

THE CFIDS CHRONICLE

Advocacy,
information, research
and encouragement
for the CFIDS
community

FALL 2003 ■ VOLUME 16 ISSUE 4

Headaches and CFIDS

Taming the pain, easing the pressure

“**I** don't remember ever having had a headache before CFIDS. About eight months after a very acute onset of flu-like symptoms and memory and concentration problems later diagnosed as CFIDS, I had my first headache. At the time I was already spending 20 hours a day in bed — wrung out, brain-fogged and very weak. I didn't think it was possible to feel any worse. I was wrong; when I have a headache I am at my very worst. Sometimes they last several days.” — Carra, describing her tension headaches

By Kim
Kenney



“Headache of a new type or severity” is one of the eight symptom criteria listed in the international case definition for chronic fatigue syndrome. Headache is very common in the general public: Ninety percent of men and 95 percent of women report having had at least one headache in the past year. However, for people with CFIDS (PWCs), headache is layered on top of other symptoms and can profoundly affect function and quality of life. Researchers and clinicians are learning more about how to treat and prevent headache, so new options for diminishing its impact for those with CFIDS warrant exploration.

Types of headache

Tension headaches affect 75 percent

of those who get headaches. It is generally defined as a steady pain on both sides of the head and is caused by tightening of the shoulder, neck and head muscles. Soreness and pressure can accompany the pain and it may be brought on or made worse by stressful events or a hectic day. Relaxation techniques can be helpful as part of an overall treatment program, discussed in more detail below.

Migraines are the most debilitating form of headache; an estimated 25–30 million people in the U.S. have experienced them. Twenty percent of sufferers describe a distinctive group of symptoms that immediately precedes the throbbing pain of a migraine — visual

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

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

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

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MESSAGE TO MEMBERS

“Tipping” the scales in our favor

Writer Malcolm Gladwell coined the term “tipping point” to describe “the dramatic moment when an idea, trend or social behavior crosses a threshold, tips and spreads like wildfire.”

In his best-selling book, “The Tipping Point: How Little Things Can Make a Big Difference,” Gladwell reminds us that it doesn’t take much to create dramatic change – for better or worse. A little gold box on a record club advertisement “can suddenly make record buying by mail seem irresistible.” On the other hand, it only takes a single sick person to start an epidemic of the flu.

Do the tipping point theory and Gladwell’s other key principles — the Law of the Few (social epidemics are created and sustained by very small groups of extraordinary

people), the Stickiness Factor (messages must be memorable to move us to action) and the Power of Context (epidemics are sensitive to the conditions and circumstances of the times and places in which they occur) — apply to CFS?

I believe so. Those of us holding this issue of *The CFIDS Chronicle* represent a relatively tiny subset of the population. But we’re a group of people who share an exceptional commitment to a cause.

We understand that we won’t win the battle to conquer CFS on merit alone. There are thousands of illnesses to fight, thousands of worthy causes to support. So we’re taking steps to educate and build awareness about the seriousness of CFS. And we’re working to “package” the right message, one that resonates, cuts through the clutter, moti-

vates key audiences and turns passive support into action.

A message that matters. A message that inspires people to ask, “How can I help?” — this will be our tipping point.

The CFIDS community has fought for years to defeat this devastating and debilitating illness. At times bureaucracies and beliefs seem immovable. They are not. As the Greek mathematician and scientist Archimedes said, “Give me a lever long enough and a fulcrum on which to place it, and I shall move the world.”

Or at least get it tipping in the right direction.



Jamie Davis
Director of Development and
COO, The CFIDS Association
of America



Davis

Correspondence with the Chronicle editor



In the Summer 2003 issue, the Chronicle asked readers to respond to this Hot Topic question: "When your CFIDS symptoms flare, what gets you through the day?"

When I have a bad flare-up, I go to the closet and pull out My Comforter. It used to be on my youngest daughter's bed, yesterday long ago. She loved it because it was so colorful, with bright yellow, red and blue flowers. I love it because it is a reminder of all the wonderful memories of her.

The colors are faded now and the fabric worn and thin, but it is more beautiful today than ever. As I wrap it around my shoulders, I forget about myself and welcome the comfort. The softness caresses my body and shuts out the rest of the world. The laundry to be done, the bills to be paid, the telephone calls to make are all

forgotten for now as I retreat into a place of peace, love and healing.

Helen M. Brooks, Arizona

I'm 58 years old and have had CFIDS for 12 years. I have the most loving, 4.4-pound Yorkshire Terrier. She is full of love, and extremely flexible. If I can't get up for hours, she will curl up with me. Finally she gets hungry and barks at me. I have to get up to feed her. Even if I can barely move, taking care of someone else makes me feel better and makes me feel life is worth living.

Evelyn Lief, New York

I did social work for 19 years before I had to quit because of my illness. At the time I was diagnosed, I had a part-time job for the ALS (also known as Lou Gehrig's disease) Association of Los

Angeles. One of my responsibilities was to help set up alternative communication systems for patients who needed them. During advanced stages of ALS, patients may lose the ability to walk, eat, talk and even breathe.

On my bad days, I remember the relief I could see in patients after the system was set up and they could communicate again. Some could only move a finger or blink an eye, yet they carried on bravely. This always reminds me that as bad as it is for me, it could be worse. We must go on.

Chaz, California

The power of prayer!

Jane Bradford Thurber, Virginia

Praise for a hero

I have been thrilled to read so much lately about Laura Hillenbrand's success with Seabiscuit. Three cheers to her for the dual achievements of writing a book and becoming such an articulate voice for CFIDS.

But I want to send up three more cheers for Laura's partner, Borden Flanagan, who stood by her through all her difficulties and gave her the kind of support we all wish we had. He's a true hero in my eyes; a fine match for our new heroine. My best wishes to both of them.

Carol Greentree, California

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

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

"Besides a cure, what do you hope the New Year will bring the CFIDS community?"

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

Headaches and CFIDS

(continued from front cover)

disturbances (e.g., flashing lights or “floaters” in the field of vision), nausea and increased sensitivity to light, sound and odors. These symptoms are called an “aura” and usually fade as the headache sets in. Cutaneous allodynia, hypersensitivity to contact with the skin of the face, head and forearms, is a recently recognized feature of migraine attacks. (See box on p.6) Migraines are thought to be caused by chemical and/or circulatory changes in the brain. There is often a family history of migraine and set of activities or circumstances that trigger the start of a migraine attack. Prevention is a key treatment strategy.

Cluster headaches affect more men than women and account for just one percent of all headaches. These headaches are short-lived, but come in groups — hence the name. They are usually localized to one side of the head and may be accompanied by a bloodshot eye or runny nose. Cluster headaches are described as being more severe and intense than other types of headache.

Rebound headaches occur as a response to overuse of headache medications; as the medicine wears off, the pain builds. This can lead to escalating use of painkillers if not treated appropriately. The term **secondary headache** refers to headache caused by another organic condition, such as infection (e.g., strep often causes headache) or increased pressure in the brain due to a tumor or other structural abnormality. Headaches can also signal inflammation and/or infection of the sinus cavity, or can result from problems with vision or improper vision correction. Providers generally try to rule out these possibilities before beginning a headache treatment program.

Headache types have some overlapping features and it is possible for an individual to experience more than one type of headache (e.g., a person who has frequent tension headaches may also get occasional migraines). Being able to distinguish between headache types enables the patient and provider to

determine which treatment strategies will be most effective in combating pain and preventing future headaches.

Assessment

There is no objective sign or diagnostic test for headache, so diagnosis is based on medical history and patient reports. While primary care providers can often manage routine headaches, there are a growing number of professionals who specialize in the treatment of headache disorders. Neurologists, pain management specialists, physiatrists, psychologists and other professionals may participate in advanced education or research about the diagnosis and management of headache. Additionally, headache clinics may offer a one-stop, multi-disciplinary approach to patient care.

The provider will generally rely on information collected in the patient interview to determine if brain scans or other tests are warranted. If the headache pattern, presence of other symptoms and/or an abnormal neurological exam suggest encephalitis (swelling of the brain and spinal cord) or tumor, the doctor may order an MRI or CT scan before determining a course of treatment. The physical exam can reveal signs of muscle tightness, sinus cavity tenderness, blood pressure disorders and other clues as to underlying sources of head pain.

Tools that help track headache triggers, frequency, severity and impact on function can be very beneficial in establishing an accurate diagnosis and developing a treatment plan. Keep a headache diary for several weeks, making note of how and when the pain starts, what other symptoms accompany it, what might have provoked it (e.g., environmental conditions, activity that preceded it, foods or drinks taken before the headache, etc.) and how long it lasts. You may want to note such things as the weather, barometric pressure, day of the menstrual cycle — all have been reported to trigger headache in some individuals. Also record what treatment you undertake, whether it's medication or stress relief techniques, and what seems to reduce, if not alleviate, the pain.

(continued on page 4)

Bring the diary to each appointment with the treating provider.

The Migraine Disability Assessment (MIDAS) is a five-item questionnaire “scored” to help determine the level of disability caused by headaches over the past three months. The Headache Impact Test is a more in-depth questionnaire developed to provide a headache profile for patient and provider to use in setting a treatment plan and tracking changes in headache patterns. Both can be found online through the National Headache Foundation, at www.headaches.org.

Treatment

There are many, many different ways to treat headaches. These strategies are usually broken into (at least) two categories: acute or abortive (treatment that helps end or diminish a headache once it occurs) and preventive or prophylactic therapy (that helps reduce frequency with the eventual goal of eliminating headache). Further, treatment can be divided into other categories: medical, behavioral and complementary/alternative.

Most sufferers find that achieving success requires a combination of approaches, and that

Modality	Abortive	Preventive
Medications		
Non-steroidal anti-inflammatory drugs (NSAIDs)	Ibuprofen, acetaminophen, aspirin, diclofenac potassium	Naproxen sodium
Beta-blockers		Propranolol, timolol, methysergide
Pain killers	Codeine, DHE 45, butorphanol, hydrocodone	
Antidepressants		Amitriptyline, serotonin-reuptake inhibitors
Anticonvulsants		Divalproex sodium, gabapentin, topiramate, lamotrigine, phenytoin
Triptans (5 HT agonists)	Sumatriptan, almotriptan, naratriptan, rizatriptan, zomatriptan, frovatriptan, eletriptan	
Other	Caffeine	Verapamil (calcium channel blocker), lisinopril (ACE inhibitor), riboflavin (vitamin B2), oral contraceptives
Trigger point injections		X
Botulinum toxin injections		X
Relaxation and stress relief techniques		
Meditation	X	X
Deep breathing	X	X
Massage/bodywork therapy		X
Complementary/Alternative approaches		
Acupuncture	X	X
Chiropractic/osteopathic	X	X
Biofeedback		X
Herbs, Chinese medicine		X
Behavioral techniques		
Good sleep hygiene		X
Elimination diet		X
Apply cold/ice	X	
Increased water intake		X
Cognitive behavioral therapy		X
Physical therapy	X	X
Occupational therapy (posture, ergonomics)	X	X

different treatments may be effective at different times. It often requires a considerable amount of trial and error, working with a provider or therapist to suggest logical combinations, monitor success and make changes. Using a chart like the one on p.4 can help you track what you try and how well it works. The example contains generic names of commonly prescribed medications and a general guide for how each of the other modalities is used to treat headache.

Medications

All medicines carry side effects and can interact with other drugs, supplements and herbal preparations being used. Because so many people with CFIDS are sensitive to even low doses of medications, it's essential to communicate openly with your health care provider to assess the possible effects, interactions and trade-offs associated with medicines. Some drugs used to treat headache can disrupt sleep while others have sedating effects. The goal should be finding the most effective medication using a dose with the fewest side effects. Here is an overview of some of the medicines used for headache:

The drugs most commonly prescribed to treat the pain of a headache after it's already started are "triptans" and non-steroidal anti-inflammatory drugs (NSAIDs). Triptans are among the newest drugs developed for migraine. They moderate the levels of serotonin and constrict blood vessels in the brain. Due to the frequent occurrence of nausea with headache, many of these medications come in a variety of forms, including pill, nasal spray, suppository and injection. Effectiveness of a given medication may vary based on the method of delivery (e.g., nasal spray may be more effective than tablet, even at the same dose).

As with treatment for other forms of pain, there are numerous analgesic medications often tried in increasing dosages and strengths. Providers usually begin with over-the-counter NSAIDs, a few of which have been formulated for migraine, often adding caffeine to boost its effect. Narcotics are generally reserved for short-term relief of the most treatment-resistant

US HEADACHE CONSORTIUM Guidelines for Managing Acute Migraine Headache

Clinicians are advised:

- To educate migraine patients about their condition and its treatment and encourage patients to participate in treatment decisions;
- That when patients respond poorly to NSAIDs or combination analgesics such as aspirin, acetaminophen, and caffeine, migraine-specific agents, such as a triptan, dihydroergotamine, or ergotamine, should be used;
- That patients who experience nausea and vomiting early in migraine should be selected to receive non-oral medication formulations;
- That patients who have been refractory to treatment should be considered for self-administered rescue medications; and
- To avoid causing medication overuse headache, also known as rebound or drug-induced headache.

Multiple well-designed randomized clinical trials support recommendation of the following medications:

- Oral combination opiates
- Dihydroergotamine nasal spray
- NSAIDs (oral) and combination analgesics
- Butorphanol nasal spray
- Triptans

American Academy of Neurology, 2000

forms of pain. Concerns about developing tolerance, dependence and addiction to painkillers are expressed by many patients and providers; taking these medications only as directed can minimize the likelihood of these problematic outcomes.

Anticonvulsants, beta-blockers and antidepressants are frequently used to help prevent headaches by regulating "switches" in the brain that control certain activities. A few have been approved for use in headache while others are considered "off-label" treatments. This classification may impact medical insurance reimbursement; some medical plans will not pay for medications that are not used as specifically prescribed. If so, consult with your provider about other covered treatments that may be appropriate substitutes.

Trigger point injections and Botox have shown some benefit in treating headache. For tension headache caused by knotted, painful

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“EVEN MY HAIR HURTS...”

In an article published Sept. 4, 2003 in *Headache: The Journal of Head and Face Pain*, cutaneous allodynia (CA) is described in detail as a feature of migraine headache. The paper explores the decades-old observation that patients avoid hair brushing and touching the scalp, shaving, brushing teeth and wearing glasses, contact lenses, earrings, or tight clothes during migraine attacks. This heightened sensitization is also described by people with CFIDS in the acute phase of the illness and/or during a relapse.

Research shows that a cascade of complex chemical reactions occurs in each phase of migraine, and that CA may be responsible for reports of pain in the head and neck area that frequently extends beyond the “headache” region. The presence of this symptom in about 75 percent of migraine sufferers suggests that the pathophysiology of migraine may involve peripheral, central brainstem and thalamic neurons. Further studies indicate that treatment of CA is best accomplished by giving abortive drugs (particularly triptans) within 30–60 minutes of the onset of migraine pain. Early intervention ends the attack more effectively and can help prevent the onset of CA. The same study reported that later intervention was generally unsuccessful in treating CA once it starts.

muscles, periodically shooting a local anesthetic such as lidocaine into the most gnarled sites can relax the muscle and speed relief. The injection itself is unpleasant, but can be made less so by alternating heat and ice at the site and stretching after the immediate pain subsides. Botox, a neurotoxin popular for smoothing age-related wrinkles, is gaining fans as a treatment for severe chronic headache. One course of treatment can last three to four months. Cost and insurance reimbursement vary, as does acceptance of this use of the broadly promoted “vanity” drug.

Non-medicinal approaches

As indicated on the treatment chart, there are a vast number of other strategies used to reduce the impact headache has on function and quality of life. Some are no-cost or low-cost, such as deep breathing and applying cold-heat and ice to the head. Others, like practicing good sleep hygiene, require more discipline or the help of a professional, as with acupuncture or physical therapy. Some people choose to use

these strategies as an adjunct to medications, while others use them in place of a more traditional medical approach.

Either way, the goal should be to reduce the pain associated with the headache as well as its frequency and duration. Avoiding activities, environments or substances that trigger headache is essential. Reducing stress and learning about proper body positioning during periods of rest and work can help the body care for itself. The headache diary (discussed earlier) can be an important tool in identifying patterns and triggers and tracking what helps and what doesn't.

A bright horizon

Progress in understanding and treating headache is occurring faster than ever, thanks to recognition of the significant disability and cost associated with inadequately treated headache and the large and lucrative market for pharmacologic treatments. About half of all people with CFIDS report headache to be a substantial component of their overall symptom complex — for this segment of the patient population improved management of headache can lead to better function and quality of life.

For other PWCs, the strategies used to treat headache may be beneficial in addressing other symptoms — joint and muscle pain, impaired concentration, etc. Both conditions involve a highly individualized approach to treatment, patience and persistence on the part of patient and provider, and constant assessment of treatment successes and failures. With luck, the payoff is reduced suffering and disability until more effective, lasting solutions are available.

Resources:

American Council for Headache Education
1-856-423-0258
www.achenet.org

National Headache Foundation
1-888-NHF-5552
www.headaches.org ■

Your CFIDS Public Policy Report

It was the Lobby Day that wasn't. Perhaps the Lobby Day that wasn't meant to be.

In January, with war looming in Iraq and heightened warnings about possible terrorist action, we grew increasingly concerned that it might be difficult to attract participants to the Association's 12th Lobby Day, planned for March 19–20. The state of "high alert" might also have impacted lawmakers' interest in other, less immediate, issues. After much consideration, the decision was made to reschedule the event for Sept. 17–18 — strategically important because funding decisions for federal programs are generally completed on Sept. 30, the end of the government's fiscal year.

We considered numerous factors when the decision to postpone was made. But the one authority we neglected to consult was the *Farmer's Almanac*. That the new date fell in hurricane season wasn't something we even thought about.

As international tensions and domestic fears eased somewhat, Lobby Day registrations began picking up steam. By the sign-up deadline we had a record number of participants — more than 100 people with CFIDS (PWCs), family and concerned friends.

Media coverage, sparked by PWC Laura Hillenbrand's success as the author of the book-to-movie story of race horse Seabiscuit, helped build excitement for the annual advocacy event.

In September, The Sheridan Group went to work requesting and making appointments for the registrants. Training materials, information packets and logistical plans were prepared. Early reports of a Class 5 hurricane building in the Atlantic were a distant concern. But by Sept. 13 we started hearing from advocates worried that Isabel's predicted path through the Washington, D.C., area might affect travel and could even jeopardize the entire event. Still, it seemed unlikely that the storm would have adequate strength to disrupt a city 100 miles from the ocean. We chose to stick to the plan, scaling numbers back to reflect the cancellations already received.

When training began on Wednesday, Sept. 17, the group was down to half its original size. Those who came were enthusiastic, eager to share their stories and master the congressional requests we'd be making the next day. Weather and cancellation "intelligence" reports filtered into the room, sparking discussion of contingency plans should the government decide to close.

Although tempered with the kind of giddy excitement Southerners feel on a rare snow day, disappointment swept through the room as the group broke for the evening. Those who had traveled long distances and temporarily overcome illness to get there were determined to make the best of it, no matter what.

By 7 p.m. the decision by the rapid transit authority to close the Metro led quickly to an announcement that the federal government would be closed all day Thursday. We worked to contact the people who had attended training and worked with hotel staff to secure a meeting room for the next day.

On Thursday morning a group of 25 advocates gathered to write personal notes to Congressional staffers we would have been meeting with under normal circumstances. Some of us chose to use hotel stationary, underscoring the disappointment of having come to D.C. then lost the opportunity to meet with our elected representatives. One lucky couple from Tennessee found by phone that one dedicated staff member they were scheduled to meet with had gone to work despite the storm, so they headed to the Hill and had a productive meeting with Senator Bill

(continued on page 8)



By Leah
Moseley

Frist's staffer. A casual luncheon at lobbyist Tom Sheridan's home offered more time to socialize and share experiences on a wide range of issues.

Those who participated in the truncated events left feeling cheated by the storm, but positive about the relationships they made or renewed. All departed D.C. committed to contacting their members of Congress at home in district offices and to building relationships with local staff to complement The Sheridan

Group's efforts to follow up on cancelled Lobby Day meetings. Most planned to return in 2004 to try again.

Next year the cicadas are expected to infest Washington, D.C., an every-17-year natural phenomenon. When planning our 13th lobby day we will consult the Farmer's Almanac — and maybe a psychic, too.

Join in the Virtual Lobby Day!

We need you to write to your members of Congress about CFIDS and what the

federal government must do to speed progress. Ideas for how to help, plus Lobby Day materials including talking points and Congressional requests, are available on our Web site at www.cfids.org/advocacy/. Or, call the Resource Line at 704-365-2343 to have a packet mailed to you.

2004 Lobby Day Plans

We'll soon finalize the date and other details for our next Lobby Day. We are considering several dates and venues for early spring. Let us know now if you'd like to receive advance information. Send a message to lobbyday04@cfids.org or call the Resource Line (704-365-2343) and ask to be added to our Lobby Day mailing list.

Appropriations Update

Health funding decisions remain tied up in Congress, stalled by squabbling over bigger issues such as predicted revenue levels and aid to Iraq. We'll continue to monitor the health appropriations bill to ensure that CFIDS-related language and directives clear each step of the process. It's not too late to write or call your elected officials — ask them to support increased funding for CFIDS research. Detailed requests are available at www.cfids.org.

Leah Moseley is Public Relations Coordinator for The CFIDS Association of America. ■

WASHOUT DOESN'T STOP STEINS FROM LOBBYING

For Jonathan Stein, the disappointing decision by the government to close federal offices on Sept. 18 was not enough to douse his commitment to meet with Sen. Arlen Specter (R-Pa.) to share his daughter's story and ask for greater federal resources for CFIDS.

Stein, a Philadelphia legal services attorney, is no stranger to advocacy. He passionately fights bureaucracy, red tape and disinterest every day on his clients' behalf. But because his adult daughter Rachel has been totally disabled by CFIDS for four years, his determination was even greater.

Jonathan began calling and e-mailing Senator Specter's offices in Washington, D.C. and Philadelphia soon after he returned home from Lobby Day. Using materials he obtained at Lobby Day training, he emphasized the magnitude of CFIDS and the need for increased federal funding for CFIDS research. Through persistent follow-up, he and Rachel were invited to meet with Sen. Specter, chairman of the Senate Health and Human Services Appropriations Subcommittee, on Sept. 26.

The meeting was brief but extremely productive. Rachel, a graduate of Yale and Princeton, described the sudden onset of her illness while she was working as a consultant for KPMG. The two gave Specter updated prevalence figures and spoke about the personal and collective economic toll the illness exacts. They asked him to provide leadership on the issue and to insist upon increased spending by the National Institutes of Health (NIH) on CFIDS. They impressed him and earned his commitment to follow up on these requests.

Since the meeting, Sen. Specter's staff has contacted The Sheridan Group to obtain more detailed information. As appropriators meet to determine federal health spending this fall, the Steins' requests will be reflected among Chairman Specter's priorities. His staff will seek information from NIH about current spending levels and the research projects those funds support. And Rachel and her dad will feel a sense of encouragement and empowerment in knowing their efforts made a difference for all those who suffer.

*Activities and opportunities from The CFIDS Association of America***Branding generates response**

An article in the summer 2003 *Chronicle* explored the use of “branding” strategies to elevate awareness and deepen understanding of CFIDS. Questions raised in the article about the name “chronic fatigue syndrome” may have been mistaken for a shift in the Association’s policy on the name change. In 1998 The CFIDS Association of America’s Board of Directors adopted the following policy statement on the name change: “The Association’s Board is solidly committed to facilitating a change from the name ‘chronic fatigue syndrome’ to a name that more accurately describes the illness and leads to greater acceptance of the illness.” This policy continues to guide Association activities related to the name change.

Although the name of a product or cause is an essential element of any branding or education campaign, in the case of renaming CFS, the decision about what to call it must be considered in a broader context. The two processes — building consensus on a name change and developing a public education and advocacy campaign — can occur simultaneously, as long as there is continuous sharing of information to maximize the success of both efforts in enhancing the credibility of

CFS. In fact, when the name is changed, a cohesive education campaign will be paramount to the public’s acceptance and adoption of the new term.

Branding may need some image enhancement of its own. A few readers responded with disdain for the “Madison Avenue spin” approach to expanding awareness. However, a true branding campaign is the antithesis of “spin,” because it seeks to create a positive social context that enables advocacy to create results — not to make temporary adjustments in public perceptions. In the case of CFS, the goal is to create empathetic public awareness for CFS as a means to create changes in public and social policy, public health and private health care treatment.

CFIDS identified as research priority

The National Institute on Disability and Rehabilitation Research (NIDRR), a component of the U.S. Department of Education, has identified CFIDS as an “invitational priority” in its Sept. 25 announcement of \$4.5 million in field-initiated research grants. NIDRR funds research into methods, mechanisms and technologies that maximize disabled persons’ inclusion and integration in social, educational and employment activities.

The Association has been invited to participate in a

Department of Education event to highlight this grant announcement. The department will celebrate PWC Laura Hillenbrand’s accomplishments and feature her inspiring story in its press kit. Laura is not able to be present; her partner Borden Flanagan has been asked to share how they used technology to enable her to research the story of Thoroughbred racing legend Seabiscuit for her best-selling book.

Study leads to Web hits

This summer the Association was a *pro bono* participant in an online survey project conducted by Mindshare Internet Campaigns. As part of a case study, Mindshare created and placed banner ads for the Association and other groups on *The New York Times* Web site. The project sought to test whether proximity to online content affects the likelihood that a user will click on a banner ad for a non-profit group.

Although the results are preliminary, 59 percent of people who clicked on the ad and filled out a survey indicated they had heard of CFIDS and were looking for more information. During the campaign, the Association received one million free impressions on the *Times* site — resulting in increased traffic on the Association’s Web site, www.cfids.org. ■



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

New Committee Convenes After 32-month Wait



By Kim Kenney

In a large conference room tucked away on the Bethesda, Md., campus of the National Institutes of Health (NIH), a new era of CFIDS advocacy was quietly ushered in earlier this fall. Despite a two-year, eight-month wait, there was little fanfare as the new Department of Health and Human Services (DHHS) Chronic Fatigue Syndrome Advisory Committee (CFSAC) convened for the first time.

A handful of people gathered, waiting for the 11 committee members appointed from the public to enter the room and begin the meeting. Next door, appointees were concluding a closed-door session with the General Counsel to learn about the federal regulations that define their advisory roles. Only the placards arranged around the table gave away the committee membership. The sluggish selection process was rushed at the end to ensure that the committee met before the fiscal year ended. It was Sept. 29, 2003 and the feds had beaten the deadline with a day to spare.

The History

For advocates, the meeting marked a dubious victory. In January 2001, when DHHS announced its intent to morph the existing CFS Coordinating

Committee (CFSCC) into a formal advisory committee governed by the Federal Advisory Committee Act, no one expected that it would take nearly three years to assemble the group. The extended transition of the Bush Administration, 9-11, anthrax, SARS and an overhaul of all federal advisory committee slowed the process.

Working with Congress and numerous department staff assigned for brief periods to manage formation of the committee, The CFIDS Association of America made regular inquiries about the status and structure of the new body and repeatedly reinforced the need for continuity, appropriate representation and regaining lost momentum. The advisory committee charter was signed by Secretary Tommy Thompson on Sept. 5, 2002 and the nomination process was announced on Dec. 6, 2002, with nominations due Jan. 31 of this year. The Association nominated 19 advocates, researchers, clinicians and disability experts in an effort to balance broad representation with diverse experience.

The purpose of the CFSAC is to “provide expert advice and recommendations to the Secretary of Health and Human Services on a broad

range of issues and topics pertaining to CFS.” The CFSCC and CFSAC differ in size — 7 appointed members of the public vs. 11 — and in the voting status of the federal representatives. Only public appointees have voting privileges on the CFSAC; it is chaired by a public appointee, whereas the CFSCC was chaired by a federal employee. The CFSAC structure is more consistent with other DHHS advisory committees. Changes were prompted by a June 2000 General Accounting Office report that identified incongruities in federal CFS activities.

Months passed with little more than assurances from the department that the bureaucracy wheels were turning and that our concerns were heard and understood. Verbal pledges to continue the unexpired terms of three CFSCC members and to convene the committee before Sept. 30 were regularly questioned and confirmed. Calls made by the department during the summer months to nominees to explore possible conflicts of interest were a sign that at least there was some forward progress. However, on July 9, I was informed that consideration of my nomination had ended, citing the department’s concern surrounding my dual role of Association CEO and board member and the Association’s perpetual engagement

in public policy activities. Our broader interest in securing the first meeting and appropriate committee membership edged out instincts to delve more deeply into the motivations behind the decision; we elected not to protest.

With some suddenness, a Sept. 29 meeting was publicly announced in the Congressional Daybook on Sept. 17, short-changing the usual 30-day requirement for public notice. I was contacted by Dr. Larry Fields of DHHS and asked to attend and participate as an “invited guest,” but told that the department could not yet announce the committee membership.

Checking in with the Association’s nominees allowed us to identify half of the committee appointees. It also revealed that there would be no carryover from the CFSCC of Dr. Leonard Jason, attorney Jeff Rabin and CFSCC co-chair (and Association board Chairman) Jon Sterling, contrary to assurances made by several different DHHS staff members during the interim period. This news compounded concerns about the hasty scheduling and inadequate time for interested parties to submit public testimony or travel to the meeting; the refusal to release the names of committee appointees or federal ex-officio members; the absence of a stated meeting agenda and

overlap with the Rosh Hashanah holiday. Could a meeting held under these circumstances be productive?

The Inaugural Meeting

After a call to order, brief introductions and some opening remarks from Dr. Fields, NIH’s Dr. Donna Dean presented a historical overview of DHHS’s CFS activities, including the CFS Coordinating Committee for which she served as the last federal chairman.

Agency reports from each of the ex-officio members recounted research and education activities stretching back to early 2001. CDC’s Dr. William Reeves detailed the enormous growth in CDC’s CFS research program made possible by the restoration of \$12.9 million in funds diverted to other programs between 1995 and 1998. He informed the committee about the proteomics and genomics technology being used to find a marker for CFS, a massive clinical study in its final stages in Wichita (see *The CFIDS Chronicle*, winter 2003) and a population study being planned for three distinct geographic regions of Georgia. He reported that for FY2003, CDC will spend \$12 million on CFS – one-tenth of one percent of the annual \$10 billion direct economic loss attributable to CFS, as estimated by CDC.

Dr. Eleanor Hanna of NIH’s Office of Research on

Women’s Health spoke about her efforts to broaden interest in CFS across the campus to reflect the need for a multi-disciplinary approach. She also reported on a June 2003 conference, Neuro-Immune Mechanisms and Chronic Fatigue Syndrome, sponsored by NIH and a Request for Applications that she is working to develop in collaboration with several institutes. Dr. Hanna reported that NIH funding of CFS studies totals \$7.2 million and agreed to provide the committee with a listing of CFS grants and their total budgets at the next meeting.

FDA’s Dr. Cavaille-Coll indicated that FDA currently has applications from pharmaceutical companies for fewer than 20 products in any stage of development for the treatment of CFS. He reminded the committee that federal regulations prohibit him from disclosing any details beyond what the manufacturer has made public.

Dr. William Robinson, chief medical officer for DHHS’s Health Resources and Services Administration (HRSA), expressed his regret that as a result of significant staffing changes and reorganization of programs, HRSA’s participation in collaborative provider education efforts had ceased in 2001. He pledged his renewed commitment to identify ways in

(continued on next page)

CHRONIC FATIGUE SYNDROME ADVISORY COMMITTEE

Voting Members

David S. Bell, MD
CFS Advisory Committee Chairman
Lyndonville, N.Y.

Nancy C. Butler
Dubuque, Iowa

Jane C. Fitzpatrick
Punta Gorda, Fla.

Kenneth Friedman, PhD
Short Hills, N.J.

Nelson Gantz, MD, FACP
Boulder, Colo.

Anthony L. Komaroff, MD
Boston, Mass.

Charles W. Lapp, MD
Charlotte, N.C.

Lyle Lieberman, JD
Miami, Fla.

Nahid Mohaghehpour, PhD
San Francisco, Calif.

Roberto Patarca, MD, PhD
Miami, Fla.

Staci R. Stevens
Ripon, Calif.

Ex-officio members representing federal health agencies:

Eleanor Hanna, MD
National Institutes of Health (NIH)

William Reeves, MD
Dru Barrett, MD
*U.S. Centers for Disease Control &
Prevention (CDC)*

Marc Cavaille-Coll, PhD, MD
Food and Drug Administration (FDA)

William Robinson, MD
*Health Resources and Services
Administration (HRSA)*

William Anderson, MD
Social Security Administration (SSA)

Larry E. Fields, MD, MBA, FACC (*Acting
Executive Secretary*)
*Office of Public Health and Science, Dept.
of Health and Human Services (DHHS)*

which HRSA could augment ongoing efforts.

Reporting for the Social Security Administration, Dr. William Anderson outlined efforts to better serve applicants for disability benefits arising from CFS through the publication of Ruling 99-2p for CFS and education of disability adjudicators as to the disabling features of CFS. He reported on new initiatives to identify severe impairments earlier in the process and to help those who wish to attempt a return to work.

Public comments

Question and answer periods followed each of the agency reports. After a lunch break, I was invited to address the committee to share The CFIDS Association's priorities with the group. I conveyed the importance of this committee to the overall effort to conquer CFIDS, as well as its symbolic importance as a forum for the exchange of information and the discussion of challenging issues confronting CFIDS patients, health care professionals, researchers and policy-makers. I expressed the need to improve the rigor of CFIDS research, attract more scientists to its study, better understand the impact on the body and the individual, meet patients' health care and social service needs and raise the profile of the illness as a serious and

complex public health concern.

After receiving a question about the name change working group I had served on as a member of the CFSCC, Dr. Fields suggested that Carol Lavrich and I provide our report to the committee. Carol, the chairman for the working group which had been convened by the CFSCC, referred to a draft set of recommendations that had been shaped by three years of monthly conference calls, paper and Internet surveys, open meetings at CFS conferences and discussions with advocates, health care professionals, researchers and agency staff. The recommendations called for developing a slightly less restrictive "umbrella" for chronic fatigue syndrome that would include cases that nearly meet the current 1994 "Fukuda" case definition for CFS. The larger construct would be called Neuroendocrine-immune Dysfunction Syndrome (NDS), with subgroups (including CFS and myalgic encephalopathy) falling under the NDS term. Carol asked the committee to endorse the continued efforts of this working group, allowing it time to further refine the recommendations and to hold a session in conjunction with a future CFSAC meeting to explore consequences of a name change on processes like medical coding, private insurance, HMOs, etc. Following discussion by several committee members about the timing of a name change, the

impact of it on definitional and research issues and its general advisability, Committee Chairman Dr. David Bell thanked the working group for its efforts and asked that they provide to him the information collected. He informed the committee that he would summarize it at the next meeting to determine future action.

Two other advocates addressed the committee and a third presented written testimony, read by Dr. Fields. Jill McLaughlin, executive director of the National CFIDS Foundation, presented her top priorities — the name change and recognition of children with CFIDS. Mary Schweitzer, a long-term patient and activist, shared her experience with the experimental drug Ampligen and pleaded for the committee to recognize the poverty that often follows the onset of the illness due to an inability to work and the difficulty of obtaining medical and disability benefits. In her written comments, Wisconsin support group leader Pat Fero asked for greater attention to life threatening conditions that doctors overlook in long-term CFS patients. She requested that the committee “choose to do one thing and do it well.”

As the meeting came to a close, committee members revisited some common themes in an effort to focus

future dialogue on priority matters. The education of health care providers, increased public awareness, expanded research and committee communication mechanisms rose to the top of the working agenda. They agreed that the committee should meet frequently at first and set a target of early December for the next meeting. There was earlier agreement that a Web site and listserv be created to provide information to interested parties and to facilitate sharing between meetings. Dr. Bell made some assignments to members expressing interest in certain topics and adjourned the meeting.

First impressions

Two observers, both of whom had come on behalf of their adult children with CFIDS, felt cautious optimism after the meeting. Sandy Solomon, whose son is ill, expressed early concern: “I was disappointed that The CFIDS Association was not represented on the committee and hope that members will take advantage of Kim Kenney’s offer to be a resource. It was clear from the agency reports and the comments made by the DHHS representatives on the committee that The CFIDS Association has played a significant role, both as a collaborator and advocate, in progress made by the federal government.”

Rick Baldwin, who serves as the Association’s Treasurer, shared his hopes. “There is a lot of ground to cover because of all the new members and the need to catch up after two and a half years of not meeting. I was disappointed that there was such short notice of the meeting, and that this probably contributed to three members not being present. However, I was pleased that the committee recognized the need to meet more frequently than originally expected and to use a listserv to facilitate communication. Hopefully, these actions will help to regain momentum.” Rick’s daughter, Alison, has been ill since 1995.

In all, the session provided a good start for a committee long in the making. The Association remains committed to continued collaboration with the department, federal agencies and the CFS Advisory Committee. It will use the opportunities this committee creates to assess federal efforts, express concerns and make policy recommendations.

Meeting announcements and updates on the committee’s activities will be shared through the Chronicle, the Association’s Web site and the CFIDS Activist listserv. For more information, visit www.cfids.org/advocacy/cfids-activists.asp or send an E-mail message to C-ACTMembership@cfids.org.

Kim Kenney is President and CEO of The CFIDS Association of America. ■

A report on coverage of CFIDS in the mainstream media



People magazine. The Aug. 11 edition included an article on best-selling author Laura Hillenbrand and her battle with a crippling case of CFIDS. The article discusses how Hillenbrand struggled to be diagnosed, includes quotes from Association President & CEO Kim Kenney and contains a sidebar that lists facts about CFIDS and the Association's Web site. *People* has a readership of more than 36 million.

Hispanic community educated. *Vista* magazine, a monthly insert in Sunday newspapers in cities with large Hispanic communities, published an article on CFIDS in its September issue. The article gives a comprehensive overview of the illness including prevalence and diagnosis. It also highlights a few common misconceptions about CFIDS.

CFIDS featured. *Alternative Medicine*, a magazine that offers the latest news and research updates in the fields of complementary medicine and alternative therapies, featured an article on CFIDS in its October issue. The article profiles person with CFIDS (PWC) Carol Sieverling and suggests several complementary treatments for the illness including supplements and herbs, relaxation strategies, bodywork and acupuncture.

PWCs profiled. Author Cara Nissman of *The Boston Herald* profiled several people with CFIDS in the Sept. 7 issue of the newspaper. The article discusses the challenges adolescents face as a PWCs and lists symptoms needed for a proper diagnosis of CFIDS. The CFIDS Association worked with the author, resulting in www.cfids.org being listed as a source for readers as well as a mention about Lobby Day.

USA Today. The Aug. 4 edition featured an article detailing Laura Hillenbrand's 16-year battle with CFIDS. The article's author quotes several CFIDS experts, including Dr. Eleanor Hanna from the National Institutes of Health (NIH) and Nancy Klimas from the University of Miami, and discusses how researchers are still working to solve the mystery of the debilitating illness.

Des Moines local profiled. The Aug. 18 edition of the *Des Moines Register* published an article profiling 27-year-old PWC Jacob Parsons. The article gives a thorough overview of the illness and details the difficulty in diagnosing CFIDS.

CFIDS on CNN. CFIDS was featured on the Aug. 9 edition of CNN's Saturday Morning News, a weekend news program that provides

an in-depth look at the most prominent news of the week. The call-in segment featured an interactive conversation with several medical experts to help answer viewer questions about CFIDS.

CDC study. The Aug. 12 edition of *The Wichita Eagle* featured an article on how Wichita residents are helping the U.S. Centers for Disease Control and Prevention (CDC) study CFIDS. About 250 Sedgwick County residents, half of whom have CFIDS, have participated in the study that originated in 1997. The article reports the most recent study of those individuals will assess whether gene profiles, sleep characteristics, stress history or other measurable factors contribute to CFIDS.

Symposia feature update. In late February, the Association released a camera-ready article to local newspapers across the United States through the North American Precis Syndicate (NAPS). The article, based on three research symposia held in 2000 and 2001 and sponsored by the Association, highlights consensus conclusions reached by researchers and scientists on problems that play a role in CFIDS. So far, it has generated coverage in more than 212 newspapers in 15 different states with a readership of more than 4.5 million. ■

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

Sinusitis, CFIDS linked

A Georgetown University professor has discovered a possible link between CFIDS and common sinusitis, two conditions that have never before been associated with each other.

In the August 11 issue of *Archives of Internal Medicine*, Alexander C. Chester, MD, outlines a study he conducted with 297 patients in his general internal medicine practice. Sixty-five patients (22 percent) had unexplained chronic fatigue, while 11 percent presented with unexplained chronic pain and nine percent presented with both conditions.

These ratios are not uncommon in general practice. But Dr. Chester also found that sinus symptoms were nine times more likely to occur in patients with unexplained fatigue and six times more likely in patients with unexplained chronic pain. The association with unexplained fatigue and sinusitis also was stronger than the association between sinusitis and other types of fatigue that could be explained by physical or mental conditions.

Of the 65 patients with unexplained chronic fatigue, 15 met the criteria for CFIDS. The majority of these patients had sinus symptoms. In addition, many of the CFIDS patients said they had a sudden onset of their condition, which often occurs in patients with sinusitis.

Dr. Chester says it's too early to speculate on the reason the two conditions appear linked. But he says people with CFIDS should be checked for treatable sinus symptoms.

"While sinusitis will not be the answer for everyone who comes to an internist with unexplained fatigue or pain, this study does suggest that it should be considered as a part of a patient's medical evaluation," Dr. Chester said.

Mycoplasma debate continues

CFIDS researchers have long disagreed about the role that infections by a group of bacteria called mycoplasmas may play in the development or symptomology of the illness. In fact, there's debate about whether mycoplasma strains are even present in the tissue of people with CFIDS (PWCs) in unusual numbers.

Newly published research does little to quell the debate. Studies appearing in *The Journal of Chronic Fatigue Syndrome* and the Scandinavian journal *APMIS*, both authored by the same research team, found that the blood of more than half of PWCs tested were infected by one of four mycoplasma species.

But in a letter to the *British Journal of Medical Microbiology*, researchers from the U.S. Centers for Disease Control and Prevention (CDC) present findings that indicate no

unusual amount of mycoplasma infections in PWCs. The researchers used blood collected during CDC's large-scale CFIDS population study of the residents in Wichita, Kansas (see related *Chronicle* article, winter 2003). The CDC authors argue that their detection methods, which employ DNA sequencing, produces more reliable results than the polymerase chain reaction (PCR) assays used in previous studies.

NIH funds mono study

A five-year, \$2.6 million study funded by the National Institutes of Health (NIH) will examine the relationship between mononucleosis and the development of CFIDS in about 400 Chicago-area teenagers.

No direct link has been made between mono and CFS. But many people with CFIDS report an attack of mono or another infectious condition prior to the onset of their illness.

Renee Taylor, PhD, of the University of Illinois-Chicago, says the study will give her and other researchers a rare chance to study CFIDS cases before they even start. "We can look at patients before they develop CFIDS, at the stage where they've just developed an infection, and then follow them over a two-year period to determine what characteristics of these mono patients...may lead to the development of post-infectious CFIDS," Taylor said. ■



Chronicle Q&A

Fixing the “brain sprain” of CFIDS

By Mark
Giuliucci

Eric R. Braverman, MD, believes that an integrative approach is the key to successfully treating CFIDS. His practice, *The Place for Achieving Total Health (PATH Medical)*, utilizes a wide range of alternative and complementary therapies — in addition to Western medical techniques and drugs — as part of its treatment protocol. In this edition of the *Chronicle Q&A*, Dr. Braverman outlines some of his unconventional beliefs about the care of people with CFIDS.

Q. In your opinion, what causes CFIDS?

A. Fatigue is a multi-factorial problem. Chronic fatigue syndrome patients come here with a very rich history. They may have had Lyme disease in the past, or Epstein-Barr virus — but it’s not uncommon for people to come in with past head trauma, or having undergone chemotherapy. I’ve had patients with infections of unknown origin, or with borreliosis (diseases, such as Lyme, caused by spirochetes), Q fever, you name it. I have treated every rare, treatment-resistant condition imaginable. And fatigue is commonly part of that picture.

The key, however, is that it doesn’t really matter that much what happened in the past. The key is what’s going on now in the patient’s brain. The brains of chronic fatigue patients don’t make enough dopamine (a neurotransmitter, similar to serotonin) — and this is what causes the problem.

People end up looking for a direct cause. But in most cases, the infection or trauma or immune episode is gone, no longer active. What patients are left with are residual effects. MRIs or CAT scans come out normal, and the patients are told that it’s all in their heads. But MRIs don’t show anything useful.

Q. What’s wrong with MRIs and CAT scans?

A. They’re anatomy tests. If a person comes to you and says, “I have three arms,” all you have to do is look at them and count the arms. That’s all you get with an MRI. It’s an internal anatomy look.

Most disorders of the brain are functional. You get no value from an MRI in that respect. What’s revealing is the function of the brain, the speed of the brain, the energy of the brain. The sleep cycle, the rhythm.

That’s why we do a procedure called the BEAM (Brain Electrical Activity Mapping). It takes about 40 minutes. Basically you put a cap with electrodes on the head of a patient and you stress the brain. It’s kind of like a cardiac stress test. The BEAM gives us a functional look at how your brain is working. We can see how you respond to different stimuli, and compare that to how a typical brain responds. This gives a much better picture of what’s really going on, and how we can treat the problems.

Brain health check-ups are the cornerstone of our practice. We have discovered a lot about fatigue this way. We think that fatigue, for instance, is why a lot of people use cocaine. It’s the same for overuse of caffeine in working men, and for nicotine use and other stimulants. Fatigue is really a very multi-factorial diagnosis. But, as I’ve said, while chronic fatigue has a lot of etiologies, the etiology is not as important as the repair. I don’t need to know that to fix people.

Q. So how do you fix people with CFIDS?

A. Here’s an analogy for you. When you sprain a leg, you treat it in several different, synergistic ways. You put ice on it. You elevate it. You do some physical rehab. And maybe you treat the pain with medication.

Chronic fatigue is a sprained brain. In all cases. It’s a sprained brain that gets rehabbed

with electrical therapy, massage therapies like chiropractic, relaxation therapies, adequate sleep, proper sleep. You add in neuro-rehabilitative approaches including hormones, nutrients, lifestyle changes. It's multi-modal human repair.

Every program is different, but we match them all to the four great areas. The first is the brain and brain chemistry. Each patient has a brain print, so to speak, based on the BEAM results. There are also psychological needs, and emotional needs, that have to be met. Plus, heavy metals and toxins need to be removed.

Number two is the hormonal state. If a woman is in perimenopause, for instance, she may need progesterone. That could be contributing to fatigue. She may be missing estrogen. A man might be missing testosterone. Both could be missing growth hormone.

Third, you match it to their nutritional state. Better diet. Nutritional supplements, amino acids, whatever it takes to make them whole nutritionally.

Finally, conventional medicine can bail people out. This is generally a short-term fix, whatever they need immediately. But sometimes people are very broken. Sometimes people are like Humpty Dumpty, and they need medication to hold them together. In that case, they can be on medication the rest of their lives.

Q. What works best?

A. I can say that dopamine agents, stimulants, are the single most effective agents in dealing with chronic fatigue. Also amino acids, tyrosine and phenylalanine. Hormones are essential. And conventional drugs, from antidepressants like Wellbutrin and Effexor to the mega-drugs like Provigil, and drugs like Ritalin.

How long they stay on these treatments depends on how well they heal. Remember, it's a brain rehab program, just like someone would rehab a sprained leg. You immobilize it and treat it until it's working OK on its own.

Q. How is compliance with your program?

A. We ask people to do a lot more than just

take a pill. Compliance is a challenge. A physician has to be his patient's therapist. You have to deal with people's emotions.

Probably 80 percent of what a doctor knows will help patients, what will improve them, is not complied with. My success is when I can connect with a person. Building rapport is successful. We have to convince them that what we're doing is going to work — but only if they'll follow the program.

Q. Why do you feel that your approach works?

A. It's integrative. It's multi-disciplined. It doesn't stop at taking a pill.

When I interviewed at Harvard Medical School 23 years ago, the interviewer rejected me. He said that nutrition had no role in health care. He said that the EPA was right when it said that lead wasn't toxic to children. Since then, I've seen the FDA, the EPA, Harvard Medical School — all the so-called geniuses of 23 years ago — admit that they were wrong. These things do play a role in health and well-being.

American medicine makes a bundle on specialization. The economic niche of promoting overall well-being for citizens was lost. That's what we have returned to, and that's why our integrative approach has been successful in chronic fatigue and many other conditions.

PATH Medical has offices in New York City, greater Philadelphia and New Jersey. For more information, visit www.pathmed.com, or call (212) 213-6155.

The CFIDS Association of America does not endorse any products, claims or practices mentioned in the Chronicle's Alternative and Complementary Therapies features. ■

Tips, strategies, ideas and helpful thoughts about CFIDS**Shopping with sunglasses**

Here's a tip for those who are able to go shopping but still find it extremely draining. When I go to the mall, Wal-Mart or any other large store I wear my sunglasses and only take them off when I'm looking at the specific item I want to buy.

I find this cuts down on the "sensory overload" that makes our fatigue so much worse. Shopping isn't nearly as much fun as it was pre-CFIDS, but this enables me to do at least some.

Mary Ann Tricsko Sotero
Florida

Supplements for IBS

I have irritable bowel syndrome (IBS) in addition to CFIDS. I have found relief by using supplements and changing my dietary habits. I maintain a gluten-free diet and ingest a high-potency "good bacteria" supplement. I also avoid processed foods and white sugar whenever possible. In addition, I consume a number of "power foods" including Spirulina (a high-protein algae), Noni juice (a medicinal tropical fruit), high-quality whey protein, flax seeds and plenty of fresh fruits and vegetables.

I also use some licorice root in my tea to help keep my blood pressure up. I season my food with oils such as olive, coconut, flax, hemp, etc., and avoid hydrogenated fats.

Char Tara Albert

High-salt for OI

I have orthostatic intolerance (OI), which causes lightheadedness and many other problems. I have found that a high-salt diet helps improve my symptoms. My doctor tells me that the extra salt in my system increases the volume of blood — and that helps my body regulate my blood pressure better.

You can try salt tablets, but I find it best to eat healthy high-sodium foods like vegetable juice or even a little pickle juice.

Mary Frederick
New York

Editor's note: High-salt diets should be discussed with your doctor.

PREVENTING PRESSURE SORES

People with severe cases of CFIDS are at increased risk of developing pressure sores, also known as bed sores. They are painful and can lead to serious infections — but with a little prevention, they can usually be avoided.

The Tissue Viability Society, based in Great Britain, offers these tips:

Pressure sores can be caused by sitting in one position for a long time. If you can get up briefly, even for a few minutes an hour, do so. If you must remain in bed, change positions every one or two hours. You can use pillows to redistribute your weight away from bony areas like your hips. If you're sitting in a chair, try to rock from one buttock to the other for short periods of time.

When you're moving in bed or a chair, try not to drag your skin across the fabric. You also can try special tools, such as a pressure-relieving mattress, mattress overlay or cushions designed to distribute your weight more evenly. Changing bed sheets on a regular basis is highly recommended, especially if you are sweaty.

Make sure you drink plenty of water to keep your body hydrated and at lower risk for sores. If you notice that parts of your body feel numb, or become darkened or reddened (especially if the area stays red when you press it), you may be developing a sore. Take special care to keep your weight off the area.

If you think you have a pressure sore, contact your doctor immediately.

— The editor

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

Holiday Happiness: A Guide for PWCs

By
Sharon
Clem

For people with CFIDS, the holidays can sometime seem like just one more hurdle to clamber over. But if you plan ahead, you can save energy, money and time, lower your stress level — and enjoy the season much more.

Christmas will always be different than what it was before you got sick. Try not to compare how much better everything was in the past, but focus on what's good about this year's celebration and the things you can still do.

Here are some tips to help you unplug the Christmas Machine and make everything more manageable:

Take a hard look at family traditions and discard those you don't want to (or can't) continue doing. Don't let false guilt make you endure things that just aren't fun, appropriate, necessary, meaningful or affordable.

Learn to say "no" to activities and people that are "life-takers" rather than life-givers. If a family member is highly critical of CFIDS, limit exposure to him or her as much as possible. Choose to be around those who love and support you instead. That's the whole idea of the holidays, anyway.

Carefully pace yourself. Before you do anything else, write down all activities on your calendar/date book — including wrapping, shopping, parties and scheduled rest time. Stay within your energy envelope by doing only half of what you have energy for so you won't relapse.

Eliminate and simplify as much as possible. I used to bake oodles of goodies the whole month of December. Now I just make one special dessert for Christmas dinner and buy other treats at the bakery if I need them.

Delegate tasks to family members or friends. Send them to do some shopping with ads from the newspaper. Have them address envelopes or decorate. No one said that women — *especially* those with CFIDS — have to do everything that's done for Christmas.

Go to only those parties that you really want or need to attend. Allow yourself a set amount of time, perhaps an hour or so, then say your good-byes. That way, you can enjoy your time and keep your energy for another day. To keep from becoming tongue-tied, think of some topics of conversation ahead of time. Eat wholesome food before you go so you'll have some energy. Avoid alcohol and sugar because CFIDS patients don't tolerate them well. Rest all day before going and schedule a day or two afterwards to rest.

Don't try to visit everyone in your family on Christmas Day. For example, have one of the get-togethers the Sunday before. In the old days, we visited my in-laws at 8:30 a.m. to open presents, then dashed to another relative's home for breakfast and more presents. We returned to the first house for dinner, to be followed by a visit to a different family for more festivities, finally dragging home about 8–9 p.m. Stop! That's too much!

Spend wisely and you'll save money that you need for the other 364 days.

Try drawing names from a hat so that you're not required to buy gifts for everyone. Or give gifts only to children. Buy practical, useful gifts; don't splurge on gag gifts. Begin shopping several months early to take advantage of sales (make sure you save receipts in case someone needs to return a gift). Do not feel pressured to keep up with others' spending, because they will not be paying your credit card bills for you.

Have your children make a list of everything they want, in order of importance. Buy the first three or four things on it. If a friend or relative asks you what your child wants, give them something from farther down the list.

Send cards to out-of-town friends only, and purchase them when they're on sale. Recycle old cards into post cards for next year — the postage is less.

(continued on next page)

Use Sunday comics in place of expensive wrapping paper. Buy spools of yarn or ribbon to make your own bows. And be sure to save and re-use bows you receive on your presents next year.

Buy a few decorations on sale after the holidays. You'll have a couple of new pieces for next year, and you won't have to break the bank. Going out the day after Christmas is not a good idea, however; the crowds and traffic can be very difficult to handle. There will still be plenty on sale a day or two later.

You can make decorations yourself — or embellish those you already have with a new ribbons, glitter, sequins or gold paint. String popcorn for garland. Cut fresh greenery from trees in your yard (or ask the Christmas tree salesman for a few pieces he cuts off the bottom of his trees). You can make these boughs into wreaths, centerpieces of decorations for your mantel. Fill a pretty bowl with bright red apples or fresh lemons, and garnish with a sprig of evergreen.

Take advantage of catalogue and Internet shopping. You can save lots of time, energy —

and money — if you buy gifts this way. You also could adopt a year-round buying strategy. If you see something that would make a great holiday gift, buy it and save it until Christmas. That will even out your spending, and keep you from buying gifts that are too expensive or not exactly what you want just because you have to buy *something*.

Remember that Christmas is basically an American and Western European celebration. Most people in the world don't observe it, so keep things in perspective.

And if your holiday doesn't turn out as perfectly as you had hoped it would, remember that others in the world don't have it as good as you. When I focus on that, my own disappointments don't seem so painful.

I hope this gets you started on the road to a happier and more satisfying Christmas. Feel free to come up with your own ideas and new traditions, and discard those that didn't interest you or work for you.

Most of all, Happy Holidays!

Sharon Clem lives in Tennessee. ■

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

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Travel with CFIDS: Plan first, and the sky's the limit

I took my first trip to a foreign country when I was 16, and knew immediately that I had been bitten by the travel bug. I loved the thrill of seeing someplace I had never been before. I took another trip after high school and spent my junior year of college living in southern France, spending every vacation and long weekend traveling to wherever I could afford. I knew that life after college would be full of trips to all parts of the world, as many and as often as my budget would allow.

But when I was 23 I became ill with what was eventually diagnosed as CFIDS and fibromyalgia. The first couple of years were so debilitating I couldn't imagine traveling around the block, much less a foreign country. My plans for seeing the world, like most of the plans for my life, would have to wait.

After a few years, my symptoms had improved a bit, and had stabilized. More importantly, my husband Paul and I had learned how to adapt and manage things from one day to the next.

I don't remember exactly how the idea of traveling to France got started, but once it did, it was hard to stop. We thought about waiting, but wait for what? A cure? Were we supposed to make a list of Things to Do Once CFIDS Is Gone? It didn't seem right to keep putting our lives on hold. I was doing better than I had been in the past. Airfare was cheap, and the dollar was strong. We were fortunate to have the financial resources to travel. We talked about it in depth, made lists of the pros and cons, and finally crossed our fingers and bought two tickets to Paris.

The planning that followed probably seemed, to most people without CFIDS, excessive bordering on obsessive. We decided to go to the town where I had lived in college — it was familiar, and it was number one on Paul's list of places to see. As I checked over my old maps and worked on a manageable

itinerary, Paul took a crash course in French. I had been fluent when I lived there, but all of my cognitive abilities had been seriously impacted by CFIDS. In case my language skills failed me, Paul needed to know the basics, including how to get me to a doctor, in case of a serious problem.

Needless to say, traveling with CFIDS is not quite like traveling was before I got sick. The days of taking off on a moment's notice are certainly gone for good. But traveling with CFIDS is possible, and enjoyable. Following are some of the things that have made our travels abroad easier:

Be realistic. You almost certainly won't be able to do as much in a day as you have in the past. Traditional travel itineraries or pre-packaged tours are going to be out of the question. Try to assess what you can handle, and plan accordingly. Be your own advocate: request wheelchair service for the airports and special meals on the plane if you need them. Trying to forget about CFIDS while you're on vacation will only make things worse.

Prepare and plan. Books, videos, the Internet, all can give you a good idea of what is available to see and do at your destination. You can familiarize yourself with the layout of the town, landmarks, methods of transportation, currency and basic language skills all before you leave home. I like to photocopy and enlarge sections of maps and use colored highlighters to mark out how to get from one place

(continued on next page)

By Heather
Duncan-
Whiteman



to another. Whatever makes sense to you and eases your confusion and stress, do it.

Meet with your doctor. Discuss emergency contact information and get instructions on how to handle symptom changes. Also discuss any medications you may be on, including how to handle dosing while changing time zones. Check customs regulations for carrying drugs in and out of the country, and remember to take extra doses of everything, in case you get delayed returning home. It is best not to rely on purchasing medications while abroad, since many prescriptions and over-the-counter drugs are classified differently in other countries. Also check with your health insurance provider so you know what to do in case you require medical attention during your trip.

Be good to your body. Much has been written about how to beat jet lag, but usually the best thing to do is to get as much rest as possible on the flight and immediately set your daily schedule to local time. Even if you normally take a nap during the day, do not give in to the temptation on your first day in your new time zone. Jet lag can also be made worse by dehydration, so drink plenty of water before, during and after the flight. Keep your arrival day's activities simple, have a good dinner and make it an early night.

Speaking of food, if you are sensitive to dietary changes you may want to make a note of American chain restaurants or "American-style" eateries in your destination city. In most places you can find simple, relatively

bland meals somewhere on the menu, and local grocery stores are a great source of simple foods you are probably accustomed to.

After checking into my hotel, my first stop in a city is the local market to pick up ginger ale for any stomach upsets and yogurt to keep my system in balance. And don't forget the trip back home. For your body, coming home is a second round of jet lag, dietary changes and new daily routines. Give yourself time to re-adjust.

Expect the unexpected. Flights get delayed or cancelled, luggage gets lost, ankles sprain, flu can run rampant. The stress of having something unforeseen happen on your vacation is unpleasant for most, but is especially difficult for someone with a chronic illness. The more you plan and prepare, and the more you can keep your sense of humor, the more easily you can handle any surprises that may occur. Hopefully you will never need the number for the U.S. embassy or the address of the English-speaking hospital, but having them at your disposal will be hugely comforting.

Happily, our trip went pretty smoothly, and we had a wonderful time. I did experience some worsening of my symptoms, during the trip and particularly after we had returned home. For me though, it was worth it. I had found a way to reconnect with a part of myself that I thought I had lost forever. The world was still out there, and I could still go out and see it.

For our next trip Paul and I are going to Scandinavia with my mom. She and I have talked about going for as long as I can remember, to see where my grandma lived before she came to America. We always talked about it in terms of "someday". Last year for Christmas Paul and I bought a travel book for her and language tapes for ourselves. If all goes well, we'll travel sometime in the next two years. After all, what are we waiting for?

Heather Duncan-Whiteman lives in New York state. ■

BELATED THANKS

The CFIDS Association of America would like to recognize Mr. Timothy Hrehocik, a donor who was inadvertently left out of the Association's 2002 Annual Report. Mr. Hrehocik is a member of the Chairman's Circle and a Pacesetter donor. Our thanks to him and all donors.

Your guide to published resources

Handbook of Chronic Fatigue Syndrome

Edited by Leonard A. Jason, Patricia A. Fennell and Renee R. Taylor, 2003, John Wiley & Sons, Inc., \$90, 794 pp.

Written by a virtual Who's Who of CFIDS researchers, clinicians and patients, the Handbook touches on every aspect of the CFIDS experience — from assessment, treatment and symptomatology to patient perspectives. While it does not break new ground in terms of research or patient care, the book serves as a comprehensive primer. Although it's written with health-care professionals in mind, astute lay readers should find the *Handbook* an enlightening guide.

If You Would Just Get Out of Bed: My Life with Chronic Fatigue Syndrome

By Stephanie Kelly
2003, KK Bell LLC \$12.95,
<http://www.ifyouwouldjust.com>

This book starts with a victory — the author's wedding day. And it ends with hopeful words from a person who has learned to cope with the illness that has dogged her for nearly 20 years. In between lay the personal tales familiar to so many people with CFIDS — the daily struggles to accomplish the smallest tasks, the insensitive comments of people unfamil-

iar with the toll CFIDS exacts, the lingering doubts if life will ever improve.

Kelly's message is realistic but upbeat. "My internal battle is quieting, and my soul and spirit are winning more often," Kelly writes. "...whether it is in sickness or health, I look forward to every day."

Previously published book reviews and a list of online books are available

on *The CFIDS Association of America's Web site*. Click on <http://www.cfids.org/about-cfids/book-list.asp>. ■



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

**THE CFIDS BOOKSHELF
BY DOROTHY WALL**

The list of books written by people with CFIDS (PWCs) about their experience is growing rapidly, particularly as electronic formats and self-publishing become easier. This is a list of a few of the best books by PWCs published by major publishers. Not how-to-cope or informational books, these are stories and investigations that take readers inside the CFIDS world, the illness, the politics, the day-to-day struggles.

Floyd Skloot, *In the Shadow of Memory* (University of Nebraska, 2003). Like his previous work, *The Night Side: Chronic Fatigue Syndrome and the Illness Experience*, this is a collection of award-winning essays and poems, personal, moving and humorous, giving a graphic account of how CFIDS impacts a life.

Susan Griffin, *What Her Body Thought: A Journey into the Shadows* (Harper San Francisco, 1999). Griffin confronts economic, social and philosophical aspects of illness in a ruminative, interwoven tale of her experience with CFIDS, her childhood memories, her journal entries, and the story of Marie Duplessis, popularized as the fictional Camille, a 19th-century courtesan who died of tuberculosis.

Lynn Sharon Schwartz, *The Fatigue Artist* (New York: Simon and Schuster). The only novel written about CFIDS, this is a stellar book by an acclaimed novelist that paints the CFIDS experience with humor and honesty.

Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996). Written by a PWC, this book explores how our culture defines and understands disability, the way the authority of the medical establishment shapes the illness experience, and how we can both embrace and transcend the body that suffers.

Dorothy Wall is co-author of Finding Your Writer's Voice: A Guide to Creative Fiction (St. Martin's Press), and is completing a collection of essays about CFIDS.

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



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

The CFIDS Association of America assumes no responsibility for content. Send notices to The CFIDS Chronicle at chronicle@cfids.org or mail to PO Box 220398, Charlotte, NC 28222-0398.

INFORMATION NEEDED

Patients and/or physicians who have found a suitable replacement for the recently withdrawn medication Kutapressin are asked to e-mail their information to capt_h2o@yahoo.com. Data on acceptable substitutes will be shared with members of the Co-Cure online listserv. To join Co-Cure, go to <http://www.co-cure.org/sub.htm>.

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 angelseverywhere100@msn.com.

Author Donna Delaney is looking for contributors who are able to fight CFIDS with occasional humor and laughter.

If you think chocolate is a health food because it grows on a green plant, send in your anecdotes. Only the positive should apply! Send e-mail to donna_delaney@hotmail.com, or write to 230 Spencer Landing West, LaPorte, TX 77571.

Contributions requested for a new book describing what CFIDS actually feels like through the words and pictures of sufferers. All prose, photos and artwork considered. For guidelines and submission form see www.geocities.com/mecfsbook, or send a note and self-addressed reply envelope (with international postage) to: CFS Contributions, 18 Bishops Way, Buckden, Huntingdon, Cambs, PE195TZ, UK.

RESOURCES

A free online mailing list is available to PWCs who want to explore alternative treatments, energy work and the effects of positive thinking on healing. Sign up at: <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, contacts Renee Dahlen at 1032 15th St. NE, Mason City, IA 50421, or write to reneejoel@netconx.net.

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. One visit to Stony Brook Hospital is 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.

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

For the latest nationwide listing of patient conferences, please visit the Association's Web site at www.cfids.org and click on the What's New icon. ■

WHAT IS CFIDS?

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

HOW IS CFIDS DIAGNOSED?

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

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

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

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

HOW IS CFIDS TREATED?

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

some of the symptoms which can be relieved through the use of prescription drugs, over-the-counter medications and other interventions such as physical therapy. 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.

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

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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