous level of illness. My cognitive impairment is worse. Fatigue is constant. The hardest part about having CFIDS is not knowing the prognosis. Will I ever be able to function as I did before? Will I work again? Who would want to marry me? Will I have to live the rest of my life on an income that is below the national poverty level?

Two years ago when my sister said, "That was your old life," it hit me hard. I wanted to scream: I'm still in here! The person who earned a B.F.A. in painting, who took voice lessons with dreams of becoming a professional singer, who could dance for hours—she still exists. Don't tell me my life is over!

I wanted to tell her my dreams are still alive. I dream of being married to a Christian man, of showing my oil paintings and selling them, of finishing the manuscript I began and publishing it. I dream of a day with no fatigue, with no pain. I dream of being able to think again.

But Jewel has fibromyalgia and she seems resigned to her illness—and to mine. I'm not. The illness seems to have taken all the fight out of her. I'm still fighting, and hoping.

How many people like me are sitting by the window looking out, waiting for research to find a treatment plan for CFIDS, waiting for a chance at a normal life again? Hang tough. You're still in there! ■

Reprieve

By Mary Anne Mitchell, PWC

Since becoming ill with chronic fatigue syndrome, I have grieved for the loss of energy that had been with me since childhood. On more than one occasion, I have found myself planning my first day of freedom from this illness—one day with no emotional or physical pain, just the sweet, exhilarating intoxication of boundless health and the exquisite joy of movement. I have my day all planned, should I ever be granted a reprieve.

On this day of reprieve, I open my eyes and stretch, feeling the blood flowing through my body. I jump in the shower, as hot as I can stand it, until the hot water runs cold, with no fear of fainting from the extreme temperature and no vertigo and nausea from washing my hair. Clothing myself only takes a minute; no muscle pain or dizziness slows me down. I run down the stairs, two at a time, jumping the last few to the bottom. The pleasure of breakfast awaits, my favorite meal of the day. I think I'll have pancakes, thick and heavy, smothered in real butter and golden syrup, and coffee—the strongest, richest brew I can make. A far cry from the

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simple fare I'm used to consuming.

Now for the moment I've been dreaming of. I pull my mountain bike out of storage and pump up the tires. I racked up more than one thousand miles on this bike before I became ill, and I haven't forgotten the feel of it under me. I pedal slowly at first, building up a rhythm, getting the feel of the wheel. Then as I start to put on speed, I pull myself up off the seat and dance on the pedals. I stay with this until I feel a tightness in my lower arms and my legs start to burn and twitch. The sweat drips into my eyes, and I slowly sink back into the saddle. No stopping for breaks today, so I drink from my water bottle and snack on a power bar as I pedal.

Back home to another hot shower, longer than the first one, savoring the feel of heat against my body. Next, I'm off for lunch with my friends. I had to give up restaurants because the noise and visual stimuli threw my immune system into overdrive and sent me to bed with fevers, nausea and muscle aches. But not today. I'm sharing lunch with all the people I've been unable to socialize with for four years. We're a noisy crowd, laughing and talking nonstop. I'm quieter than the others, but only because I'm drinking them all in, their faces, their voices, subtle changes that have taken place since I last saw them. These are the people who didn't drift away when I was forced by my illness to retreat from social activity, and I want to hold them in my gaze as long as possible.

After we part I turn homeward, grab my swimsuit and head for the indoor pool. The tingling feeling of icy cold water when I first jump in jolts through my body and I shudder, goose bumps popping out on my arms. Pushing off slowly, I start to breast stroke my way across to the other side of the pool, breathing in the strong smell of chlorine, trying not to swallow any while steering around the crowd of young kids. I watch their faces as they prepare to take a dive, that intense look of concentration and hope and perhaps a little fear before they jump and a grin of triumph spreads across their faces.

In her former life, Mary Anne Mitchell and her husband, Klaas, bike along the Oregon coast. Although she has been housebound for four years, Mary Anne hopes mountain biking and all the other physical activities she used to enjoy are part of her future.

Leaving the pool, I start my homeward trek on foot. It feels good to stretch my legs. Halfway home, I pick up the pace and break into a jog. The ache I feel in my thighs and the quickened heart beat come from working my muscles, not from the basket of symptoms that is my illness.

Next, dinner. This time I dress up, something that rarely happens now. We reserved a window seat at our favorite restaurant, looking out toward the channel, fishing boats heading into harbor, seagulls screaming in their wake. The sun is just beginning its evening descent, casting a lemon and lavender glow across the faces of the people strolling the walkway. The pleasure of being able to sit in a restaurant for two hours without collapsing, and having a conversation without losing my concentration, is beyond description.

Then, a walk along the promenade to watch the last rays of the sunset dipping below the horizon as we head home. I have one final indulgence in store and it's all about sleep. I'm going to curl up in bed after a long, hot bath and drop instantly into a deep, pain-free slumber, with no night sweats or vertigo to wake me in the darkness, just blissful oblivion for eight hours.

I'm thankful I have retained the memories of my life prior to CFIDS. Who knows, one day I may look back on this time of illness as a unique experience. Should that day ever come, I don't think I will dream for a reprieve from health like I yearn so terribly, so wistfully, for a reprieve from illness. ■

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BY KIM (KENNEY) MCCLEARY, PRESIDENT & CEO

CFSAC meeting report

The federal government's CFS Advisory Committee (CFSAC) held its fourth meeting on June 21, 2004, in Washington, D.C. The committee worked on recommendations for research and education on chronic fatigue and immune dysfunction syndrome (CFIDS, also known as chronic fatigue syndrome, CFS, myalgic encephalomyelitis and ME), received updates from health agency representatives and heard public testimony from persons with CFIDS and their family members.

Chairman of the CFSAC, Dr. David Bell, opened the meeting by reading a quote from Dr. Vance Spenser's foreword in the book, *Shattered.* "For the first time, the authentic voices of people with ME are heard, their narratives brought together expertly into a rich tapestry that highlights the central themes which dominate this illness: the lack of a recognised diagnosis; the scepticism of medical professionals; the lack of support from family and friends; the deserts of fatigue and pain; the loneliness involved in the search for help and empathy. . . . These are not the voices of professionals with careers to promote; rather they are the voice of real people with terrible stories to tell."

His selection of this quote was highly relevant; the public testimony that followed later in the day reflected these same themes. Of particular note were first-time appearances from young-adult PWC Lauren Bean, her mother, Diane, and Lori Tylutki, a critical care nurse from Michigan who is on medical leave due to CFIDS. Lauren's father and brother were recognized by executive secretary Dr. Larry Fields for attending in support of Lauren.

The committee reviewed draft recommendations prepared by separate subcommittees evaluating current education activities and research efforts on CFIDS conducted by the National Institutes of Health (NIH), the Centers for Disease Control (CDC), the Health Resources and Services Administration (HRSA), the Food and Drug Administration (FDA) and the Social Security Administration (SSA). Dr. Bell led discussion about possible strategies presented by subcommittee chairmen that seek to strengthen federally sponsored CFIDS research and education of health care providers and the public. Debate about research funding and review processes was sparked by committee member Dr. Kenneth Friedman's submission of a paper he titled "Fish or War," which outlines disparities between research programs for CFIDS and those for other diseases of similar or lesser magnitude.

Recommendations for research and education submitted to the committee by the CFIDS Association can be read at http://www.cfids.org/advocacy/ research-recom.asp and http://www. cfids.org/advocacy/education-recom.asp.

Dozens of strategies were proposed, discussed and considered, and the committee will work to refine and prioritize those deemed most worthwhile. Public comment on the draft recommendations will be solicited later this summer via the committee's website (http://www.hhs.gov/advcomcfs/index.html). At the next meeting, tentatively scheduled for September 27, 2004, the committee will present and approve a final list of recommendations that will then be directed to Secretary of Health Tommy Thompson.

The committee also heard two special presentations. Dr. Donna Pickett of the National Center for Health Statistics addressed current classification of CFS in the International Code of Diagnoses (ICD). While the rest of the world utilizes a version of the ICD referred to as ICD-10, the United States uses a modification of an earlier version, ICD-9-CM. In the ICD-9-CM, CFS is listed under "Signs and Symptoms" at 780.71—chronic fatigue. However, in the ICD-10, CFS is indexed to G93.3, a listing under "Diseases of the Nervous System" along with "benign myalgic encephalomyelitis" and "postviral fatigue syndrome." Codes are used by physician groups, hospitals and insurers to track morbidity and mortality rates due to various conditions. The CFSAC will consider among its recommendations whether to urge adoption by the United States of the ICD-10 coding for CFS used internationally.

Dr. Dharam Ablashi presented a series of recommendations from the American Association of Chronic Fatigue Syndrome, an organization of researchers and providers that fosters research, publishes a newsletter and sponsors a biannual research, clinical and patient conference. Invited guests Jon Sterling, chairman of the board of the CFIDS Association of America, Jill McLaughlin, executive director of the National CFIDS Foundation, and I were permitted to participate throughout the meeting, including the lengthy sessions during which committee members discussed draft recommendations.

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NIH representative Dr. Eleanor Hanna announced that NIH would issue a Request for Applications (RFA) on CFS research initiatives in November. RFAs carry a designated fund for successful proposals, making them more attractive to prospective researchers than more general Program Announcements that don't carry set-aside funds. Dr. Drue Barrett, alternate representative from the CDC, notified the committee that a new report from CDC researchers documented an annual loss to the economy due to CFS of $9.1 billion. (For more on this study, see page 4 of this issue.)

The CFSAC's charter will expire on September 5, 2004, although Dr. Fields indicated that the process to renew the charter is under way and no obstacles to timely renewal are anticipated. Changes in the leadership of the Department of Health and Human Services are expected regardless of the outcome of the November elections; only time will tell the impact this may have on the status and function of the committee. Further information about the CFSAC and a roster of its members can be found at http://www.cfids.org/advocacy/CFSCC.asp. ■

Public Witnesses:

Diane Bean
Lauren Bean
Victoria Bell
Cheri Borsky
Barbara Comerford, J.D.
Steven Du Pre
(read by Victoria Bell)
Jonathan Gilbert
Marly McKibben
(read by Kim McCleary)
Lynn Royster
Diana Saba
Mary Schweitzer, Ph.D.
Lori Tylutki

"Never before have I run up against so much opposition and such poor attitudes towards symptoms as I have with CFIDS. I became so disenchanted with the medical community, I was ashamed to say that I was part of the profession."

—**Lori Tylutki, critical care nurse**

Where there's a will, there's a way . . . to expand CFIDS research, public policy and education

Your will is one of the most effective means of ensuring that you provide for your family and that your assets are distributed as you wish. Many people—those living with CFIDS, their friends, family members and others—have chosen to express their commitment to ending CFIDS by remembering the CFIDS Association of America in their wills.

Gifts by will, or bequests, both large and small, are vital to the Association's work. And because it's easy to execute or amend a will, a bequest is the most common type of deferred gift received by the Association.

Please send me further information on:
❑ Wills and bequests
❑ Gifts of stock
❑ Trusts and other planned gifts

Name ____________________
Address ____________________
City ____________ State ______ ZIP ________
Phone ____________________
E-mail ____________________

If you have already included the CFIDS Association of America in your will, tell us about it and let us express our gratitude for your bequest today. Simply check the box below and return this form to the Association.

❑ I have included the CFIDS Association as a beneficiary of my will or other estate plans.

Call Jamie Davis, Director of Development, at 704-364-0466 if you'd like to discuss making a charitable gift to the Association.

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NEVADA PASSES LAW REQUIRING INSURANCE COVERAGE FOR SOME CLINICAL TRIALS

Last year the American Cancer Society sponsored a bill which will have a historic impact on Nevada cancer and CFIDS patients who are involved in clinical trials. Assembly Bill 502 is now law in Nevada, and it requires insurance companies to cover treatment for Phase II, III and IV clinical trials for patients with cancer or CFIDS. The bill may be a model for other states to follow. The final bill includes this language:

A policy of health insurance must provide coverage for medical treatment which a policyholder or subscriber receives as part of a clinical trial or study if:

a. The medical treatment is provided in a Phase II, Phase III or Phase IV study or clinical trail for the treatment of cancer or chronic fatigue syndrome;

b. The clinical trial or study is approved by:
   - i. An agency of the National Institutes of Health as set forth in 42 U.S.C. 282(b);
   - ii. A cooperative group;
   - iii. The Food and Drug Administration as an application for a new investigative drug;
   - iv. The United States Department of Veterans Affairs; or
   - v. The United States Department of Defense

c. The medical treatment is provided by a provider of health care, and the facility and personnel have the experience and training to provide the treatment in a capable manner;

d. There is no medical treatment available which is considered a more appropriate alternative medical treatment than the medical treatment provided in the clinical trial or study;

e. There is a reasonable expectation based on clinical data that the medical treatment provided in the clinical trial or study will be at least as effective as any other medical treatment.

The bill passed because of the hard work and combined effort of legislators, cancer and CFIDS advocates, and CFIDS patients and their families. Thanks go to Buffy Gail Martin of the Reno chapter of the American Cancer Society and to oncologist Dr. John Ellerton for creating the bill and laying the groundwork for its passage.

Appreciation is also due to Harvey and Annette Whittemore, parents of CFIDS patient Andrea Whittemore, who has been in trials for Ampligen, a drug that has been used to treat CFIDS since the late 1980s. Harvey, a longtime lobbyist in the state capital, not only gave moving testimony on behalf of Andrea and his wife, he motivated legislators to recognize the seriousness of CFIDS. Without his efforts the bill would not have included CFIDS along with cancer.

Governor Kenny Guinn (seated) signed the bill into law in June 2003. Pictured with him, from left to right, are Annette Whittemore, Anita Patton, Harvey Whittemore, Andrea Whittemore, Courtney Alexander, Senator Bill Raggio, Buffy Gail Martin and Senator Raggio's assistant.

Also testifying in support of the bill was CFIDS advocate Jerry Crum and CFIDS patients Anita Patton, Robert Miller and Carol Reid, who talked about the tremendous financial burden of being in the Ampligen clinical trials. Accompanying this testimony was a petition signed by all of Nevada's Ampligen patients, as well as others supporting the bill.

Credit also goes to the elected officials who led the passage of the bill. These include Assemblyman David Goldwater, Senator Randolph Townsend, Assembly Majority Leader Barbara Buckley, Senate Majority Leader Bill Raggio and Governor Kenny Guinn.

This is the only bill in any state to provide coverage of clinical trials for CFIDS treatment. Congratulations to Nevada for its leadership in this important area. We encourage other states to provide the same support for CFIDS research and for improving the quality of life for patients and their families.

Thanks go to Bob Patton for his assistance with this article.

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CFIDS featured on talk radio

AWARE Talk Radio aired a 30-minute program on CFIDS in June. The program, which features health care news and treatment updates, airs on more than 600 radio stations in more than 95 cities. Senior producer LaVeda Peterlin reported that the program reaches about 8,000,000 people.

For the show on CFIDS, the producers interviewed an "ordinary" patient with CFIDS, a celebrity patient with the illness—Laura Hillenbrand—and Dr. Jacob Teitelbaum, who is a well-known clinician and author. The CFIDS Association was instrumental in helping AWARE Talk Radio interview Hillenbrand, and the show referred listeners to the Association's website for additional information.

This radio program is also available on the Walgreens website at http//:www.walgreens.com/about/community/aware.

UPI wire story

United Press International covered the high price of chronic fatigue syndrome in a wire story published June 22. The story cites the CDC study recently published in an online journal, *Cost Effectiveness and Resource Allocation,* which measures the annual cost of CFIDS to the U.S. economy at $9.1 billion, not counting health care costs.

Writer Dar Haddix put the cost in human terms by interviewing PWCs Cheri Borsky, John Trussler and Elly Brosius. The Association assisted Haddix by helping identify the PWCS who were interviewed for the story and by providing background material.

Hispanic audience

Recent prevalence studies indicate that Hispanic and African American populations are at risk for CFIDS. Getting information to these audiences is critical. A Florida magazine, *Aventura En Español,* recently published a one-page article on CFIDS called "El Síndrome de Fatiga Crónica: Un Misterio Médico."

The article describes CFIDS, with attention given to possible triggers, gender differences, neurally mediated hypotension, cognitive impairment and sleep abnormalities.

Mainstream press

There is more evidence that CFIDS awareness is increasing in mainstream publications. In *Redbook* magazine's December 2003 issue, a brief overview and discussion of CFIDS is included in the article, "Are You Tired—Or Is It Something More?" The article encourages readers who are experiencing certain symptoms to see their doctor and ask to be evaluated for CFIDS or fibromyalgia. It is encouraging to see CFIDS included with mainstream illnesses such as diabetes, anemia, depression and hypothyroidism.

Special interest coverage

Fibromyalgia AWARE published an article on CFIDS in its March-June 2004 issue as part of the magazine's ongoing coverage of overlapping conditions. Writer Elisabeth Deffner covers symptoms, myths and misconceptions, treatments and the role of the CFIDS Association in promoting research and awareness and in providing patient support. PWCs Susan DeRoehn, Shirley Taylor and Allison Baldwin were interviewed for the story. Baldwin, daughter of Association board member Rick Baldwin, commented for the article: "I will always need to be aware of this, budget my energy and balance my life out—but I've slowly been finding ways that work for me, and that are allowing me to live life."

Kim (Kenney) McCleary, who was also quoted in the article, discusses the overlapping nature of some chronic illnesses, saying that receiving a specific diagnosis can depend on which health care provider a person visits. A rheumatologist may diagnose symptoms as fibromyalgia, while an internist may diagnose them as CFIDS.

In-flight reading

The February 2004 issue of *Southwest Airlines Spirit* featured a six-page article on CFIDS titled "Why Am I Always Tired?" The article provides a careful overview of the disease, including information on prevalence, symptoms, diagnosis, treatments and current research.

Author Heather Millar profiles four PWCs and interviews clinicians and researchers, including Dr. Leonard Jason (DePaul), Dr. Nancy Klimas (University of Miami) and Dr. Veeraindar Goli (Duke). Association president Kim (Kenney) McCleary is also interviewed and quoted in the story.

Workshop coverage

The *Morehead News* published a front-page story on CFIDS and fibromyalgia in October 2003. The story covered a workshop on the illnesses hosted by the Northeast Area Health Education Center. About 80

people attended the workshop and 80 more participated through teleconferencing. Dr. Charles Lapp of the Hunter-Hopkins Center in Charlotte, North Carolina, was the workshop speaker.

The newspaper coverage of the event quotes Lapp as saying, "Chronic fatigue and fibromyalgia are much more severe than everyday fatigue. I call it the pain, brain and energy drain."

The article also tells the story of PWC Fannie Madden-Grider, a teacher at Morehead State University who has had the illness since 1995. She is trying to start a local support group in Morehead, Kentucky, for people with CFIDS and fibromyalgia.

Attitudinal shift

In an article entitled "Sea Change," published in the winter 2004 issue of *Bitch* magazine, writer Sharon Wachsler explores the changes that have occurred in the public's perception of CFIDS since Laura Hillenbrand's media exposure and the publication of her article in the *New Yorker.*

Wachsler writes that the *New Yorker* essay offers "an antidote to decades of misinformed media coverage of CFS." She goes on to describe the attitudinal shift some PWCs have observed in recent months.

Many thanks to those readers who help us monitor and respond to media coverage. Please clip articles about CFIDS and send them to: Media Relations, The CFIDS Association of America, PO Box 220398, Charlotte, NC 28222-0398.

AWARDS BRING AWARENESS

Laura Hillenbrand

Laura Hillenbrand's article, "A Sudden Illness," was one of the winners of the 2004 National Magazine Awards sponsored by the American Society of Magazine Editors (ASME). The annual ASME awards are considered the Oscars of the magazine world. Hillenbrand's article earned the *New Yorker* and the writer the prize in the essay category.

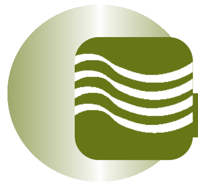
On conferring this award, the judges wrote, "In this essay about her long, nearly unfathomable fight with chronic fatigue syndrome, Laura Hillenbrand delivers rich, suspenseful, cinematic details and imagery that transport the reader deep into the heart of her nightmare—until it seems you are experiencing her claustrophobic and horrific reality. 'A Sudden Illness' champions the importance of respecting personal experience as valid (despite an army of 'authorities' who work to discredit it) and creates an inspiring testament to the will to live and create."

Hillenbrand, who authored the award-winning bestseller *Seabiscuit,* was also named one of *Glamour* magazine's 12 Women of the Year for 2003, an honor she shared with CDC director Julie Gerberding and Vera Wang, among others. *Vogue* named Hillenbrand one of its Extraordinary Women of 2003, along with other luminaries like Renee Zellweger, Hillary Rodham Clinton and the Dixie Chicks.

Floyd Skloot

Floyd Skloot often writes about the experience of living with CFIDS. He focuses on the difficult and challenging neurological problems caused by the disease. It takes weeks to write short passages as he struggles for words and fights for concentration. Balance problems and lack of stamina force him to break his day into short work periods.

Clearly, all the effort is paying off—both in awards and awareness. Skloot's latest book, *In the Shadow of Memory,* continues to win awards and accolades, expanding awareness of CFIDS as the author explores the personal toll of living in the shadow of this devastating illness for more than 15 years. The book received the 2004 Independent Publishers Book Award in the category of creative nonfiction/essay. It also was honored with the 2004 PEN Center USA Literary Award in creative nonfiction, which will be presented in October at ceremonies in Los Angeles. Barnes and Noble named the book third-prize winner of its Discover Awards, which include a monetary award and publicity for the winning books.



ASSOCIATION NEWS

Activities and accomplishments of the CFIDS Association of America

Association awards research grants

The CFIDS Association is pleased to announce a commitment of $237,710 to fund pilot research projects for 2004-05—the most since 1997. After an intense review process, three studies were approved for funding beginning in July 2004.

We are also negotiating with a fourth research group and hope to announce that study in the next issue of the *CFIDS Chronicle.*

Brigitte Huber, Ph.D., of Tufts University School of Medicine in Boston, will study HERV-K18 as a risk factor for CFIDS. In particular, the Tufts group is interested in analyzing patients who suffer from Interferon alpha (INF-*a)* associated fatigue. Dr. Huber's laboratory has shown that Epstein-Barr virus (EBV) infection, as well as exogenous IFN-*a*, activate transcription of the env gene of Human Endogenous Retrovirus, HERV-K18. This retroviral gene encodes a class of proteins, known as superantigens, that is capable of deregulating the immune system. The purpose of this investigation will be to establish whether a differential distribution of HERV-K18 allele and genotype frequencies exists in CFIDS patients as compared to healthy controls.

To do this, Dr. Huber has developed a novel technique for genotyping HERV-K env that can be performed in a reasonable time frame and is relatively inexpensive, allowing efficient genotyping of large numbers of samples. If differential distribution is seen in patients suffering from CFIDS, when compared to the healthy control group, this pilot study has the possibility of leading to the development of a clinical treatment for CFIDS.

Addressing the need for a scientifically validated test for CFIDS, Dikoma Shungu, Ph.D., of Weill Medical College of Cornell University in New York, will use hydrogen magnetic resonance spectroscopic imaging (H MRSI), a brain imaging technique very similar to the conventional MRI, to study H MRS neurometabolites as diagnostic markers for CFIDS. Dr. Shungu's research group will record the levels of certain important brain chemicals or neurometabolites in individuals suspected to suffer from CFIDS.

Prior investigations suggest that refining the H MRSI technique could establish a basis for using the changing levels of brain chemicals as measured by the H MRSI as diagnostic markers for CFIDS. Results of this project will allow researchers to establish not only that CFIDS has a distinct and abnormal profile of certain brain chemicals compared to the healthy human brain, but also that its profile is different from that of certain psychiatric disorders.

The third study, conducted by Christopher Snell, Ph.D., and J. Mark VanNess, Ph.D., both of the University of the Pacific in Stockton, California, will use an exercise challenge to investigate the pathophysiology of CFIDS. The study hopes to clarify the biological bases for the symptoms of CFIDS and suggest therapeutic interventions directed at treating the causes of the symptoms rather than merely treating the symptoms themselves.

Integrating several scientific fields that have traditionally studied CFIDS in isolation, they will examine the physical cognitive responses of CFIDS patients to the processes involved in the production and supply of energy. In doing so, Snell and VanNess hope to identify possible abnormalities that might point to the origins of many CFIDS symptoms and provide evidence of a possible relationship between CFIDS symptomatology and immune system function.

Each of the three studies funded in 2004-05 gives light to innovative directions in the development of methods, markers and treatment of CFIDS. We'll report the progress of these investigations in subsequent issues of this publication.

Social Security disability brochure

Did you know that most attorneys don't charge a fee if your Social Security claim is denied? Or that most claims are denied twice, and that perseverance is the key to winning your claim?

These facts and many others are detailed in the revised edition of the Association's free brochure, "Social Security Disability and CFIDS." The brochure helps you navigate the complex process of pursuing disability benefits and covers five important rules for winning benefits. It also includes information about Supplemental Security Income (SSI), as well as advice on choosing an attorney.

To request your free brochure, call the Resource Line at 704-365-2343 or visit http://www.cfids.org/ecommerce/products.asp?setcategory=23.

Provider ed website is revamped

Launched in June 2004, the redesigned Provider Education Project website merges the need for provider education with trends in

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online education. The site is unique in that it offers accredited provider learning tools on CFIDS for health care professionals in various disciplines.

The site's most requested tool is the online self-study, used by 548 registered participants in 2003 and 338 so far in 2004. This module allows providers to complete the two-hour course for continuing education credit at no charge. From the site, providers can also request the course in print, VHS or DVD formats, receive the *Pocket Resource Guide* and apply for a Grand Rounds presentation, which our trainers and consultants give at teaching hospitals and other venues.

Visit http//:www.cfids.org/treatcfs to learn more about the nationwide impact of the Provider Education Project, a collaborative effort of the Centers for Disease Control and Prevention (CDC) and the CFIDS Association.

GET INVOLVED!

You can help speed progress toward better health for the men, women and children living with CFIDS by getting involved in the work of the CFIDS Association of America. Here are just a few ways you can make a difference:

Build CFIDS Awareness

Help amplify awareness among members of the media—and Congress—by visiting our new Grassroots Action Center at www.cfids.org. There you'll find messages you can customize, links to your members of Congress, a directory of local and national press people and much more. And when you sign up for our new listserv, we'll alert you when issues need your attention and prompt you with text and the other resources you'll need to help generate a groundswell of support for increased research, awareness and understanding.

Support Association Programs

When you join the CFIDS Association, or renew your membership, you share a stake in efforts to conquer CFIDS. Of course, you also receive valuable membership benefits including the *CFIDS Chronicle,* the *CFS Research Review,* free educational pamphlets and publications and a 10 percent discount on Association materials. Your tax-deductible donation is also essential to strengthening the research, public policy and education programs critical to eliminating the suffering this illness causes.

Educate the Medical Community

Good patient care begins with good information. Send us the name and complete address of one or two health care professionals who need to know more about CFIDS so we can give vital information about CFIDS diagnosis and management to those on the front lines of patient care. Call the Resource Line at 704-365-2343 with this contact information, or send an e-mail to cfids@cfids.org.

DID YOU KNOW?

- **The Association places a great value on all charitable gifts—and on all monies raised through Association dues and activities. Careful stewardship of our financial resources is a top priority for us. That's why the Association has a stellar record in recent years of keeping our overhead, management and development expenses considerably below the national average for non-profit organizations. In 2003 our supporting services ratio was 14.3 percent—well under the 25 percent threshold that the best-run nonprofits stay below.**
- **Approximately 25 percent of people with CFIDS are disabled according to recent CDC studies. Thanks to the three-year effort of the CFIDS Association, the Social Security Administration's landmark ruling, SSR 99-2p, was issued in May 1999, making it easier for disabled CFIDS patients to get federal disability benefits.**
- **The Association's income from revenues, grants and donor gifts was $1.87 million in 2003. Two-thirds of the income was from charitable gifts, foundation grants, membership dues and sales of educational materials. The remaining third came from government grants.**
- **Nearly 3,500 donors made gifts to the Association in 2003. Gifts ranged from a single dollar to $95,000.**
- **The CFIDS Association of America is the nation's largest and most active charitable organization dedicated to conquering CFIDS.**
- **CFIDS*Link,* the Association's monthly e-newsletter, now has 18,000 subscribers.**

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ASK THE CEO

Q: I've been a member of a CFIDS support group for five years. There is so much frustration being expressed about how the public, and some of our own friends and family, still perceive CFIDS. We need to be making better progress on this! What is the Association doing on this issue?

A: You are hearing the same thing we are. One recent example came at the June meeting of the Chronic Fatigue Syndrome Advisory Committee when the need for more public awareness was woven into comments from several people on the committee. Members of the public who testified that day echoed those sentiments in heartfelt ways. We are also hearing from longtime supporters like you that progress is urgently needed on this front.

While the Association is very proud of many past successes, it's clear that we need to redouble our efforts to educate the public and reach a mainstream audience. In recent months we have been taking a closer look at what public perceptions really are, we have been investigating strategies to improve perceptions, and we have been discussing how to generate the needed financial support to accomplish this vital public education goal.

We hired a nationally known marketing firm to conduct some research that will guide our decision-making progress, and I encourage you to read their findings on pages 16-19 of this issue. Based on this research, and the long-term goals of the Association, we are developing a strategic plan to address both public awareness and provider education. Our plans are ambitious, and we'll need significant private and/or federal funding to accomplish them. As details come into sharper focus and funding is secured, we'll share this news with you. We *are* directing attention and resources to public education efforts in 2004 and 2005.

K. Kimberly (Kenney) McCleary

CFIDS impacts whole families, not just the person who is ill. We need stories from family members!

CFIDS is a life-altering illness, not just for PWCs, but for their families. We think these stories can help generate empathy and understanding among the general public, legislators, policymakers and adjudicators in insurance companies, HMOs and the Social Security Administration.

Spouses, children, parents and siblings, please send us your stories about the PWC in your life and tell us how:

- your spouse's illness affects the marital relationship
- your mom can't do the things with you she used to do, such as taking you shopping, cooking supper, going to your sporting events or attending your graduation
- your child's illness has changed the family dynamic and led to problems with siblings
- the illness has placed such a burden on the family's finances that it's impacting daily living and future financial security
- your sibling, ill with CFIDS, gets the lion's share of your parents' time and attention

Please send your stories to
Marcia Harmon at stories@cfids.org

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