

THE CFIDS CHRONICLE

Advocacy,
information, research
and encouragement
for the CFIDS
community

SUMMER 2003 ■ VOLUME 16 ISSUE 3

The “Branding” of CFIDS *Working to change the way the world views us*

Call it public awareness. Education. Marketing. Public relations. Aside from a cure, it's what people with CFIDS (PWCs) say they want most. They want CFIDS to be discussed with the same “respect” associated with cancer or heart disease or multiple sclerosis. They want relief from the burden of having an illness that is widely misunderstood, regularly diminished and frequently derided. They want credibility. Understanding. Acceptance. Empathy.

By Kim
Kenney

The situation is improving. The unbridled success of author Laura Hillenbrand's account of 1930s racehorse Seabiscuit has brought her a high degree of public visibility. She has responsibly used the spotlight to share her own against-all-odds story of the 16-year battle she's waged with CFIDS. Articles about her fight in *The New Yorker* magazine, *Newsweek*, *Smithsonian*, *USA Today*, *The Washington Post* and numerous other publications, complemented by appearances on “20/20” and hundreds of radio programs, are making an impact on how the public views the illness.

And cutting-edge research, led by scientists at the Centers for Disease Control and Prevention (CDC), is illuminating the subtle, sophisticated

interplay of abnormalities in the immune, neuroendocrine and central nervous systems that may explain the perplexing syndrome. Provider

education efforts are reaching health care professionals; they report greater confidence in making a CFIDS diagnosis, but tremendous frustration with the present health care system that makes managing chronic illness a tormenting challenge for patients and providers.

Still, on a personal level it takes just one insensitive remark to reduce this sense of progress to despair. Offhand comments like, “I'm tired all the time too — I must have that,” remind us how far we still have to go.

The name game

In 1988, the original case definition was published, coining the term “chronic fatigue syndrome” (CFS) and providing criteria by which to evaluate possible CFS cases for research purposes. Soon after, PWCs launched efforts to rename the illness. They objected to the singular focus on fatigue,

SEABISCUIT SCREENING A SMASH



ESPN's Tony Kornheiser and author Laura Hillenbrand at The CFIDS Association's special screening of *Seabiscuit*. See p. 18 for story and photos.

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THE CFIDS CHRONICLE

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of America
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SUBMISSIONS: *The CFIDS Chronicle* is interested in articles, stories, book reviews and other materials on topics of interest to people with chronic fatigue and immune dysfunction syndrome (CFIDS), their friends, families and supporters, clinicians and researchers. Submissions are reviewed by the editorial staff and may be edited for content, clarity and space. Publication guidelines can be obtained from the editor. Send submissions ATTN: Editor to the address above. You can also send articles direct to mgiuliucci@cfids.org in a Windows-compatible word processor file. Include your name, address, daytime and evening telephone numbers, fax number and e-mail address (if available). If possible, please include a Windows formatted disk with your article saved in a Windows-compatible word processor or ASCII text file. It is the policy of The CFIDS Association of America **not** to pay for articles published in the *Chronicle*.

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

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

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

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

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

For more information on chronic fatigue and immune dysfunction syndrome (CFIDS) or to view a copy of our IRS 990 form, visit our Web site, www.cfids.org. 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

Back in the saddle, back in the race

Sixty-five years ago, a knock-kneed racehorse and his ragtag handlers took on the world’s greatest thoroughbred in a match race that ended with...well, you’ve heard the story by now.

The tale of Seabiscuit has captured America’s heart this summer — and provided the CFIDS community with the rarest of opportunities: A chance to be heard on the national stage. Laura Hillenbrand, author of the best-selling book about Seabiscuit that became a major motion picture, has told millions of television viewers, magazine readers and radio listeners about the toll CFIDS exacts on her and so many others.

For years, people with CFIDS have been seeking

a credible voice, a champion for the cause. It’s unfair to ask Hillenbrand to assume that role, no matter how eloquent and sincere she may be; after all, she is afflicted with an illness so severe that she had to write much of “Seabiscuit” lying flat on her back with her eyes closed.

But her efforts have given us a badly needed jump-start. The momentum is there. For the first time in years, there’s a genuine sense of hope that public opinion can be swayed, that politicians and scientists and other decision-makers can be persuaded that CFIDS is an illness worth fighting full force.

The Seabiscuit phenomenon also dovetails with the branding concept that’s discussed in this issue’s cover

story. To become a “branded” illness, CFIDS must work its way into the nation’s permanent vocabulary, just as “MS” or “Lou Gehrig’s Disease” or “Alzheimer’s” have in the past. It’s a long-term project, built through repetition, recall and relentless work. Seabiscuit and Laura Hillenbrand won’t do the trick for us by themselves. But they have put us back in the race, given us a shot.

It’s up to the CFIDS community to grab the reins and run.



Kim Kenney
President & CEO, The
CFIDS Association of America



Correspondence with the Chronicle editor



By Craig
Maupin

Commentary: Missing the Point in Moorestown

It is spring of 2003, and Moorestown, N.J., school superintendent Paul Kadri's phone is buzzing. Coming across loud and clear are the voices of parents who believe their children did not receive a fair shake in their quest to be valedictorian at Moorestown High School. As the pressure mounted, Kadri would soon come to a decision: senior Blair Hornstine, whose GPA was the highest in the class, had an easier road to valedictorian than her classmates. Kadri decided that Hornstine, who took some of her classes at home due to a disability that appears to be CFIDS, should share the honor with others whom he felt had traveled a tougher road.

The Harvard-bound Hornstine had other ideas. She made a decision of her own, one that brought the wrath of the small, upper-class community crashing down on her. She wouldn't share the title. She would sue the school to have her title reinstated — and sue for discrimination as well.

In the weeks that followed, the normally tranquil Moorestown erupted. Newspaper columns decried Hornstine's action. Locals blasted her for selfishness. Harvard students and alumni circulated a petition to have

her admission denied for fears that she would ethically compromise their school. Eggs were thrown at Hornstine's house, obscenities spray-painted on the walls. Charges of plagiarism against Hornstine appeared in the local paper.

Perhaps the polite thing for Hornstine to do would have been to share her title. But while Hornstine may not have come across as charitable, pursuant speculation about the underlying cause(s) of the public indignation toward Hornstine was the true catalyst behind the story's national appeal.

An Oft-Unseen Perspective

Nothing about the furor surprised me. Unlike many of the folks in Moorestown and Harvard, I know CFIDS well. My career, education and personal goals have been indefinitely put on hold because of it.

It also didn't surprise me that the CFIDS community failed to come to Blair's defense. Many of us, myself included, cannot attend school in any form due to the physical limitations imposed on them. Stir into those particulars a lawsuit that was widely perceived as selfish, and this controversy understandably

becomes something many with CFIDS would just as soon avoid.

I think back to my own experiences with CFIDS. I remember the day I first got the "flu." Like any successful, athletic teenager, I didn't take it seriously. But within three months tests confirmed my stomach was unable to digest food. I lost 30 pounds. My grades slipped. One spring day of my senior year, I called my mother with tears in my eyes and said, "I cannot go on."

I remember my father encouraging me; he said my dreams for my life would materialize. They never have. I remember a teacher informing me that if I did not show up in her class I would be flunked, despite a schedule that had been worked out with the assistance of my doctor, parents and school administrators. I remember the sadness I felt when I learned my illness' name would be changed from chronic Epstein-Barr to the benignly broad term chronic fatigue syndrome.

While those who suffer from other chronic illnesses often receive an outpouring of community and family support, those with CFIDS sometimes receive an outpouring of scrutiny and disbelief. With a trivializing name headlining

the illness, many form their impressions quickly — and even the most skillful media consultant could do little to shift them.

A letter to the editor in the Moorestown paper asks: “How can Hornstine even consider herself part of the class when she doesn’t have to take physical education or deal with the everyday rigors of high school because of her chronic fatigue syndrome?”

A proud Harvard Law student adds: “Disability? We probably ALL have chronic fatigue back in good old Cambridge, MA. Welcome to the life of every over-stressed and under-slept student on campus.”

That’s a small taste of what makes life with CFIDS different. Many at Harvard and in Moorestown came to the conclusion that my illness is somehow the “easier road” or opportunistic pretense. These statements reveal that CFIDS isn’t only a physical nightmare. It is so much more.

A voice of reason

An opinion issued by U.S. District Court Judge Freda L. Wilson was perhaps the only piece of analysis to rise above the fray. She delivered the most concise and sane commentary on the episode yet: “...I want to make clear that the evidence in this case has

shown that Ms. Hornstine earned her distinction as the top student in her class in spite of, not because of, her disability.

“[The school, parents and community]...adopted the assumption that somehow the plaintiff’s disability and accommodations have given her an academic advantage over other students. They have lost sight of the fact that plaintiff, unlike her peers, suffers from a debilitating medical condition.”

What if we had removed CFIDS from whole episode in Moorestown and replaced it with a racial profile, a religious belief or another chronic illness? Would the furor, the controversy and the scrutiny have been replaced with compassion, understanding and benefit of the doubt? I can only wonder.

While a town and university community is embroiled in a perceived defense of the universal ideals of charity, I can only feel sadness. I cannot imagine much progress coming against the illness that struck me down until public attitudes toward CFIDS change. Perhaps a proposed name change will help. But maybe it will take a look below the surface of a name, to the devastating illness that lies underneath. Above all of the cries for sharing, caring and fairness, this is the only

point I took from the debacle in Moorestown.

Blair Hornstine’s case is a microcosm of a larger problem. Beyond a girl’s unwillingness to share her academic honor, and a town’s zeal to adjust the rules, is an unseen perspective. Most people missed the point in Moorestown. But for those of us with CFIDS, it’s simply a new twist on an old story: The continued lack of public respect for an illness that has cost us all so dearly.

Craig Maupin can be reached by e-mail at editor@cfidsreport.com. ■

THE CHRONICLE HOT TOPIC: YOUR TURN TO SPEAK OUT

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

“When your CFIDS symptoms flare, what gets you through the day?”

Send your responses to: The CFIDS Association of America, P.O. Box 220398, Charlotte, NC 28222-0398, Attention: *Chronicle* Hot Topic. You also can send your thoughts to us online at chronicle@cfids.org.

The “Branding” of CFIDS

(continued from front cover)

a common symptom and an imprecise term. Despite the rapid introduction of the alternative “chronic fatigue and immune dysfunction syndrome” (CFIDS) and perpetual promotion of the historical term “myalgic encephalomyelitis” (ME), the term CFS has persisted — and so has the loathing it inspires.

A name change working group convened three years ago by the U.S. Department of Health and Human Services (DHHS) has surveyed patients and providers, held discussion sessions at research conferences and surveyed the literature, all in hopes of establishing consensus for a new term that reflects the wishes of the patient community and can be supported by objective evidence. Their recommendations have stalled while waiting for a broader DHHS advisory committee for CFS to be assembled. Members of the working group have settled on a new term — “neuroendocrineimmune dysfunction syndrome,” or NDS — to describe a condition slightly broader than the one identified by the current CFS definition. But working group members recognize that without a serious and sustained public education campaign to announce the change, the cumbersome term for the larger “umbrella” classification of illness may never be fully adopted.

A new approach?

Creating a distinct image through the choice and promotion of a name is the daily work of professionals who engage in a select type of marketing known as “branding”. Now common corporate practice, branding is increasingly being used by not-for-profits and other institutions to change societal views and, ultimately, individual behavior.

The patronizing, preachy approach of public health campaigns like “Just Say No” is being replaced by clever, pop culture-driven messages that appeal to a more media-savvy public. CDC has used a campaign called “VERB” (www.verbnow.com) to encourage kids to engage in more physical activity, in hopes of

curbing the epidemic of obesity and Type II diabetes in young people. *TheTruth.com* uses gritty urban images and shocking statistics to turn people against “big tobacco” and tobacco use.

Branding engages people in an unexpected way; it creates a unique space in the consumer’s mind for a product, service or issue. As a brand, “chronic fatigue syndrome” has little going for it. The word “chronic” suggests whininess. “Fatigue” is an everyday experience in our overscheduled world. “Syndrome” seems to say “not quite a disease,” at best. Images of unfulfilled, neurotic housewives and burned-out professionals linger, even though the term “yuppie flu” is rarely used these days. The lack of scientific consensus, the absence of a diagnostic test and the difficulty of trial-and-error symptomatic treatment may be more closely identified with the term than any of the abnormalities supported by the research literature.

Building a memorable brand

Brand development forces discussion about strategic priorities and direction. The process requires research-based decision making, broad participation across multiple stakeholder audiences and formation of strategic partnerships to implement strategies. It also requires the investment of considerable intellectual and financial resources, over many months.

Branding involves more than choosing just a catchy name or pleasing logo. Credible and consistent messages, accompanied by one or more distinctive visual images, must be repeated over time and in a variety of venues. With branding, you must determine not only what facts you wish to convey, but the emotions you would like to invoke and the actions you want people to take. This specialized approach cuts across many dimensions of understanding.

Strategic decisions

The brand chronic fatigue syndrome, while problematic for many reasons, still carries with it some recognizability. When companies evaluate a particular product or service brand, they conduct research to determine whether it is more effective to launch a different brand or to

“re-brand” an existing one. There is merit to exploring this topic with regard to chronic fatigue syndrome, to ensure that our assumptions about what the broader public “thinks” about chronic fatigue syndrome are accurate.

The outcome of this market research may suggest a new name (e.g., NDS), an alteration to the existing name (for example, branding “CFS” rather than chronic fatigue syndrome) or maintaining the existing name, but changing perceptions about it. It’s important that every effort be made to transfer value in the existing brand to the new one, while minimizing negative “baggage” that may persist independent from the name itself (see box).

Feasible? Worthy?

The CFIDS Association of America has been investigating the merits, strengths and drawbacks of employing branding strategies to deepen understanding about CFS. We have consulted with branding professionals, with public health educators experienced in the use of branding and with patient advocates. The opportunities such a campaign would enable are very exciting. It is a multi-faceted approach to addressing nearly all the issues raised in the context of a name change, although setting realistic expectations for the impact of the campaign is an important part of planning, too.

We’re interested in your thoughts. What messages would you like to send to the general public, to the medical community, to the media? Is there any “value” to be preserved from the name “chronic fatigue syndrome”? Can branding strategies help raise awareness, educate and improve credibility? What can the general public do to help those with CFIDS? Share your thoughts by e-mailing them to branding@cfids.org or by writing to us at the address on the inside front cover.

Making the case

On paper, CFIDS certainly warrants more broadly based and vigorous efforts to understand, treat and prevent it. A study published in the July 14, 2003 issue of *Archives of Internal Medicine* makes the case well. CFIDS is

JUST ANOTHER ACRONYM?

Our lives and our language are filled with acronyms and other forms of verbal shorthand. IRS, MBA, SARS, e-mail and Y2K are just a few examples of how a few letters come to replace many. In the lexicon of disease, long, complicated medical terms are often represented the same way. Some acronyms become so entrenched that the words they represent are all but forgotten. Think ALS for amyelotropic lateral sclerosis, also known as “Lou Gehrig’s disease.” Even AIDS is regularly used without any reference to Acquired Immune Deficiency Syndrome.

CFS, on its own, is rather innocuous. The phrase it represents is more problematic; people with the illness consistently protest against inclusion of the word “fatigue” — the community’s own version of the “f” word.

But, if chronic fatigue syndrome is supplanted by neuroendocrineimmune dysfunction syndrome and NDS becomes the phrase commonly used, how much do we gain? Is NDS a more valuable brand than CFS?

among the most prevalent chronic illnesses of our time, affecting approximately 800,000 U.S. adults and an unknown number of adolescents and children. The vast majority of those who would meet the strict research definition for the illness don’t have a name for the poor health and reduced function they endure; this report indicates that 80 percent of those with CFS have not been diagnosed. An earlier study from DePaul University placed the figure at 90 percent. And soon, CDC will report the direct economic impact of CFS. Estimates approach \$10 billion a year, even without including the cost of medical care or disability benefits.

CFIDS is a big problem — for individuals, for our medical care system, for our economy and for our nation. Whether we can marshal adequate resources to improve recognition of all the ways in which CFIDS impacts our lives remains to be seen. Branding offers a new approach to addressing problems we have wrestled for almost two decades. With the heightened visibility of the illness brought by Laura Hillenbrand and *Seabiscuit*, there may never be a better time to try it. Just as in horse racing, the stakes are high and the risks are real. But in the credibility contest, the rewards are great too.

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

Don't Derail Your Disability: Tips for Winning Your Insurance Claim



By Ben
Glass

Dealing with CFIDS is challenging enough without the additional stress of fighting a disability insurance company. Many workers are insured under policies that are supposed to provide financial protection in the event that they cannot work full-time in their current occupations. But a great number of these claims are denied — not because the claimant is not disabled, but because either the claimant or her doctor made a preventable error when dealing with the insurance company.

Here are six common mistakes, and tips on how to avoid them:

Mistake #1 **Not knowing what is in your doctors' records before you make your claim**

Insurance companies will only pay benefits if they are convinced that your medical records contain adequate, objective proof of disability. As soon as you file your claim, these companies will request records from your doctors (and from any doctors referenced in those records) and carefully scrutinize them. You must get these records in your hands before you file your claim. Review them yourself. Are they accurate? Are they complete? Has the doctor recorded all of your complaints?

In one case, an insurance company denied benefits because included in the records sent by the doctor were the records of another person! Those records said “all is well” and the insurance company relied on those records. The claimant never knew that the files her doctor sent had someone else's records in them because she didn't get her doctor's records first. It was only after she hired a lawyer and sued the insurance company that she discovered this.

Mistake #2

Not understanding your policy before you file your claim

Insurance policies are notoriously hard to understand. You should obtain and review your policy before you file your claim. If your policy is an employer-sponsored policy, you should obtain both the Summary Plan Description (SPD) and the insurance policy itself before you file your claim. The Employee Retirement Income Security Act (ERISA) requires that these documents be made available to you upon written request to the employer's plan administrator. If you have a private policy and cannot locate it, call your agent. You can obtain a replacement policy (usually for a small fee) from your insurance company. Whether you have an employer-sponsored plan or a private policy, make sure you obtain and read all amendments and endorsements to the policy. It's also an excellent idea to review the plan with a qualified attorney prior to filing, to avoid costly mistakes.

Mistake #3

Trusting the advice of the H.R. department

Oftentimes employees have been taught to take all questions about benefits, including long-term disability benefits, to the Human Resources department. This well-meaning advice can be fatal to your claim if the advice you get is wrong. We don't suggest that your employer would deliberately mislead you, but our experience tells us that (1) most human resources personnel are not legally trained in the interpretation of insurance policies; and (2) human resources staffers generally have no pull whatsoever with the insurance company.

Again — unless the employer is actually funding the monthly benefits (and this is a rare occasion) — it is the insurance company that is protecting its own assets. Our experience, based upon reviewing many insurance claim files, is

that no amount of pleading by your employer will influence an insurance company that wants to deny benefits to you. You need to take personal responsibility for your own claim.

Mistake #4

Using only insurance company forms to document your claim

When you make a claim for benefits, the insurance company will send claim forms for you and your physician to complete. Typically, the physician forms will have questions such as: “How much can this person lift? How long can he sit? Can she walk long distances?” These questions are irrelevant to many CFIDS claims. The doctor will dutifully answer the questions the insurance company asks, but later the insurance company will say that those answers just weren’t enough information.

You should sit down with your doctor (after having fully reviewed your own records), explain the terms of your policy and get your doctor to set out fully in a report why your sickness or illness prevents you from performing the substantial and material duties of your occupation. The doctor may charge you for this report. Pay the charges! It is far better to have a well-documented claim from the beginning than to have to go back, after you have been denied benefits, and justify your claim. Also, if you have been denied benefits and are appealing your claim, you and your doctor will have a limited time (as defined in your policy) within which to submit additional reports. Why be under time pressure when all of this work can be done before you ever submit your claim?

Mistake #5

Using the insurance company’s lawyers to file for Social Security

If the disability insurance company pays you long-term benefits, you will usually be required to file for Social Security benefits. If you win your case, you typically will be required to reimburse the insurance company, and further benefits will be reduced by the amount of the Social Security payment. If

your dependents receive Social Security benefits because of your disability, your payments will also be reduced.

Many insurance companies will offer you the services of their lawyers (or an affiliated law firm) to file for and pursue your Social Security benefits. Don’t use them. We have seen too many instances where these lawyers have steered the claim towards a disability that is favorable towards the insurance company — for example, a mental condition that limits the insurance company’s payments to two years.

We have also seen situations where an insurance company lawyer who is representing a claimant in Social Security proceedings quits the case because the disability insurance company decides to terminate your benefits anyway.

Mistake #6

Not hiring a lawyer experienced in disability insurance litigation

A new client told me recently that “you guys are hard to find.” I asked him what he meant and he told me that he had searched for a long time before he found an attorney who specializes in disability income insurance litigation. Unfortunately, there are just not many of us out there.

Litigation of a long-term disability insurance claim is different from litigation of an automobile accident claim. It is different from many other contract claims. The world of insurance dispute litigation has its own body of case law, history, procedure and terminology. Your attorney should know, before the case begins, what you will need to prove in order to win your case. You should look for an attorney experienced in disability litigation.

Ben Glass is an attorney in Fairfax, Va., who has represented individuals against insurance companies for 20 years. This article is excerpted from his booklet, “14 Ways to Guarantee that Your Long Term Disability Claim is Denied, and You Lose in Court (avoid them and you may have a chance at winning).” The complete booklet, which contains examples and documents from actual cases, is available for free by calling 800-561-1670, ext. 320. ■

Activities and opportunities from The CFIDS Association of America**Annual report available**

Last year was arguably the most difficult in a decade for The CFIDS Association of America. At a time when the organization found itself stronger and more capable than ever to advance its mission of conquering CFIDS, the weakened economy and national uncertainty hit the Association hard. Across the charitable sector, donors reflected the mood; they made smaller gifts and sometimes postponed planned gifts and annual contributions.

We are grateful, however, that many of our supporters continued to make the Association one of their top philanthropic priorities.

As you review the pages of the 2002 Annual Report, we hope you will share our enthusiasm about what we accomplished in a year when we were tested to do more with less. We will move forward buoyed by the potential we have to bring remarkable progress to people with CFIDS. For a copy call 704-365-2343 or read it online at <http://www.cfids.org/about/2002-ar.pdf>.

Web site has new look

On June 30th the Association launched its newly redesigned Web site. The revised site has added a special section for medical professionals as well as a new community area for patients seeking

support and other resources. Please visit www.cfids.org and send your comments to webmaster@cfids.org.

“Seabiscuit” hats and shirts available

Visit <http://www.horsehats.com/seabiscuit-cfids.html> and purchase a “Seabiscuit” hat or sweatshirt to commemorate the release of the movie. A portion of the purchase price of each item sold will go to the Association to help support our efforts in CFIDS education, public policy and research. The Association would like to extend special thanks to HorseHats owner, Dave Williams, for his generosity and interest in CFIDS.

CAA joins Congress on Women’s Health

The Association joined the 11th Annual Congress on Women’s Health as a collaborating organization. The Congress, presented by the *Journal of Women’s Health* and held May 31–June 3 in Hilton Head, S.C., allowed the Association an opportunity to introduce itself as a source of timely and pertinent information on CFIDS to a national audience of physicians, nurses and leaders in the field of women’s health.

Other collaborating organizations included the Arthritis Foundation, The Lupus Foundation of America and

the National Women’s Health Resource Center.

Meetings on the Hill

On May 13–14, Leah Moseley, public relations coordinator for the Association, and Mary Beth Buchholz of The Sheridan Group met in Washington with freshman members of Congress and key appropriators of the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. A total of 10 meetings were held to discuss CFIDS and federal agency response from the National Institutes of Health, the Centers for Disease Control and Prevention and the Department of Health and Human Services.

Offices visited included Senator John Ensign, R-Nev.; Rep. Kendrick Meek, D-Fla.; Rep. Ernest Istook, R-Okla.; Sen. Elizabeth Dole, R-N.C.; and Rep. Bill Young, R-Fla..

On September 17-18, CFIDS advocates from across the country will unite to meet with representatives on the Hill to again discuss CFIDS and how the illness has impacted their lives. There’s still time to join us for Lobby Day. For more information, visit the Association Web site at <http://www.cfids.org/advocacy/lobby-day.asp>, or call the Association’s Resource Line at 704-365-2343. ■

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

Dr. John Stewart

The CFIDS community lost a compassionate ally this summer when Dr. John Stewart died after a fall at his home.

Dr. Stewart worked at the U.S. Centers for Disease Control and Prevention (CDC) for more than 40 years. For half his tenure, he served as Chief of the Virology Section, Viral Exanthems and Herpesvirus Branch, Division of Viral and Rickettsial Diseases at the CDC's National Center for Infectious Diseases (NCID). In this capacity, he helped lead study of the causes, impact and treatment of numerous diseases — including Epstein-Barr virus and CFIDS.

Dr. Stewart was a friend of The CFIDS Association of America. Terri Lupton, the Association's coordinator for educational opportunities, remembers him as a "determined advocate" whose open-minded approach to studying CFIDS led to greater understanding of the illness. His dedication and kindness will be missed.

NIH conference on CFIDS

On June 12–13, a hundred researchers and program staff gathered for a National Institutes of Health (NIH) conference on Neuro-Immune Mechanisms and CFS. The meeting, supported by the NIH Office of Research on Women's Health and the

Trans-NIH Working Group for Research on CFS, brought together senior investigators from areas with relevance to CFS and CFS experts. The agenda was designed to shed light on promising avenues of research, based on progress in other disciplines.

Dr. Vivian Pinn, director of the Office of Research on Women's Health, announced that NIH would use the meeting to craft a Request for Applications (RFA) for CFS research, a high visibility solicitation due to the availability of designated funds for successful applications. NIH will issue a meeting summary, followed by full proceedings late this year. The RFA will be a joint effort of several NIH institutes and will take several months to draft, revise and approve.

Disability workshop

The Interagency Commit-

tee on Disability Research (ICDR) held a stakeholders meeting on June 26 in Washington, D.C. to gather input on future federally funded disability research. Kim Kenney represented The CFIDS Association at this session, as one of 40 invited participants from a wide range of disability organizations.

Discussion focused on the use of assistive technologies to enhance disabled persons' abilities to engage in employment, education, health care and their communities. Assistive technology is defined as anything that improves function, from eye-glasses to specially equipped laptop computers to lightweight collapsible wheelchairs.

The mission of the ICDR is to promote coordination and cooperation among federal departments and agencies conducting rehabilitation research programs. ■



I Had My Gift Matched — You Should Too!

With the help of my employer, my \$100 donation to The CFIDS Association of America was doubled to \$200.

Matching gifts can make that happen!

Although many people with CFIDS are no longer able to work, you can still take advantage of the power of matching gifts. Ask your spouse, family members and friends to participate in their companies' matching gift programs. Anyone who makes a contribution to the Association may be able to have it doubled if they work for a company that sponsors a matching gift program.

To find out if a business participates in a matching gift program, ask the company's human resources office or contact the Association's development office at 704-364-0466 or development@cfids.org. We have details on thousands of companies with matching gift programs.

Q&A: Leonard Jason, PhD

Finding the true face of CFIDS



Leonard Jason, PhD, is among the most prolific of all CFIDS researchers. For more than a decade, Jason and his team at DePaul University's Center for Community Research have

worked to define the scope and impact of CFIDS worldwide. In recognition of his contribution to the CFIDS community, Jason received the Dutch ME-Foundation International ME-Award for 2003 for outstanding work in the past 10 years in the field of chronic fatigue syndrome (CFS). The award came with a prize of 5,000 Euros as well as specially commissioned piece of artwork by Marika Meershoek.

Q: How did you get involved in CFS research?

A: In the early 1990s, Judy Richman, a sociologist at the University of Illinois–Chicago, and I began discussing the prevalence data for CFS (then believed to be about 4–9 cases per 100,000 people), which suggested that CFS was a relatively rare disorder that affected primarily white, middle-class, women. When we looked closely at the way the data were collected, we realized that there were serious methodological problems with this research.

The epidemiological studies derived their samples from physician referrals in hospital and community-based clinics. These studies under-represented low-income and under-served minorities, people who manifest higher levels of chronic illness while also being less likely to have access to the health care system — and who are thus less likely to be counted in prevalence rates derived from treatment sources.

These studies also underestimated the prevalence of CFS in the general population

because they depended on diagnoses by health-care providers who discounted the existence of the illness and would thus fail to diagnose it.

Q. How did you go about finding the real prevalence figures?

A: We began our work in this area in 1991. In our first epidemiology study, we directly surveyed nurses. Out of a sample of 3,400, 202 nurses (6 percent) indicated that they had experienced debilitating fatigue for six months or longer. Thirty-seven nurses met case criteria for current CFS, yielding a prevalence rate of 1,088 per 100,000.

In 1993, we collected pilot data for the presence of CFS in a random community sample of 1,031 people (with funding from The CFIDS Association of America). Sixty-four percent of the fatigued group indicated that they had no current medical doctor overseeing their illness. The DePaul University research team found a prevalence rate of 200 per 100,000, a number higher than one would have expected, given rates from past epidemiological studies.

After many efforts to get funding, we finally were successful in obtaining a National Institutes of Health (NIH) grant. From 1995 until 1998, we attempted to contact a sample of 28,673 households in Chicago by telephone. Of that sample, 18,675 individuals were screened for CFS symptomatology. The sample was stratified to ensure that it reflected the diverse ethnic and socioeconomic groups comprising the Chicago general population.

Approximately 420 per 100,000 of the sample were determined to have CFS, and rates of CFS were higher among Latino and African-American respondents when compared to white respondents. These data suggested that there might be as many as 800,000 adults in the U.S. with this syndrome, suggesting that it is one of the more common chronic health conditions. Data were also collected for youth, and

the findings indicated a CFS prevalence of .06 percent, or 60 cases per 100,000.

Q: Epidemiological studies are not always seen as “sexy” by a patient community eager for treatments and a cure. Why are they so important?

A: Quite simply, if there are few cases of CFS in the population, it is more difficult to generate funds for research and treatment. Without funding, progress is difficult if not impossible. It’s easier to make the case for funding when you’re dealing with a patient population of 800,000 people than it is when you’re talking about a rare disorder affecting a fraction of that figure.

Epidemiological studies also aid the design of other research. The better we know the patient population, the better the overall science will be. Most existing prevalence studies have had poor sampling plans and systematic biases that excluded certain people (i.e., studies were conducted in medical settings, so that they likely excluded people of lower socioeconomic status and people of color who were less likely to have access to health care). In addition, there is a vital need to examine the incidence and course of CFS over time, particularly in random, community-based, multi-ethnic populations.

A recent technical report issued by the Agency for Healthcare Research and Quality (Defining and Managing Chronic Fatigue Syndrome, 2001) concluded that estimates of recovery/improvement or relapse from CFS are not possible because there are so few natural history studies and those that are available have involved selected referral populations. This report recommended that there was a need for studies to properly determine the long-term natural history of CFS. This report clearly indicated the need to conduct epidemiologic studies that provide estimates of CFS incidence in community-based samples, and to identify risk factors for prognosis and onset of CFS in socioeconomically diverse samples.

Q: What is your research team focusing on now?

A: We believe that the most important work

that is now needed in the field is to develop sub-types within the CFS population, and our research group is currently working on this topic.

Individuals with CFS have been found to differ with respect to many characteristics. As a result of this heterogeneity, findings emerging from studies in a number of areas are, at best, discrepant, and at worst, contradictory. Heterogeneity among participant groups can also contribute to a lack of observable abnormalities in some laboratory studies.

One central, methodological explanation for observations of discrepant findings across studies involves issues related to sampling and participant selection. A majority of investigations have employed non-random, medically-referred samples. There probably are different types of illnesses now contained within the CFS construct, which makes it even more difficult to identify commonalities in all people with this diagnosis.

Q: Other than funding and better study design, what does the CFS research field need most?

A: Given the prevalence and seriousness of this disorder, there is a clear need for advocacy, in which the general public and the medical community become better educated about the problems and difficulties associated with CFS.

Some patients with CFS need assistance from others in order to complete daily living tasks, while others need basic medical services and housing. Unfortunately, there are few funding opportunities for these more innovative types of social and community interventions. Given that this syndrome is one of the more common chronic health conditions, and the documented personal and familial costs associated with this condition, there is a clear need for public policy officials to devote more resources to developing a better infrastructure of support for individuals with CFS.

Dr. Jason is co-author of the new “Handbook of Chronic Fatigue Syndrome” (Jason, Patricia A. Fennell, Renee R. Taylor; 2003; John Wiley & Sons). It is available through Amazon.com and bookstores. ■

Your CFIDS Public Policy Report

By Jamie
Davis

CFS committee denied key leader

In 1996, Donna Shalala, then Secretary for the Department of Health and Human Services (DHHS), chartered the DHHS CFS Coordinating Committee (CFSCC) — the first federal committee dedicated to CFS. Kim Kenney, The CFIDS Association's president and CEO, was one of seven members of the public appointed to the committee. She served a four-year term, extended by DHHS until February 2002.

The CFIDS Association was instrumental in building support for the formation and maintenance of the Coordinating Committee. A 2001 report from the General Accounting Office, a congressional accountability agency, found that the CFSCC's structure was not in full compliance with the Federal Advisory Committee Act. The Association launched efforts to restructure the CFSCC to expand the number of non-federal members, limit voting privileges to the non-feds and to provide for a non-federal committee chairman. These changes would make the CFSCC more like other DHHS advisory committees.

With support from the current administration, a charter for a new committee was signed and nominations for committee members, seven

researchers and four others with broader professional experience (disability experts, patient advocates, medical professionals, etc.), were solicited. The Association submitted 19 nomination packages, among them one for Kenney, who had satisfied the required one-year break in service.

The Sheridan Group and the Association carefully monitored sluggish progress and met regularly with key DHHS officials charged with evaluating nominees and creating an initial charge to and agenda for the committee. In doing so, we balanced persistence with patience, as installation of a new administration, 9-11, bioterrorism, SARS and other crises dominated the attention of DHHS staff.

In July, Dr. Larry Fields from DHHS contacted Kenney to clarify her role within the Association. A few days later, Fields informed Kenney that her position as chief executive officer posed concerns about potential conflict of interest. He stated that the department's general counsel would not support her appointment to the committee and that she had been removed from further consideration.

Their decision is, of course, a great personal disappointment for Kenney, but it is also a great loss for the CFIDS community. When the committee finally meets for the first

time (probably late this year), she will not be able to share her unmatched command of scientific and policy issues, and perhaps as important, her understanding of the various federal health agencies and federal funding processes.

The Association remains committed to ensuring that the new committee reflects the appropriate experience and representation of all stakeholders in CFIDS issues. Two members of the Association's Board, chairman Jon Sterling and Joe Lane, remain in consideration as appointees to the committee. Both would serve admirably, as would the other people nominated to the committee by the Association. We are also making inquiries to ensure that the decision by DHHS is consistently applied to the CFS committee and other advisory bodies.

Lobby Day

The Association is gearing up for our 12th annual Lobby Day, to be held in Washington, D.C. on Sept. 18, with mandatory participant training on Sept. 17. We welcome all advocates — PWCs, family, friends — to participate in this empowering event. For more information or to register, send an email message to: lobbyday03@cfids.org, or call the Resource Line at 704-364-2343. Please make plans to join us on the Hill! ■

Snapshots OF CFIDS

A SPECIAL SUPPLEMENT TO THE CFIDS CHRONICLE • SUMMER 2003



Ghost Life

By Christina Gombar

I am a ghost. I walk beside you. You may have seen me in the supermarket, on a park bench, standing in line next to you at the library. But I am not really in the world.

I am still on the organizational chart at the company where I used to work, though my desk has been turned over to someone else. My name still appears in the address books of friends, though they no longer call. A van with tinted windows parks across the street and runs a camera on my house, and trails me on my errands to report back to my employer. But this is happening less and less. As time goes on, I am growing more invisible.

They say that ghosts wreak havoc because the spirits don't understand they are dead. This is how I feel. I have had some version of CFIDS since I was 31, but it took nearly a decade to progress to the point where I had to drop out of the world — stop working, shut down my social life, put all plans for the future on hold.

When that devastating attack came, I didn't quite understand what had happened. I had long forced myself to function while sick — get out of bed before daylight and dress, ride the train into New York and my job at a large mid-town financial firm. My condition was hidden under full makeup, business attire and my determination to lead a normal life.

Yet I often sat through management meetings with all the appearance of professionalism, but all the intelligence of a department store dummy. I have an image of a headless horseman, still going

about trying to function, wandering the aisles of the grocery store, furious that they had rearranged the shelves, wondering when someone had broken into my car and changed the control panel, why the world had moved up ten speeds.



Christina Gombar

I Didn't Know I Was Sick

I had lost my first job to CFIDS eight years earlier. After suffering a severe attack of the Epstein-Barr virus, which is sometimes but not always a precursor of CFIDS, I was fired from my Wall Street job. I could no longer perform many of my duties — rapidly read, process and respond to information, do financial calculations and juggle the myriad tasks of a public relations manager. I had not been diagnosed with CFIDS. My doctor at the time was of the old school — he didn't believe in any illness he hadn't learned about in med school back in the 1940s. So I had no idea what was happening.

It is terrifying to lose your health and consequently, your ability to earn a living, when you are barely past 30. For years after being fired, I lived ill and nearly destitute in New York, often able to do only very low-paying, mindless work. I could not afford good health insurance, which might have helped me find out what was wrong.

Through a course of trial and error that included elimination diets, yoga and other

(continued on next page)

moderate exercise, acupuncture and quiet living, my health slowly improved to the point where I felt I was at sixty percent of my original strength. Four years after the first attack, I landed a full-time job at a company where I was freelancing. I knew a full schedule would likely floor me, but part-time jobs don't come with benefits. I was 35 and still harbored the same dreams as everyone else — a baby and a real home.

Don't Ask, Don't Tell

I was torn over telling prospective employers about a health condition I didn't really understand myself. If I'd told them I was disabled, they wouldn't have hired me. Predictably, I began to get sick almost as soon as I started. Though I was one of the top writers in my department, my math and logic skills were gone — I couldn't balance the simplest of budgets.

Strangely enough, it was my boss at the time, who had a friend similarly affected, who recognized the pattern of illness and referred me to a doctor who specializes in treating people with symptoms like mine. Five full years into this altered state, I was saddled with the unfortunate label of "chronic fatigue syndrome". The doctor respected my wish to work, and tried to keep me going with a course of treatments that ranged from dietary changes to vitamin therapy to herbal remedies and prescription drugs. Everything helped incrementally; none of it could forestall my eventual collapse.

After little more than three years, during which time I had many humiliating and painful stints home on short-term disability, I got so sick that my employer would not even take me back. Since then my brain has been affected to the point where I have trouble doing basic things — driving, paying bills, writing down a phone number correctly, shopping and errands. If I overdo in any way — meaning just trying to do the normal things people do apart from their jobs — I can be completely immobilized for weeks at a time.

The Disability Dilemma

I would like to have a career again, but am trapped by the disability system. My doctors and lawyers advise I do nothing to endanger my

company's comprehensive medical benefits. Remembering the terror of being poor and ill, I must agree. I was a published writer and author long before I got sick, and would like to be so again, but the terms of my company's disability policy say I cannot accept any payment, and therefore cannot even try to re-establish a writing career based from home.

I've depleted my savings, sold my home and relocated to a cheaper part of the country. Away from my New York specialist, I've had trouble finding doctors who even believe in CFIDS, let alone know how to treat it. Now the private insurance provided by my employer may be farmed out to another company which simply doesn't believe in the illness. Surveillance is a constant threat: if I am well enough to brush my teeth myself, they reason, I ought to be working at a factory. If I am well enough to get my mail, I ought to be working a 40-hour week.

Casualties of Illness

CFIDS has taken almost everything. I studied hard, established a career, paid off student loans and was just trying to pull it together to have a family. CFIDS killed all these dreams. It is theft not only of health, but of friendships, marriages, prosperity and the basic of sense of security and predictability others take for granted.

My best hope is research for a cure, or at least effective treatment like that which partly tamed the AIDS epidemic. This only happened after a huge push for research and education. Unfortunately, the huge stigma once attached to AIDS still belongs to CFIDS.

I wish I had a rosier picture to paint of life with this condition. All I can say is I haven't given up. I am determined to find a way to be financially independent again, whether or not the illness is completely cured. New friends will have to take me or leave me as I am.

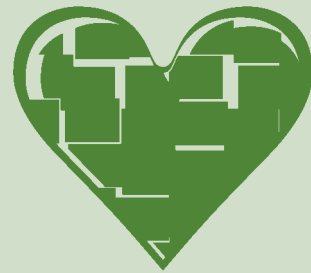
One part of my life is over — jobs, friends, goals. The other hasn't really started yet. Until a cure is found, I remain in limbo. A Ghost.

Christina Gombar lives in Rhode Island. ■

Orthostatic Intolerance

My grieving heart
 Lost in disability
 Longing, crying, reaching
 Weary body slumped in a wheelchair
 Heart racing and arrhythmic when I stand
 Warm nurse hands place a warmed blanket over me
 Another heart monitor shows dips, double-beats, rectangles
 My husband sighs, settling in his chair for the familiar wait
 The doctor finally comes, chart in hand
 “Nothing shows on the test
 Must be anxiety”
 Eyebrows raised in surprise
 “But I collapsed and couldn’t get up”
 “Should I carry her to the car?” my husband moans
 “Nothing wrong with you, go home”
 Frustrated, lost, denied
 My broken heart

Anna B. Wilder
Arizona



By Julian Lake. Reprinted with permission from “The Chronic Fatigue Syndrome Follies” (Rubicon Media). Available online @ <http://hhv6.freeservers.com>.

Expectations

It is said the stage only mirrors life.

Is that why we act hurt
when presented with our shortcomings?

If we are satisfied
to be just workers in the vineyard,

Then we should occasionally
expect sour grapes.

C. Eric Hellmann
Ohio

Reprinted from “Among the Reeds”
 (Writers Club Press, 2001)

Soul Powers

Disabled: To make useless. *Useless.*

I am not disabled. I am fighting a bizarre, cyclical, invisible illness, yes. Every day, every minute, is a struggle, yes. But useless? Never.

I am able to do things no one else in this world can.

I am able to show incomparable love to a five-year-old boy, and he in turn is able to show his very own take on beauty and magic to those in his life. I enchant him with stories about ladybugs and fairy castles and what makes a child special. I entertain him by coloring magic houses with stained glass windows, towers, purple paint and a garden containing trees and ponds, with the occasional turtle and cat thrown in for good measure.

I am able to create comfort and splendor on a limited budget, nesting in my bedroom with paper lanterns, purple holiday lights and silk flowers, the flow of my water fountain providing a soothing background for my spiritual home.

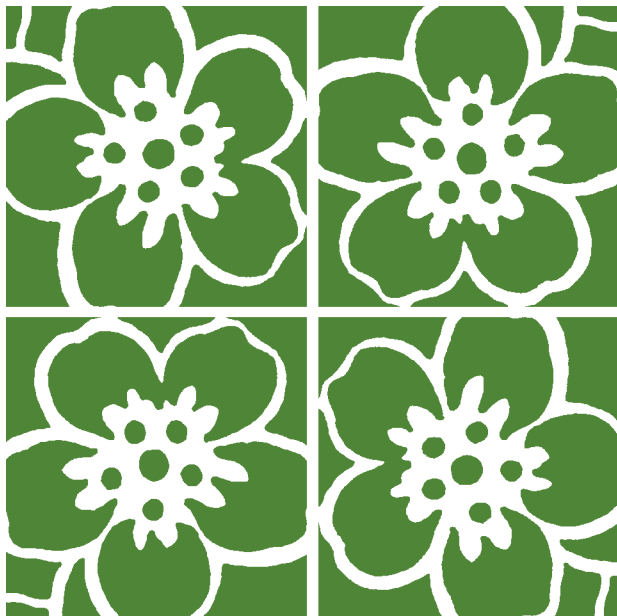
I am able to allow creative vision to flow through my fingers into cards, small gifts and symbols of love to those with whom I am inextricably linked. Not a season goes by where I don't find a new inspiration for creating new tokens of my esteem.

I am able to make short trips to the grocery store and choose the freshest produce available. I chop and season and cook bits and pieces until a whole forms, pungent and nourishing, warming my parents' kitchen — feeding my body with Earth's gifts and my soul with the knowledge that I am independent enough to do so.

I am able to feel a divine presence in my life; in the people I love, the trees bared in winter, the earth frozen yet fertile beneath my feet, the very air I breathe. Lots of days I even feel hope all around me, aided, I am sure, by the gentle nudging of that divine spirit.

I affirm my illness, I own my illness, I may well be frustrated and depressed by it — but I am not my illness. I assert, uncategorically, that I am not disabled. I am differently abled. No more and no less worthy than any stranger. The gifts we have been given and give to others are of the soul, not of the body. Disability has nothing to do with our bodies. You disable a bomb, a car, a criminal, by taking away power. Our power lies not in the flesh but in the spirit. I am — and you are — limitlessly abled.

Sara Zeno lives in Pennsylvania. ■



Be a part of Snapshots of CFIDS

The articles, photos and artwork and poetry in this section come from readers of *The CFIDS Chronicle*. Snapshots will be produced in each winter and summer *Chronicle*.

Readers are invited to share their stories for future issues. How are you coping with CFIDS? What are your successes, frustrations and dreams? How has CFIDS changed your life? Send your submissions to The CFIDS Association of America, P.O. Box 220398, Charlotte, NC 28222-0398, Attention: Snapshots.

A report on coverage of CFIDS in the mainstream media

CFIDS on CNN. CFIDS Association President and CEO Kim Kenney was interviewed in a July 28 segment on CNNfn, the financial network for CNN. Person with CFIDS (PWC) and documentary film maker Kim Snyder was also interviewed. The program focused on funding issues for CFIDS research and

the serious, debilitating nature of the illness.

Medical manual updated.

In 1997, the “Merck Manual of Medical Information,” a long-respected source of information to the medical community, published its first edition for consumers. Last month, Merck released

the first update of that edition and now features diseases of unknown causes — including chronic fatigue syndrome (CFS). *The Washington Post* (May 20) and *The New York Times* (Jun. 3) published articles about the new edition, and mentioned the addition of CFS. ■



By Leah Moseley

SEABISCUIT GENERATES MEDIA WAVE

The recent interest in PWC Laura Hillenbrand and the July 25 release of a star-studded motion picture based on her phenomenal best-selling book, “Seabiscuit: An American Legend,” has created a wave of positive media coverage for CFIDS. Laura has proven to be an articulate spokesperson for the illness, and has used the media to catapult genuine interest in CFIDS. The most recent and prominent Seabiscuit-related coverage includes:

National Public Radio (NPR). On the July 24 edition of NPR’s “Fresh Air” show, Laura talked about her struggle to write her book about the famous Depression-era racehorse while dealing with CFIDS.

Chicago Sun Times. The July 24 issue featured a compassionate article by sports columnist Rick Telander that discusses the movie based on Laura’s best-seller and her personal battle with a crippling case of CFIDS.

ABC’s 20/20. As part of a July 18 segment on Laura, host Bob Brown states, “although many doctors once dismissed [CFIDS] as psychologically based, it is now recognized medically as a disabling physical condition.”

The Washington Times. The July 10 issue included an article written by Rick Snider, who covers thoroughbred racing for the paper and has written several books on the topic. Snider tells of Hillenbrand’s battle with CFIDS and the

tremendous sacrifices she made to write Seabiscuit. Laura tells Snider: “I’ve lost a lot to this illness. It’s deprived me of everything but the inside of my bedroom for the last 16 years.”

The New Yorker. The July 7 issue of the magazine featured an essay written by Hillenbrand. The harrowing piece offers a personal and detailed account of Laura’s fight with CFIDS and the devastating impact it has had on her life.

The Diane Rehm Show. During the July 3 airing of the popular National Public Radio program, Laura again talked about her battle with CFIDS. Her physician, Dr. Alan Pocinki, and The CFIDS Association of America President and CEO Kim Kenney participated in the conversation.

The Washington Post. In the June 22 issue, columnist William Gildea compares Laura’s struggles to those of the characters in Seabiscuit, calling it “a story of persistence in the face of hardship.” He remarks that it was “at times severe enough that she could not roll over in bed, leaving us to wonder how the name given the illness can be so badly understated.”

USA Today. The May 29 edition included an article in its LIFE section about the release of new editions of Seabiscuit. The article discussed Laura’s battle with CFIDS and how the illness kept her from attending the Hollywood premiere of the movie.

'Biscuit Bash: A Sold-Out Smash

Movie screening draws hundreds to benefit CFIDS

The fight against CFIDS hit the silver screen on July 28, when nearly 400 celebrities, politicians, scientists, friends of The CFIDS Association of America and people with the illness gathered in Washington, D.C. for a special screening of the movie *Seabiscuit*.

The event, organized and sponsored by the Association, featured a rare public appearance

by Laura Hillenbrand, author of “Seabiscuit: An American Legend,” the best-selling book about the 1930s racehorse that inspired the movie.

Hillenbrand’s success — and her willingness to speak out about her illness — has helped the CFIDS cause immensely. A grateful community showered her with praise during the screening.

“It’s an inspiring story,” CFIDS lobbyist Tom Sheridan told the crowd. “The jockey is inspiring. The horse is inspiring. But really the most inspiring story is the author.”

“We hope you’re all inspired a little bit to help us conquer this illness.”

Tony Kornheiser, star of ESPN Radio’s “The Tony Kornheiser Show” and ESPN’s “Pardon the Interruption” television show, was the event’s honorary chairman. He praised Hillenbrand’s efforts before the screening, as did U.S. Sen. Harry Reid and Dr. Julie Gerberding, director of the Centers for Disease Control and Prevention (CDC).

NBC’s Bob Costas was also in attendance, as was radio personality Diane Rehm, *Washington Post* writer Andrew Beyer, Washington-area entertainment reporter Arch Campbell, *Inside Edition* reporter Les Trent,



Laura Hillenbrand and Borden Flanagan



Bob Costas with Kim Kenney (second from right), Association COO Jamie Davis (right) and Taylor Costas (left).



Kim Kenney with CDC chief Dr. Julie Gerberding and Tom Sheridan.



Laura Hillenbrand

actress Mary McDonough and Kornheiser’s TV co-host, *Washington Post* sports columnist Michael Wilbon.

Dr. Gerberding said the evening was all about “C-words”: Celebration, commitment and collaboration. “Hopefully, this leads to this last c-word, which is ‘cure,’” she said. Dr. Gerberding then thrilled the crowd by announcing that the CDC will allocate an extra \$100,000 toward the Association’s Physician Education Program.

But the star of the night was Hillenbrand. She attended a VIP gathering before the screening, as well as a special tea held in her honor the day before. With longtime boyfriend Borden Flanagan at her side, Laura walked slowly to the

front of the movie theater to a standing ovation.

Hillenbrand said she was incredibly moved by the gathering and the words of praise. “Thank you so much. To Kim Kenney, to the Association, and to everyone who is working to find a cure for CFIDS,” she said.

Seabiscuit enjoyed immediate success at the box office. On the first weekend of its release (July 25–27), it ranked first nationally in amount of tickets sold per screen. It opened to a wider release the following weekend. The film, released by Universal Pictures/Dreamworks/Spyglass Entertainment, stars Jeff Bridges, Tobey Maguire and Chris Cooper. The movie also won widespread acclaim from critics. ■



Diane Rehm



The full house awaits the *Seabiscuit* screening.

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



Terms in bold type appear in the CFIDS Glossary box.

Dual treatment shows no benefit

A new study from Belgium reports that combining hydrocortisone and fludrocortisone therapy to treat CFS symptoms was not effective in a six-month trial.

Urine samples from many CFS patients show lower-than-normal levels of cortisol, a stress-related hormone also called hydrocortisone. It's not known whether low cortisol is a cause of CFS symptoms, or an effect triggered by other abnormalities.

In the past, researchers have attempted to treat CFS symptoms by supplementing the body with hydrocortisone. The results have been mixed, and there have been reported side effects that include a suppression of natural cortisol production.

Fludrocortisone, a synthetic hormone known by the brand name Florinef, is sometimes used to treat orthostatic intolerance. But at least two previous studies have shown that Florinef does not significantly alleviate CFS symptoms.

The latest research involved 80 CFS patients who met the 1994 **Fukuda** criteria for CFS. The patients were given a daily treatment that included both fludrocortisone and hydrocortisone. The

treatments were randomized and double-blinded over six months, so that neither the patients nor the researchers knew who was receiving the drugs and who was receiving a placebo treatment. After the treatment period, researchers found no difference between the treatment group and the placebo group in terms of patient-reported fatigue or overall well-being.

The study appeared in the June 15 issue of the *American Journal of Medicine*.

CFS-vaccine link probed

The Brighton Collaboration has launched an initiative to develop assessment guidelines for patients who have an onset of a CFS-like illness after being vaccinated.

An international working group of experts in CFS and vaccine safety has been assembled; Association President & CEO Kim Kenney is a member. The group will: conduct a literature review; define various levels of diagnostic certainty for evaluating possible CFS cases that follow vaccination; and write guidelines for data collection, analysis and presentation to enhance comparability across research and clinical settings. The process is expected to take about a year; all meetings are held by conference call.

The Brighton Collaboration was begun by the Centers for

Disease Control and Prevention in 2001. So far, nine case definitions with guidelines have been written. CFS was selected as a topic based on sporadic reports of CFS-like illness following Rubella and hepatitis B vaccines. Brighton staff emphasize that the group's interest in a particular condition does not imply a causal link between vaccines and that illness.

Wichita study reaches med journal

Research results from a large **population-based study** of CFS patients in Kansas have been published in an international medical journal.

In July, Archives of Internal Medicine featured a paper called "Prevalence and incidence of chronic fatigue syndrome in Wichita, Kan." The multi-year study was conducted by the Centers for Disease Control and Prevention (CDC) in conjunction with other research teams.

In the study, more than 30,000 households were contacted and screened for people with CFS-like symptoms. Researchers gave questionnaires and/or medical examinations to a group of 7,162 residents, then re-checked their status after one year. The results showed that the overall rate of CFS in the general population is about 235 per 100,000 residents (95% **confidence interval**, 142–327).

The prevalence of CFS was higher among women (373 per 100,000) than men (83 per 100,000). These figures roughly correspond to earlier prevalence studies done on smaller groups. The new report concludes that “Chronic fatigue syndrome constitutes a major public health problem.”

The Wichita study began in 1997 and took four years to complete. CDC teams have recently conducted thorough medical examinations and numerous research tests on more than 400 city residents who were tracked during this period, including those with and without CFS. Results from these examinations are expected to be published over the next several years. Wichita was chosen as a test site because the makeup of its population is representative of the overall U.S. population.

“Intriguing” result from Lyndonville study

A new study related to the Lyndonville, N.Y., outbreak of CFS shows that environmental and genetic factors may combine to cause the illness in susceptible individuals.

The study looks at aspects of the immune systems in 90 people with CFS and 50 healthy controls. Included in the study were people from Lyndonville, where scores of residents developed CFS in the mid-1980s. Other subjects, who came from Buffalo, N.Y., were used for comparison.

Study authors said they discovered an “intriguing outcome” when looking at the cytotoxic T-cell levels in the patient groups. This type of T-cell attacks body cells that are infected or have become malignant. The CFS patients who lived in Lyndonville during the outbreak showed an increased level of the T-cells, as did the CFS patients from Buffalo. But the non-CFS controls from Lyndonville also showed higher T-cell counts, while the non-CFS Buffalo controls did not.

This could indicate that some agent was present in Lyndonville that caused the

residents’ immune systems to gear up for a fight. It’s possible, the authors say, that residents who developed CFS were predisposed in some unknown way to develop CFS, while those who remained healthy had the ability to fight off the illness.

The Buffalo residents with CFS may have been exposed to the same agents as the people in Lyndonville — although the whole city apparently did not receive the same exposure.

The study was published in the journal *Cytometry Part B: Clinical Cytometry* (53B, 2003). ■

CFIDS GLOSSARY: TERMS YOU NEED TO KNOW

Confidence interval: In statistics, a range of figures in which the true value being sought most likely resides. This is expressed in terms of percentage. The term “95 percent confidence interval” means that the true value will be within the given range 95 percent of the time.

For instance: A report says that 300 people out of 100,000 have CFS (95 percent confidence interval: 250-350). This means there’s a 95 percent chance that the figure is somewhere between 250 and 350 people.

Fukuda criteria: Another term for the 1994 International Research Case Definition of Chronic Fatigue Syndrome. This is the most commonly used criteria for identifying CFS cases for use in research studies. Although not originally intended for use by physicians to diagnose CFS in individual patients, it is often used for this purpose. Keiji Fukuda of the Centers for Disease Control and Prevention was the lead author of the definition.

Population-based study: As the name implies, a study that seeks information by looking at the residents of a particular geographic region. These studies can be particularly useful in determining the prevalence of a disease. By taking a representative sample of the population, scientists can imply how many people are affected by a given condition. This sampling method helps avoid conclusions that are biased by subjects’ differing access to medical care, as often occurs with clinic-based studies.

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

Tips, strategies, ideas and helpful thoughts about CFIDS**Epsom salts ease pain**

I have CFIDS and fibromyalgia, and I am chemically sensitive. I find that taking an Epsom salts bath relieves pain and stiffness in my muscles without any potentially irritating fragrances. I also believe that the baths loosen my bowels and relieve bloating without having to drink any of the salts. Be careful not to take hot baths when you're fatigued; sometimes, it can make you more tired or even trigger a relapse.

It takes about two cups of Epsom salts to make a

good bath. You can add one-half teaspoon of glycerin to the bath water as a moisturizer, if you wish.

A reader in Minnesota

Thump away the aches

As a former massage therapist, I cannot speak highly enough of the general benefits of massage. Recently I have discovered a new tool to handle the muscle tightness, aches and tender trigger points. It's called the Thumper Mini Pro 2. It has dramatically reduced, or temporarily eliminated, much of

my worst pain. It is also wonderful for improving blood circulation and muscle tone. The product is available through the Sharper Image (800-3440-4444) or Wellness America (800-THUMPER).

Peter Anastasia, New Mexico

Get a celiac test

During the 16 years I've had CFIDS, the best advice I've been given was to be tested for celiac disease. A simple, three-part blood test confirmed I have it. Since I have been on a gluten-free diet my health has improved. Intestinal problems, headaches, insomnia and brain fog have all gotten better.

I highly recommend a book on the subject: "Wheat-free, Worry Free" (by Danna Korn; Hay House, 2002). It covers every aspect of celiac disease, plus other food allergies.

Diane Steinberg, South Carolina

TUNING OUT TINNITUS

One of the most prominent symptoms of CFIDS for me is tinnitus, or constant ringing in the ears. It used to drive me crazy, but I have found several ways to block it out.

First, I use hearing aids. Because I hear other sounds better while wearing them, I tend to notice the tinnitus less.

Second, I try to avoid foods that make my tinnitus flare up. These include foods with caffeine, like coffee, tea, soft drinks and even chocolate. Salty foods can also cause flare-ups for me. I don't smoke, but I know that smoking also increases the ringing for some people.

I also try to surround myself with pleasant background noises that help me forget about the ringing. I have several CDs of sounds – ocean waves, waterfalls, gentle rainstorms and meadow birds – that are naturally relaxing and don't interfere with my concentration.

Finally, I try to make sure that I don't make my tinnitus worse. That means wearing earplugs when I'm in loud places such as shopping malls and movie theaters. I use the small foam plugs that fit snugly inside your ear. People don't even know you're wearing them!

Jeannette, New York

Editor's note: For more information on tinnitus, contact the American Tinnitus Association at 800-634-8978.

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

Acupuncture: Let the Energy Flow

By Mark
Giulucci

It's all about the chi.

For thousands of years, practitioners of Chinese medicine have believed that blockages in the body's "life energy" — chi — are responsible for illness and disease. Acupuncture and other traditional Chinese treatments seek to restore the natural flow of chi and return the body to harmony.

Yet you don't have to believe in ancient theory to believe in the power of acupuncture. Many Western researchers contend that acupuncture's benefits can be explained in their terms. Acupuncture needles may stimulate nerve endings under the skin, sending impulses to the brain that result in the release of pain-easing endorphins and other hormones. Some researchers using brain scans have found that acupuncture increases blood flow to the thalamus, which is responsible for relaying pain messages to the rest of the body.

The National Institutes of Health (NIH) and the World Health Organization (WHO) formally recognize acupuncture as a method of pain relief. An NIH advisory panel has concluded that acupuncture is a useful treatment for fibromyalgia, headache, asthma and other conditions. Hundreds of acupuncture studies are underway to determine just how effective acupuncture may be for conditions ranging from arthritis to CFIDS.

"I have been treating chronic fatigue syndrome with Chinese medicine, including acupuncture, since 1985," says Maoshing Ni, PhD, DOM, a doctor of oriental medicine in Santa Monica, Calif. "I have seen it work. Certainly, people have different beliefs about how it works, but the bottom line to me is that it is effective."

Stick-y treatment

The main tool in acupuncture is a hair-thin, flexible needle. Skilled practitioners insert a series of needles in specific points just under the skin. In Chinese medicine, these points are located along meridians, the channels through

which chi flows. These points correspond to body systems or organs — the heart, the kidneys or the spleen, for instance — that may be suffering from blockages of chi.

Western acupuncturists use many of the same points; although they may not agree with the meridian theory, practice has shown that the points can be effective for relieving pain and other symptoms.

The treatment is, by nature, somewhat invasive. Insertion of the needles can be a little uncomfortable for some people, although they rarely cause serious pain. Some patients may also feel mild tingling or burning sensations once the needles are in place.

The placement and duration of the needle insertions varies by symptom. Generally, a dozen or so needles are used during each treatment, and they may remain in place for anywhere from 10 to 40 minutes. Practitioners may move needles or twist them slightly during treatment to achieve desired effects.

Sessions are usually held weekly. A typical series of treatments may last for several months. In some cases, the treatment is ongoing, as in chiropractic regimens.

Putting it together

The first time you visit an acupuncturist, expect him or her to take a thorough medical history. You'll be asked about your symptoms, current medications and other health conditions that may conflict with treatments.

In traditional Chinese medicine, acupuncture is practiced in conjunction with a number of other treatments, including herbal remedies, meditation and dietary changes. Dr. Ni says that he devises an individualized program for each patient.

"A typical diagnosis for chronic fatigue syndrome would involve kidney-adrenal exhaustion, spleen-stomach digestion deficiency, liver stagnation and blockage, and then a disturbed

(continued on next page)

spirit,” Dr. Ni says. “Mainly I think we’re looking at the overtaxation of one’s vital energy resources. Treatment with Chinese medicine would involve trying to resolve those issues.”

A typical CFIDS patient would begin a new dietary regimen — including organic foods supplemented with digestive enzymes. Herbal remedies will also be a part of the protocol, as well as meditation and treatment for sleep disorders. Gentle exercise will also be introduced according to the patient’s ability to handle it.

But of all the treatments, Dr. Ni says, acupuncture seems to deliver the most immediate benefit. “The other things take more time. But patients can often feel a more immediate change with acupuncture. After they get off the table, they get more of an immediate energy boost.”

Self-help points

If you’re interested in checking out acupuncture, you can start with a little self-administered routine. It doesn’t involve needles — just a little pressure.

“Not everyone has access to acupuncture, but certainly they have a finger they can use,” Dr. Ni says. “It will stimulate in much the same way as an acupuncture needle.”

Stomach point #36 is located just below the knee. Dr. Ni says he uses it to help increase immune function in his patients. This point is found about three inches below the outside of the knee. Feel for the head of your shin bone, and then apply pressure just behind it. Press steadily for about one minute, just hard enough to feel a little tenderness.

Kidney point #3 is located in the ankle. “This fortifies the kidney-adrenal system, which is so important in people with CFS,” Dr. Ni says. “The kidneys and adrenal systems have virtually become exhausted.” The point is in the inside back of the ankle, between the Achilles tendon and the ankle bone. Again, apply firm pressure for about one minute.

The third area, known as large intestine #4, is a common point used to relieve pain. It’s located in the web of the hand, between the

thumb and index finger. To find it, make the “OK” sign and feel for the bump of muscle on the back of the hand. Press on that point firmly for about one minute. Dr. Ni says this point helps fight bacterial, fungal and microbial problems as well as pain.

Finding an acupuncturist

There are more than 10,000 licensed acupuncture practitioners in the United States. Licensing is done on a state-by-state basis, and requirements can vary widely. Physicians are permitted to perform acupuncture after receiving proper training. Look for a doctor who has been certified by the American Board of Medical Acupuncture.

Non-MDs — including naturopaths (ND), chiropractors (DC) and professional acupuncturists (LAc) — can receive state licenses for acupuncture after completing training and passing examinations. Because state requirements vary, it’s best to look for someone who has been certified by a professional organization such as The National Certification Commission for Acupuncture and Oriental Medicine.

Some insurance plans will pay for acupuncture treatments with physician referrals. If your doctor can’t recommend a practitioner, Dr. Ni suggests checking with your chiropractor, massage therapist or even friends who have had good experiences with an acupuncturist.

Several Web sites, including www.acupuncture.com and www.acupuncturetoday.com can help you locate a qualified practitioner as well. ■

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The CFIDS Chronicle will begin accepting paid advertisements for products and services related to CFIDS beginning with the Winter 2004 issue. For more information, please contact the Chronicle at chronicle@cfids.org, or call 704-364-0016, ext. 118.

On the Inside Looking Out

Editor's note: The author, who has Parkinson's Disease, is the mother of CFIDS Association President & CEO Kim Kenney.

I see life from the same side of the window as you. Although I don't have CFIDS, my experiences living with Parkinson's are similar in more ways than you might imagine. You and I face many of the same challenges — and we can draw strength and wisdom from each other as we cope with the illnesses that have so drastically altered our lives.

I started reading about CFIDS when one of my longtime friends was diagnosed with it after many, many years of illness. Betty was one of the few people who understood when Parkinson's forced me to cancel plans or cut an evening short without much notice. I didn't need to explain to her why I spent twice as long looking for an up-close parking place as it would have taken to walk from the far end of the lot. And when she'd call at a time when I didn't feel up to talking, a few words of apology were all that was needed before hanging up.

Many of our symptoms are the same. Betty and I both have problems with sleep — restless legs, night sweats, difficulty falling back to sleep if we wake in the night. Medications seem to behave strangely, with even low doses causing disproportionate side effects or unexpected reactions. I have plenty of fatigue and whole body weakness; I have poor stamina and only brief and unpredictable periods of good function. When my medicine isn't working properly I am brain-fogged and “jiggly” (my term for dyskenesia or involuntary limb movements). I often get confused and waste precious energy shuffling from room to room, trying to remember what I am looking for. On the other hand, I can recall a childhood visit to the family farm or the first day of 8th grade with impressive detail.

We're alike in other ways, too. I was diagnosed with Parkinson's at a relatively young

age — 48. Several friends and extended family members questioned the credibility of the diagnosis. (Remember: This was before Michael J. Fox brought better awareness to the fact that Parkinson's can hit well before the “senior” years.) Because I continued to look pretty “normal,” held on to my nursing job after cutting back to part-time and was still able to travel, it was hard for some to understand that I was dealing with slowly worsening health problems.

Fairly early on, I joined the local Parkinson's support group. Although I met wonderful people there, I often felt out of place as a middle-aged woman with an old man's disease. Through that group I learned that many patients and family members feel burdened by the lack of understanding and awareness of Parkinson's. My father had Parkinson's and I was a nurse, so I don't remember ever not knowing about it. I also learned that efforts were being made to change the name “Parkinson's Disease.” Some wanted a term that was more descriptive; others just wanted to drop the word “disease” because they felt it conveyed contagion.

Finding a celebrity spokesperson was a frequent topic of discussion. At the time it was known that Muhammad Ali and the Pope had Parkinson's, but they wanted someone even more famous to take up the cause. Of course, Michael J. Fox's disclosure intensified awareness and support for research. I pray that the same thing will happen for people with CFIDS.

Betty and I have plenty of empathy for one another. Feeling isolated by illness is one of the hardest things to deal with. It's good to know that it's possible to connect with someone who shares so many common experiences, even if we don't share a diagnosis. Neither of us has all the answers for the other, but we gain comfort and strength from our common bond. At least we're not alone watching the world from the inside. ■

By Karen
Burke

Keeping it Real: Self-Talk for CFIDS



By Gail
Caissey,
EdD

CFIDS is a difficult illness to live with because there's so much negativity associated with it. Having to continuously and simultaneously deal with debilitation, ongoing losses and lifestyle restrictions — plus physical pain and mental distress — can certainly be demoralizing.

Because the potential for depression and despair is never far away, it's essential that people with CFIDS (PWCs) keep their spirits up by finding ways to mentally cope with the illness. One of the most effective ways to do this is by developing a positive attitude and using appropriate self-talk to control negative thoughts. This is not about Pollyanna, pie-in-the-sky thinking. It's about developing realistic thoughts and responses to situations that we face every day.

Talk to yourself the right way

When people encounter a situation, they mentally evaluate it and instruct themselves how to feel about it using a silent inner voice. This is self-talk. People can talk to themselves positively about an event or negatively about it.

There is a direct relationship between how people think and how they feel. If they think positive thoughts, they feel positive emotions. If they think negative thoughts, they feel negative emotions. Similarly, if people interpret an event in a positive light, they will have positive thoughts about it, which in turn will generate positive emotions and feelings.

It is not the occurrence of an event that causes people to feel a certain way about it. It's what people tell themselves about the event, or the way they interpret it, that determines how they will feel and react to it. While we don't always have control over what happens to us, *we do have control over our thoughts and feelings about what happens to us.*

Positive means realistic

Positive thinkers have a hopeful attitude about the future, but their thinking is accurate and realistic. Having a positive attitude means

trying to make the best of every situation as it happens. While positive thinkers recognize and acknowledge the negative aspects of a situation or event, they do not dwell on them. Rather, they look for the positive aspects or the good that can come from negative situations — even if it's the fact that things can't get any worse.

Simply thinking or saying the words that everything will be OK when in reality things are not isn't positive thinking. Idealistic, wishful thinking and mindless optimism aren't, either. People engaging in this type of behavior are not coping realistically with a situation. Rather, they are deluding themselves into thinking that things will work out simply by telling themselves that they will.

Positive thinkers may not like the circumstances they find themselves in, but they recognize that they can handle things as they are. Because positive thinkers are realistic thinkers, they know that things aren't going to go well all of the time, and they don't expect them to.

Positive thinking and positive self-talk go hand in hand. One is used to achieve the other. Developing a positive attitude about life, including a life with CFIDS, can make a tremendous difference in how you experience it. While it won't make the illness go away, it can help you deal with daily difficulties and help keep spirits up, hope alive and despair at bay. Best of all, it's something you can tap into and use any time, anywhere.

Putting it together

Positive self-talk can be used in a variety of circumstances associated with CFIDS. Here are three examples:

Nixing negative thoughts.

Instead of saying: "I feel awful. I hate being sick. I can't stand it. I'm never going to get better," say: "Looks like I'm having another bad day. That's what happens when you have CFIDS. There's no use getting upset. I don't

like it but I can handle it. I've handled bad days before and I can handle this one, too."

I find it useful to apply the One-Third Principle here. I know I'll have bad days (weeks, months) about one-third of the time, good days a third of the time and neutral days a third of the time. The fact that I'm having a bad day today means that I'm getting another bad one over with, and that I'm closer to having a good or neutral day. I have planned how I'm going to make it easier for myself on a bad day — so now that it's here, I'm going to follow those plans and get through it as best I can. Tomorrow is another day.

Easing anxiety.

Instead of saying: "There it goes again! My heart is racing faster and faster! What if it doesn't stop," say: "It looks like my heart is racing again. Well, I'm going to lie down, stay calm and not panic to help keep it under control. Then I'm going to wait it out. It usually only lasts for about 10 minutes, so it will probably do the same this time. In the meantime, I'll count to 1,000 to distract myself. If my symptoms get very bad, my doctor told me what to do (call 9-1-1)."

Alleviating stress.

Instead of saying: "Oh no! My son's birthday party is tonight and I can't function. How am I going to prepare? I'm going to disappoint my son. What a bad mother I am. I hate CFIDS," say: "I don't feel well at all but I've done what I could in advance to prepare. My family knows I have this illness, so when they come over, I'll apologize for not feeling well and ask them to help. I'll call my sister now and ask if she can pick up the birthday cake. I'm disappointed that I won't be able to participate much but at least my son will have his birthday party and he'll be happy about that. Now I'm going to lay here and rest. Who knows? — I might feel better in a few hours."

In each example, you're accepting the reality of your circumstances. You're not pretending that nothing is wrong. You're dealing with difficulties realistically and practically and making the best of things as they are. Most

importantly, you are not allowing yourself to be consumed by negative thoughts.

We all have times when it is difficult to be positive. But if we can keep those moments to a minimum by using positive self-talk and having a positive attitude, we can live more comfortable, less stressful lives while maintaining a sense of hope for the future. Even though it is not always easy to have a positive attitude with CFIDS, when you consider the alternatives — depression, despair and hopelessness — the choice is easy to make.

Gail Caissy, EdD, is a PWC who lives in Clarence, N.Y. She is author of "Unlock the Fear: How to Open Yourself Up to Face and Accept Change" (Perseus Books, 1998). ■

All You Need is a Wealth of Spirit

Estate gifts aren't about large homes and millions of dollars. They're about making an enduring commitment to the cause of conquering CFIDS.

A bequest in your will is the simplest way to give. It can be for a stated dollar amount, a percentage of your estate or the remainder of the estate after all other bequests are fulfilled.

Please remember the Association in your will. Provide your attorney or financial planner with the Association's correct legal designation: *The CFIDS Association of America, Inc., a 501 (c)(3) tax-exempt organization incorporated by the laws of the State of North Carolina. Federal Tax ID Number 56-1683450.*

Thank you for your contribution.

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



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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. Include full name and address.

RESOURCES

The Cost Containment Research Institute is offering a booklet called "Free & Low Cost Prescription Drugs." The 48-page document lists contact information on how and where to obtain more than 120 drugs directly through the manufacturers. The programs usually have income limits. To order the booklet, send \$5 to cover printing, postage and handling to: Institute Fulfillment Center, Booklet #: PD-65, P.O. Box 210, Dallas, PA 18612-0210.

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. Three visits to Stony Brook Hospital are required. For more information, contact Fred.Friedberg@stonybrook.edu or call 631-632-8252.

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

A Los Angeles area research team is now recruiting people with CFIDS for a clinical study. Subjects will undergo baseline studies of brain SPECT scans, tilt-table testing and hormonal measurements and treatment studies to

improve blood flow to the brain that may improve symptoms of fatigue. Open to both genders, all races and ethnicities. Ages 18-49. Subjects will be compensated, but must be willing to be off all medications for duration of the study. Please call Dr. Friedman or Dr. Zuckerbraun at 323-563-9353 or mail@goodhormonehealth.com for more information or to enroll.

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>.

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. ■

WHAT IS CFIDS?

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

HOW IS CFIDS DIAGNOSED?

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

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

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

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

HOW IS CFIDS TREATED?

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

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

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

WHO GETS CFIDS?

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

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

DO PWCs GET BETTER?

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

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

This document is an abridged version of "Introducing CFIDS," a comprehensive booklet about CFIDS published by The CFIDS Association of America. Copies of the booklet (item #6040) 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