

THE CFIDS ASSOCIATION OF AMERICA

# THE CFIDS CHRONICLE

Advocacy,  
information, research  
and encouragement  
for the CFIDS  
community

A QUARTERLY PUBLICATION OF THE CFIDS ASSOCIATION OF AMERICA ■ FALL 2004



**Want a  
fighting  
chance of  
winning your  
long-term  
disability  
claim?**

**Information on  
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increase the odds of  
filing a successful  
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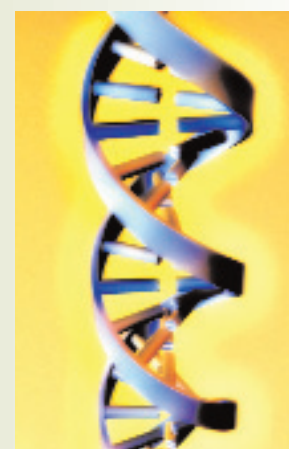
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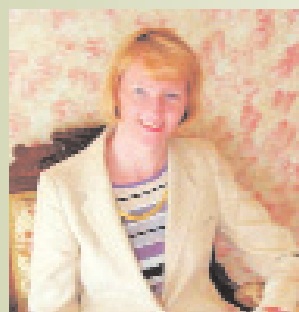
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# Message to Members

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The word *advocacy* is a deceptively simple term used to describe complex human action and reaction. The CFIDS Association has led national CFIDS advocacy efforts since 1992 and has provided resources, support and counsel to others working on the state and local levels.

Some say those advocacy initiatives haven't achieved enough. I agree.

There are an overwhelming number and variety of unmet needs among persons with CFIDS and those who care about them, and advocacy is a means of getting those needs met. In the 14 years I have worked in this community, my *greatest disappointment* is that, so far, we haven't achieved the critical mass necessary to vault our cause forward. We must recruit more researchers to the study of CFIDS, more clinicians to care for patients, more high-visibility spokespeople to educate the public, more advocates to influence public and social policy and more financial resources to sustain it all. We'll only achieve this through partnership. My *greatest hope* is that we will achieve critical mass, push beyond the tipping point and propel our common cause in significant—and lasting—ways.

I am grateful to Marla McKibben, founder of P.A.N.D.O.R.A., for telling me about a book, *Emerging Illnesses and Society: Negotiating the Public Health Agenda*. It's packed with case studies of how various illnesses have come to public recognition. CFIDS/CFS is featured throughout, and our history is recounted, with a more generous "final grade" than we might give ourselves. In the introductory chapter, the editors offer this commentary on the social processes by which illnesses achieve prominence:

"Communities of suffering (COS) (and those at risk) deserve to have a 'seat at the table' of research and public health policy decision making. There needs to be greater sensitivity to the etiological understandings of COS. On the other hand, communities of suffering also need to recognize that their etiological understandings may not be correct. Adversarial actions taken primarily for media attention can impede the process of getting new health problems on the agenda. Until we have all the answers, each side needs to be willing to listen and adapt, and research agendas need to be broadly based and not prematurely narrowed to meet the interests of either party. Public health and medical research institutions can benefit in their mission of improving society's health from collaboration. Medical researchers, public health officials and communities of suffering need to be partners."

Through this book, those outside of the CFIDS community may learn what we, as advocates, have achieved so far, and how we've done it. In turn, those of us still working in the trenches of CFIDS activism can learn to strengthen collective efforts through diverse approaches, rather than weaken our cause by competing with one another. In doing so, we can achieve historic impact experienced at a national, even international, level.



## STAFF

K. Kimberly McCleary  
President & CEO  
kmcclary@cfids.org

Jamie Davis,  
Director of Development & COO  
development@cfids.org

Kristina Hopkins,  
Controller  
kphopkins@cfids.org

Marcia Harmon,  
Director of Communications  
mharmon@cfids.org

Angenette Rice-Figueroa,  
Director of Publications  
afigueroa@cfids.org

Terri Lupton,  
Coordinator for Educational  
Opportunities  
talupton@cfids.org

Kim Almond,  
Development Project Coordinator  
kalmond@cfids.org

Nova Bouknight,  
CFIDS Support Network  
nbouknight@cfids.org

Gloria Smith,  
Front Office Manager  
gsmith@cfids.org

Lois Infanti,  
Accounting and Personnel  
Assistant  
linfanti@cfids.org

Kasia Faryna,  
Marketing Associate  
kfaryna@cfids.org

Julie Carothers,  
IT Specialist  
jcarothers@cfids.org

## OTHER E-MAIL ADDRESSES FOR THE ASSOCIATION

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

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

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

General questions  
cfids@cfids.org

Board of Directors  
board@cfids.org



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E-mail the editor:  
afigueroa@cfids.org

E-mail the Association:  
cfids@cfids.org

Website:  
www.cfids.org

Information line:  
800-44-CFIDS  
(800-442-3437)

Resource line:  
704-365-2343

Fax:  
704-365-9755

The CFIDS Association  
of America  
PO Box 220398  
6827-A Fairview Road  
Charlotte, NC 28210

## BOARD OF DIRECTORS

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The CFIDS Association of America, Inc.

PO Box 220398, Charlotte NC 28222-0398

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## OUR MISSION

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

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



### Exercise and relapse

I have suffered from CFS for more than 16 years. The article called "Working to Understand Why Activity Causes Relapse in CFIDS" was perfection. I want more articles like this. It's in simple, understandable language and made so much sense to me. In fact, this is the first article I will take in to my doctor. Now I understand why I have relapses. Thanks so much for this information.

**Vicky Ward**

### Kudos on Annual Report

I have just read the Association's *Annual Report*. I would like to express my gratitude to your staff. You do a wonderful job. Mr. Sheridan's work in Washington hopefully will find more funds for research.

I feel very lucky that since the onset of CFIDS in December 1991, my body has been able to recover. I have resumed my full-time practice of dentistry. The Association's work in physician education is very important. I have lunch with several general practitioners in our area and have given them the Association's printed materials for M.D.'s. I was surprised how little they know about CFIDS. Please keep up the good work.

**Richard Gagne, D.D.S.**

### Need info on severely ill

You asked for input on the *CFIDS Chronicle*, so here's mine. I have had severe CFIDS for 24 years. Both long-term and severely ill patients are largely ignored in the *Chronicle*. My doctor is very concerned about the severity and progressive nature of my illness. But because there are no articles regard-

ing this aspect of the illness in the literature, I have no information to show him.

I understand that you want to present hopeful articles, but we need real information about the severely ill. Articles about patients who are well enough to drive to do errands are depressing for those of us who are housebound or bedbound. Please, please cover this issue in the *Chronicle*.

**Sally Dunn**

**EDITOR'S NOTE:** Thanks for this suggestion. We will plan to provide more information on the severely ill in 2005 in both the *Chronicle* and our online newsletter, *CFIDSLink*.

### Sabotaging CFIDS efforts

I'm a person with CFIDS and am not a member of any advocacy group at this point. It has been my observation that one of the surest ways for a group to sabotage their own efforts is to squabble among themselves in the presence of those in a position to help them advance their cause. In the case of CFIDS advocacy, this group would include members of the medical profession, scientists, government officials, the media and the general public.

Dissent is essential to any political process, but there has to come a point at which people who are working toward common goals reach some kind of consensus and move forward. Compromise does not necessarily require an individual to abandon principles, but it may mean that someone who has been charged with responsibility for representing a larger group must develop a sense of when and how to argue a point or defend a position. Airing complaints

about rival advocacy groups in public meetings and in the press, no matter how veiled the references may be, could prove disastrous.

The fact is that nobody cares as passionately about CFIDS as we do. Some doctors and scientists are interested, but most are not. Some members of the general public are curious and empathetic, but most are not. Some government officials would like to be helpful, but they are working with dwindling resources and competing demands, many coming from groups with a great deal more political clout than we have. This makes it all the more critical that we find ways to resolve our differences in private so we can present a unified front in public. If we can't do this, then our efforts are doomed.

**Nancy Hall**

### Living with CFIDS

Thank you very much for the article, "Wisdom from the Rose Pavilion," by Sharon Stomer Cherry in the spring 2004 *Chronicle*. It always helps me to read the stories of others who share the experience of CFIDS. And while the author admits to feeling discouraged now and then, she does a wonderful job of writing about the need for acceptance of limitations, while living fully by doing and enjoying the things she *can* do.

I am sending a copy of this article to my mother, who is 83 and strong as a horse. I'm 58, a PWC, and I haven't been able to work for 12 years. She is already very understanding, but I believe that reading this story from the perspective of another mother and grandmother will help broaden her understanding of CFIDS.

**William Livergood**



## RESEARCH NEWS

*The latest information on research, clinical trials and treatment protocols*

### **New clinical study on role of cytokines in sleep**

A group of researchers at the New Jersey Medical School is studying the role of cytokines in sleep in CFS patients. This three-year study is funded by the National Institutes of Health (NIH).

Principal investigator Benjamin Natelson, M.D., explains the goal: "One of the major hypotheses for the cause of CFS is immunological dysfunction, but no firm data exist to confirm this hypothesis. We believe this is because prior researchers have ignored the role of cytokines in producing restful or restless sleep. Many CFS patients have disrupted sleep, and we hypothesize that this occurs because of abnormalities in the pattern of sleep-disrupting and sleep-producing cytokines in some patients."

Dr. Natelson and his research team are recruiting 80 CFS patients for the study. All will be women and must be between the ages of 25 and 50. Women are being studied because CFS is predominantly an illness of women, because researchers want to exclude subjects with primary sleep disorders that occur mostly in men and because women have substantially higher levels of cytokines than men.

Participants can't take any brain-active medications at the time of the study because of their effect on sleep and the immune system. Because depression alters cytokines, women with depression will be excluded from the study. Patients will be compensated with \$100 per night, but no travel expenses are covered.

CFS patients will be matched by age and gender with 80 healthy

controls. The study will require CFS patients to spend three nights in the sleep laboratory. The first night is designed to deal with the well-known "first-night effect" so subjects can become habituated to the sleep lab. A few days later CFS patients will return for a second night when researchers will measure sleep-disrupting cytokines and sleep-producing cytokines. Patients will return again to perform an exercise test in the afternoon, followed by a third night in the sleep lab so researchers can test blood to see how exercise perturbs cytokines.

"We anticipate that exercise, which is known to exacerbate CFS symptoms, will worsen an already dysregulated cytokine sleep network," explains Dr. Natelson.

Since many CFS patients sleep without disruption, researchers have developed a 2x2 design to test CFS patients vs. controls and sleep-disturbed vs. normally sleeping subjects. This design will enable researchers to determine whether the illness (CFS) rather than a symptom of the illness (disturbed sleep) is responsible for altered cytokine patterns.

### **CFS treatment study in Los Angeles**

Subjects are being recruited for a study on a new diagnostic test and a treatment agent for CFS. The study is sponsored by the CFIDS Association of America and Pfizer Pharmaceuticals. Principal investigators are Ted Friedman, Ph.D., and Erik Zuckerbraun, M.D.

The purpose of this study is to determine whether CFS is caused by defects in adrenal hormones, leading to inadequate blood flow to the

brain, and to test a medication that may help increase blood flow to the brain and improve the symptoms of CFS. Patients will participate in hormonal measurements, tilt-table testing and brain SPECT scans, followed by a six-week treatment with an experimental medication.

Patients must be between the ages of 18 and 49. The study will occur at King-Drew Medical Center in Los Angeles. Participants will be compensated. For more information, contact Dr. Erik Zuckerman at 310-668-8754 or at [STUDY@goodhormonehealth.com](mailto:STUDY@goodhormonehealth.com).

### **A link between CFS and Hodgkin's lymphoma?**

Dr. David Hudnall, M.D., a research hematopathologist, is studying a possible link between CFS and Hodgkin's lymphoma. A professor of pathology at the University of Texas Medical Branch, Dr. Hudnall has prepared a brief questionnaire that he encourages CFS patients to fill out and send to him at [shudnall@utmb.edu](mailto:shudnall@utmb.edu). Go to <http://www.cfids.org/cfidslink/questionnaire.asp> to participate in this research project.

### **MAKE YOUR OWN DECISIONS**

**The CFIDS Association of America publishes information about clinical trials as a service to the community. It is not our policy to endorse such studies. Patients must consult their own physician and make their own determination about whether or not to participate in a particular study.**



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

### An ounce of Prevention

In the October 2004 *Prevention* magazine pullout guide, "More Than Just a Slump," writer Julia Evans explains that because they are such common complaints, tiredness and fatigue are easily overlooked as possible warning signs of serious illnesses such as CFIDS, fibromyalgia (FM), anemia and hypothyroidism.

The guide describes what the fatigue associated with CFIDS and fibromyalgia feels like, lists other related symptoms and encourages readers experiencing the symptoms to find a physician knowledgeable about CFIDS or fibromyalgia.

*Prevention* magazine has a circulation of 3.3 million.



### Body & Soul explores the pain

*Body & Soul* magazine, with a circulation of 230,000, published an article about the pain associated with CFIDS and FM in its March 2004 issue. In "Who'll Stop the Pain?" writer Michael Castleman covers treatment options, the continuing mystery surrounding the exact cause of both illnesses and whether CFIDS and FM are two distinct conditions or manifestations of the same illness.

Interviewed for the article were PWC Janice George; Dr. Daniel Clauw, director of the Chronic Pain and Fatigue Research Center at the University of Michigan; and well-known clinician and author Dr. Jacob Teitelbaum. The article discusses integrating pain relief, sleep

normalization, exercise, meal modifications, supplements, support and an open-minded attitude about treatment options into a multifaceted approach to alleviating the symptoms of the two illnesses.

According to Castleman, "the treatment of CFIDS and fibromyalgia has become an important example of a quiet trend in health care—the blending of mainstream medicine and alternative therapies."

### CFIDS topic of radio discussion

Radio station WVNR/WNYV featured a 40-minute program about CFIDS in August. Dr. Kenneth Friedman, professor of pharmacology and physiology at the University of Medicine and Dentistry of New Jersey Medical School and a core trainer in the Association's Provider Education Project, was the station's featured guest during the morning drive "Coffee Break" show. Listeners in Vermont and upstate New York heard Dr. Friedman discuss what CFIDS is, how it is diagnosed and how it can and should be treated.

### Local newspapers telling story of CFIDS

Many stories about CFIDS have appeared recently in local papers, including two in California and Arizona.

Citing information received from the Association and others, writer Mary McIntyre's column in the *Elk Grove Citizen* offers a primer on CFIDS and FM. The article tells the story of PWC Michelle Oliva and includes a list of symptoms, possible causes, treatments and related information. Dr. Jacob Teitelbaum, who treated Oliva, is also quoted in the article. McIntyre

notes that PWCs are often misunderstood, misdiagnosed and/or misjudged, and that children can be mistakenly diagnosed as having behavioral problems.

PWC Rena Dreisen of Kingman, Arizona, is the focus of an *Arizona Republic* article. Dreisen talks about the initial mystery surrounding her illness, the CFIDS diagnosis she received just last year and the treatments her doctors have prescribed. Dreisen goes on to tell writer Terry Organ that CFIDS is "gradually gaining recognition. But because it's not a killer like cancer, heart attack, stroke or AIDS, it's not heavily funded" for research.

### PWCs lose an ally

Longtime CFIDS and FM patients of Deborah Robinson, M.D., received a shock in September when Dr. Robinson drowned while scuba diving. Covered extensively in area media, Dr. Robinson's death brought the subject of CFIDS to the forefront.

Current dilemmas faced by Utah PWCs include finding new doctors who understand the illness and are covered by insurance, getting prescriptions filled and dealing with the physical and mental setbacks caused by their doctor's sudden death.

A *Desert Morning News* article reports that during a standing-room-only meeting with more than 100 of Dr. Robinson's patients, Lucinda Bateman, M.D., who treats many CFIDS and FM patients in her Salt Lake City clinic, offered several "survival" tips to the group and encouraged patients to make their health insurer a partner in finding a new physician with knowledge about CFIDS.





Feel like you're **playing a war game** with your insurance company? Does it seem like they make all the rules and hold all the good cards? Learn how long-term disability claims are being examined by insurance companies and **steps you can take to improve the odds** that your claim will ultimately succeed.

BY JUSTIN FRANKEL AND JASON NEWFIELD,  
GUEST CONTRIBUTORS

# Finding Success in the Disability Wars

**D**iagnosing chronic fatigue immune dysfunction syndrome (CFIDS) and fibromyalgia (FM) is extremely difficult since most of the symptoms can't be objectively verified. Currently there is no medical test available that will clearly diagnose either condition. Neither illness presents one single physical trait that can easily be recognized by a physician, and without a lesion or tumor to biopsy for a quick diagnosis, or a universally accepted lab test to rely on, physicians are often reluctant to diagnose these "invisible illnesses."

Similarly, insurers are often equally reluctant to treat these illnesses seriously, and they routinely use the lack of medical certainty about CFIDS and FM against patients who file disability claims. While this practice puts a greater burden on the patients to prove their cases, and it sometimes puts patients in

an adversarial relationship with their insurers, there are steps you can take to significantly enhance the chances of your claim being successful.

The purpose of this article is to provide individuals who suffer from CFIDS or fibromyalgia with practical information to assist them in their pursuit of long-term disability benefits and to identify common problems that occur.

## Handling of claims by insurers

Unfortunately, individuals suffering from chronic illnesses are frequently surprised to find that their disability insurer refuses to approve their claim. Here are the most common positions taken by insurance companies when denying claims:

■ **Lack of objective evidence.** Insurance companies routinely delay or deny CFIDS



and FM claims because the claimant failed to provide objective evidence substantiating the disability, even though it's well known in the medical community that objective tests don't yet exist to confirm such conditions. Claims are delayed or denied while claimants attempt to develop support for their claims. Unfortunately, many treating physicians are either unwilling to assist the claimant or are unfamiliar with the insurers' claim requirements and don't adequately support the claim with the kind of information and documentation that is needed.

■ **Skepticism about the existence of these conditions.** This skepticism causes many claims to be delayed or denied. This can result in instances of secondary depression for patients, which sometimes leads insurers to conclude that the claimant's condition is actually psychological, not physical.

■ **Self-reported illness.** Some insurers deny claims because of the subjective, self-reported nature of many symptoms related to CFIDS and FM. Some policies actually require objective support for the disabling condition, while other policies limit benefit periods for self-reported claims, essentially treating those suffering from CFIDS or FM differently than other claimants.

■ **Mental condition.** Many medical professionals and insurance companies attribute the complaints and symptoms to psychological or psychiatric disorders, or worse, to malingering. Claimants are left with delayed or denied claims. When coverage is provided, insurance companies often limit benefits to two years under a "mental or nervous" limitation clause in the policy.

### Claim requirements for CFIDS and FM patients

To be entitled to disability

## Did You Know?

■ According to the U.S. Census Bureau, Americans have a one in five chance of becoming disabled. One out of every seven workers will suffer a disability lasting five or more years before age 65. Given these statistics, insurance companies are highly motivated to find ways to deny claims. Perseverance is essential to winning your claim.

■ According to researchers at the CDC, 25 percent of Americans with CFIDS are unemployed due to the illness. The 2004 study also showed that those who continued to work lost one-third of their annual income to reduced hours and other factors related to CFIDS.

■ Many long-term disability (LTD) claims are governed by a federal statute called ERISA (Employee Retirement Income Security Act). Don't be fooled by the name. The statute was designed to protect the integrity of pension plans, but it offers more protection to insurers than employees and can make winning a LTD claim difficult. It's advisable to work with an experienced attorney on such claims.

■ When you interview attorneys to see who will best represent you, ask if you can get punitive damages. If they say yes, they don't know ERISA law. If your long-term disability claim falls under ERISA, you're not entitled to a jury trial, you can't make a bad-faith claim, and punitive damages aren't available. You can, however, receive back benefits and may also get attorney fees and costs associated with your claim.

benefits, a claimant suffering from CFIDS or fibromyalgia must demonstrate that as a result of injury or sickness, you are "disabled" as that term is defined in the policy. It is therefore critical to understand what the definition of disability is in your policy. Although the terms vary among policies, there are generally two different definitions:

■ **Own occupation.** Here, disability is defined as the inability to perform the material and substantial duties of your "own occupation," and as being under the regular care of a physician. Insurance companies will also define an individual's own occupation as how the job is performed in the national economy as opposed to how you actually perform your own job.

■ **Any occupation.** Usually after 24 or 36 months of disability, policies routinely change the definition of disability to a less restrictive defini-

tion. Instead of determining whether you can perform your own occupation, the policy changes to an analysis of whether you can perform "any occupation" for which you are reasonably qualified by education, training and experience. Insurance companies often perform a vocational analysis to determine if you're capable of performing any job in the economy, even if no job is actually available.

### Claim considerations

So how do you ever win a claim when the insurance companies have so many weapons in their arsenal? Fortunately, there are effective and proactive steps you can take to increase your chances for success.

When you're preparing to file a long-term disability claim for benefits, you must review and analyze (or have a professional review and analyze) the policy to understand

## **FIVE COMMON LONG-TERM DISABILITY CLAIM MINEFIELDS**

**... and what you can do to avoid them**



**Submitting a long-term disability insurance claim form or giving an interview to the insurer without fully understanding the significance of the statements you make.**

Insurance companies are very skillful at utilizing your own claim form to deny a claim. A dentist with CFIDS may answer a question about the activities she performs in her job with, "I perform chair dentistry, I sometimes assist the other dentists in their procedures and I submit insurance claims and pay bills." The problem is that the insurer can then deem this dentist only residually or partially disabled because she can perform administrative functions as well as be a "dental assistant."



**Not working with your attending physicians so they fully understand the definition of disability contained in your long-term disability insurance policy.**

Even physicians who support your claim need guidance on the terms and conditions of your policy. You should get a copy of your medical records and review them carefully. Then set up an appointment with your physicians to explain the definition of disability contained in your policy and ensure that both your medical records and the report they submit detail how your illness restricts or limits your ability to perform the material duties of your occupation. Make sure you include all your health care providers in this process, including rehabilitation counselors, exercise physiologists and any others who are familiar with the functional limitations you experience.



**Attending an Independent Medical Examination or Functional Capacity Evaluation at the request of the insurer without preparing for it.**

Appear at IMEs and FCEs only after significant negotiations with the insurer regarding the examiner, the testing to be conducted and the scope of the examination. In addition, have a third person appear at these examinations with you to record events.



**Not hiring an attorney who is experienced in disability insurance litigation.**

Only a small number of attorneys in the U.S. understand how to handle disability cases. Litigating such claims is very different from handling other contract claims. Interview candidates by phone or in person before hiring a lawyer, and check out the firm's website.



**Failing to engage counsel early enough in the claims process to avoid costly delays.**

Effective assistance of counsel at the outset of a long-term disability claim can prevent delays in claims processing. Insurers rely on the relative inexperience of claimants to manipulate and delay the claims process. An experienced attorney can work with your physicians to get needed documentation, negotiate the terms of an IME or FCE with your insurer, help you understand your policy, file your claim and handle an appeal if your claim is initially denied.

what the insurer actually requires from you in order to issue benefits. For instance, careful attention must be paid to the material and substantial duties of your occupation, and thought must be given to articulating how you are unable to perform such duties. Having a disorder or syndrome does not make you disabled under a policy of insurance; rather, the symptoms, restrictions and limitations of the disorder or syndrome determine disability.

When you experience chronic pain, concentration difficulties and chronic fatigue, those symptoms are likely to limit you in the performance of many occupational duties. You must have your treating physician address these symptoms and relate them to employment. It's absolutely essential to work with your doctor and make sure your medical records reflect how you are disabled in terms that relate to the language of your policy. That's why knowing your policy is so important.

The insurer may take the position that the pain is self-limiting, but not objectively verified, that the concentration difficulties are not supported by neuropsychological testing or that the fatigue is not disabling. Consequently, it's imperative that you provide as much support for the limitations as possible. To do this effectively, you can maintain a journal or diary of activities, describe your physical condition after engaging in various activities and address the lack of functionality you experience. This may constitute some supportive evidence for the restrictions and limitations you're claiming.

### **Avoiding potential claim investigation minefields**

There are several common tools utilized by insurance companies to verify disability either before your

claim is approved or to deny continuing coverage at some point after you have begun receiving benefits. Each of these techniques poses potential problems for CFIDS and fibromyalgia claimants. Contractual support for many of these tools may be buried in your insurance policy. However, any request by an insurer to invoke any contractual rights must be balanced with a reasonableness standard.

■ **Independent Medical Examination (IME).** The IME is actually a PME (Paid Medical Examination), and the results are often skewed as such. If the PME physician is being paid by the insurer, it's safe to assume that objectivity can be questioned. Claimants faced with an IME must arm themselves for battle. You should bring a witness, request to videotape the examination and request the insurer to demonstrate the validity and/or necessity of the testing.

When an insurer exercises a contractual right to an examination, a claimant usually has the obligation to attend an examination. However, in any policy there are implied terms of good faith and fair dealing which guide the process. Thus, it may be unreasonable for an insurer to require you to undergo invasive testing by the insurer's doctor, or it may be improper to require you to travel a significant distance to have an examination performed, or it may be unreasonable to schedule an examination on two days' notice. You do have some control over the process.

■ **Functional Capacity Evaluation (FCE).** An FCE is an entirely different scenario. An FCE is not generally contractually required, but insurers nonetheless act as if it's mandated. This test is utilized by insurers to test your maximal effort, which can then be used to

extrapolate that you can work full-time on a sustained basis due to your ability to perform a myriad of tests one time. The results are inherently unreliable, and the tests lack validity.

■ **Peer reviews.** An insurer peer review of the claim relies upon a non-examining physician to address a claimant's functional abilities. This has inherent problems because it precludes you from receiving an appropriate evaluation of the claim. Even when an outside physician is used, it's difficult for a doctor who has never examined you to opine properly on your restrictions and limitations from just a review of the records. Thus, you must ensure that your own treating physician provides well-developed, organized office notes and narrative reports to support your claim.

■ **Field investigations.** Field investigations are common in subjective complaint claims. An investigator will often stop by unannounced to speak to the claimant. The investigator wants to ascertain your activity level, determine whether you are working in another interest or gather other information to be used by the insurer. Caution should always be used when speaking to your insurance company or their investigator. Remember that the investigator is not on a social call.

As noted above, insurers are supposed to adhere to a reasonableness standard, so you should feel free to advise an investigator who shows up unannounced that the timing isn't convenient and that while you are willing to meet, it must be a scheduled visit.

■ **Surveillance.** Surveillance is a common technique used by insurers in CFIDS and FM cases because of the subjective, self-reported nature of these illnesses. It's also used in high-benefit claims where the

insurer is willing to invest significant money to terminate or deny a potentially expensive claim. Claimants must be wary not only of their activity levels while on claim (including going to the gym, even if physician prescribed), but of statements made to the insurer about their daily activities. Inconsistencies can be fatal to a claim, and the expression "a picture is worth a thousand words" holds true with regard to surveillance.

We hope this article has provided helpful information to guide you in filing long-term disability claims and in navigating the minefields in the claim process. In a future article, we will provide more in-depth information regarding treatment by the courts on specific cases and issues that commonly arise in disability claims based on CFIDS or fibromyalgia. ■

#### About the authors

*Justin Frankel and Jason Newfield are the founders of Frankel & Newfield, P.C., a New York law firm focusing on disability insurance claims and litigation. They are the authors of LTD Management, a quarterly publication addressing various issues concerning disability claims. They have handled a multitude of disability insurance claims, appeals and litigation involving chronic conditions, including CFIDS and FM. They can be reached with any questions at 516-222-1600, or by e-mail at [jcf@frankelnewfield.com](mailto:jcf@frankelnewfield.com) or [jan@frankelnewfield.com](mailto:jan@frankelnewfield.com). Or visit [www.longtermdisabilityclaim.com](http://www.longtermdisabilityclaim.com).*





Finding ways to stay in the workforce can be challenging for CFIDS sufferers. In this article, a well-known expert helps guide you through the process of **securing workplace accommodations.**

BY GAYLE BACKSTROM, GUEST CONTRIBUTOR

# Staying on the Job

Having a hidden chronic illness such as CFIDS is stressful by itself, but when combined with the normal stress of a job, you can begin to feel overwhelmed. The state of the current job market, along with the possibility of new layoffs, can leave you feeling like you have absolutely no control over your life. You worry about keeping your job and being able to perform all the tasks that are a part of it. The more you worry, the more stress you experience, and the more the stress impacts your ability to work. It can become an endless cycle, taking its toll on your physical and emotional state. But there *is* something you can do about it.

“Playing the Hand You’re Dealt,” the first article in this series on working with CFIDS (see spring 2004 *Chronicle*), considered the pros and cons of informing your employer about your illness, so that topic won’t be addressed again here. However, that decision will dictate what you do next. In this article I’ll cover ways to help you do your job without revealing your illness, as well as accommodations you can request under the Job Accommodation Network (JAN) if you’re ready to tell your employer about having CFIDS.

## Putting your own accommodations into practice

When you have CFIDS and you want—or need—to keep working, you must decide how to cope with it in the workplace. It’s up to you to take charge of as much of your life and health as possible. You must actively strive to be *proactive*, rather than just being *reactive* to your illness. Because you know your personal situation best, you’ll probably be able to come up with some solutions on your own for accommodating your limitations.

You may have already done things to help in the workplace without even thinking about it. Perhaps you make lists or write yourself notes to help you remember phone numbers, appointments, project due dates and infrequent, but important, tasks. When making those notes, you may already be prioritizing your job tasks by putting the most important first.

Take a conscious, realistic look at the limitations you’re now facing. The most



common symptoms of CFIDS are fatigue, cognitive difficulties, muscle or joint pain, headaches, and sensitivity to light, noise, medications and temperatures. Whether depression and anxiety are a part of CFIDS or a result of it, you may have to cope with these conditions as well. What are your major limitations? How do they impact your work life? How can you compensate for these limitations? How can you perform all the minute details you once took for granted? Asking yourself these questions may sound simplistic, but it's an important step in developing coping mechanisms that can lead to the creation of accommodations you can put in place without your employer's involvement.

Let's look at some of the physical limitations a PWC might face and what kind of accommodations might help you perform your job. Many individuals with CFIDS, as well as those with fibromyalgia, often have difficulty concentrating, are easily distracted and have trouble remembering information on a short-term basis. What can you do to compensate for these problems?

*Celia worked as a secretary/receptionist for a mid-sized firm. She found herself transposing telephone numbers and misplacing important papers on her desk, which rivaled that of the cartoon character Shoe. She was easily distracted from tasks and lost time in picking up where she left off. She knew if she didn't do something soon, she could lose her job.*

*Her first step was to obtain a written copy of a detailed job description, which she then kept handy. She came in on a Saturday and organized her desk and work area, setting it up so she could be more efficient. She set up a tickler file ranking her tasks by importance and subject. While she couldn't con-*

*trol other workers in her office, she did try to minimize the distractions as much as possible. She cleared it with her supervisor to switch her telephone to voice mail to prevent phone interruptions and then returned calls only at set times.*

*She made a point to take frequent breaks away from her tasks, even if it was only to direct her attention away for a few minutes. Although the cost was a bit high for her, she bought an electronic organizer, which stored all the information that was so much a part of her job, and which had an alarm clock to remind her to take a break. She knew there would still be times when rush work and emergencies disrupted her schedule, but it was easier to return to it once the emergency was resolved.*

### **JAN accommodations**

The Job Accommodation Network (JAN) has been providing information on accommodations since 1983 to employers, government agencies, nonprofit organizations, rehabilitation specialists and individuals. This information is provided free and can be obtained online, via a toll-free phone number or with on-site consultants. JAN was designed to help facilitate hiring and retraining people with disabilities, as well as to help retain or promote these individuals by providing accommodation information.

Anyone can contact JAN for a confidential consultation. When the Americans with Disabilities Act (ADA) was first passed, most requests for JAN services came from employers who wanted to ensure they were conforming to the new guidelines. However, in recent years many individuals with so-called hidden disabilities have begun to contact the network, hoping to find ways to keep working.

Accommodations are defined by

## **HOW IT WORKS**

The Job Accommodation Network (JAN) is the most comprehensive resource for job accommodations available. The network provides assistance to employers, rehabilitation professionals and persons with disabilities.

JAN has established a uniform job accommodation process to evaluate what accommodations or modifications an individual needs in order to perform the tasks of a specific job. The process looks at existing products or services that could be utilized as accommodations, even exploring the possibility of designing a new product or service if nothing available meets your needs. If JAN professional consultants are unable to find or create a means of enabling you to perform the tasks of your job, the possibility of an alternative job within your company is explored.

While JAN can be an invaluable resource, there are no guarantees. Sometimes, despite the efforts made, no accommodation is available and you must look for another job somewhere else, consider self-employment or take some time off work until your condition improves enough to try to work again.

## **CONTACT INFO**

Online information  
<http://www.jan.wvu.edu>

Toll-free numbers  
1-800-232-9675 or  
1-800-526-7234

On-site consultations  
Call the numbers listed above  
for information

## DID YOU KNOW?



**The average cost of JAN accommodations is about \$500, but employers who have provided accommodations have found that the benefits to their business have been in the neighborhood of \$5,000. There are tax credits and other incentives available for employers who choose to make the recommended accommodations.**

JAN as any modification or adjustment to a job or the work environment that will enable a “qualified” employee with a disability to perform the essential job functions. To be qualified, you must have the job skills and knowledge necessary to perform the job.

Let’s look at how some limitations imposed by CFIDS can be handled through JAN. Fatigue, for instance, is a major problem for PWCs, and it can have a negative impact on work attendance and punctuality. There are several possible accommodations in this instance; most of them, however, require you to inform your employer about your chronic illness for permission to use them.

*James, a PWC, had been struggling for months to keep working and finally discussed the situation with his supervisor. He had used all of his sick days and often came in late because it was so hard to get up in the morning. With the permission of his supervisor, he was able to work flexible hours, arriving later in the mornings and scheduling regular rest breaks during the day. He could even work later with the help of the rest breaks. On his worst days, James was allowed to work from home using his notebook computer. The company also purchased an ergonomic, adjustable chair, as well as some less expensive items such as copy holders, electric staplers and hole punches, and a telephone headset to help with fatigue and the muscle and joint pain James experienced.*

Another typical symptom suffered by CFIDS patients is headaches, which can cause havoc in your workday. JAN counselors routinely help PWCs find accommodations that can help.

*Ann, a social worker, often had migraine headaches caused, in part, by extreme light, noise and chemical sensitivities. To help decrease the factors that contributed to the headaches, her employer changed the lighting in her workstation from fluorescent lighting to task lighting, added a glare guard to her computer monitor*

*and installed window blinds to block outside light. A fragrance-free policy was adopted for the facility, and her company added air purification devices. The noise levels were also reduced by providing environmental sound machines and headsets.*

### Act today

Whether you purchase equipment yourself or your employer does, the important point is to find accommodations that will allow you to either keep your current job or find a new one. There is help available, and it doesn’t always have to be expensive. Many times common sense can provide possible solutions to energy-draining tasks. Sometimes the modifications are more extensive, but there are tax credits available to help with the expense, and there are nonprofit organizations that can provide funding. According to JAN, the average cost of accommodations is approximately \$500, but many employers found they received tangible benefits of around \$5,000, not to mention the intangible goodwill generated by their efforts to retain good employees.

What is important is that you as a PWC step up and begin the process of finding some accommodations that will fit your limitations. No one else has more of a vested interest in the accommodations than you do, so it’s up to you to start the ball rolling. The reality is that no cure or effective treatments are available right now, and many PWCs need to work for their own self-esteem, as well as to support their family. Don’t be hesitant to find ways to function better in the workforce. And don’t let inertia keep you suffering when some proactive steps could help your workday be more productive, less painful and less frustrating. ■

*Gayle Backstrom is the author of I’d Rather be Working, When Muscle Pain Won’t Go Away, and The Resource Guide for the Disabled. She has had fibromyalgia since childhood and was more recently diagnosed with CFIDS, diabetes and peripheral neuropathy. She has used a wheelchair for the last 3 years and an electric scooter for 10 years before that.*

*Gayle has been a professional writer for more than 35 years and during much of that time, she found unique ways to keep working, often developing accommodations before she was even aware of the term. She lives in Denton, Texas, with a new roommate, who takes care of the more physical tasks so Gayle can continue writing. She also has five cats who bring love and laughter to her life.*

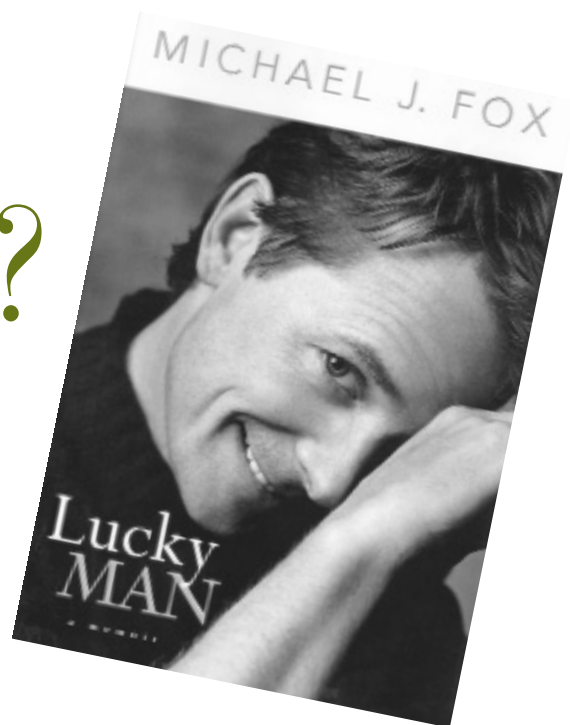




# Lessons Still Unlearned?

In the world of CFIDS activism and advocacy, there are still lessons to be learned about the **power of shared purpose.**

BY ANGENETTE RICE-FIGUEROA, DIRECTOR OF PUBLICATIONS



With an estimated 800,000 Americans suffering the physical and emotional effects of CFIDS, there's plenty of room for a variety of local, regional and national advocacy organizations and for divergent opinions on the challenges that face us in the coming decade.

Most CFIDS groups and individuals share common goals—for instance, to stimulate research into the cause of and cure for this life-altering illness. However, a reluctance to work cohesively and acknowledge the contributions of others can make it difficult to project a collective voice on issues that would make our common goals more attainable.

Not surprisingly, organizations associated with other illnesses deal with the same issues. Unfortunately, patients themselves are sometimes drawn into these contentious circumstances. Maggie Wallace, a CFIDS advocate from the United Kingdom, suggested that the CFIDS community could benefit from Michael J. Fox's perspective on infighting in the Parkinson's community.

In the following excerpt from his 2003 book *Lucky Man*, the actor writes about the various organizations he encountered after publicly announcing his diagnosis of Parkinson's disease.

Whenever people debate federal funding for medical research, there's an assumption it's a zero-sum game. Any number of "special interest" groups, be they AIDS, cancer, or Parkinson's advocates, are all competing for a bigger slice of the pie. What's really needed, of course, is simply a bigger pie. So why do some patient groups get more than others? And why are others left out in the cold when the money's being doled out? The answer

lies, in part, with the fervor and commitment of the lobbying effort, and that starts in the patient community.

By the end of 1998, my desk was covered with correspondence bearing the letterhead of various Parkinson's organizations across the country. All of them wanted my help in one way or another. The names of some of these groups implied a national reach, but on closer inspection, they turned out to be local organizations affiliated with universities or hospitals or even individual researchers. Some were not set up to address research at all; instead, they were dedicating their time and resources to more basic patient concerns—caregiver support groups, quality-of-life issues, and other worthwhile considerations.

It was a bewildering and daunting landscape, and I set out to study the various players, reading their literature and meeting with them when possible. I soon began to understand that one of the reasons that the Parkinson agenda had not been carried out with a sense of purpose and unity had a lot to do with the factional nature of many of these groups, which refused to work together. The director of one foundation seeking my help even went so far as to say to me, in so many words, "Well, if you don't help us, then, at least, don't help them."

Competing for attention with health-related hot topics like flu vaccine shortages, SARS and plastic surgery means that a chronic illness like CFIDS needs strong advocates. Overcoming a divisive climate like that mentioned by Fox to create a common agenda can go a long way to building a strong voice. ■



# The Role of Neuropsychology

CFIDS patients are often **resentful** when their doctor suggests a neuropsychological exam—and **downright angry** when their insurance company requires it for disability insurance claims. But this exam can actually **help you in unexpected ways.**

**BY LEO J. SHEA III, PH.D.,  
GUEST CONTRIBUTOR**

Often when a physician suggests a neuropsychological evaluation to CFIDS patients, they think: “My doctor thinks it’s all emotional” or “She thinks I’m crazy, but I’m not making this up.” Nothing could be further from the truth. What doctors are saying is that they have noted that your cognitive ability has been compromised, and they are seeking a better understanding of how your thinking brain has been affected by the illness.

The suggestion to get a neuropsychological evaluation can leave you with questions about the whys and hows of the evaluation. A neuropsychological examination, which is also called a neurocognitive evaluation, is administered to assess the clinical relationship between a person’s neurological or brain function and its impact on cognitive and behavioral functions. Its focus is to evaluate the multidimensional impact of neurological

disease, injury and illness on a patient. It can also highlight emotional changes that have occurred due to a patient’s medical or neurological condition.

It should not, however, be confused with a psychological evaluation, which is more limited and largely focuses on the emotions and personality characteristics that have been disrupted by some life event or stressor (divorce, loss of a child, loss of employment, household move, etc.) that directly impacts and limits a person’s emotional functioning and often leads to negative or maladaptive behaviors. While the neuropsychological evaluation will take into account those emotional domains assessed by a psychological evaluation, its primary focus is to understand how CFIDS has impacted the daily functioning of the “whole” person.

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### The basics of neuropsychological testing

The neuropsychological evaluation involves taking an extensive history (including review of medical records) and comprehensively assessing cognitive and behavioral functions using a set of standardized tests, tasks and procedures. It takes approximately 8 to 12 hours of face-to-face contact with a qualified neuropsychologist who has a specialty in CFIDS. During the process, the patient will undergo tests related to general intelligence; effort; reaction time; attention and concentration; speed of processing different types of both visual and verbal information (ranging from simple to complex); a wide range of memory functions; ability to perform multitasking, planning, organizing and prioritizing tasks, problem solving; language usage and verbal and written communications; and sequential thinking and reasoning through simple and complex problems.

The purpose of the testing is to understand how you're presently using your cognitive abilities to get through the day and what problems you're encountering. The tests assess why and how your decline in thinking ability has negatively affected the way you handle the vocational, academic, economic, family, interpersonal and personal

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demands of everyday life.

The testing time can vary depending on a patient's medical condition, medication regimen, energy level or travel time on the day of testing. For CFIDS patients it's best to test over a series of days, normally two to four hours per session. CFIDS patients don't have the stamina to sustain more than four hours of testing, and even that amount of time in a single session will require a number of refresher breaks. Any time beyond that in one session becomes so taxing for CFIDS patients that results of the neuropsychological evaluation are likely to be meaningless, and patients won't have the stamina to put forth their best effort. Often, CFIDS patients will need approximately one week between sessions to effectively recover from the testing procedures.

### Using the results to benefit you

The results of the neuropsychological evaluation are used in a variety of ways to benefit CFIDS patients. You should use it to:

**1 Create an effective treatment plan.** A treatment plan is designed to address the cognitive weaknesses that have been uncovered by the evaluation. Treatment typically involves cognitive remediation with a qualified neuropsychologist who specializes in CFIDS. Cognitive remediation, a treatment intervention that was originally used with patients who suffered brain injury, is now widely used for patients who are affected by neurological illness, attention-deficit disorders and other medically involved illnesses. This method teaches CFIDS patients compensatory strategies that will help improve cognitive problems. Most often, the treatment plan will also include psychotherapy to help you deal with the significant emotional losses that have accrued because of the devastating effects of CFIDS (loss of job/work; reduced interaction with a spouse, significant other, family or friends; financial problems; or depression, mood changes and anxiety).

**2 Support your disability claim.** Many CFIDS patients become so disabled by the illness that they can no longer work and must seek some form of compensation to provide for even basic living expenses. This is done by seeking compensation from Social Security and/or from a private disability insurer (if you have a preexisting policy at the time of illness onset). Apart from medical records, these funders will usually require a neuropsychological evaluation that documents the cognitive and emotional declines that justify your need for disability benefits.



**3 Justify job accommodations.** Like many CFIDS patients, you may still be able to carry on your functional duties and daily roles, but the effects of this illness—especially reductions in your level of physical and mental energy—require you to reduce the demands of your roles in the workplace and at home. If your ability to perform is limited, you can use the results of a neuropsychological exam to seek accommodations from supervisors and family members to assist you. This may include such things as reducing your work schedule, taking some assignments home, limiting the complexity of tasks, redefining your job role and extending time limits for task completion.

**4 Educate all your medical specialists.** Unfortunately, some medical specialists are not aware that the psychological presentation of the CFIDS patient is neurologically/organically based, and they may ascribe your functional status solely to emotional problems. Furthermore, they may not have a precise understanding of the differences among the fields of

psychology—for instance, neuropsychology vs. clinical psychology vs. experimental psychology. Consequently, they may refer you inadvertently for a psychiatric or psychological evaluation when your problems are cognitively based. A thorough neuropsychological report can help such physicians understand the basis of a patient's presentation as well as provide further understanding of the cognitive domains that are negatively affected. This allows physicians to offer better and more precise referrals for you in the future.

**5 Educate your family members and significant others.** CFIDS is not only a systemic illness that disrupts your physical and psychological life, it's also one that invades and disrupts all your external support systems. A CFIDS patient's decline in personal functioning is impacted by the frustrations and burdens the illness places on those most needed for support. The findings of the neuropsychological evaluation can be used to help educate those individuals and help them better understand the nature

and complexity of the deficits you experience. It can guide them in how to interact with you to reduce stress and reconstruct more positive vocational and social roles and interactions.

### When tests should be performed

A neuropsychological evaluation should be ordered by your physician as soon as a CFIDS diagnosis is made so that a baseline of cognitive functioning can be established early in the medical treatment. This has advantages both to the patient and the physician since it helps both understand the nature and degree of cognitive deficits and how they impact your life. By having this information early in the process, you can gain greater insight into your thinking, feelings and behavior so you can lessen the emotional consequences that can result from uncertainty.

The knowledge derived from the evaluation often verifies patients' internal assumptions about their functional deficits. The physician can use the information to track a patient's cognitive and psychological progress and make any regimen or medicine changes that will enhance the patient's performance. Serial neuropsychological evaluations should be conducted one year after the first evaluation to evaluate treatment response and then approximately every two years thereafter.

### Choosing a neuropsychologist

It's usual practice for a physician ordering a neuropsychological evaluation to provide you with the name and contact information of a qualified neuropsychologist who is familiar with CFIDS. If your doctor doesn't provide a referral, ask for one. Since this evaluation is usually uncharted territory for a CFIDS patient, there are a number of things

## Did You Know?

- If you file a claim for Social Security or long-term disability insurance, you may be required to take a neuropsychological exam. (See related story on page 6.) It's important to use this evaluation to your advantage. A neuropsychologist who understands CFIDS can be a crucial ally in that process.
- A neuropsychological evaluation can also help you secure needed workplace accommodations from your employer so you can continue working on a full-time or part-time basis. (See related story on page 10.) The information can also help your family members understand the cognitive and functional impairments that impact family life in stressful ways.
- Neuropsychological testing is not the same thing as a psychological evaluation. If your doctor refers you to a neuropsychologist, don't assume your mental state is being questioned.
- A neuropsychological evaluation isn't cheap. It typically costs between \$2,500 and \$3,500.

to keep in mind when contacting and interviewing a proposed neuropsychologist:

**1 Interview the neuropsychologist by phone prior to making an appointment.** Ask about the doctor's experience with CFIDS patients, how many patients he has evaluated and how many patients he has treated for CFIDS following evaluation.

**2 Clarify fees and payment schedule.** It's important to know the cost of the entire evaluation before making an appointment. This should include the clinical interview, all testing sessions, the finished report and the feedback session. The feedback session is a face-to-face meeting with the neuropsychologist to explain and clarify any questions you may have about the results of the evaluation.

Professional charges vary according to geographic area and how the reports will be used. Reports used for disability purposes tend to be more extensive due to the requirements of the disability funders and are usually more expensive. While the face-to-face portion of the neuropsychological evaluation takes 8 to 12 hours, the time required by the neuropsychologist to complete the scoring, data analysis, report writing and feedback will normally double that amount for a total of approximately 20 to 24 hours of work. Costs typically vary from \$2,500 to \$3,500.

You should also be aware that many neuropsychologists don't take insurance, but they do provide an invoice you can file with your insurer for reimbursement. While most insurers cover approximately 80 percent of the fee, some cover

the entire cost. You will need to discuss this with your insurer, especially if your plan requires preapproval for services.

**3 Clarify the number and duration of sessions.** It's important to know how many sessions you need to plan for and how long each session will be. You should explain to the neuropsychologist about your energy level and what times are best for you during the day. Most CFIDS patients have a specific period of time each day when they function best, and this needs to be shared with the neuropsychologist for scheduling purposes.

**A neuropsychological examination, which is also called a neurocognitive evaluation, is administered to assess the clinical relationship between a person's neurological or brain function and its impact on cognitive and behavioral functions.**

**4 Discuss terms of the written report and feedback.** You will want to know how long it will take after the completion of testing before the final report will be issued. You'll also want to know if the report will be provided at the feedback session or if you will receive it prior to the feedback session so you can make notes and discuss particular concerns at the session. If you wish to bring a parent, spouse or significant other to the feedback session, you should inform your neuropsychologist's office so they can make space accommodations.

**5 Find out what to bring.** You'll want to know what you must bring to each session, such as glasses, hearing aids, medication, refreshments and form of payment. Also ask what medical records the

doctor will need and if you should send them prior to the first appointment or bring them with you. Inquire if any other information is needed, including insurance forms if the doctor takes or participates in an insurance plan. Be sure to bring a list of all medications and dosages you're taking at the time of your first session, as well as the full contact information for all insurers, doctors, therapists, lawyers and agencies with whom you are working.

Far from something to avoid like the plague, a neuropsychological evaluation can actually be very useful in improving your quality of life. It's helpful for CFIDS patients to view this evaluation as a beneficial and necessary adjunct to advance your holistic treatment and rehabilitation. The testing will be stimulating and interesting, and the detailed information that's gathered will contribute to a better understanding of the impact of CFIDS on your life and therapeutic outcome. ■

*Leo J. Shea III, Ph.D., is a clinical assistant professor of rehabilitation medicine at the NYU Medical Center and a neuropsychologist in the Outpatient Psychology Department at Rusk Institute (NYUMC). Dr. Shea maintains a private practice called Neuropsychological Evaluation and Treatment Services in both New York City and Boston.*



# Unraveling the Puzzle

BY SUZANNE VERNON, PH.D.,  
GUEST CONTRIBUTOR

Those of us who have dedicated our scientific careers to research on chronic fatigue syndrome (CFS) have accepted the ambitious challenge of piecing together the puzzle of one of the most complex illnesses. Before we knew the entire sequence of the human genome, scientists would study a few genes at a time. Even as late as a decade ago, only around 500 genes were available for study in the public domain. We were trying to put together a 30,000-piece puzzle with only 500 pieces. Then that number grew to 3,800 puzzle pieces (genes) available to us. Today, all the pieces for this massive jigsaw puzzle are finally before us with the completion of the human genome sequence.

Now we can study all the genes in the human genome, the activity of these genes and how tens of thousands of genes and proteins work together to maintain the body in a state of health and well-being. It's an exciting yet humbling task. The CFS laboratory at the Centers for Disease Control and Prevention (CDC) is currently measuring the activity of 30,000 genes from 200 subjects enrolled in a clinical evaluation of CFS conducted in Wichita, Kansas. Fortunately, we have learned how to deal with the overwhelming amount of data generated by gene sequencing, and we have the computational means to make sense of the data. Within six months to a year, we hope to be able to use the Wichita data to zoom in on the likely pathways that are altered or abnormal in the peripheral blood mononuclear cell population.

The molecular epidemiology component of the CDC's CFS program was established seven years ago with the intent of establishing a strong laboratory effort for biomarker discovery and pathophysiology studies that was tightly coordinated and integrated with the epidemiology component of our CFS program.



# ing the Cause of CFS e Post-Genomic Era

In the world of CFS research, a **multidisciplinary approach may hold the most hope** in the race for a biomarker. A collaborative team at the CDC is integrating genomics with proteomics to understand the pathogenesis of the illness so **therapeutic and prevention strategies can be developed.**

Several of the intervening years have been spent in the research, development and optimization of powerful and novel genomic and proteomic technologies. We purposefully chose methodologies that were exploratory and hypothesis-generating since no one etiology or biomarker has been identified for CFS.

## **The basics of genome biology**

To appreciate the wealth and complexity the human genome has to offer to our CFS research, it's worthwhile to first review some basic aspects of genome biology. The genome is made up of DNA (deoxyribonucleic acid), a molecule comprised of four substances that are represented as the letters A (adenine), T (thymine), G (guanine) and C (cytosine). So DNA can be thought of as a four-letter alphabet. These four letters are used to make "sentences," or genes. It's estimated that the human genome consists of at least 30,000 genes. The DNA of the genes can be active, producing message RNA (ribonucleic acid)

from the DNA. This activity is called transcription, and it's the intermediate step before a gene becomes a protein.

We measure gene expression activity in an attempt to identify markers of CFS and to further our understanding of disease pathogenesis. Gene expression is an important step, but it doesn't necessarily provide all the information necessary to understand CFS. To make our search for disease biomarkers more complete, we also assess blood proteins, the result of gene expression activity. This protein profiling is called proteomics.

Our CFS research effort is based on the premise that peripheral blood serves as the representative sample of the systemic state, allowing for evaluation of multiple pathologic and physiologic pathways potentially involved in the illness. This premise derives from the fact that each of us has about five liters of blood that travel throughout our body on a daily basis. The peripheral blood is packed with a variety of cell types called peripheral blood mononuclear cells, each with dis-

tinct functions. These cells travel throughout the body, including to and from the central nervous system, helping to maintain homeostasis, or potentially causing immune-mediated pathology.

By measuring the activity of peripheral blood cell genes, we anticipate that we can identify markers for CFS and, most optimistically, that we can identify the pathophysiological processes involved. Both the cellular component and the liquid component of the peripheral blood are rich sources of information for unraveling the cause of CFS.

## **Understanding the technologies being used**

Before discussing the kind of information that gene activity and protein analysis provide, I will briefly review the relevant technologies. The technology we use for measuring peripheral blood cell gene activity is called microarray technology, or gene expression profiling. It's worth noting here that microarray technology had to be adapted for use with our human samples, which are very precious and very limited. For example, we routinely only withdraw one 10-milliliter tube of blood from people, and when we started using microarray technology in 1998, the procedure required the equivalent of one liter of blood, 100 times more than we had!

Optimizing microarray technology for use with limited biological samples from our human subjects took us several years, and now we have it down to a fine art. First, we isolate cells after the peripheral blood has been collected by routine venipuncture. The cells, which are very similar to balloons, are burst open and the RNA from any gene that is active is isolated. This gives us thousands of RNA molecules

representing the activity of the estimated 30,000 genes in our DNA.

To make any sense of the RNA molecules we have captured in a tube, we have to be able to see them. The only way to see RNA molecules is to put a tag on them that we can subsequently detect. To do this, a copy of each RNA molecule is made, and in this replication process detector molecules are added that allow us to see, or detect, these RNA copies. This enables us to measure gene activity.

To understand how gene activity is measured, recall that RNA molecules are derived from the DNA (RNA represents the activity of DNA). Because of this, RNA is complementary to the gene it's derived from and will stick to the complementary gene in a way similar to how a zipper comes together. Here is where our knowledge of the complete human genome sequence comes in handy. Because we know the sequence of all the genes in the human genome, we can synthetically make portions of these DNA molecules and put them onto a microscope slide. The result is a slide with 30,000 known genes spotted, or arrayed, in an orderly fashion on the slide, hence the name *microarray*.

Now the researcher has a microarray with all the known genes and a labeled RNA sample from a subject with all the unknown gene activity contained in one tube. The labeled RNA sample is placed onto the microarray, and because RNA is complementary to DNA, the active gene molecules will stick to, or hybridize to, the gene it was derived from. The labeled RNA that hybridizes is detected with light, and the amount of gene activity directly correlates with the light intensity. The light intensity, representing the gene activity, is analyzed and compared in this way for each of the 30,000 genes on the microarray.

Measurement of the gene activity for the 30,000 genes generates an expression profile for each person we study. The expression profiles are compared to each other, and using sophisticated analytical techniques, similar expression profiles are grouped together. In fact, microarray gene expression profiling of the peripheral blood has shown us that several genes exhibit different activity in people with CFS compared to nonfatigued controls. Quantitative analytical techniques can identify genes that have more or less activity in people with CFS.

Gene expression of peripheral cells tells us how the body is responding to the illness from the "eyes" of the blood cells. The differences in gene activity give clues to what may be going wrong in CFS patients.

For example, we know that peripheral blood cells travel throughout the body to respond to stressful triggers (for example, infection). If one of the causes of CFS is in the ability of the blood cells to respond appropriately, we would anticipate seeing gene activity differences in signaling pathways. Even if the primary cause of CFS is not in the blood cells, but somewhere else in the body, the peripheral blood cells will serve as disease sentinels, giving clues to where in the body the problem may lie.

Indeed, the blood is a rich source of information, both when examining the cells in the blood and when examining the blood fluid, called serum. The serum contains proteins and protein fragments from every cell in the body. We measure serum proteins to get an assessment of total body gene activity using a technique called SELDI-TOF (surface enhanced laser desorption ionization time of flight). While the name is incredibly long and complicated, the technique is a beautifully simplistic

approach that boils down to zapping proteins with a laser to see how long it takes them to fly to the detector. This flight time determines the exact size of the protein. Knowing the size, we can determine what the protein is.

Proteomics, the protein profiling just described, holds some of the greatest promise for diagnostic marker discovery in CFS.

Why? Because serum is the "liquid dumping ground" for all organs and cells in the body. By comparing serum proteins from people with CFS to nonfatigued people, we will be able to determine the differences. In addition, this protein information can be integrated with the gene activity information to determine what may be causing these differences.

With all of this wonderful technology available, you may be asking why, in spite of more than a decade of CFS research resulting in more than 3,000 peer-reviewed scientific and medical publications, there are no confirmatory physical signs, laboratory abnormalities or known etiologies. One of the most likely reasons is because there is no known or accessible lesion to sample. Researchers have studied a variety of biologic

**Prior to the completion of the human genome sequence, the CDC's Molecular Epidemiology Program successfully demonstrated that measuring the activity of approximately 1,600 genes could distinguish most people with CFS from healthy, nonfatigued people.**

samples including urine, muscle, blood and saliva in search of clues to this debilitating illness. We know CFS is not the result of a single gene mutation or environmental factor. That has made the puzzle of CFS difficult to solve. We'll have to integrate clinical, epidemiological and molecular information to understand CFS.

### **Integration holds the most promise**

It's unlikely that one group or one discipline is going to solve the puzzle of CFS. The illness is probably the result of a number of different triggers or multiple system breakdowns. Thus, the CDC's CFS group is multidisciplinary and includes immunologists, neurologists, molecular biologists, epidemiologists, psychologists and endocrinologists. We need to integrate past anecdotal data from the patient population, research information from various disciplines and the knowledge base gained through those 3,000 past research studies to help us decipher the genomic and proteomic information we are gathering.

Prior to the completion of the human genome sequence, the CDC's Molecular Epidemiology Program successfully demonstrated that measuring the activity of approximately 1,600 genes could distinguish most people with CFS from healthy, nonfatigued people. While this study was limited because of the small numbers of genes that could be assessed, it demonstrated the utility of the peripheral blood in identifying differentially expressed genes in CFS.

We have gone on to show that the activity of approximately 100 genes differs between people who describe their illness as coming on suddenly vs. those who report it as gradually occurring. We have also

## **CDC HOSTS MEETING ON HIGH-TECH SOLUTIONS TO CFS PUZZLES**

Researchers, engineers, computer whizzes and rocket scientists recently gathered for two-and-a-half days at the prestigious Banbury Conference Center on the campus of Cold Spring Harbor Laboratories, where DNA-discoverer Dr. James Watson fosters leading-edge research on a wide array of topics.

The meeting, which was held September 19-22, in Cold Spring Harbor, New York, was the third in a series of CFS-inspired think tanks sponsored by the CDC. It brought renowned experts in immunology together with those using mathematics, physics and engineering principles to analyze complex data sets and model intricate biological systems. Organizer Dr. Suzanne Vernon structured presentations to provide guidance for the CDC's CFS research program, seeking to link results of epidemiology, clinical studies and high-tech proteomics and genomics investigations. In the final session, small groups formed to conceive possible computational solutions to integrate a huge data set from the Wichita clinical study of more than 200 CFS patients and control subjects. This study amassed thousands of discrete data points on multiple body systems and cognitive and physical functioning for each subject. The CDC is considering continued involvement of some of these experts to generate novel means of analyzing and interpreting results as they search for a CFS biomarker.

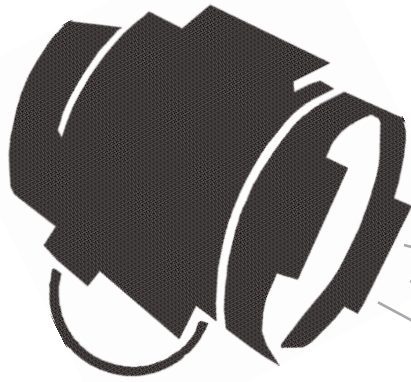
demonstrated that gene activity is different in people with CFS in response to an exercise challenge and in response to infection. Both these studies measured the activity of 3,800 genes and are being prepared for publication.

I hope the work described here gives you an idea of our CFS program and goals and an understanding of how these advances will propel the CDC's CFS program into data-driven experimentation. It's this systematic and methodical research approach that gives us the greatest opportunity for developing diagnostic tools and therapeutic and prevention strategies for CFS. ■



*Suzanne Vernon, Ph.D., is the team leader of the CDC's Molecular Epidemiology Program. She works with a multidisciplinary team of 14 intramural and 10 extramural researchers who are trying to unravel the mysteries of CFS. Dr. Vernon (right) is pictured here with Dr. Toni Whistler, senior investigator and laboratory manager of the CFS genomics research effort.*





# Spotlight on Giving

Whether it's a **gift of time, money or expertise**, there are countless ways to support the Association's battle against CFIDS. Young Morgan Schafer found a **meaningful way to make a difference** with his bar mitzvah project.

BY MEGHAN BRAWLEY, SUMMER INTERN

Anyone can empathize with a cause, but not everyone spends the time or energy to go the extra mile to raise funds for that cause. As a rule, teenagers busy with school, sports and hanging out with friends often don't see beyond their day-to-day concerns. With only 13 years under his belt, Morgan Schafer is already an exception to that rule.

The California eighth grader raised more than \$2,500 for the CFIDS Association of America this spring. He undertook the task for his bar mitzvah project to help support research to find a cure for CFIDS; but most of all, he did it to help families like his that include a parent with CFIDS.



**Morgan Schafer worked hard to raise funds for CFIDS research to benefit his mom, Rosalind.**

Morgan's mom, Rosalind, was diagnosed with CFIDS five years ago. Since then, Morgan has seen the toll the illness has taken on his mom and learned to take on new responsibilities to help her. "When she's just sitting in bed, I feel really sorry for her," said Morgan.

A cheerful, upbeat guy, Morgan has adjusted well to most of the changes in his family life, but admits to being disappointed his family can't vacation to faraway places anymore. "I'm kind of bummed out that we can't go on vacations, but I hope my mom will get better and that will change."

As part of becoming a Jewish adult at age 13, Morgan celebrated his bar mitzvah with a big party on March 27. A bar mitzvah ceremony culminates a yearlong study into the intricacies of the Torah and denotes the new obligations and privileges held by an adult Jew. Many synagogues encourage or require students to participate in or initiate a mitzvah project in order to contribute to the community or to help the less fortunate.

In preparation for his bar mitzvah, Morgan looked at many opportunities to volunteer his time and energy and eventually chose to lead a fund-raiser for the CFIDS Association. "I chose this specific disease not just because it's interesting, but because my mom is diagnosed with it. Slowly, she is regaining her strength and health. Someday I hope the illness will be gone," wrote Morgan in the letter he sent out to family and friends asking for donations.

Morgan's first experience with fund-raising was a great success. In less than a month, he collected \$2,515 from 51 donors and was very thankful for their "help fighting an illness that strikes so many around the world."

Whether you raise money or awareness, imagine the possibilities for the CFIDS community if each person affected by the disease would take the initiative to go the extra mile as Morgan has done. As he says, "Maybe together we can conquer it." ■

# One Victory at a Time

Many longtime *Chronicle* readers will remember PWC Heather Frese. Here, she shares a poignant story of **conquering CFIDS one milestone at a time**.

Her latest milestone is graduation from college, made especially bittersweet by her father's battle with cancer.

BY HEATHER FRESE, GUEST CONTRIBUTOR

**H**old on to your tassels, folks, because I've finally done it. I graduated from Muskingum! It's been a bit hectic since then, with moving out of my apartment and looking for new digs in Athens (where I'm now in grad school at Ohio University), but I wanted to share the news with the many members of the CFIDS Association I've met and worked with over the years.

At rehearsal the day before graduation, the vice president of academic affairs announced that "with a 4.0 in all previous coursework, I am pleased to announce that your valedictorian is Heather Frese." My jaw dropped, and then I sat and giggled with disbelief while people congratulated me.

May 8 was a beautiful, sunny Saturday, and my emotions were all over the map. Saying goodbye to everyone, doing my sorority wills, taking my last finals—everything was so bittersweet. My friends Holly and Ashley helped me get my robe ready with all my nifty cords. I had black and red for Sigma Tau Delta (English honorary); gold and white for Order of Omega, the Greek Academic honorary; navy, cream and light blue for Omicron Delta Kappa, the leadership honorary; and three burgundy Dean's List cords.

I had asked the powers-that-be if Dad could give me my diploma and received varying replies. The best we hoped for was that maybe he could shake my hand after the bigwigs handed out the parchment. But I have to hand it to the Muskingum faculty and staff, they came through big time, and I got to receive my diploma from the most influential person in my education—my daddy.

It pierced my heart that Dad was too sick to be in the faculty processional and recession lines that the new graduates walk through. I'd always planned on breaking rank and jumping out to give him a hug. He was so incredibly sick from chemotherapy that he was driven up

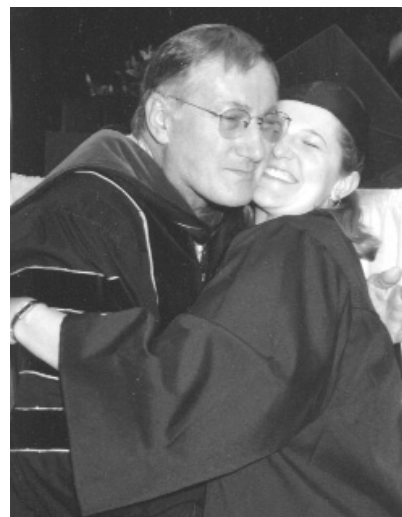
to the door, rested in someone's office and watched the commencement on TV. He wasn't brought out until right before it was time for my name to be called. He was too weak to go up the steps to the platform, so I had my name called, walked across the platform, shook hands with the president and a Board of Trustees dude, then went down the steps to Dad and he gave me my diploma.

It was such a beautiful moment, and so heart-wrenching at the same time. I grabbed him for a hug as soon as I could, and he was cold despite temperatures in the high 80s. He was shaking and thin, far too thin, and a little stooped over. But we were still smiling, still happy, so happy to be there together. I found out a couple of days later that the faculty gave us a standing ovation. Mom had to take him right home, so they both missed the rest of the ceremony.

It almost seemed as if we had switched roles, and I couldn't help remembering all the years when I was so desperately ill that sitting up for an hour was a huge accomplishment. Through it all, my father was a tower of strength. On graduation day I was stronger and healthier than he was, and I hated the illness that was gripping him with the same intensity I hate CFIDS.

Finally graduating from college at the age of 29 is a huge victory. I've come a long way from the days when I used to attend CFIDS Association board meetings in my wheelchair. I'm far from cured, but my life is moving forward, and I just wanted to let all my old friends know.

My father, who died in August, was after me for years to write an update piece for the *Chronicle*. So this is for you too, Dad. My family gives me endless strength, support and love, and I'll do my best to keep on keepin' on. ■



# What's in a Name?

BY MARCIA HARMON, DIRECTOR OF COMMUNICATIONS

In *Romeo and Juliet*, Shakespeare asks “What’s in a name? That which we call a rose by any other name would smell as sweet.” In the CFIDS community, we have been struggling with the question of what impact changing the name chronic fatigue syndrome (CFS or CFIDS) to another name would have on the illness. Would it still “smell as bad”—have as little respect and legitimacy—as many believe it does now?

The question, of course, is far more than rhetorical. Many people are convinced the current name has detrimentally affected public perceptions and research dollars for this illness. The name chronic fatigue syndrome is so woefully inadequate and so misleading that it has generated disdain in the patient community and confusion among the general public since it was first coined. It’s no wonder, then, that the belief that a more medical-sounding name would improve perceptions, and the social and scientific context, of this illness is widespread in the patient community.

One contingent in the CFIDS community favors a name change to ME or myalgic encephalomyelitis. ME advocates are filling listservs, chat rooms and support group meetings with their reasoning—some sound and some questionable. The argument is complicated by the fact that some ME advocates believe myalgic encephalomyelitis (brain or spinal cord inflammation) is the correct term for ME, while others prefer myalgic encephalopathy (which emphasizes the brain, but doesn’t connote inflammation). Still others, including most in the research and medical arenas, believe both terms are incorrect because they emphasize brain dysfunction when the pathophysiology of the illness has yet to be determined. This contingent believes changing to a brain-central term would steer research away from other promising tracks that don’t point to neurological etiology.

We’ll take a look at ME advocacy in the next issue of the *Chronicle*. In this issue, we’d like to share the results of a questionnaire the CFIDS Association sent in September to the subscribers of our e-newsletter, the *CFIDSLink*, who live outside the United States. We wanted to examine what ordinary CFIDS patients and doctors—as opposed to activists or people affiliated with a patient organization with a name change agenda—think of the name and how they think the name has impacted the way providers and the general public view

the illness and how their government has responded to it.

More than 10 percent of our foreign subscribers have responded to the questionnaire so far, and the feedback is fascinating. For instance, perceptions are clearly impacted by personal experience. Some respondents in Canada, for instance, fervently believe that most doctors still think the illness is psychological, while other Canadians are convinced that attitudes have changed and that most providers in that country believe the illness is physiological. Interestingly, about a third of the respondents worldwide support the name ME, a third don’t like ME and a third don’t think the name matters and believe efforts should focus on educating people about the illness instead of a name change.

Another surprising finding is that support for the name ME is higher among people in countries where that name has never been used. There seems to be a “wishful thinking” dynamic that makes them convinced that a more medical-sounding name would improve the way the general public, providers and government agencies treat CFIDS patients. But that hasn’t been the case for many patients in other countries, as you will see in our coverage of survey results, which begins here and continues in the January issue of the *CFIDSLink*. If you’re not a subscriber to the *Link*, just call us today at 704-365-2343 or send a message to [kalmond@cfids.org](mailto:kalmond@cfids.org) and we’ll sign you up for this free newsletter. ■

“The illness is usually called ME here, but there is still a certain stigma attached to this disease. It doesn’t generate the same respect as other illnesses such as MS. Most doctors view ME as a physical illness here in Ireland. My own doctor has been amazing. I was his first patient with ME and he has had to learn all about this illness. I have given him a lot of information over the years, especially from the *Chronicle*.

Among the general public, some people still have the attitude that it’s all in my head. I don’t think that will change until we know what causes ME. I have lost some friends. They were very insensitive, and so I decided I didn’t want toxic people like them in my life.”

—Caroline Sweeney, Ireland



“I have been ill for 10 years. I live in Ecuador in South America. Most doctors don't know this illness exists. I have asked several doctors what's wrong with me and they think I am faking and not really ill. I am treated like a mentally disabled person here. I feel very angry and want to scream, 'Please, somebody help me!'

The government doesn't help citizens here, much less those with a disease they don't know about. My parents are giving me economic help because they are able to, but when they can't help anymore, I will be in the street. That's why I'm desperately seeking help outside this country and why I am contacting the CFIDS Association.”

—Carmen Alicia Ripalda Quevedo, Ecuador

“The illness has gone from being called ME in the late '80s and early '90s to the name CFS. ME was seen as the 'yuppie disease.' There wasn't much information available about it.

I have actually given up on mainstream doctors in the U.K. They seem to shrug their shoulders and say, 'Sorry, there is no cure.' You are very much on your own. There are some so-called specialists, but I have spent so much of my own money with various healers, all of which amounted to nothing.

All in all, I'm not looking for help in this country. I think the U.S. will become the real pioneer for this disease, and then it will gradually filter over to Europe. But if it's going to cost money, forget it; the British government has no interest in spending money in the health sector!”

—Kevin O'Sullivan, United Kingdom

“I always use the term ME since it is a much better name than CFS. I think it gives the illness more credibility and reflects the serious nature of the disease. The name CFS trivializes the condition in my opinion. I would do anything to just be fatigued!

It is the general public I have had misunderstandings with, not doctors. I am lucky to have Rosamund Vallings as my doctor, who is wonderful and very knowledgeable about ME. She gives free talks regularly and is very supportive. I think with other doctors it varies, but I would say ME is recognized as an illness of physical origin more nowadays.”

—Claressinka Anderson, New Zealand

“Most doctors in Bogota don't really know what CFIDS is. I'm a doctor myself and had to live the nightmare of the ignorance of most specialists about my condition. I have not yet met a single doctor who understands and treats the problem from an integral point of view. We are seen as the unwanted patients because we don't get better.

I absolutely know this is a real physical disease which somehow (perhaps a chronic viral infection) wreaks havoc in the neuroendocrine system and the autonomic nervous system, causing a constellation of symptoms. The disease has disabled me, and I only work part-time as a radiologist now.

The term ME is not known here. I am absolutely sure it would make a huge difference to use it instead of CFS, both from the medical and social point of view.”

—Dr. Arturo Velez, Colombia

“As for the name, most people in this country call it *fatiga cronica*, which is chronic fatigue. Worrying about changing the name to myalgic encephalomyelitis to get more respect is typical American nonsense. Is respect dependent on a name?

Doctors here don't know whether its origin is physical or psychological. Some think it has to do with the limbic system. Personally, I'm not much influenced by doctors because I've had very bad experiences with them. I had to find my diagnosis myself and then check with a doctor, who said I was right. So I follow my own knowledge and find the treatment I'm comfortable with—mostly alternative medicine.”

—Sibila Seibert, Argentina

“I'm a practitioner, not a person affected by this illness. Since the name myalgic encephalomyelitis is not accurate, most doctors here don't like this term. Many health professionals still believe people with ME/CFS have a psychological disease or are malingerers, though attitudes have been changing more rapidly in the past two years. I think some of this is due to the fact that many health care workers feel impotent when dealing with this condition.

The illness is covered by benefits, although securing them is a lottery that those affected by ME/CFS often do badly in compared with people afflicted by other conditions.”

—Dr. Kelly Morris, United Kingdom

“Personally, I have no problem with the term CFS. I think the way the media, medical practitioners and other professional bodies portray the illness is more important than giving it a serious-sounding medical name. I refer to the illness as CFS rather than ME, although I have friends who insist on the name ME. I have found that most people have at least heard of CFS and have some limited understanding that it's a nasty illness.”

—Carolyn Gee, Australia

“It is called CFS or ME here in Canada. Neither name gets more recognition or respect than the other. ME seems too technical for people to understand, and CFS makes most people just assume it's a fancy name for being lazy. There's quite a stigma attached to this illness here, no matter which name is used. Maybe through further education that stigma will be eliminated.”

—Shelley Whiting, Canada

## The Invisible Burden

I came down with CFIDS in September 1984, but I wasn't diagnosed until eight years later. My history and symptoms read like a textbook case. In one day I went from a healthy, tennis-playing, 25-year-old to a handicapped person with the energy of an 84-year-old.

The first six weeks were the hardest. I was unable to climb even one flight of stairs to go up to the kitchen to eat. I was in bed and completely unable to run the computer software consulting firm I had just started.

CFIDS destroyed my ability to function properly and work a full-time job. At the time I became ill, my big client was a Department of Defense contractor. The paranoia of the Cold War was running rampant. With my cognitive abilities severely impaired, I made an innocent mistake at work. To make a long story short, they thought I was some kind of spy. Even though I was one of the best consultants they had, they fired me just before Christmas. I don't know which was worse: being incurably sick, losing the job or being suspected of not being a loyal American.

The years rolled slowly by, punctuated with frustrated hopes and abandoned dreams. This unknown disease was like a quicksand that pulled me down whenever I struggled against it. I was the kind of person who got a sense of self-worth from what I accomplished. In my mind, the lack of accomplishments equaled a lack of self-worth.

Unable to work full time, I searched for meaningful ways to use what little energy I had. I decided to

go to school one day a week. I hoped that if I had two days to recover for every day I spent out of the house, I could maintain an even energy level instead of losing ground. I managed two days a week out of the house, one day for school and another day out for getting groceries and prescriptions and doing other errands.

It was then that "my life on the balance beam" started in dead earnest. I learned a very important principle: Only do what is most important. I tried to protect my energy level and my time. Not being able to sleep at night and falling prey to bronchitis, colds and other infections was a recurring fight. The fevers, swollen glands, sore throats, joint pain and other CFIDS problems were constant companions.

It took four years to finish the school program, but it was time well spent. Then in 1987 I got married. For our honeymoon we went to Epcot Center, and I remember lying exhausted on a park bench and being completely miserable. My husband, who knew I was sick, couldn't understand why I couldn't just get up after 30 minutes of rest. The park required way too much walking, and I wasn't pacing myself or planning my activities around my energy level.

Boredom became my biggest enemy, and I was constantly tempted to do more than I should to keep it at bay. If I did too much I ended up in bed for three days in a row. My limitations seemed to change from week to week, making it very difficult to know what I could manage. I had to learn



patience. I simply couldn't do what I wanted to do, even after reducing my expectations again and again. I went backwards much faster than I could make progress by resting. I realized I had a certain amount of gas in my tank. I could use it up quickly or slowly. The burning questions were "How much gas is left?" and "How can I get more gas in the tank?"

I then started studying my energy levels. I discovered that on the days I needed a two-hour afternoon nap, I was quite sick and could only be out of bed and functioning normally for about two hours. When I required a one-hour nap, it was an indication that I had an average energy level that day, so I could manage three or four hours of normal functioning. On days when I only needed a 45-minute nap, I discovered I could handle a glorious four to five hours out of bed.

Eventually I found I could gauge when to quit and rest. This led to being able to slowly gain ground. So principle number two was forged: Stop everything and rest before you lose ground.

After seven years of fighting a mysterious illness, I finally accepted the fact that I was sick. I stopped

looking for a quick cure. Acceptance brought some relief, psychologically at least. I learned not to take every up and down so seriously. I was out of the worst of the mental quicksand of angst and guilt so many of us experience.

But CFIDS is always presenting new challenges mentally and physically. Although the mental quicksand diminished, the mental fog did not. Words didn't come easily anymore. That was a shock because I had always been a brilliant student with an unusual ability in languages. I was no longer just fighting infections, but a mental fog as well.

The first sign of the speech problems came when I asked my husband to hand me a utensil in the kitchen. I said, "Hand me the hole with spoons in it," instead of "Hand me the spoon with holes in it."

Sometimes I use similar sounding words incorrectly. The one I substitute always has the same first letter as the one I was trying to say. I think my brain's speech generation ability and word search memory pathways are damaged. The words are wrong in my brain before they are ever spoken.

I finally had the courage to take a full-time job in 1990 because I was feeling stronger. Two months later I was exhausted and had contracted pneumonia from the added pressure of working full-time and commuting. Luckily they let me stay on part-time. I took Wednesdays off and worked 20 hours a week.

After working part-time for about a year, I went steadily downhill. I had to quit even part-time work so I could get my stamina back. A sabbatical was a must.

I was not diagnosed with CFIDS until 1992. One day I heard an ad on the radio for a seminar on chronic fatigue and its various causes. I went to see the doctor

conducting the seminar and finally had my answer: fibromyalgia and CFIDS. He gave me something to correct my sleeping problem. Suddenly, I was sleeping at night! I finally had a handicapped parking pass! I knew what was wrong with me. Hooray! My life had turned a corner.

The next eight years were full of hard-fought rehabilitation. The hardest thing to do was make myself exercise. In 1993 I adopted an adult dog named Darien who, like me, was handicapped. Slowly, he and I rehabilitated together. The first goal was to walk to my mailbox. It was only 50 yards away, but looked like a mile. But we did it, and I started to believe I could do more. By doing a tiny bit of exercise twice a day, we were able to walk around our small block. Months later we walked around the large block.



I wondered what goal I should set next. I wanted to be able to run. I had even stopped running in my dreams because my subconscious had finally accepted the fact that I could no longer run. I set a goal to jog around the big block. This goal was a lot harder than the rest. Progress was anything but slow and steady. Some days I couldn't even walk around the block, much less run part of the distance. I almost gave up believing I could do it.

At this point Darien had put on muscle and was getting stronger, so my 95-pound German shepherd did most of the work by pulling me around the block. The neighbors laughed and said he was taking me for a walk and not the other way around. Still, I kept it up, sometimes twice a day, for 15 minutes. He kept pulling me along until I could do it

for myself.

Finally the day came when he and I jogged the whole way around the large block. I felt like I was crossing the finish line at the Olympics when I got home. But there were no cheering crowds. No one understood what I had accomplished. I hugged Darien and cried. I finally had more gas in my tank, but it had come very slowly. And so principle three was proven: You can improve!

We people with CFIDS live in a twilight world where joy is a hard-won commodity. We not only suffer from this unrelenting quicksand of a disease, but from the ignorance of the people around us. Even our friends, families, co-workers and churches don't understand us. That is perhaps the biggest hurt of all. A doctor who specializes in CFIDS told me this disease is more stressful than cancer. Cancer patients get attention and sympathy. Instead, I get stared at or chewed out for parking in a handicapped space, even though I have a permit. It took me 20 years to reply calmly to these busybodies.

Despite everything, progress is possible. Do you want to be 100 percent better? My advice, gained through personal experience, is to learn how to do 100 things 1 percent better. Eat 1 percent better. Take vitamins 1 percent more consistently. Sleep 1 percent better. Assess your energy levels 1 percent better. Pace yourself 1 percent better. Set reasonable goals 1 percent better. Believe you can improve just 1 percent more. Stop feeling sorry for yourself 1 percent less. There is no miracle cure for CFIDS yet. So for now we must rely on 1 percent improvements. In time they add up. ■



**Under the microscope: NIH funding gets close scrutiny**

The Association carefully studied information from the National Institutes of Health (NIH) budget office this summer as we sought to document the nature and extent of NIH support for CFS research between 1999 and 2003. This data was not easy to get. Even after a February 2003 personal meeting with NIH director Dr. Elias Zerhouni, it took more than a year and intervention from members of Congress to extract the list of funded projects from NIH.

The NIH reported total spending of \$31.6 million; however, careful research into the 76 listed projects showed the total was vastly overstated. The budget office included 12 projects that had no relevance to CFS and 9 other projects for similar, but diagnostically distinct, illnesses. Adjusting for these misclassified research projects resulted in actual support of \$25.8 million for the past five years and less than \$4 million for FY2003, little more than the amount spent on CFS research by the NIH in 1992. Over this same period, NIH funding overall increased a whopping 75 percent.

The Association presented this report to the DHHS CFS Advisory Committee (CFSAC) at its September 27 meeting. (See related story on page 30.) The following day, we shared the report with Congressional staff responsible for formulating NIH directives and setting funding levels. We have also sent it to committees examining the impact of the huge increases in the NIH budget. Congress expected that this major funding initiative would propel advances in disease-specific

research, but early results have fallen short of expectations. The NIH's track record on CFIDS spending is not unique, and other organizations are raising similar concerns about the classification of research projects, the increasing "opacity" of NIH operations and the failure of overall increases to translate into new money for underfunded areas of study. The Association will continue vigorously pressing this matter when Congress returns to Washington to conclude its session after the election.

The Association's report calls for NIH to "take immediate steps to reverse the shocking decline in CFS research and to build a robust program commensurate with the magnitude of the illness." Specific recommendations—including the release of a well-funded Request for Applications and creation of clinical and research "Centers for Excellence"—are included in the 45-page report, as is detailed documentation to support the analysis.

The American Association for Chronic Fatigue Syndrome (AACFS), an organization of researchers and clinicians, has agreed to join efforts to boost NIH support. Other groups and individuals are encouraged to help too. Visit [www.cfids.org](http://www.cfids.org) and click on the Capitol building icon to voice your concern to Dr. Zerhouni and your members of Congress. So far more than 525 advocates have responded to our call by writing to Dr. Zerhouni. You can obtain a copy of the full report by calling our resource line or sending an e-mail message to [nihreport@cfids.org](mailto:nihreport@cfids.org).

**OTHER FINDINGS IN THE NIH REPORT**

■ 53 individual investigators representing 43 institutions have been awarded CFS funds. Only 1 CFS project outside the U.S. was funded by NIH between 1999 and 2003.

■ Intramural research accounted for 7.5% of total funding; 91.7% was granted to researchers in academic institutions.

■ 8 NIH institutes and 1 NIH office (Office for Research on Women's Health (ORWH)) have supported CFS research.

■ Only 9 grants, representing less than 15% of total CFS funds, support treatment studies. Interventions studied include Siberian ginseng, fludrocortisone, Midodrine (2 studies), skin-cooling, Viagra, Procrit and cognitive behavioral therapy (2 studies).

■ 3 studies focus on adolescents/young people with CFS. Combined funding for these studies is \$959,018, or 3% of total funding.

■ Over the 13-year period from 1990 to 2003, annual NIH funding rose every single year, from \$7.6 billion to \$27 billion. Over this entire span, total CFS spending by NIH amounted to \$78 million.

### Advocates gather to discuss joint efforts

The AACFS conference in Madison, Wisconsin, provided advocates with two opportunities to meet both informally and in a structured setting. An impromptu lunch meeting brought together individuals and representatives of organizations located throughout the United States and in Norway, Korea and Australia. The discussion, organized and led by Rebecca Artman of the Patient Alliance for Neuroendocrine-immune Disorders Organization for Research and Advocacy (P.A.N.D.O.R.A.) headquartered in Miami, focused on shared goals and ways to more effectively channel independent efforts to achieve greater progress.

A more formal advocacy session closed the conference with a panel discussion moderated by Dr. Nancy Klimas. In this first-ever joint session with researchers and clinicians, speakers emphasized the different forms advocacy takes and recognized the opportunity for people to engage in activities that should complement, rather than compete with, one another. Dr. Klimas invited audience participation and maintained a positive, supportive spirit of dialogue. While there were no direct outcomes from either session, many left feeling empowered by the discussions and more hopeful about potential collaboration.



The formal advocacy session was the final session of the AACFS conference held October 8-10 in Madison, Wisconsin. Panel members pictured are John Herd, Kim McCleary of the CFIDS Association and Rebecca Artman of P.A.N.D.O.R.A. Pat Fero of the Wisconsin CFS Association and Jill McLaughlin, formerly of the National CFIDS Foundation, also participated.



An impromptu panel comprised of Dr. Leonard Jason, Dr. Kenneth De Meirlier, Dr. Nancy Klimas, Dr. Anthony Komaroff, Dr. Brigitta Evengard, Kim McCleary and Dr. William Reeves was convened at the conference to discuss the pros and cons of a proposed central research network for CFIDS.

### ADVOCACY MATTERS!

In the CFIDS community, advocacy can mean something as basic as helping family members and friends understand the disabling and often unpredictable nature of the illness. It can mean finding and getting access to community support services or appropriate medical care. For others, it means forming and finding resources to conduct a local support group to provide a safe environment for sharing the CFIDS experience. In New Jersey and Nevada, advocacy translated into state legislation providing expanded insurance coverage for CFIDS treatment and statewide medical education about CFIDS.

On the national level, advocacy has produced a Social Security Ruling (99-2p) that identifies CFS as a disabling condition. It uncovered a funding scandal at the Centers for Disease Control that led to \$12.9 million in restored research dollars and findings of much greater prevalence, staggering economic impact and severe functional disability. It produced a formal forum, the Department of Health and Human Services CFS Advisory Committee, where advocates and federal public health officials meet to report on activities, voice concerns and recommend policy change. Advocacy has also empowered thousands of individuals through participation in 12 annual lobby days, six Congressional briefings and sending more than 10,000 letters to legislators, public health officials and media outlets through the Association's Grassroots Action Center.

## Advisory Committee begins second term

The Department of Health and Human Services CFS Advisory Committee met on Monday, September 27, 2004, in Washington, D.C., its fifth meeting overall and the first since its charter was renewed through September 2006. The committee, chaired by Dr. David Bell, heard agency updates from the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) on their CFS research activities. Representatives from the Social Security Administration (SSA), the Food and Drug Administration (FDA) and Health Resources and Services Administration (HRSA) were on hand to answer questions about disability, drug approval and education issues. Committee members also reviewed and discussed a set of 11 recommendations they had sent to Secretary of Health Tommy Thompson on August 23, 2004.

Although the meeting was lightly attended by advocates, testimony was provided by seven members of the public. Utah clinician Dr. Lucinda Bateman made a presentation on behalf of her patients who were enrolled in the double-blind study of Ampligen, a drug she feels offers substantial clinical benefit to "carefully selected patients." She reported that several of her patients were able to return to more active lives and that there were relatively few side effects in her group. Dr. Bateman urged the FDA to approve the drug. Ampligen is administered twice weekly intravenously; the 40-week study enrolled 220 patients at more than a dozen sites around the country. (At the October 9 clinical track of the AACFS conference, Dr. David Strayer, scientific officer for Hemispherx, stated that they await receipt of complete data from each of the sites before they can break

**"In the opinion of the CFSAC, the greatest priority for the DHHS is to substantially increase research efforts and funding. Future research efforts must apply an integrative approach because CFS is characterized by dysregulation of a number of highly integrated body systems, particularly the immune and nervous systems. Forming multidisciplinary research teams would provide a platform to conduct well-controlled, methodologically sound, longitudinal studies to clarify the pathophysiology of this syndrome and to develop effective treatment modalities. Serum and tissue banks for future investigations should be established."**

**—CFSAC report to Tommy Thompson**

the study code and analyze results.)

PWC Elsie Owings presented her own testimony and read remarks submitted by two others who were unable to travel to the meeting. She expressed her belief that CFS is "lost in a sea of fatiguing illnesses," largely as a result of the name and diagnostic criteria. Dr. Budrose shared some of these same sentiments in her testimony. Ed Jelinski, a law student who has recovered enough to attend school full-time, spoke about the lack of resources and support systems for young people with CFIDS. Mary Schweitzer, Ph.D., echoed Dr. Bateman's support for approval of Ampligen, a drug that she has benefited from under special cost recovery provisions that allow her to purchase the drug even though it's not yet approved for marketing. Several of the speakers offered their appreciation for the committee's efforts.

As an invited guest, I used my time before the committee to present the analysis of data from the NIH budget office on CFS research grants made from 1999 through 2003, as described on page 28. Committee members asked for clarification of the methodology used in conducting the analysis and were curious about other trends and patterns I observed in preparing the 45-page report. NIH representative Dr. Eleanor Hanna responded to

committee members' questions as well, informing the committee of the process used to compile the budget office's data. She also spoke about difficulties they encounter in accurately identifying all the NIH studies that may contribute to better understanding of CFS. The committee formed an ad hoc task force to develop criteria for assessing whether a particular study is relevant to CFS.

The committee's recommendations to the Secretary for Health were the focus of the afternoon session. Dr. Roberto Patarca and Dr. Ken Friedman urged the committee to think more expansively about where CFIDS research and education should be in the future. With renewal of the committee's charter through September 2006, topics for future meetings were also discussed. It was decided that the committee would focus on CFS in young people at its first 2005 meeting, tentatively scheduled for January 10. At the spring meeting, the committee will invite participation from several professional organizations like the American Medical Association to learn how they view CFS and possible partnership activities.

Visit <http://www.cfids.org/cfids-link/oct-cfsac-update.asp> to view the recommendations made by the CFSAC. ■





*Activities and accomplishments of the CFIDS Association of America*

### **CFIDSLink subscribers double**

Just three years ago, our CFIDSLink e-newsletter had less than 10,000 subscribers. Today, more than 20,000 subscribers receive the latest on education efforts, research studies, public policy updates and Association news via the *Link*. It's free and easy to subscribe; just visit <http://www.cfids.org/subscribe.asp>.

### **Printing with ease**

The Association website has a new feature that makes printing easier. Readers can now click on the "Printable Page" icon that appears at the top of each page. The text will appear in a separate window without the navigational tools and can be printed on a standard sheet of paper without cutting off any information.

### **Advocates take action**

In response to the Association's September 27 Action Alert, Grassroots Action Center listserv members have sent 525 letters to Dr. Elias Zerhouni at the National Institutes of Health (NIH). The

letters request Dr. Zerhouni to take immediate steps to reverse the alarming decline in NIH funding for CFIDS research.

To read more about the funding crisis and the related Association report presented to the Department of Health and Human Services CFS Advisory Committee, see "DC Dispatch" beginning on page 28.

This Action Alert was the sixth issued since the Grassroots Action Center debuted in April. The Center listserv replaced the CFIDS-Activist (C-ACT) advocacy listserv. Members of the C-ACT listserv were automatically included in the new listserv and continue to receive Action Alerts. To subscribe to the Grassroots Action Center listserv, visit <http://capwiz.com/cfids/mlm/> or visit [www.cfids.org](http://www.cfids.org), click on the Capitol building icon on the left navigational bar and follow the instructions.

### **Share the knowledge**

The Association is looking for "hot tips" for its "Patient to Patient" page ([http://www.cfids.org/hot\\_tips.asp](http://www.cfids.org/hot_tips.asp)). The page, which

changes daily, is an opportunity for PWCs to share tips, strategies and helpful thoughts on CFIDS. Forward tips to [kalmond@cfids.org](mailto:kalmond@cfids.org).

### **Donor news**

The Association gratefully acknowledges donors Michael and Doris Vander Ploeg and Chairman's Circle donor Wayne Lucas, whose names were inadvertently omitted from the 2003 *Annual Report*. The Association thanks all of its donors for their generosity and commitment to our ongoing mission of conquering CFIDS.

### **Nurses with CFS form support network**

Lorraine Steefel (RN, MSN, CTN), senior staff writer at *Nursing Spectrum* magazine and a core trainer for the Association's Provider Education Project, has received a great deal of positive feedback in response to a recent online chat.

With the sponsorship of *Nursing Spectrum*, Steefel organized and moderated the event specifically for nurses who are PWCs. The partici-

## **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.**

**To find out if a business offers a matching gift program, ask its human resources office or contact the Association's development office at 704-364-0466 or [development@cfids.org](mailto:development@cfids.org).**

pating nurses were pleased to find people in their own profession who could identify with also having CFIDS.

As a result of this success, several participants have decided to continue the chat on an ongoing basis and have formed an online support group.

For more information or to join, visit <http://health.groups.yahoo.com/group/nurseswithcfs>.

### Association board news

The CFIDS Association has added three new members to its Board of Directors for 2005 and bids farewell to four valued members who resigned this year.

Elected during the October 2004 meeting and joining the board in November are Diane Bean, Katrina Berne, Ph.D., and Terry Hedrick, Ph.D.

Bean is the mother of 21-year-old PWC Lauren, who has had CFIDS for six years. Diane and Lauren both provided public testimony at the June 21, 2004, meeting of the CFSAC. Diane also attended the Association's June 2004 donor dinner in Washington, D.C. Along with her husband, Jim, Diane and Lauren attended the July 2003 screening of *Seabiscuit*. Diane and Jim both work for the U.S. Department of State.



Dr. Berne is a clinical psychologist who recently retired from private practice due mostly to health issues related to CFIDS. While practicing, Dr. Berne's specialties included CFIDS, fibromyalgia, chronic pain syndrome and other chronic disorders. The author of *Chronic Fatigue*



*Syndrome, Fibromyalgia and Other Invisible Illnesses: The Comprehensive Guide* and *Running on Empty: The Complete Guide to Chronic Fatigue Syndrome*, Dr. Berne has also authored several articles, audiocassettes, brochures and online publications about CFIDS.

Dr. Berne has served on several advisory committees to the Association, assisted in the early development of the Provider Education Project curriculum and was a speaker at the Association's Chicago conference, where she received the 1997 Iverson Award for Distinctive Service and commitment to the CFIDS community.

Dr. Hedrick, who was instrumental in helping the Association bring to light the misuse of CFIDS research funds by the CDC, was assistant comptroller general of the U.S. General Accounting Office prior to the sudden onset of CFIDS in 1994. In her previous position, Dr. Hedrick led large-scale investigations into the administration of international vaccination programs, Medicare funding and other complex federal programs.



A member of AACFS and the American Psychological Association, she authored "The Royal College's Report on CFS: Insidiously Biased and Potentially Harmful," a review of the British Royal Colleges of Physicians, Psychiatrists and General Practitioners report on CFS. A reviewer of CFS researchers' draft papers, Dr. Hedrick regularly serves as a member of the Association's Scientific Advisory Committee, was a member of the Long-Range Strategic Planning Committee and sits on the *CFS Research Review* editorial board.

The Association thanks departing board members for their countless contributions and many years of dedicated service.

Jon Sterling, who was the Association's board chairman until his resignation in August, has been in the trenches fighting CFIDS for more than a decade. He was stricken with the illness in 1989, forcing him to leave his position as a high school principal.



In the past he has served as president and treasurer of the New Jersey Chronic Fatigue Syndrome Association and as a support group leader in New Jersey. For the past five years Jon was a board member of the CFIDS Association, where he was a highly visible and effective spokesperson for the CFIDS community and a true leader.

Patti Schmidt has been a key figure in the fight against CFIDS. She became ill in 1979 when she worked as an editor for Gannett Newspapers. She served as leader of the Montgomery County CFIDS Support Group and co-founder of the Greater Philadelphia CFIDS Alliance. She also created a listserv for CFIDS patients and their families.



Patti served on the board of the CFIDS Association for seven years, during which time her work as a contributing writer for the *Chronicle*, as chairman and as a member of several board committees made a lasting impact on the Association.

Barbara Comerford has been practicing Social Security disability, private long-term disability and personal injury law for more than 17 years. She has served on numerous

boards which dealt with health and legal issues, including the American Association of CFS and the New Jersey CFS Association.

Barbara's professional expertise and her personal experience with the illness have given her important insights that she generously shared with the Association during her tenure.



Joe Lane, who resigned after 18 months on the board, is the director of the Center for Assistive Technology at the State University of New York in Buffalo, which provides research, training and service programs for the disabled. While he will no longer serve on the CFIDS Association board, he is still actively engaged in the battle against CFIDS because of his wife's struggle with the illness.



Remaining board members are John Trussler, Jane Perlmutter, Rick Baldwin, Susan Jacobs, Kim McCleary, Mark Peterson, Lynn Royster and Adrienne Ryan. Officers for 2005 will be elected in November.

### **New staffer is welcomed**

Angenette Rice-Figueroa has joined the CFIDS Association as director of publications. She comes to the Association from the University of North Carolina at Charlotte, where she was publications manager. She has more than 10 years of experience in the field and will serve as editor of the *CFIDS Chronicle* and the *CFS Research Review*.



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

Gifts by will, or bequests—both large and small—are vital to Association-led efforts aimed at ending the pain and disability caused by CFIDS.

For many, a carefully planned will is the foundation of their estate plans. With a will, you decide how best to provide for your loved ones, as well as ensure your assets are distributed as you wish. In the absence of a will, your state will dictate the disposition of your estate. (Sadly, estimates are that 50 to 80 percent of all Americans die "intestate.")

Executing a will, or revising your existing will, is neither difficult nor expensive. Make an appointment with your attorney or financial planner. (Your local bar association may be able to help you find an attorney if you don't already have one.) These professionals can advise you about ways to: precisely direct who will receive your assets, who will handle your estate and who will serve as guardians for children; meet your objectives to support the charitable organizations and causes that matter to you; and minimize estate taxes and other related costs.

However you choose to invest in the campaign to end CFIDS, the Association urges you to consult your attorney, financial planner or accountant before making any decisions that may impact your estate or long-term financial plans.

Many CFIDS Association donors have told us their planned bequest to the Association is simply a continuation of the support they have demonstrated during their lifetime. To include the Association in your will, please note the organization'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, 56-1683450.

For further information about planned gifts and other ways of giving, please contact Jamie Davis, the Association's Director of Development, at [jdavis@cfids.org](mailto:jdavis@cfids.org) or 704-364-0466. If you have already included the Association in your will, tell us about it and let us express our gratitude for your planned gift/estate gift today.

*The CFIDS Association of America does not provide legal or financial advice.*

*Learn more online at <http://www.cfids.org/support/donations.asp>.*



## ASK THE CEO

**Q:** Some of what I read online suggests that the CFIDS Association has lost touch with the needs and wishes of people with CFIDS. I don't necessarily agree, but reading these things makes me wonder.

**A:** Every member of the Association's board and staff is intensely aware of the challenges that people with CFIDS face, either through personal experience (their own illness or that of a loved one) or frequent contact with CFIDS patients, caregivers and professionals who care for CFIDS patients. Since the Association was founded in 1987, 68 individuals have provided direction for the organization through service on the Board of Directors. Collectively, these volunteers reflect the diversity that exists within the community. While there have been many goals shared by the majority of these directors, divergent opinions and differences among them have also shaped the Association. It's convenient to suggest that there is a singular "patient perspective" that the Association should represent, but in reality, views and priorities are as individual as the people who hold them. It's the challenging job of the board to blend these views into cogent policies and pursuits that serve the community as a whole.

Another process in the evolution of the Association has been the formation of partnerships with other organizations and federal agencies to accomplish long-term strategies widely endorsed within the CFIDS community, such as expanding research and educating physicians. Some see this as "selling out," but the goal of shifting the burden for funding promising CFIDS research and education from the patient community to other institutions was established for our advocacy program more than a decade ago.

In *Emerging Illnesses and Society*, author Steven Epstein observes that within the AIDS movement, "it was not possible for the key treatment activists to become authorities on clinical trials and sit on the [NIH] committees without, in some sense, growing closer to the worldview of the researchers—and without moving a bit away from their fellow activists engaged in other pursuits." This seems to be a natural dynamic as movements and organizations grow and change. Still, the CFIDS Association's Board of Directors is watchful in this regard and is in the process of evaluating present programs and long-term direction.

**K. Kimberly McCleary**

**THE CFIDS ASSOCIATION OF AMERICA**  
**PO Box 220398**  
**Charlotte, NC 28222-0398**  
**Phone: 704-365-2343**  
**FAX: 704-365-9755**  
**Website: [www.cfids.org](http://www.cfids.org)**

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