

# THE CFIDS CHRONICLE

Advocacy,  
information, research  
and encouragement  
for the CFIDS  
community

SPRING 2003 ■ VOLUME 16 ISSUE 2

## Chronicle Q & A Why Advocacy Matters

**T**om Sheridan is the point man for CFIDS in Washington. His lobby firm, The Sheridan Group, represents the interests of the entire community in all the corridors of the federal government, from Capitol Hill to the National Institutes of Health.

*In this interview, Sheridan talks about the victories the CFIDS lobby has won over the years — and the tremendous challenges that lie ahead.*

**Q. Why does advocacy matter?**

A. I see advocacy as a way to solve problems. It's how we, as citizens, make sure laws and policies are responsive to the issues and problems that most concern us. To me, it's a vital element of democracy. We have a certain responsibility to make our voices heard, to express our opinions and to offer solutions to those we've elected to represent us.

There are so many interests competing for attention in Washington. Without a strong advocacy program, the CFIDS community would struggle to win — and maintain — the funding, recognition and policy changes we're seeking.

**Q. How did you become involved in advocacy?**

A. I entered by a rather unconventional route. Most of my colleagues have practiced law or worked on Capitol Hill in one capacity or another.

My Master's degree is in social work. My first act of advocacy occurred when I was working to establish a home for developmentally disabled adults in a neighborhood that really didn't want such a place located there.

I learned about political organizing while working for Walter Mondale on his 1984 presidential campaign. And I gained valuable experience — and tough skin — when leading public policy efforts for AIDS Action Council in the late 1980s. During that time I helped craft legislation, the Ryan White CARE Act, which has provided over \$2 billion in services to people with HIV/AIDS.

Now, the firm I started in my kitchen 11 years ago represents numerous non-profit health and welfare organizations and socially conscious corporations. The CFIDS Association was one of my first clients, so the work



CFIDS lobbyist  
Tom Sheridan

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# THE CFIDS CHRONICLE

SPRING 2003 ■ VOLUME 16 ISSUE 2

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**ABOUT THE CHRONICLE:** *The CFIDS Chronicle* is published four times a year by The CFIDS Association of America, Inc., PO Box 220398, 6827-A Fairview Road, Charlotte, NC 28222-0398. It is distributed free of charge to members. Send change of address information to the circulation director.

**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, Inc. serves as a clearinghouse for information about chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS), myalgic encephalomyelitis (ME), and other names. The Association does not endorse products or services, and the ideas expressed in the *Chronicle* are strictly those of the authors or quoted individuals. The CFIDS Association of America, Inc., and the *Chronicle* assume no liability for any medical treatment or other activity undertaken by readers. For medical advice, consult your personal health care provider.

**REGISTRATION AND FINANCIAL INFORMATION:** The latest registration and financial information filed by The CFIDS Association of America, Inc. may be obtained by contacting The CFIDS Association of America, Office of the Controller, PO Box 220398, Charlotte, NC 28222-0398, fax 704-365-9755.

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

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

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MESSAGE TO MEMBERS

*Lobby Day makes our case — and here's why*

This issue's cover story focuses on advocacy, the art of making yourself heard. To conquer CFIDS, our community needs strong, consistent advocates where it matters most: in Washington, D.C., where lawmakers and bureaucrats decide which causes get funded and which fall by the wayside.

Advocacy is critical to our shared cause for three simple reasons:

**Advocacy works.** I know this from firsthand experience. At each Lobby Day we ask for a set of well-documented and clearly stated actions, and year after year those actions occur. The allocation and/or restoration of funds; the creation and promotion of advisory committees; the establishment of education and training programs; the changing of regulatory and reimbursement language — all these resulted from advocacy. Such progress happens because, and only because,

people like you and me travel to Washington and ask our elected officials to make it happen.

**Advocacy gratifies.** It's a great antidote for the feelings of frustration and helplessness associated with CFIDS. Lobby Day allows us to make meaningful contributions on many levels. We help each other prepare our presentations, carry our materials and find our meetings. We represent those people with CFIDS who are too sick to travel and speak for themselves. We support the Association by populating the D.C. meetings with constituents. We guide our elected officials by providing the faces and stories that inform their decisions. We validate our democracy by communicating our collective needs in Washington.

**Advocacy matters.** Advocacy matters because you matter. It's a contact sport that requires us to stand face to

face with people who are in a position to help, and then to ask for that help. Advocacy also requires us to follow up with our elected officials back home, to be sure they and their staff did what they promised to do. No association can substitute for this grass-roots work. Your involvement will ensure that The CFIDS Association of America makes a difference for us all.

The CFIDS Association retains professional lobbyists to push our worthy agenda. But we need more than that. We need you to add your voice — especially at this fall's Lobby Day.

I hope to see you there!

*For more information on Lobby Day, see page 4.*



*Joseph P. Lane  
Board of Directors, The CFIDS  
Association of America*

*Correspondence with the Chronicle editor*



*In the Winter 2003 issue, the Chronicle asked readers to respond to this Hot Topic question:*

*“If you could wish away one CFIDS symptom, what would it be — and why would you choose it?”*

If I could wish away one symptom it would be fatigue. Before I got CFIDS I would ride my bike all over town with my family, work, go to nursing school and maintain my household (cooking, cleaning, paying bills, etc.). Today I am finding myself lying in bed 90 percent of every day because I have no energy. I am a parent of one son and want to be able to play with him and take care of him before he’s all grown up.

Laura Gregory, Arizona

They call it “post-exertional malaise.” I call it “shock the monkey.” Like a caged rhesus monkey, I am now

punished for doing anything I love to do. For me, those things would be: a daily three-mile hike; a weekly bike ride on mountain trails; landscaping and gardening; backwoods photography; swimming; traveling and more. It is discouraging and frustrating to be imprisoned in a body that looks out and craves to touch all those things — that *is* all those things.

I would keep all the “normal day” symptoms — fatigue, fog, palpitations, pain, burning eyes, etc. — if it meant they wouldn’t be intensified tenfold on “PEM” days. I could focus enough on other interests and grow in other ways that better accommodate this illness and allow me to accept the new “CFIDS me.”

Lois Ventura, Pennsylvania

If I could wish away one symptom, it would, without a doubt, be brain fog. I can face any pain better if I can use my

brain’s power of concentration to help rise above all the symptoms of CFIDS and fibromyalgia. It’s bad enough to feel as if I am one of the walking dead without being able to tell anyone else just what I am going through. After 14 years, the brain fog has continued to sap what little strength and dignity I once had, and has had devastating consequences to my roles of wife and mother, and to my former career as a clinical laboratory scientist.

Linda E. Lowe, California

I would wish away insomnia, because I have at least twice as much energy after a good night’s sleep. Although I quit worrying about what time I fall asleep a while ago, it is still boring to lie in bed at night, too tired to even read, waiting for sleep.

Inez Storck, Maryland

I would wish away my brain malfunctioning. I can handle physical limitations, but at least, if nothing else, I’ve always had my mind to rely on. Now, I’ve had several car accidents because of my cognitive problems, have a difficult time remembering the most simple tasks and lose my train of thought in conversations very easily. It’s extremely embarrassing! I just want my brain back.

Cindi Boykin, Alabama

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

Each issue, The CFIDS Chronicle gives readers a chance to respond to a question concerning CFIDS. Here’s the Hot Topic question for Spring 2003:

**“What’s the best advice anyone ever gave you about dealing with CFIDS?”**

Send your responses to The CFIDS Association of America, P.O. Box 220398, Charlotte, NC 28222-0398, Attention: *Chronicle* Hot Topic. You also can send your thoughts to us online at [chronicle@cfids.org](mailto:chronicle@cfids.org). Letters may need to be edited to meet our space and style considerations.

If you have an idea for a future Hot Topic question, please send it to the above address.

*Chronicle Q & A*  
(continued from front cover)

we've done together to put this issue on the political "map" is very meaningful to me. I've found that my strengths are best put to work in situations where I am fighting for the underdog.

I'm told that I have a little pit bull in me too.

***Q. What's the top priority for the CFIDS lobby in Washington?***

**A.** Remaining relevant. The Centers for Disease Control and Prevention (CDC) scandal that broke in 1998, when Dr. William Reeves presented evidence that CDC had lied to Congress about the use of CFIDS funds, was a very powerful event. CFIDS was suddenly in *Washington Post* headlines, the subject of several Congressional hearings, and at the top of the agenda for the director of a major public health institution. We used that notoriety to make very important gains for CFIDS research, through restoring nearly \$13 million in funds to the CFIDS program at CDC, and for deepening the Association's credibility on the Hill.

We proved that we were vigilant watchdogs over how federal CFIDS funds were being used. Members of Congress and their staff people developed tremendous confidence in the information we regularly provided about how the federal agencies were responding to CFIDS.

Now, with all the distractions of war, bioterrorism and SARS, on top of the usual parade of causes and initiatives, we must work even harder to make sure CFIDS doesn't fade from memory. We have to constantly remind Congress of the magnitude of CFIDS—how many people have it, how it impacts the economy, what individuals and our society lose through the disability it causes. We have to be able to translate those "costs" into policy that makes sense. We have to be tenacious. Most of all, we have to follow through on every commitment we make and every one we get. In advocacy, lawmakers count on the lazy advocate. We can't let them off the hook by not doing what we say we will.

***Q. What is the most important achievement made through CFIDS advocacy?***

**A.** Of course, helping to reveal the misuse of CFS funds at CDC, and then getting those funds restored, was an enormous accomplishment. Even more important was being involved in determining how that money—\$12.9 million—has been used. It would take a lot of bake sales and car washes to raise that sum for research funds. It's a perfect example of how effective advocacy can result in better, and more, research.

However, in my personal opinion, the work we did to get the Social Security Administration to issue a ruling for how to deal with disability claims for CFIDS is the single most important thing we have accomplished. Kim (Association President Kim Kenney) and I made a series of trips to Baltimore over a couple of years and, through persistence and the involvement of a few key experts in medicine, research and dis-

*(continued on page 4)*

**CFIDS ADVOCACY HIGHLIGHTS**

**1988** An Illinois man whose daughter has CFIDS becomes the first person to testify before Congress seeking research funds for the illness.

**1990** Congress instructs NIH to fund CFIDS Cooperative Research Centers.

**1992** First CFIDS Lobby Day held.

**1995** First CFIDS Congressional briefing held, sponsored by Sen. Harry Reid (D-Nev.) and Rep. John Porter (D-Ill.).

**1998** CDC funding scandal erupts over claims that the agency diverted \$12.9 million in CFIDS research funds to other programs.

**1999** Social Security Administration releases ruling that standardizes CFIDS disability claims.

**1999** CDC issues public apology for misspent CFIDS funds and offers restitution plan.

**2001** After Rep. Porter's retirement, The CFIDS Association begins effort to find a new CFIDS "champion" in Congress.

**2002** Federal funding for CFIDS research approaches \$14 million annually.

**2003** Work begins to populate the new CFS Advisory Committee, which will report directly to the Secretary for Health and Human Services.

ability policy, we convinced them that there was sufficient evidence and potential cost savings to warrant a ruling.

Now we hear from patients around the country, and from disability attorneys too, that the ruling has significantly decreased the time it takes to get an SSDI CFIDS claim approved. This means people are accessing benefits sooner and with less of a fight than had almost uniformly been the case before the ruling. There are still problems, but the situation is much, much better.

***Q. What can PWCs do to help?***

**A.** First and foremost: support the Association. Without The CFIDS Association of America, there is no responsible, organized advocacy. Your issue will cease to be considered. By support I mean by writing letters to your elected officials and by writing checks to help fund the Association's programs. I cannot stress that point strongly enough.

### JOIN US AT LOBBY DAY 2003

Advocates from across the country will gather in Washington, D.C., on Sept. 17-18 for The CFIDS Association's 12th annual Lobby Day event.

Over the past few years, the event has drawn 70-80 participants, including people with CFIDS, family members and friends. Most participants report being energized by the opportunity to engage members of Congress about the pressing needs of those with CFIDS, even though it can take a physical toll on patient-advocates.

A training session and event veterans help newcomers become comfortable with both the message and its delivery.

The more advocates we have participate, the greater our impact. There's plenty of time to register, so consider joining us in the capital this fall. For more information, call 704-365-2343, or send an e-mail message to [lobbyday03@cfids.org](mailto:lobbyday03@cfids.org).

Hopefully the September dates will also free us from weather-related issues associated with March dates (possible cold and snow) or summer dates (certain heat and humidity) that impose an extra barrier for many CFIDS patients.

Second, learn to tell your story. There is nothing more compelling than a thoughtful, well-told story that illustrates how CFIDS has impacted your life and changed your outlook for the future. Believe me, your elected representatives and their staff members listen to what you say. The more polished your message, the greater its impact.

Encounters with politicians and public health people are almost always brief. You can be more effective by selecting a few concrete examples than by sharing a thorough report of what you went through to find a compassionate doctor.

Try making comparisons: "I used to keep the books for our three family businesses. Now the cognitive problems I have make it hard for me to complete the order for my kids' school pictures." Or: "I used to enjoy performing in our community theatre musicals. Now I have trouble processing the noise and sensory input involved in going to the grocery store." Use these scripts when talking with or writing to public officials. They help make the experience real to people you're trying to influence.

***Q. What else?***

**A.** Participate in Lobby Day. For 12 years we have gone to Capitol Hill, meeting with 70-80 congressional offices, giving advocates the opportunity to tell their stories and ask for things that will further research and education about CFIDS. It's important to demonstrate that the issues we bring to the Hill have a real, human dimension. Lobby Day is our chance to do that. (See box for details on this fall's Lobby Day.)

***Q. Any final thoughts?***

**A.** Don't give up. I understand that CFIDS is not just a physical illness. Because it's not well understood and not accepted in some circles, it can also bring isolation, despair, financial hardship and strained relationships. But we are making progress. Advocacy offers a chance to do something positive and to take action against the very thing that has stolen so much of your life. Use advocacy to fight back in a way that might leave you feeling exhilarated rather than exhausted. ■

# Endocrine Causes of Chronic Fatigue: A Review of Symptoms, Treatments

*Diagnosing chronic fatigue and immune dysfunction syndrome (CFIDS) can be a time-consuming and complex process. Numerous diseases and disorders cause long-term fatigue — and doctors must eliminate all of them before arriving at a diagnosis of CFIDS.*

*Diseases of the endocrine system are among the most common causes of non-CFIDS fatigue, and in some cases can closely mimic CFIDS. The endocrine system includes a number of glands that produce hormones controlling metabolism, growth, sexual development and other body processes. In this article, Dr. Theodore Friedman discusses several key endocrine causes of fatigue — and ways to differentiate them from CFIDS and treat them.*

Although fatigue may be the earliest manifestation of endocrine diseases, patients usually will have other symptoms as well. These endocrine symptoms differ from the classic infectious symptoms associated with CFIDS such as fever, sore throat and swollen joints. Symptoms suggestive of an endocrine cause of fatigue as opposed to an infectious cause or immunological cause are listed in Table 1. If the patient has some of the symptoms listed in the table, an endocrine cause of chronic fatigue may be suspected.

Some of the more common endocrine diseases that often cause chronic fatigue include the following:

- Thyroid disease
- Impaired conversion of the thyroid hormone T4 to T3
- Adult growth hormone deficiency
- Adrenal insufficiency
- Mineralocorticoid insufficiency
- Metabolic syndrome (Insulin resistance)
- Diabetes
- Hypoglycemia

- Vitamin D deficiency
- Cushing's Syndrome
- Androgen deficiency
- Estrogen deficiency

A quick reference guide to several major endocrine causes of fatigue is provided below. Because these diseases can be tricky to diagnose, a primary care physician should carefully consider a specialist who is current on the latest developments in endocrinology and is experienced in its many subtleties. These endocrine diseases, unlike CFIDS, are often very treatable.

## **Hypothyroidism**

This condition, marked by a reduced production of thyroid hormone, is probably the most common endocrine cause of chronic fatigue. Besides fatigue, patients may also have weight gain, sluggishness, decreased memory, coarse, dry skin, heavy periods and fluid accumulation, and also may feel cold. They could have an enlarged thyroid (goiter).

There is growing realization that patients with mild (often called subclinical) hypothyroidism may show only mildly elevated thyroid stimulating hormone (TSH, a marker for the condition) and the symptom of fatigue. Patients with a goiter found by an experienced endocrinologist, or with positive anti-TPO antibodies, are more likely to benefit from thyroid hormone replacement.

It is also noteworthy that patients with pituitary causes of hypothyroidism may have low-but-normal levels of TSH and the thyroid hormone T4. Some endocrinologists are finding that treatment with levothyroxine (synthetic T4) alone is not enough in patients with hypothyroidism and that some patients need treatment with liothyronine (synthetic T3) in addition to T4.

*(continued on next page)*

**By  
Theodore C.  
Friedman,  
MD, PhD  
and  
Camille  
Kimball**

### **Cushing's syndrome**

Cushing's syndrome is often due to a tumor of the pituitary gland. This tumor will cause the adrenal glands to make too much of the stress-related hormone cortisol. Fatigue may be the earliest presentation of Cushing's syndrome. Weight gain, trouble sleeping, irregular periods, extra hair growth (hirsutism) and depression are other common symptoms. Many doctors, who have only seen textbook, severe cases of Cushing's syndrome, may not recognize milder cases.

Cushing's syndrome may be very difficult to diagnose. Early in the disease progression, some of the screening tests may be normal. Patients should be sent to an endocrinologist who may collect urine for cortisol (urinary free cortisol (UFC) and 17-hydroxysteroids) or collect nighttime salivary cortisol samples. Surgery to remove the tumor is often the treatment for Cushing's syndrome.

### **The metabolic syndrome**

The metabolic syndrome (also called Syndrome X or insulin resistance) is a newly identified syndrome associated with fatigue. These patients have elevated insulin levels and central (abdominal) obesity. They often have high blood pressure and hyperlipidemia (high

cholesterol and triglycerides). Men may have gout or balding, and women may have extra hair growth and irregular periods. A high carbohydrate diet may be involved in this disease. These patients are at risk for having heart disease. In addition to weight loss and exercise, these patients may also benefit from a low carbohydrate diet

or treatment with agents that improve insulin action, such as metformin (Glucophage).

Your endocrinologist may want to measure fasting insulin and glucose levels to make the diagnosis. A simple blood glucose level or even a glucose tolerance test may not be sufficient to detect insulin resistance.

### **Growth hormone deficiency**

Adults with growth hormone deficiency have severe fatigue, weight gain (especially around the abdomen), are often depressed and have poor quality of life. Children, but not adults, with growth hormone deficiency are short. Most cases of adult growth hormone deficiency are due to damage to the pituitary gland, often due to a tumor (usually not malignant).

Symptoms of growth hormone deficiency may be the first manifestation of a pituitary tumor. However, a tumor is not always present even though a patient is truly growth hormone deficient.

Growth hormone therapy is effective only for patients who are truly GH deficient. Patients with other causes of chronic fatigue will not be helped by growth hormone therapy and some may be harmed by it. It is very important to be correctly diagnosed. You should not take growth hormone unless you are found to be growth hormone deficient.

Growth hormone is secreted in pulses so a single measurement of blood levels is not helpful. Rather than measuring a random growth hormone, your endocrinologist will probably screen you by measuring a plasma IGF-1 level. If it is low, your doctor may do sophisticated tests that stimulate growth hormone secretion and measure its levels. These tests should only be performed by personnel experienced with GH testing.

### **Estrogen deficiency**

Many female patients develop fatigue around the time of menopause. This could be due the drop in estrogen at that time, although decreases in testosterone may also play a role.

Hormone replacement therapy has been a common treatment for this condition. Recently,

**TABLE ONE**

#### **SYMPTOMS SUGGESTIVE OF AN ENDOCRINE CAUSE OF FATIGUE**

- Irregular periods in women
- Depression
- Dizziness on standing
- Weight gain in spite of dieting
- Weight loss
- Body hair growth in women
- Osteoporosis
- Breast discharge
- Sleep disturbances
- Loss of memory
- Trouble concentrating
- Carbohydrate cravings
- Decreased interest in sex
- Trouble with erections in men

however, many women have been told by their doctors not to take estrogen due to two recent studies that showed a slight increase in risk of breast cancer and heart disease in patients taking a synthetic estrogen, called Premarin, and a synthetic progestin, called Provera.

But there have not been any studies showing increased risk in breast cancer and heart disease in women taking just estrogen or more natural forms of estrogen plus progesterone. In fact, many women note an improvement in their fatigue when their low levels of estrogens are increased by being placed on estrogen supplementation.

Estrogen replacement is a complex subject as estrogens can interact with many other hormonal systems. Even the form of the estrogen is important. Oral estrogen can alter thyroid requirements and actions of growth hormone. Yet estrogen delivered by patch or by a gel does not interfere in the same way. The effects of different preparations of estrogen even vary from patient to patient. The body itself makes different estrogens, including estradiol and estriol.

The symptom of fatigue may be relieved with more specific estrogen preparations. Relying solely on the common but rather generic Premarin, which is a broad preparation from the urine of pregnant horses, may not be the best course for many women.

### **Testosterone deficiency**

Low levels of testosterone may be due to a pituitary, adrenal or ovary/testis problem. If either men or women have fatigue and low libido (interest in sex), their doctor may want to measure their testosterone levels. If low levels are found, measurement of the pituitary hormones, LH and FSH, may help find the source of the problem. There are many good products for testosterone replacement in men, including gels and patches. There are fewer options for testosterone replacement in women, although taking DHEA, which gets converted to testosterone, may be one option. (*Editor's note: Dr. Friedman is currently performing a study of testosterone replacement in women with pituitary problems. For more information see his*

*Web site at [http://goodhormonehealth.com/trials/clinical\\_trials.html](http://goodhormonehealth.com/trials/clinical_trials.html).)*

### **Addison's disease**

Adrenal insufficiency (Addison's disease), like Hashimoto's thyroiditis, is an autoimmune disease. Patients with one autoimmune disease often develop another. Patients with adrenal insufficiency can have severe fatigue, weight loss, abdominal pain and diarrhea, increased skin pigmentation and salt craving. They often have low blood pressure when they stand (orthostatic hypotension).

The adrenal gland makes two important hormones, cortisol and aldosterone. Cortisol, the glucocorticoid hormone, is the hormone involved in the stress system, while aldosterone, the mineralocorticoid hormone, regulates salt and water retention. It has recently been found that some patients with Addison's disease may have deficiencies of only cortisol, only aldosterone, or both and that deficiencies of either hormone may give patients the symptoms of fatigue. Aldosterone deficiency may lead to lightheadedness, dizziness on standing, salt-craving and palpitations. Cortisol deficiency may lead to abdominal pain, diarrhea, weight loss or fever.

Your endocrinologist may want to measure hormones such as cortisol, ACTH, DHEAS, renin and aldosterone. You may be treated with replacement hormones including hydrocortisone, fludrocortisone (Florinef) and DHEA.

### **Finding out more**

More information about the endocrine causes of fatigue can be found at <http://www.goodhormonehealth.com>. The Web site includes an easily readable table of symptoms associated with excesses and deficiencies of various hormones. It is hoped that a treatable endocrine cause for debilitating fatigue can be found for some patients.

---

*Dr. Friedman is an associate professor in the Division of Endocrinology at the Charles R. Drew University of Medicine & Sciences-UCLA School of Medicine in Los Angeles. He can be reached at (310) 335-0327, or by e-mail at [mail@goodhormonehealth.com](mailto:mail@goodhormonehealth.com). ■*



By Kim  
Kenney

With the world's attention focused on the rebuilding effort in Iraq and the spread of a deadly new infectious disease, Severe Acute Respiratory Syndrome (SARS), The CFIDS Association of America is working to ensure that the needs of people with CFIDS are not forgotten by top health officials and federal legislators.

Over the past three months, we have met with leaders of the country's two most important medical institutions: Dr. Julie Gerberding, director of the Centers for Disease Control and Prevention (CDC) (meeting held in Atlanta on March 11) and Dr. Elias Zerhouni, director of the National Institutes of Health (NIH) (Washington, D.C., April 7). We also met with the two Department of Health and Human Services (DHHS) staff members now in charge of the CFS Advisory Committee, Dr. Larry Fields and Dr. Deb Nichols (Washington, D.C., Feb. 2). Here are updates based on information obtained during these meetings.

**CDC.** Dr. Gerberding reiterated the commitment of her agency to strengthening the CFS program being led by Dr. William Reeves, and to fully restoring the CFIDS community's trust in CDC's scientific approach to CFS and its financial management. As reported in the winter 2003 issue of the *Chronicle*, CDC has dramati-

cally expanded its CFS research program to include cutting edge genomics and proteomics studies, clinical investigations and promising collaborations with academic scientists. CDC also provides funds to The CFIDS Association of America to carry out provider education activities, through a contract approved last fall.

We are already working with top CDC officials to maintain the current level of funding — which includes “payback” funds arising from the 1995–1998 diversion of CFS funds to other programs — so that the gathering scientific momentum is not lost when the payback period ends in 2004. Dr. Gerberding and her staff agreed that productive research should not be put in jeopardy, and that it is helpful to have agency officials and advocates working together to overcome the budgetary challenges posed by this year's funding legislation.

**NIH.** Having come to NIH in 2002 from Johns Hopkins University, Dr. Zerhouni related his experience working with his Hopkins colleagues to evaluate CFS patients with autonomic nervous system abnormalities. He recalled the extent of the impairment suffered by those patients and expressed his view that complex, multi-system illnesses will require a new medical paradigm to make progress in research and treatment.

He also cited the need for ongoing dialogue with researchers from a wide variety disciplines to extend findings in sleep, pain, disability, cognitive impairment and other illness dimensions in the CFS population. A scientific workshop titled, “Neuro-Immune Mechanisms and CFS,” planned for June 12–13, 2003, will provide a forum for such dialogue and will help shape future NIH efforts to encourage research on the syndrome. (See p. 14 of the new issue of *The CFS Research Review*.)

NIH funding for CFS research had been expected to decline in FY03 as a result of fewer new grants being funded and the decision to end the CFS Cooperative Research Centers program. However, Dr. Zerhouni reported that the NIH will spend \$7.2 million this year, up 16 percent from \$6.2 million in 2002. We are presently analyzing the list of CFS grants that make up the NIH research portfolio to ensure that all CFS-related grants are included in that figure and to ascertain that all grants reported as being CFS-related are fully relevant to building a stronger understanding of CFS.

**DHHS.** Drs. Fields and Nichols presented an update on their efforts to adhere to the federally prescribed process for assembling the new CFS Advisory Committee. With 24 nomination packages to review and 11 committee positions to fill, they are working as

quickly as possible to evaluate candidates and develop a committee roster that reflects scientific diversity and appropriate representation.

They have spent a great deal of time tracing the history of federal efforts on CFS and learning the issues. Grinding through the bureaucratic

requirements should be the last hurdle before Fields and Nichols launch the new CFS Advisory Committee in a productive direction.

#### Lobby Day

The Association will hold its 12th annual lobby day on Sept. 18, with a mandatory

training session held on Sept. 17. We welcome all advocates — people with CFIDS, family and friends — to participate in this empowering event. For more information or to register, send an email message to: [lobbyday03@cfids.org](mailto:lobbyday03@cfids.org), or call the Resource Line at 704-364-2343. Hope to see you there! ■

## SEABISCUIT AUTHOR STILL RIDING HIGH

by Kim Kenney

Laura Hillenbrand, the best-selling author of *Seabiscuit: An American Legend*, seems to be everywhere these days. That's quite a feat for someone who can rarely leave her Washington, D.C. brownstone.

With her finely crafted book about the beloved 1930s racehorse still riding atop numerous "best of" lists, a PBS documentary about 'Biscuit featuring her as one of the main storytellers, a star-studded motion picture based on the book headed for theatres this July and media interviews blanketing print and broadcast outlets, it seems the country just can't get enough of Laura. It's a boon for CFIDS awareness since Hillenbrand uses every opportunity to talk about the illness that has narrowed her life for the past 16 years.

Even though her health is somewhat better than it was at the worst point of her battle — when she needed help just to roll over in bed — Laura still must carefully limit her commitments. She does radio interviews by phone from her bedroom and reporters must come to her.

Laura joined Tony Kornheiser's noon sports talk radio show on April 21, the day the PBS documentary first aired. When he asked about her health (she's been his guest several times before), she sought to explain her perky voice and articulate answers. "I'm doing better, but am still not as well as you might think or as I might sound. Few people realize how serious CFS can be."

Yet the truth is evident when you hear about the opportunities she's had to give up. Even though her book has achieved staggering sales records, she's only made two public appearances since it hit shelves

two years ago. She has consulted with film producers on the *Seabiscuit* movie that stars Tobey Maguire, Jeff Bridges and Chris Cooper, but she didn't get to rub elbows with the actors (including the five horses that play *Seabiscuit*) or visit the set. And she'll miss out on the glitzy premiers being planned for Hollywood and Manhattan. She's simply too ill to take advantage of the perks to which she is entitled.

Expect to hear more from Laura as the film premier draws closer. Her own account of her harrowing CFIDS story will run in *New Yorker* magazine when war coverage subsides. *People* magazine is planning a profile about how she overcame odds to write *Seabiscuit*. Other interviews with top media outlets are in the works, too. A special illustrated edition of *Seabiscuit* and a paperback version featuring photos from the movie will soon be released, likely generating another round of media interviews.

Laura's hinted that she's finally settled on the subject of her next book. Although it will be another work of non-fiction, she remains tight-lipped about further details. "I hope it's something that will inspire the same interest and excitement as *Seabiscuit's* story." And, hopefully, it will create more venues to educate people about CFIDS and Laura's own long-shot triumphs.



Hillenbrand

Activities and opportunities from The CFIDS Association of America



**Feature on symposia released**

In late February, The CFIDS Association released a camera-ready article to local newspapers across the United States through the North American Precis Syndicate (NAPS). The article, which is the second in a series of three,

is based on three research symposia held in 2000 and 2001 sponsored by the Association. The article highlights conclusions reached by attending researchers and scientists from each symposium on problems that play a role in CFIDS, including neurological

abnormalities, hormone imbalance and the body's reduced ability to resist infections.

The first camera-ready print article, released in 2001, has generated coverage in more than 268 newspapers in 22 different states with a readership of more than 29 million.

So far, the symposia article has been featured in newspapers in nine states with a combined readership of more than 129,000.

**Web site wins prestigious privacy seal**

The Association has added a new privacy protection seal on [www.cfids.org](http://www.cfids.org). By participating in the Council of Better

Business Bureau's BBBOnline Privacy Program, the Association has made a commitment to meet the program's strict requirements regarding how we treat the information you provide us when you visit our Web site.

The BBBOnline privacy seal, awarded to just 700 Web sites, allows you to feel comfortable and secure about visiting and sharing information. The privacy seal ensures that any information you provide while visiting our Web site is kept private. The Association is the only organization with access to the information you provide; we do not sell, share or rent this information to others under any circumstances.

If you would like to view our privacy policy online, please visit [www.cfids.org/about-cfids/privacy-policy.asp](http://www.cfids.org/about-cfids/privacy-policy.asp).

**"HealthWatch" mails with CFIDS Chronicle**

The Association is pleased to share a special edition of Pro Health's newsletter, "HealthWatch," with you this month. It contains research briefs as well as treatment and illness management possibilities derived from both traditional and complementary medicine. (Pro Health has covered the additional costs associated with this mailing.)

The CFIDS Association has long advocated that people with CFIDS make informed

choices about their medical care. We hope this newsletter will serve as yet another resource for our members.

Pro Health shares the Association's commitment to advancing CFIDS science. To help make more ground-breaking research possible, Pro Health will match contributions, dollar for dollar, made to the Association's research program this spring. Please consider making a special gift to help accelerate the progress of CFIDS research. See page 3 of "HealthWatch" for more information on how to double your donation.

**CFIDS Link... the latest e-communication**

CFIDS Link is the latest e-communication offering from The CFIDS Association of America. Delivered to your computer the first Monday of every month, it keeps you informed and in the loop by highlighting the latest information on CFIDS education efforts, research studies, public policy updates and Association news.

Recently CFIDS Link added a new feature: Spotlight on CFS. In each edition, Spotlight on CFS will feature a prominent scientist, CFIDS advocate, Association board member or supporter. In April the Association focused the spotlight on CFIDS activist Brooke Herrin. Visit [www.cfids.org/about/brooke.asp](http://www.cfids.org/about/brooke.asp) to read how Brooke turned to advocacy to fight back at CFIDS. ■



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

### Fake Procrit batches found in Florida

The federal Food and Drug Administration (FDA) reports that it has discovered three counterfeit, possibly contaminated lots of the drug Procrit, also known as epoetin alfa. The drug is used in people with severe anemia to stimulate the production of red blood cells in the human body — and studies are underway to test its effectiveness against CFIDS.

The FDA's criminal investigative unit found the illegally manufactured drug lots in Florida. Some of the drugs may be contaminated with bacteria, and the FDA reports that they pose a "significant potential hazard to consumers." In addition, some of the counterfeit drug contains no active ingredients.

The company that produces Procrit, Ortho Biotech Products, has issued a warning letter to more than 180,000 health care providers who may prescribe the drug to patients.

Additional details concerning the counterfeit product are available on Ortho's website at <http://www.procrit.com/counterfeit/letter.html>. Patients who use Procrit are advised to check with their doctors about their drug supply.

### Insurer fined \$1 million for claims practices

The state of Georgia has fined UnumProvident, the

nation's largest long-term disability (LTD) insurer, \$1 million for unfair denial of insurance claims.

"They were systematically looking for any shred of data or excuse to deny a policy," state Insurance Commissioner John Oxendine told *USA Today*. "They are going to be required to maintain a certain level of fundamental fairness."

The company has been under fire nationwide for more than two years over its claims practices. Two other states, California and Florida, also are investigating UnumProvident, and at least two class-action lawsuits have been filed against the company.

Georgia has placed UnumProvident on two years probation in the state. Oxendine says the company must change its practice of allowing lesser-trained claims processors to

overrule health care professionals, and must do a better job of informing policyholders of their rights to appeal.

UnumProvident has accepted the terms of the Georgia order and said it will work to become a "more service-oriented company." The firm has more than 25 million policyholders in the United States.

### CFIDS costs in UK mainly from lost income

British researchers say that each adult with CFIDS costs the nation more than \$1,800 per month in lost wages and medical expenses. The figure was derived after a three-month study done by King's College in London. The researchers report that lost salary accounts for more than 90 percent of the monthly total. The study was published in the February issue of *Psychological Medicine*. ■



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## CFIDS LINK

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If you'd like to receive **CFIDS Link**, make sure your email address is current in the Association's database. Call us at 704-365-2343 or send a message to [kalmond@cfids.org](mailto:kalmond@cfids.org).

# Banbury Meeting Raises CFIDS Profile



By Kim Kenney

CFIDS received important exposure to the scientific community in February when 32 researchers assembled for a three-day meeting to discuss and debate mechanisms of medically unexplained fatigue. Held at the prestigious Banbury Center of the Cold Spring Harbor Laboratory on New York's Long Island, the meeting kicked off the 25th

year of small sessions designed to explore emerging scientific issues that carry social, health and policy implications.

CFIDS was the focus of several presentations; experts from other fields provided context and insight into how fatigue in other conditions is being investigated using new technologies and animal models. Studies of immune defects, neuroendocrine abnormalities, irregular sleep patterns, sex differences, genomics, proteomics and definitional issues spurred lively discussion.

Co-sponsored by the U.S. Centers for Disease Control and Prevention (CDC) and The CFIDS Association of America, the session will help shape the direction and design of CFIDS studies at CDC and will inform the Association's research grant-making program.

One key issue raised by several participants is the urgent need for a more sophisticated means of classifying CFIDS patients that would help to sort out differences possibly due to type of onset, length of illness, degree of functional impairment, concurrent diagnoses (such as sleep disorders, fibromyalgia and depression), age, sex and symptom presentation. CFIDS researchers left the meeting with new considerations for ongoing and planned studies; those from other fields acknowledged a greater appreciation for the complexity of CFIDS and some expressed interest in launching or collaborating on new CFIDS-related projects.

The meeting provided an excellent opportunity to raise the visibility of CFIDS in the broader scientific community and to draw attention to the great intellectual challenges its study poses. It was an excellent complement to the Association's symposia series (2000-2001) and will hopefully strengthen the CFIDS research effort, an outcome desired by both CDC and The CFIDS Association.

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Kim Kenney is president & CEO of The CFIDS Association of America. ■

## *Plant Your Legacy*



### *Where it Will Grow, Produce and Endure*

There's something wonderfully fulfilling about a simple act of generosity. It reflects your values, your beliefs. And it makes a timeless statement of support for a cause close to your heart.

Your gift to The CFIDS Association of America — whether a cash donation or stock gift today, or a planned gift such as a bequest in your will or life insurance policy — will sow the seeds of progress toward better health for hundreds of thousands of people with CFIDS.

Charitable contributions fuel projects in CFIDS education, public policy and research, as well as support other mission-related needs.

Your donation, along with the gifts of other Association friends, grows vital programs, produces movement towards our shared mission and makes an enduring impact on the campaign to conquer CFIDS.

To explore the many ways you can make a legacy gift, or to learn about other charitable giving opportunities, please contact the Association's Director of Development at 704-364-0466, ext. 101, at [jldavis@cfids.org](mailto:jldavis@cfids.org), or visit [www.cfids.org](http://www.cfids.org) for more information.

*The CFIDS Association of America does not provide legal or financial advice. We urge you to consult your attorney, financial planner or accountant regarding specific tax and financial implications of your charitable contributions.*

*A report on coverage of CFIDS in the mainstream media*

**Association letter to the editor.** The January 2003 issue of *SELF* magazine featured an article, "It's chic to be sick," that may discourage women from mentioning possible CFIDS symptoms to their physician by implying that tiredness and/or depression is due to lack of motivation. The CFIDS Association sent a letter to the editor of *SELF* stating that CFIDS is often misdiagnosed and that the author's suggestion that "the newest crop of diseases is only socially contagious" may perpetuate this myth and interfere with getting a proper diagnosis.

**Ampligen study.** On Feb. 1, CBSNews.com featured a story on a study of the experimental drug Ampligen as a treatment for CFIDS. The article reports on how person with CFIDS (PWC) Joan Friedman has benefited from the Ampligen trials, includes quotes from CFIDS specialist Dr. Richard Podell and provides general information about the illness.

**Doctor educated.** The March 11 issue of the *St. Louis Post-Dispatch* featured an article by Dr. Hank Clever that reveals a physician's perspective on how CFIDS is still a poorly understood and hidden illness. In October 2002, the *St. Louis Post-Dispatch* also

featured an article on CFIDS that highlighted 24-year-old PWC Doug Lindsay and his invitation to present his proposed treatment for some people with CFIDS and orthostatic intolerance at an international symposium on the autonomic nervous system.

**CFIDS featured.** *Ebony* magazine published a CFIDS article in its March 2003 issue. The article gives a comprehensive overview of the illness, lists symptoms and highlights the seriousness and debilitating nature of CFIDS. *Ebony* reaches more than 10 million readers each month.

**Disability plight.** The Apr. 10 edition of *The Columbus Dispatch* featured an article on a PWCs and the battle over long-term disability benefits. The CFIDS Association worked with the author, Phil Porter, providing CFIDS disability information and arranging an interview with a local PWC and disability advocate, Kelly West, who is also mentioned in the article.

**Nursing article.** Terri Lupton, The CFIDS Association's coordinator for educational opportunities, wrote an article on the nursing implications of CFIDS that ran in the December 2002 issue of *Nursing Spectrum*. The article addresses the importance of

provider-patient partnership and the need for informed and compassionate nursing care.

**Blood circulation and CFIDS.** WebMD, a leading provider of online information, educational services and communities for physicians and consumers, published an article on April 15 that highlights new findings that blood circulation problems may be an underlying cause of CFIDS. The article is based on research reported at a medical conference by Arnold Peckerman, MD, of the VA Medical Center in East Orange, N.J.

**HPA axis study.** A study published in the Nov/Dec. 2002 issue of *Psychosomatic Medicine* has sparked extensive media coverage, including *The New York Post*, *HealthScoutNews* and *BBC News*. The coverage highlights research that indicates subtle changes in the hormonal stress response system (HPA axis) may play a role in CFIDS.

*Thanks go out to those who are working with the media to increase awareness of CFIDS. The CFIDS Public Relations (CPR) Team helps monitor and respond to media coverage. Please clip articles about CFIDS and send them to CPR Team, PO Box 220398, Charlotte, NC 28222-0398. ■*



By Leah Moseley

# Dental Amalgams and CFIDS: Harmless Fillings — or Toxic Concern?

By Michael D.  
Fleming, DDS

*Are dental amalgams bad for your health? The debate continues to rage about the mixed-metal tooth fillings, which contain mercury and other potentially toxic substances. The topic is of particular interest to people with CFIDS, who are searching for relief from the multitude of symptoms they face every day.*

*The American Dental Association (ADA) states unequivocally that amalgam fillings are safe, since the mercury is made stable when mixed with other materials. Although other materials are now available for fillings, the ADA says that amalgams still play a role in modern dentistry — and should not be removed simply out of unfounded concern over the presence of mercury.*

*Yet not all medical professionals are convinced. Michael Fleming, DDS, writes that amalgam removal cannot promise miracles — but should not be completely rejected, either.*

CFIDS remains one of the most clinically challenging conditions to treat in the health care setting. Many people with CFIDS (PWCs) have tried so many different things to get well that they have worn themselves out emotionally, financially and physically in the process. The ongoing symptoms have often led patients on a wild goose chase searching for a cure. Some may have simply resigned themselves to a life managed with medications. Others continue the quest for healing with varying degrees of success.

A controversial treatment advocated to relieve chronic fatigue states and other disorders is the removal of mercury-based amalgam fillings and other dental materials from the mouth. In the search for wellness, many PWCs have replaced their fillings, believing that the materials in them may be working their way into the body and causing symptoms. Some PWCs have shown measurable results, and

others little or no perceived benefit. Many others have considered having their amalgam fillings removed but are not at all sure of the relevance and effectiveness of such a treatment.

The current scientific evidence does not adequately support the legitimacy of amalgam replacement treatment to treat disease or ill health. However, when considered as part of a broader long-term plan to recover health, replacement therapy can be seen as “taking a brick off the wagon” of the immune system. Treatments should therefore not be seen as offering the final answer to a patient’s health problems, but rather as taking one more step toward allowing the body an opportunity to heal itself.

Dental amalgam is a mixture of at least three metals: mercury (45–55 percent), silver and tin. Depending on the manufacturer, copper is often added for corrosion resistance, along with zinc, palladium and other trace metals. Amalgam has been the standard filling material for teeth since the mid-to-late 1800s, and its use in teeth was first recorded in France as early as the 1780s.

Virtually every dentist practicing in the world today has been trained to do amalgams and the majority of them continue to install them routinely. Dental amalgam remains a deeply entrenched treatment modality even though there has been significant decline in its use with the development of tooth-colored alternatives and growing health concerns over the presence of mercury.

When the body is exposed to mercury, the health effects include a variety of toxic, allergenic and local oral symptoms. The list is long, but typical symptoms would include fatigue, a decline in mental clarity, irritability, depression, withdrawal from family and friends, poor sleep, night sweats, anxiety, panic, premature aging and a general sense that one is losing one’s health and mind. There may be

*“Some PWCs have shown measurable results, and others little or no perceived benefit.”*

cardiovascular, neurological, gastrointestinal and genitourinary symptoms of all sorts.

Many of the symptoms of mercury toxicity mimic those of CFIDS, multiple chemical sensitivity syndrome and autoimmune disorders. Furthermore, it can take months or years for any effects of mercury to appear, making a conclusive diagnosis of any mercury-related disease nearly impossible. It is not uncommon for people with mercury poisoning to be functioning at a high level until an illness or significant life stress event occurs and health begins to decline either suddenly or more gradually.

It is worth noting that the World Health Organization has stated that dental mercury fillings constitute the main mercury exposure risk to humans, exceeding food, air and water sources combined.

Even though mercury in the mouth is a hot issue in dentistry these days, PWCs must realize the oral cavity can also contain a veritable smorgasbord of other materials as well. It is not at all uncommon in a dental practice to see patients with a combination of root canals, crowns, bridges, implants, amalgams, composite fillings, removable metal/plastic appliances and all sorts of bonding and bleaching agents, solvents, fillers and cements. These materials can contain mercury, tin, silver, copper, zinc, palladium, gold, nickel, beryllium, chromium, iridium, gallium, indium, platinum, titanium, barium and aluminum — as well as complex plastic polymers and adhesives. Root canal fillings often contain a latex rubber derivative (gutta percha), formaldehyde, eugenol (oil of cloves), heavy metals including mercury and various cements and bulking agents.

The decision for PWCs to enter into a treatment process like amalgam removal needs to be made after careful consultation with a trusted and knowledgeable physician and dentist, who, in turn, will work with each other

and the patient to establish a plan of treatment. Attention needs to be given to all the materials present in the mouth, not just the amalgams. Careful consideration needs to be given to the patient's current state of health when entering into this treatment. Fortunately, PWCs generally tolerate dental treatment very well with few complications. If a choice is made not to engage in removal therapy, in my opinion it still would be a good idea for PWCs to avoid the installation of any more amalgams.

Dentists are not obligated to provide removal treatment and many do not believe the removal of amalgam has any value in treating health problems such as CFIDS. Both dentist and patient need to mutually appreciate the need for this treatment and the risks and potential benefits must be clearly discussed and understood. Patients may wish to consult with a dentist and/or physician familiar with the new materials and procedures and experienced in managing patients with CFIDS.

Patients also must be prepared to accept the fact that no guarantees of improvement of symptoms can be made. There can be significant expense — sometimes thousands of dollars — to have removal treatments performed, depending on how much material is present in the mouth. These expenses are not always covered by dental insurance.

It is the dentist's duty to do no harm in the process of removal treatment and to give his or her best efforts to those who seek care for this purpose. While amalgam removal is a treatment worthy of consideration in the CFIDS population, it is well for all of us to remember to “be informed before anyone performs.”

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*Michael D. Fleming, DDS, has been treating CFIDS patients for more than 18 years and practices general dentistry in Durham, N.C. His wife has had CFIDS for more than 12 years; they live in Wake Forest, N.C. ■*



*Terms in bold type appear in the CFIDS Glossary box.*

By Vicki Walker

### **Blood flow normal in CFIDS patients**

The amount of blood that flows to skeletal muscles in people with CFIDS appears to be normal, according to research published in the Feb. 13 issue of the British journal *Clinical Science*. The finding is important because some researchers have speculated that poor blood flow or poor delivery of oxygen to these muscles could cause CFIDS symptoms such as fatigue and **post-exertional malaise**.

This small study compared 19 people with CFIDS to a group of 11 normal, but sedentary, control subjects. The CFIDS patients showed similar scores to the controls in the amount of blood flowing to skeletal muscles, and in terms of how fast the muscles regained their normal oxygen levels after the blood was temporarily cut off to them.

### **Stimulating drug may show promise in CFIDS**

The commonly prescribed drug dexamphetamine could be an effective treatment to improve the symptoms and quality of life in people with CFIDS (PWCs), according to a small **pilot study** from Australia.

Researchers conducted a small study of 20 PWCs, 10

of whom received treatment with the drug and 10 of whom received a fake drug called a placebo. After four weeks of treatment, the patients were asked to complete several evaluation tests to measure their progress.

The group that received dexamphetamine scored significantly better on a test called the Fatigue Severity Scale, which is commonly used to track changes in PWC fatigue symptoms. The researchers report that nine of the 10 treated patients showed improvements on the scale, while only four of the 10 placebo patients improved.

The results, while promising, are considered preliminary. The authors say, however, that their study should justify a larger trial to better determine the effects of dexamphetamine. The drug, which is also known as the trademark name of Dexedrine, is often used to treat people with attention deficit and hyperactivity disorder (ADHD) as well as narcolepsy.

This study appeared in the January/February issue of the journal *Psychosomatics*.

### **Antioxidant supplements may help CFIDS symptoms**

A new study from Italy suggests that supplements of **antioxidants** might help relieve some of the muscle-related symptoms of CFIDS.

The study looked at whether lower levels of antioxidants (specifically vitamin E) in the body — and higher levels of so-called “free radicals” and other markers — were linked to muscle fatigue and pain in people with CFIDS. Such altered levels lead to a phenomenon called oxidative stress, which has been implicated in a number of disease states, ranging from high blood pressure to Alzheimer’s disease.

The researchers looked at 21 patients with CFIDS and 20 **control subjects**. All participants were given blood tests to determine vitamin E levels and other related measures. Results showed that the CFIDS group as a whole had lower vitamin E concentrations in their blood plasma and low-density lipoproteins (LDL cholesterol). The CFIDS group also had lower pain thresholds in all muscle sites tested. The levels of vitamin E concentration were linked to the levels of muscle pain — the lower the vitamin E levels, the higher the pain levels.

Why people with CFIDS tended to have lower antioxidant levels remains unknown. The study authors suggest that the muscles themselves may be acting in ways that demand more vitamin E, thereby lowering the amount circulating in the bloodstream.

The study authors did not attempt to increase antioxidant levels through supplementation,

so there's no direct evidence that taking antioxidant vitamin pills will help relieve the muscle symptoms. But the authors said they believe their work provides a "first step" towards testing that theory. For now, patients with CFIDS are advised to seek their doctor's opinion before taking antioxidant supplements.

The study appeared in the January 2003 issue of *Neuroscience Letters*.

### **CFIDS patient registry in works**

The U.S. Centers for Disease Control and Prevention (CDC) is taking steps to build the first-ever national registry of CFIDS patients. The registry, called for by Congress, will track CFIDS patients' illness over time. Researchers will be able to use the registry to identify potential participants for CFS research studies. Records will be stored in a central data base that can only be accessed by qualified CFS researchers. Eventually, the registry might also allow patients to donate organs to CFIDS research, if they wish.

The CDC has launched a review of patient registries for various chronic medical conditions to determine the best format for the new CFIDS registry. The comparison registries are selected for their potential relevance to a CFIDS registry, including similar issues regarding recruitment mechanisms, inclusion criteria, data and

specimen collection, cost, management and purpose.

CDC has contracted with former CFIDS Association staffer Vicki Walker to conduct this research and develop a plan for a successful CFS registry. Walker stated, "I am excited to be playing a central role in developing the CFS registry. I believe a CFS registry is a crucial step toward understanding the illness. Patient registries have provided important answers for a multitude of medical conditions and I am optimistic that CDC's registry will do the same for CFS."

### **AACFS conference held**

The American Association for Chronic Fatigue Syndrome (AACFS) held its 6th International Conference on CFIDS and related syndromes in February near Washington, D.C. The four-day conference attracted dozens of the top researchers in the field for discussion on clinical treatment of CFIDS and presentations about new research.

For highlights of the proceedings, be sure to check the accompanying spring issue of *The CFS Research Review*. ■

## **CFIDS GLOSSARY: TERMS YOU NEED TO KNOW**

**Antioxidants:** By definition, any agent that inhibits the oxidation of other compounds. In humans, certain vitamins (notably A, C and E) and other substances block the work of "free radicals" that oxidate and damage cell membranes. Such damage may be linked to heart disease, cancer and other conditions.

**Control subjects:** Participants in research studies who have not been exposed to the treatment or illness being tested. They are used to help measure the effect of a treatment or procedure on the other patients in the study.

**For example:** To study a new allergy drug, researchers will treat a group of patients with the medicine and give the control subjects a fake drug called a placebo. The researchers will then measure the change in allergy symptoms in both groups to see if the drug had any effect.

**Typically,** researchers will attempt to match control subjects to the patients in terms of age, gender, race and other relevant categories. (Controls are also commonly referred to as "healthy controls.")

**Pilot study:** A small, preliminary version of a proposed research study. Pilot studies are used to help refine the methods researchers will use in the full study — and to see if the proposal shows any merit in a small sample.

**Post-exertional malaise:** One of the hallmark symptoms of CFIDS. Most people with CFIDS experience unusual levels of fatigue, cognitive problems and other symptoms after physical or mental activity. This "malaise" often does not begin immediately and can last for days following the activity. Such a degree of post-exertional malaise is rare in other illnesses.

*If you have suggestions for terms to include in future editions of the glossary, please send them to [chronicle@cfids.org](mailto:chronicle@cfids.org), or to The CFIDS Association of America, PO Box 220398, Charlotte, NC 28222-0398, Attention: Chronicle glossary.*

*Tips, strategies, ideas and helpful thoughts about CFIDS*



### Try protein for energy boost

I find that I have more energy if I eat protein-packed foods. These include chili, or a combination of hamburger and spinach. Protein-rich foods at breakfast time (including yogurt or a soy milk smoothie) are especially good; they help keep me going much better than a high-carbohydrate breakfast such as cereal.

A reader in Pennsylvania

### Allergy pill helps with sleep

Having suffered from CFIDS for 11 years, I have tried many different strategies and aids to help me sleep. Trazodone helps, but not enough.

Last summer, after cutting the grass, I took one-half tablet of generic Actifed (an antihistamine used for allergies). I noticed that I felt drowsy and relaxed. I decided to try taking one-half tablet at bedtime.

The difference in my falling asleep and staying asleep is significant. Many dollar stores carry this item at 24 tablets (48 doses for me) for about a dollar a box. That's about four cents a dose! Both my pharmacist and my medical professionals see no harm in taking this medication and it is much cheaper than allergy drugs such as Claritin.

Timothy F. Hrehocik  
Pennsylvania

*(Editor's note: It is always advisable to check with your physician before taking any new medications — even over-the-counter varieties. They may cause unforeseen interactions with other medications.)*

### Keeping the beat helps with exercise

Sticking to an exercise program dramatically relieves my muscle pain in the medium to long term. But exercise often exacerbates symptoms in the short term. I found a way out of this dilemma by buying a heart rate monitor. I quickly figured out what heart rate is safe for me, and the monitor beeps when I reach it — telling me to slow down.

I now can exercise regularly with few adverse reactions, have regained a substantial amount of fitness and energy and have very little muscle pain. It's best to consult with your doctor before beginning any exercise program, to make sure that what worked for me will work for you, too.

Heart rate monitors come in a variety of styles, including wristwatch types and chest straps. They are relatively inexpensive (less than \$100 for many good units, with some as low as about \$25) and easy to use.

Name withheld  
California

### Water bottle keeps daily fluids flowing

I use a 32-ounce, Nalgene lexan wide-mouth loop-top bottle as my daily water container. It simplifies life: if I fill it twice within a 24-hour period and drink the water I know I've consumed the equivalent of eight, eight-ounce glasses.

These bottles are completely leak-proof and come in a variety of colors. I take at least one with me everywhere. They have a very secure, handy carry loop attached to the lid, which is useful when carrying multiple items in the house, or on the way to the car. They're virtually indestructible, and can be washed in the upper rack of the dishwasher. I have found them at Campmor (800-226-7667, or [www.campmor.com](http://www.campmor.com)) for \$7.50 and under and at other backpacking/outdoor product retailers.

They also make great inexpensive presents!

VB  
California

Send your One to One tips to the *Chronicle* at The CFIDS Association of America, P.O. Box 220398, Charlotte, NC, 28222-0398. You also can send them by e-mail to [chronicle@cfids.org](mailto:chronicle@cfids.org).

# Feed Your Soul Through The Power of Creative Expression

I must be honest. Though at first glance I appear quite healthy and fit, coping with CFIDS is a real day-to-day struggle. Tiredness is only the worst part. That doesn't take into account all the other symptoms and challenges that people with CFIDS (PWCs) also face — from pain and mental foginess to lack of support and social ignorance of the disease, to name just a few.

So how do I cope? One key for me is using creative expression, especially creative journaling, to nourish my soul. I am a true believer in the mind/body/spirit connection. Anything that helps one of the three will also affect the others. So feeding my spirit or soul will also nourish my mind and body.

We are all creative beings, whether we realize it or not. Only by pursuing creative outlets will you discover just how deep your well of creativity really runs.

Although there are many activities that could technically fall under “creative expression,” for me I am talking about creative expression through art. Specifically I mean music, dance/movement, art, writing and drama. Actively involving yourself in any of these arts on a regular basis can be healthy and even healing for you, besides being plain fun.

Even though I personally love dance and movement, as a PWC I am quite limited at times in this area. Even so, stretching, yoga, meditative walking, or other types of “gentle” movement are still forms of creative self-expression (and exercise!) that I can and do enjoy most of the time.

More often, I primarily focus on listening to music, writing and art-making. Fortunately, these types of expressive arts activities can be enjoyed and engaged in even while in bed.

So how to get started? Just remember: The number one rule is that THERE ARE NO

RULES! Anything goes! To truly find and develop our creativity, we must be able to experiment, play, and goof up often in a non-critical, relaxed atmosphere. You are only doing this for you.

Get some paper or a journal, pens, markers and/or other art supplies and just begin. Start by just playing with your writing and art materials. Playing is good. Background music that you like is also recommended.

Please note that it is typically helpful to date your art and/or journal writing. You will be glad for this later.

Here are a few suggested activities to try. Try them all at least once, although you may find favorites and decide to use certain ones over and over again. Spend as much time or as little time on each activity as you wish.

Make a list of things that you love or things that make you happy. List the joys in your life. Try to come up with at least three or more each day. Barbara Ann Kipfer published an entire book like this, titled “14,000 Things to Be Happy About!” This activity helps me notice and feel grateful for the good things that I do have in my life.

Write a poem. Oh, sure, you say! Well, just try an “alpha poem” to start. Even I can do this one. Take the letters of your name or a friend's name (this makes a terrific gift) and line them up vertically. Then write down a word or phrase to correspond to each letter. You can do this with a name or with any favorite or meaningful word — like a color, a feeling, etc. Here are a couple of examples:

**SUE**  
Sincere  
Unique  
Enthusiastic



By Mary  
Lynne  
Quinnan  
Zahler

*(continued on next page)*

**FREEDOM**

Fun and laughter  
 Running with wind in hair  
 Exceptional serenity  
 Exhilarating  
 Do whatever you like  
 Or don't do anything at all; it's  
 Marvelous!

Try scribble drawing. For just a few seconds, make a spontaneous scribble on a blank page or piece of paper. Now go back to it and find an image or picture within your scribble. To find the image, you can turn the page upside-down or all around. What do you see? Embellish and enhance the image you eventually find, by adding to it, coloring it, etc. Then write about what this image might mean to you. This is a terrific way to access the creative and/or subconscious sides of yourself.

If you love music, choose a song and really listen to it. Or read the lyrics to a song that you like. Then write about how the words or music affect you. Two beautiful songs to try this with are “Hero” as sung by Mariah Carey and “The Greatest Love of All” as performed by Whitney Houston. Write down all the thoughts and feelings that spontaneously emerge in you as you listen.

How are you feeling today, right now? Write about it. You can even try to draw it, or make a magazine-picture collage of it, right in your journal or on a separate piece of paper. Remember, there is no wrong way — whatever you choose to do is right for you. Writing about your feelings is a very appropriate and healthy way to express them, even — especially — if they aren't all positive ones.

Write about or make a collage about what healing means to you. This can be very insightful. But don't sit around and think a lot about it first — just do it. Write or choose your collage pictures quickly and spontaneously and see what you come up with. Let it flow for the most interesting and insightful results. I look at my most recent healing collage often; it helps remind me of what I need to do to take care of myself. Daily.

Choose a metaphor as to how you feel with your illness, such as “sick as a dog” or “caged like a bird.” Take time to draw this, dance it (if able), or act it out, and then write about it.

Try doing a written dialogue with your illness and see what it says to you. Then you can explore this further through drawing, painting, collage making, photography, sculpture or any other art medium of your choice.

Using your non-dominant hand, draw a picture of how you would like your body to feel. Include using colors and shapes to symbolize vitality and health. Then with your non-dominant hand, write about how it feels to be in the body that you just imagined. When done, use your dominant hand to write and/or draw and explore this further. Using the non-dominant hand can be helpful when you feel stuck or when you just want to try something different.

Draw, paint or sculpt your “anger monster.” Then write about how you can tame this monster. Try playing some calming music in the background as you write.

Try doing some type of brief relaxation activity first, such as listening to a short guided imagery audiotope, meditate, or do a progressive muscle relaxation exercise. Then draw or create one or more “symbols” of losses that you have had in your life. Afterwards, write about these symbols either through poetry or journaling.

Most of us will not let CFIDS ruin our lives. But we do have to learn to cope with it on a daily basis. Using the arts for self-expression and soul nourishment is one coping technique that I have found works well for me. It is fun, creative and, above all, healthy.

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*Mary Lynne Quinnan Zahler has had CFIDS since 1993. She lives in Ohio with her husband and their menagerie of pets. She is currently employed as the Wellness Director at Family Services in Canton, Ohio. She has a Master's degree in health education and exercise science and a Bachelor's degree in psychology from Miami University. ■*

# Yoga: Stretching Away Your Stress

By Mark  
Giulucci

In the search for new ways to relieve stress and regain lost energy, some people with CFIDS (PWCs) are turning to one of the world's oldest therapies: yoga.

Yoga's breathing, meditation and gentle stretching techniques are attractive to people whose fatigue levels limit them from doing more strenuous exercise. Yoga also can change in intensity and duration to match the ebb and flow of a PWC's energy envelope.

Laura Cornell, a yoga instructor in Berkeley, Calif., knows firsthand how chronic fatigue can devastate a person's life. While never formally diagnosed with CFIDS, she developed many of the telltale symptoms — from constant fatigue to swollen lymph nodes — after receiving a series of vaccinations in her early 20s.

After finding limited success with standard medical care, Cornell decided to take an alternative route that included acupuncture, dietary changes and chiropractic treatments. But yoga was a revelation; the day after taking her first class, Cornell says she woke with more energy than she'd felt in years.

"It was amazing," she says. "Two years later I became a yoga teacher to share what I had found. I've been teaching for eight years now, and I have never felt better."

The theory behind yoga and fatigue is simple. Stretching muscles and joints increases blood flow through the body, improving oxygenation and increasing energy. The meditative side of yoga decreases mental and physical stress. And lifestyle improvements, from diet to sleep habits, help complete the therapy.

Alice Christensen, author of *The American Yoga Association Wellness Book*, says that yoga exercises tend to leave people refreshed, not exhausted, after completion. Developing a yoga routine provides a "daily support system" that promotes a normal, productive lifestyle, she says.

There's still not a great deal of scientific research into yoga and CFIDS. But a recent,

two-year study at the University of Iowa showed that yoga helped substantially improve fatigue symptoms in nearly one-fourth of subjects who had fatigue lasting more than six months. Of all the therapies tested in the study — including acupuncture, herbal remedies and dietary supplements — yoga was the only one to show a statistically significant result. The study has not yet been published.

"The people who did yoga felt better than the people who tried other things," lead researcher Arthur Hartz, MD, PhD, said in a recent interview. Dr. Hartz said he found the results surprising. "I know almost nothing about yoga. This finding just sort of came out of the blue. We weren't looking for it."

The U.S. Centers for Disease Control and Prevention also lists yoga as a potential form of exercise therapy for PWCs — although it warns that some people may find it too strenuous.

## Getting started

Yoga is more than a series of postures. It's an ancient system that combines spiritual and physical practices — in fact, the word yoga literally translates to "union."

Westerners are most familiar with Hatha yoga, which emphasizes breathing and physical postures (also known as poses or asanas). There are a number of subgroups under Hatha, some of which are more physically demanding than others.

Cornell suggests that PWCs should seek one of the gentler forms, at least at the beginning. These include Kripalu and Integral yoga, or any others labeled "restorative" or "gentle." These versions place importance on improved flexibility, movement and breathing — and allow people to progress at their own pace.

Kripalu, which Cornell teaches, begins with a series of warm-up exercises before moving on to the asanas. This can be useful for newcomers and for PWCs who have not been able to exercise or even stretch during their illness.

*(continued on next page)*

Although there are a number of how-to yoga books on the market, the best way to get started is with a teacher and a group class. Books, while helpful, cannot correct flaws people develop in their breathing and posture techniques — and they can't make individualized suggestions for improvement.

It's very important to feel comfortable with your yoga instructor, Cornell says. Student and teacher must form a bond that allows for mutual trust and friendship. Don't be afraid to interview a teacher before signing up for classes. And make sure that you can leave a class without penalty if you don't feel that the instructor is able to address your specific needs.

### Yoga 101

If you're interested in seeing what yoga feels like, Cornell offers several suggestions for beginners:

**Breathing.** We breathe constantly, but rarely do we pay it any attention. Cornell suggests finding a "beautiful place" for some mindful breathing. This can be a park, your garden or even a candlelit, quiet corner of your favorite room in the house.

"It's very simple. Close your eyes and just 'watch' your breath," Cornell says. "Breathe in and out, and check into how you're feeling." You can sit or lie down in any comfortable position.

Practice this type of reflection daily, even if you can only devote a few minutes. It's an instant stress reliever — and a good way to get back in touch with your body.

**Legs up.** This posture can be done on the floor or even in bed. Lie on your back and scoot your backside close to a wall. Then raise your legs, resting your heels on the wall. This position eases strain on the back. It also changes blood flow patterns in the body, which Cornell says can improve circulation of fresh blood to vital organs.

Hold this position for several minutes, or less if you begin to feel uncomfortable. People with orthostatic intolerance should be careful

about performing this posture, since it can affect blood flow to the brain.

**Twist pose.** Next, lie on your back and relax for a couple of minutes, concentrating on your breathing. Then slowly bend your knees and draw them toward your chest. If you can lift your legs off the ground and pull your knees into your torso, fine — if not, keep your feet on the floor instead. Then slowly twist at the waist and allow your knees to touch the floor to your left (if you can't make them touch the floor, that's fine, too). Hold this position and breathe eight to 10 times slowly. You can hold it longer if you are able. Then switch your knees to the right side and repeat.

This position relieves back stress, Cornell says, and helps "massage" your organs by bringing fresh blood to them.

When you're practicing yoga, it's very important to eliminate distractions like televisions, radios and telephones. Yoga is about paying attention to your body. "You need to attune to the body's internal wisdom," Cornell says. "Play some music if you like to help relax. Or simply enjoy the feeling of being one with yourself."

### Resources

*The American Yoga Association Wellness Book.* By Alice Christensen. Kensington Books, 1996.

*Relax & Renew: Restful Yoga for Stressful Times.* By Judith Laster. Rodmell Press, 1995.

Yoga Research and Education Center, 2400A County Center Drive, Santa Rosa, CA 95403, USA. Phone: 707-566-9000. [www.yrec.org](http://www.yrec.org); [www.iayt.org](http://www.iayt.org) ■

### YOUR PURCHASE FIGHTS CFIDS

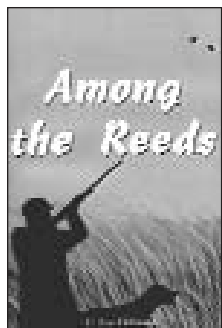
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Your guide to published resources

*The Marsh and I  
don't make the fates  
that wait for us out nigh.  
We'll live them as  
the seasons change  
and birds, they fill the sky.*

—C. Eric Hellmann  
from “Getting Older”

C. Eric Hellmann has spent much of the past 32 years paddling the waters of central Ohio. An avid outdoorsman, he loves nothing more than a quiet day on the marsh.



Since developing CFIDS, however, Hellmann sometimes finds it difficult to escape outdoors.

So he has turned to poetry as a way to restore the peace and sense of harmony that the lakes and ponds once provided.

The result is *Among the Reeds*, a collection of his favorite writings. Hellmann's anthology is one of a growing number of books written by and for people with CFIDS (PWCs).

The rise of self-publishing houses has made it easier for PWCs to get their work in print. But, as a consequence, it's a little harder for others to find them, since they're not always available in book stores or even at online sellers.

To help make these books more accessible, The CFIDS Association of America has begun listing PWC-written books (and others written by health care professionals) on its Web site, [www.cfids.org](http://www.cfids.org), along with buying information. Check the What's New page for the listings.

Hellmann's book is available for \$14.95 through [iUniverse.com](http://iuniverse.com), an online book seller. For more information, check [www.iuniverse.com](http://www.iuniverse.com).

Here are couple other books written by PWCs:

***Making the Best of Orders to Rest***  
By Annabel Hobbs  
2002, WinePress Publishing  
\$12.95, 181 pp.

This is a delightful collection of essays from a PWC in Florida. She recounts her daily struggles with an infectious sense of optimism that is strengthened by her faith — but also with an occasional poignant piece about how the illness has changed her life forever.



“Can I embrace my suffering instead of being afraid of it and thereby focus on the more important things?” she asks.

“If I wait until I am ‘fixed,’ I may never change.”

***Ten Myths about Doctors and What You Can Do to Dispel Them***

By Kay Hutchinson Benton  
2002, InchAlong Press  
\$15.00, 84 pp.

“I...write this book so that whoever reads it will know that there are indeed GOOD doctors in this world and that you should NEVER stop looking for them,” author Kay Benton writes in the introduction to her book. She then discusses her Top 10 misconceptions about doctors and ways to get the most from your relationship with every health care professional.



Far from a simple rant against the medical profession, Benton lists a number of resources, your personal “Bill of Rights” and other tips for improving your treatment. Benton's book is available online through [Amazon.com](http://Amazon.com), or at <http://www.tenmythsaboutdoctors.com>.

Tragically, Kay Benton died earlier this year after an unexpected illness. She was an occasional contributor to *The CFIDS Chronicle*, and her hard work and fighting spirit will be missed.

Mark Giuliucci is editor for *The CFIDS Association of America*. ■



By Mark  
Giuliucci

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



*Bulletin Board space is provided at no cost to individuals or groups who conduct non-profit or volunteer activities for the CFIDS community.*

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### RESOURCES

A new online chat room is available to parents of children with CFS/ME. The Tymes Trust Forum can be accessed by visiting [www.raisingkids.co.uk/forum/display\\_forum\\_topics.asp?ForumID=16](http://www.raisingkids.co.uk/forum/display_forum_topics.asp?ForumID=16).

A free online listserv is available to PWCs who want to explore alternative treatments, energy work and the effects of positive thinking on healing. Sign up at: [groups.yahoo.com/group/CFSPositiveEnergy/](http://groups.yahoo.com/group/CFSPositiveEnergy/).

*The Encourager* is a small inspirational newsletter for chronically ill Christians. It is published on a bi-monthly basis, with a suggested donation of \$6 for seven issues. For more information, contact Renee Dahlen at 1032 15th St. NE, Mason City, IA 50421, or write to [reneejoel@netconx.net](mailto:reneejoel@netconx.net).

The Medicare Rights Center provides publications, products,

information and services on Medicare. Visit their store at [www.medicarerights.org](http://www.medicarerights.org), or contact Esther Zuckerman at 212-869-3850 or via e-mail at [ezuckerman@medicarerights.org](mailto:ezuckerman@medicarerights.org).

### RESEARCH/TRIALS

Participants are needed for a CFIDS research project funded by the National Institutes of Health. The project is being conducted at the State University of New York at Stony Brook and involves the study of daily patterns of activity, energy, fatigue and stress in people with CFIDS. A two-year follow-up assessment also will be done. Participants will be paid and the medical evaluation is free of charge. Three visits to Stony Brook Hospital are required. For more information, contact *Fred.Friedberg@stonybrook.edu* or call 631-632-8252.

Study participants are needed for a clinical trial of the drug Procrit. Anyone who can travel to Miami twice each month is invited to participate. For more information, write to [CFSresearch@miami.edu](mailto:CFSresearch@miami.edu).

An Australian PhD candidate with CFIDS is seeking to create an online illness management course to help people improve their quality of life. Anyone interested in participating in an initial study can fill out an online questionnaire

at [www.ballarat.edu.au/bssh/research/Community\\_Health/projects/006/](http://www.ballarat.edu.au/bssh/research/Community_Health/projects/006/). The login phrase is "subject" and the password is "agrees."

A Los Angeles area research team is now recruiting people with CFIDS for a clinical study that seeks to improve blood flow to the brain and possibly improve fatigue symptoms. Subjects will undergo brain SPECT scans, tilt-table tests, hormone measurements and other treatments. Open to men and women of all races and ethnicities, age 18–49. Subjects will be compensated, but must be willing to be off all medications for duration of the study. Please call Dr. Friedman or Dr. Zuckerbraun at 323-563-9353 or [mail@goodhormonehealth.com](mailto:mail@goodhormonehealth.com) for more information or to enroll.

For more information on clinical trials open to CFIDS patients, see the Association's Web site, [www.cfids.org/about-cfids/clinical-trials.asp](http://www.cfids.org/about-cfids/clinical-trials.asp).

### INFORMATION NEEDED

A PWC is searching for others whose long-term disability claims have been rejected by The Standard Insurance Company, for inclusion in a possible class-action lawsuit. For more information, contact Sheryl McCoy at 11335 Mountain View Drive, #66, Rancho Cucamonga, CA 91730, or write to [angels.everywhere100@msn.com](mailto:angels.everywhere100@msn.com). ■

## WHAT IS CFIDS?

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

### HOW IS CFIDS DIAGNOSED?

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

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

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

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

### HOW IS CFIDS TREATED?

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

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

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

### WHO GETS CFIDS?

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

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

### DO PWCs GET BETTER?

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

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

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*This document is an abridged and up-to-date version of "Understanding CFIDS," a comprehensive, 16-page booklet about CFIDS published by The CFIDS Association of America. Copies of the booklet (item #6040, available for \$1 each) may be ordered by calling the Resource Line at 704-365-2343.*

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# MISSION

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

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

*Advocacy, Information, Research and Encouragement for the CFIDS Community*