

# 2005

CFIDS ASSOCIATION ANNUAL REPORT

>> **What is CFS?**

# CFS is...

Chronic fatigue syndrome is an enigma, but it is not a rare disease.

In the United States, at least one million people suffer from CFS. And contrary to old myths, CFS strikes people of every age, ethnic origin and socioeconomic bracket. Women seem to be at greater risk for developing CFS, with four times more cases reported in women than men. People in their 40s and 50s are more likely to get CFS, but it's found in people of all ages, even children.

CFS is a serious illness and can be extremely debilitating. People with CFS experience crushing fatigue, difficulty sleeping and concentrating, widespread muscle and joint pain and persistent flu-like symptoms. Most symptoms are invisible to others, making it difficult for family members, friends and the public to understand the tremendous challenges that a person with CFS faces.

CFS is often misdiagnosed and can resemble other illnesses, including mononucleosis, lupus, multiple sclerosis, fibromyalgia and chronic Lyme disease.

CFS is a complex illness. We don't know its cause. We don't know why it affects some and not others. We don't yet have a definitive diagnostic test.

**The CFIDS Association of America is working hard to deliver what we do know and to make a difference.**

Thanks to the Association's efforts in CFS education and awareness, public policy and research, more people recognize CFS and understand its implications on the individual, the family and our communities. More people — scientists, health care professionals, support groups, advocates, elected officials and volunteers — are working harder to help those who suffer from it.



**Jackie**  
THE SUPPORT GROUP LEADER



“ Isolation and despair are two things that most CFS patients experience, but that never show up in formal descriptions of the illness. I lead a CFS support group because I can't imagine trying to cope with this illness on my own, without the support of other CFS patients and my friends. My husband has been my rock. Although our life together isn't what either of us envisioned when I was healthy, he's always there for me and it's made all the difference. ”

## A Message from the CFIDS Association of America

Chronic fatigue syndrome is more tenacious, more complex and more unforgiving than we ever could have imagined when we opened our doors almost two decades ago.

Over the years our organization has adapted to meet the tremendous challenges presented by CFS and the diverse needs of those we represent, ever-determined to bring progress and promise to millions of Americans. And we have been gifted with visionary leaders, courageous volunteers, generous benefactors and dedicated staff who have the ability to identify opportunities and the conviction of purpose to act upon them.

Today we stand at the beginning of a hopeful new era.

The CFS public awareness campaign we launched in June 2006 is helping to deepen understanding of the illness, re-shape attitudes toward those who suffer from it and remove barriers to diagnosis and treatment. Association-funded research studies hold promise for identifying a biomarker for CFS, determining risk and causal factors and developing improved treatments. And thousands of advocates are working to help turn appropriate federal attention to CFS and secure adequate funding for its research.

In many meaningful respects, the CFIDS Association is different today than it was even a couple of years ago.

We're much more strategic in the way we work to implement the priorities and address the needs of those we serve — people with CFS, their caregivers and family members, health care professionals, legislators, public health officials, the media and the general public.

We're more aggressive in our efforts to engage the finest scientific minds in the study of CFS and collaborate with organizations and individuals who are equally dedicated to ending CFS and equipped to help us reach more of those who suffer from it.

We're innovative in our fundraising and transparent in the means by which we report on the use of the dollars you have entrusted to our organization.

We're lean, agile and able to respond swiftly to the opportunities that will result in the richest possible dividends for the millions of people we represent.

We are . . . a rare source of vital seed funding for novel pilot research . . . proud of the productive relationships we've forged with key Congressional decision makers and . . . unwavering in our commitment to our mission.

The CFIDS Association of America is the leading national CFS organization and uniquely qualified to focus society's human and financial resources to help the women, men and children battling this devastating, complex illness.


We are profoundly grateful for your generous support and confidence in our organization, and optimistic that, together, we will conquer CFS.



Jacobs



McCleary

  
Susan L. Jacobs, Esq.  
Chairman of the Board of Directors

  
K. Kimberly McCleary  
President & Chief Executive Officer

# The CFIDS Association is...

# Answers

Could my endless fatigue, muscle pain and poor concentration be a sign of CFS? **What are the latest treatment options?** How can I better understand my illness so I can ask my doctor the most appropriate questions? **How will CFS impact my child's school experience?** What can I do to help my wife cope with her illness and the effects it has had on our lives? **I'm struggling at the office — how and when should I communicate the impact of CFS on my work life with my employer?**

## Providing Answers

CFS can prompt scores of questions and endless concerns. The CFIDS Association of America works hard to provide reliable answers. Since publishing our first issue of the *CFIDS Chronicle* back in 1987, the Association has become the nation's most trusted sources of information for people with CFS and those who care about them. We believe that in the fight against CFS, knowledge is power.

>> The quarterly *CFIDS Chronicle* covers a broad spectrum of topics important to people with CFS, such as coping with the changes, challenges and effects of CFS on family, career and lifestyle, treating the symptoms that most impact your life, profiles of people whose experiences may mirror your own and the latest research news.

In 2005 the *Chronicle* featured articles on living with severe CFS, the search for a biomarker, treating

chronic pain and winning ERISA claims. The magazine also brought readers a powerful report on Lyme disease and its possible connections to CFS and took a revealing look at sex and CFS and the impact the illness can have on intimate relationships.

>> More than 2,000 pages of reliable, up-to-date information about CFS are available on the Association's website, [www.cfids.org](http://www.cfids.org). The website welcomed more than 995,000 visitors last year. The most frequently accessed areas include our interactive "Do I Have CFS?" health assessment tool, the Grassroots Action Center, research and treatment areas and sections for newly diagnosed patients, caregivers and young people with CFS.

>> The Association publishes a variety of fact sheets and brochures and provides single copies free-of-charge to all who request them. Tens of thousands of pieces of literature were distributed in 2005, helping

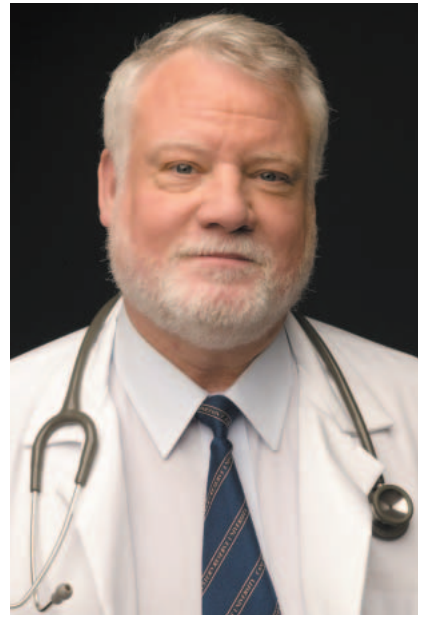


Meaghan  
THE EDUCATOR

“Chronic fatigue syndrome is invisible to everyone except the people who have it and the people who love them. I don't look sick, and I balance my symptoms with being a wife, mother and third-grade teacher every day. So some people think the illness is all in my head. But it's not. I want to help educate Americans about CFS so they can go to their doctor for help if they have the symptoms. There is no cure, but there are treatments.”

“Chronic fatigue syndrome can be challenging to treat, causing frustration for patients and health care professionals. But there are tools available now to make diagnosing and managing CFS easier. Treating sleep problems, pain and other prominent symptoms can make a huge difference in a patient’s quality of life. It can also be rewarding for the physicians, nurse practitioners and physician assistants who are on the front lines of patient care.”

David Bell, MD, family physician  
THE HEALER



people to understand the complex nature of CFS, engage in more meaningful conversations with their health care providers, learn more about treatment strategies and make informed choices about CFS-related issues.

- >> Subscriptions to *CFIDSLink*, the Association’s electronic newsletter, soared. In January 2005, the newsletter had just over 20,600 subscribers. By year-end, subscriptions to *CFIDSLink* rose 22% to 25,133 subscribers. *CFIDSLink* is delivered the first Wednesday of the month and contains research news, personal stories and updates on conferences and meetings of interest.
- >> The Internet has become a primary source of information for millions of Americans looking for health resources. With at least one million people in the U.S. suffering from CFS, and fewer than 20% diagnosed, there is a significant community of people seeking information about CFS or searching for answers about their puzzling symptoms.

The Association partnered with leading health website WebMD to help educate and motivate some of their 30 million monthly visitors to better understand and recognize CFS. From January to March 2005 four compelling CFS banner ads prompted thousands of WebMD visitors to participate in an interactive health assessment on the Association’s website. Through a series of questions, the **Do I Have CFS?** tool helped users determine whether CFS may be the cause of their decline in health and function and engage in an informed conversation with their health care provider.

### Improving patient care

Finding a health care provider who is knowledgeable about CFS can be a challenge. There are only a handful of physicians who specialize in the treatment of CFS. Many medical professionals are skeptical of the illness. Some are reluctant to diagnose it and simply choose not to handle CFS cases. And others are unsure how to treat it but are actively seeking the information and tools that will help them provide appropriate care to their CFS patients.

Without adequate information on the diagnosis and management of CFS, health care providers and patients will continue to endure a cycle of frustration that ultimately results in compromised health care.

The CFIDS Association’s health care provider education program — a joint effort with the U.S. Centers for Disease Control and Prevention (CDC) — reflects our organization’s commitment to improving the lives of people with CFS. Through Grand Rounds presentations, continuing education courses and exhibits at major medical conferences and scientific meetings, we work to enhance understanding of CFS among health care providers nationwide and deliver credible, reliable information on diagnosis and treatment.

- >> *Chronic Fatigue Syndrome: Diagnosis and Management* is a free print, DVD and online self-study course (with available continuing education credits) designed to help health care providers better recognize and manage CFS. 1,776 requests for the CFS curriculum were received in 2005 and continuing education certificates were awarded to 300 medical professionals who successfully completed the course. A second curriculum, *Chronic Fatigue Syndrome: A Primer for Allied Health Professionals*, will

# Awareness

be available in 2006. The new course focuses on behavioral and rehabilitative therapy approaches to CFS management.

- >> While there's not yet a cure for CFS, treatment strategies do exist. The Association exhibited at 15 medical conferences in 2005, interacting personally with health care providers from multiple disciplines and sharing valuable information about diagnosis and treatment of CFS. Providers could also pick up complimentary resources such as fact sheets, research articles, print or DVD copies of the CFS curriculum and the *CFS Research Review*, the Association's semi-annual publication created to meet the information needs of those on the front lines of patient care. More than 12,000 pieces of resource material were distributed to interested health care providers at their national conferences last year.

- >> As another facet of the health care provider education program, CFS Grand Rounds are offered to institutions and organizations. The presentations provide a broad-based view of the latest findings in CFS research with the goal of integrating CFS into the medical school curriculum. In 2005 Grand Rounds were held at the University of California-Davis, St. Louis University and Hunterdon Medical

Center, a teaching institution affiliated with the University of Medicine and Dentistry of New Jersey Robert Wood Johnson Medical School.

Moving forward, Grand Rounds are planned for the College of Georgia, the University of North Carolina, the University of Iowa, Wake Forest University and other leading institutions.

- >> "Recognition and Management of CFS," our pocket resource guide for health care providers, was revised in 2005. The guide contains concise information about prevalence and risk factors, prognosis, evaluation and diagnosis, symptom assessment and treatment. More than 7,000 copies were distributed last year.

## Elevating CFS awareness

Over the past few years the Association has become more proactive in its efforts to elevate public awareness of CFS, initiatives which have won praise from many and drawn concern from others who felt this might mean fewer resources dedicated to research. Yet, changing mindsets and raising the profile of CFS can actually speed up scientific progress and remove roadblocks to improved treatments. Illnesses like Parkinson's and AIDS have reaped benefits, including increased attention and research funding, as a result of their sustained public information efforts.



Brian  
THE SCHOLAR-ATHLETE

“ When I got CFS, I wanted to hide my illness, and hide the fact that my mind and body weren't heeding my commands. But I can't concentrate. I go blank on tests. I get invited to sleepovers, but don't have the energy to go. I can't play on the soccer team anymore. Some days, I can't even go to school. I don't know if all my teachers and friends really understand. Some of them think I'm a slacker. But every day, I desperately hope I'll get better. I just want to be a normal 12-year-old. ”

“ For me, CFS started as a bad case of the flu and became a nightmare that lasted six years. I had debilitating fatigue, terrible migraines, memory loss, brain fog. I would sleep, but wake unrefreshed and totally exhausted. Although I've mostly recovered, I lost a chunk of my life. And every time I start to feel unwell, I'm gripped by the memory of those six years. Today, I take nothing about my health for granted and try to make the most of each day. ”

Adrienne  
THE SURVIVOR



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We fully expect that dedicated efforts in CFS public awareness can have the same impact, dramatically increasing the amount spent on CFS research by both federal and private sources, attracting young researchers to the field of CFS science and improving the social context for CFS.

- >> The American public is accustomed to — and expects — sophisticated, high-quality communications. And millions of messages compete for their attention. To cut through the clutter and command attention, the CFIDS Association, along with marketing and communications experts at Fleishman Hillard and GMMB, spent many months in 2005 preparing for the first national CFS public awareness campaign. We conducted focus group research, tested and developed messages and compelling creative concepts, designed print and electronic materials and much more. We worked diligently to ensure that our CFS message would get people to stop, listen, think and understand.
- >> Launched in June 2006, the CFS public awareness campaign incorporates a broad range of components, including print advertisements, public service announcements, stories on TV and radio and in articles in national magazines, newspapers and online publications,

and a traveling photography exhibit featuring portraits of people with CFS taken by celebrity photographer George Lange. (The photographs appearing on the inside front cover, page 1 and pages 3 through 13 were taken by George Lange).

- >> To help improve the public's understanding of CFS, the Association provides thousands of pages of resource material, story ideas and coordinates interviews for numerous media outlets. *AARP Bulletin*, *Advance for Physicians' Assistants*, *The Boston Globe*, *Dallas Morning News*, *Glamour* magazine, *LA Times*, *Natural Health*, *New York Daily News*, National Public Radio, the *San Francisco Chronicle* magazine, *Self* magazine, the *Washington Post* and WNYU radio were just a few of the hundreds of print and broadcast outlets that have recently covered CFS.

### Driving research progress

The CFIDS Association of America is the nation's largest philanthropic supporter of CFS research, investing more than \$4.7 million in promising pilot research since 1987. We are a rare and important source of seed funding for talented CFS investigators, providing support for their high-impact, innovative projects that offer hope for new treatments and better understanding of the

# Research

disease. Through this scientific venture capital approach, the Association meets a critical need for scientists studying novel hypotheses, but who don't yet have the data required to compete for larger federal grants.

In 2005 the CFIDS Association invited eight researchers to submit proposals for a special "fast-track" funding program designed to put money to work as quickly and thoughtfully as possible, investing in studies with a high probability of accelerating the rate at which scientific knowledge translates into improvements in the daily lives of people with CFS. Investigators were carefully selected based on their record of achievement and demonstrated ability to make meaningful contributions to the understanding of CFS.

Only applications for projects exploring possible cause(s) of CFS, biomarkers, pathophysiology or treatments were considered. The proposals were peer-reviewed by an expert scientific advisory committee. Funding decisions — based on the recommendations of the scientific advisory committee and available funds — were made by the Executive Committee of the Association's Board of Directors in January 2006. \$240,000 was awarded in support of the following projects:

**Brigitte T. Huber, PhD, Tufts University School of Medicine, Boston, MA, "HERV-K18 env as a risk factor for CFIDS"** — Results from Dr. Huber's 2004 Association-funded pilot study showed a strong correlation between infectious agents and CFS and the presence of a specific HERV-K18 allele, an

endogenous superantigen which may prove to be a predictor for post-infectious CFS. Superantigens constitute a class of proteins capable of deregulating the immune system. With additional 2006 funding, Dr. Huber will significantly expand the size of the patient group to examine this relationship, furthering the collective understanding of the diverse interactions that take place between an infectious virus and the immune system of its host and determining with certainty whether a correlation exists between the presence of a particular HERV-K18 allele and the development of CFS.

**Nancy Klimas, MD, University of Miami, Miami, FL, "Mechanisms of Cytotoxic Cell Dysfunction in CFS"**

— Dr. Klimas and her research group are looking at possible mechanisms of immune system dysfunction and working to correlate those findings with symptom clusters and severity. They are focusing on a membrane associated peptidase, known as CD26 and a key neuropeptide, neuropeptide Y, as they relate to cytotoxic function in patients with CFS. In the context of CFS, neuropeptide Y has been demonstrated not only to cause defects in NK and T cell function when it is elevated, but also has roles in the inflammatory process, cardiorespiratory system, nervous system and endocrine system. Neuropeptide Y is stored in the same cells that release adrenaline during an autonomic response which we know to be abnormal in CFS. Preliminary data indicates that CD26 is depleted in CFS, most likely through chronic cellular activation, resulting in immune dysfunction and ultimately, the symptoms of CFS.



“ In the past, there have been questions about whether chronic fatigue syndrome is a real illness. There is now abundant scientific evidence that CFS is a real biological illness. It's not a form of depression or hypochondria. It's imperative for scientists to continue searching for the cause and effective treatments for CFS. ”

**Anthony Komaroff, MD, Harvard Medical School**  
THE RESEARCHER



“ My professional and personal dreams started to slip away soon after I became ill with CFS. I couldn't concentrate, couldn't make sense of physics equations I had written, couldn't muster the stamina I needed to continue teaching and volunteering in my community. My doctor thought it was just depression, but when he treated me for that and my other symptoms remained, he finally believed my illness was physical, not psychological. ”

**Dikoma C. Shungu, PhD, Weill Medical College of Cornell University, New York, NY, “<sup>1</sup>H MRS Neurometabolites as Diagnostic Markers for Chronic Fatigue Syndrome: Comparison with Major Depressive Disorder and Healthy Volunteers”** — Dr. Shungu continues to assess the measurements of certain brain chemicals through proton magnetic resonance spectroscopy (<sup>1</sup>H MRS), a technique which shows promise as a screening test for CFS. In this study, Dr. Shungu is comparing levels of brain chemicals in CFS and major depressive disorder (MDD) patients and in age- and sex-matched healthy controls. This study is a follow up to his 2004–2005 Association-funded study of patients with CFS and generalized anxiety disorder (GAD) which documented significant differences between the two disorders. Dr. Shungu and his team found that lactic acid was significantly elevated in the cerebrospinal or brain fluid of CFS patients compared to people with GAD and healthy volunteers and that the levels of brain lactic acid were highly correlated with fatigue severity across all subjects, but not to anxiety or depression symptoms. Dr. Shungu hopes the distinct differences found in the brain chemicals of patients with CFS, as compared to people with GAD, MDD and healthy controls, will be helpful in diagnosing CFS.

**J. Mark VanNess, PhD, and Christopher Snell, PhD, University of the Pacific, Stockton, CA, “Using an Exercise Challenge to Investigate the Pathophysiology of CFS”** — Dr. VanNess and Dr. Snell have observed that CFS patients can perform a maximal exercise test with results similar to sedentary but otherwise healthy individuals. Crucial differences, however, are noted when a second exercise test is performed within the same 24 hour period. Physical function is significantly reduced in CFS patients whereas healthy individuals are able to repeat the test with similar results to their



first exercise challenge. In the current Association-funded study, a double-test strategy will be used to study post-activity symptoms in CFS. Various measures of biological, physical and mental function will be taken prior to and following the initial test and again after the second test. Results will be compared between patients and healthy individuals to better characterize post-exertion effects in CFS and provide insights into their origin.

In addition to directly funding research, the Association works vigorously to attract the best and brightest scientific minds to the study of CFS, foster collaborative research teams and increase the quantity (and quality) of new studies in the research pipeline. We also work to build productive relationships among the different players in the CFS research arena — scientists in the lab, national advocacy organizations, clinicians on the front lines of patient care and government decision-makers who direct research dollars.

“ Nothing in my Ivy League education or legal training prepared me to deal with chronic fatigue syndrome. I had to dig deep to find the inner strength to cope with pain and loss this illness brought. Ultimately, I had to reconstruct my life and my sense of self. I can no longer practice law but am doing some creative writing on my good days. Although I’ve discovered hidden talents, I will always miss aspects of my life lost to CFS. ”

Kathy  
THE STORYTELLER



### Influencing CFS public policy

A stronger federal response to CFS is essential to accelerating the pace of CFS research, expanding patient access to social services and improving the way the illness is viewed by lawmakers, the medical community, the media and the public.

Public policy is a key strategy in the fight to end CFS and an area in which the CFIDS Association of America excels.

Since entering the advocacy arena in 1992, the Association has spent approximately \$2 million on public policy, an investment which has yielded \$85 million in federal CFS research funding.

Still, we have a long way to go. Not nearly enough federal funds and attention is given to CFS. Last year, the combined investment in CFS by the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) was roughly \$14 million — a small fraction of what is needed given that CFS affects at least one million Americans and costs the national economy \$9.1 billion per year, not including health care costs and disability benefits.

The CFIDS Association is a respected, responsible and successful advocate for the CFS community. We work vigorously to represent the health care concerns and medical research interests of

people with CFS to policy makers and agency officials and to urge the federal government to allocate its ample resources to finding the cause of, and cure for, CFS. The Sheridan Group, one of Washington DC’s most sought-after government relations firms, has represented the Association in its federal public policy activities since 1992.

>> The Association’s CFS-related public policy efforts were recognized in June 2005 with a nomination for a prestigious Research!America award honoring an “organization that has distinguished itself by its advocacy.” Chaired by former U.S. Representative John Porter, Research!America’s mission is to make medical and health research a higher national priority.

>> In response to a two-year campaign by the Association urging the National Institutes of Health (NIH) to make good on its June 2003 commitment (by NIH Associate Director Dr. Vivian Pinn) to fund more CFS research, the agency issued a \$4 million request for applications (RFA) in July 2005. The Association helped broadcast news of the RFA to researchers interested in CFS. At the July 17, 2006 meeting of the CFSAC, NIH’s Dr. Eleanor Hanna stated that an announcement of seven grant awards was forthcoming.

# Advocacy

- >> The Association participated in all 2005 meetings of the Department of Health and Human Services' (DHHS) Chronic Fatigue Syndrome Advisory Committee (CFSAC), a federal committee charged with providing guidance and recommendations to the Secretary of Health on issues related to chronic fatigue syndrome.

The Association is committed to creating opportunities for people with CFS, their family members and friends to have a voice in CFS public policy. The Association encourages grassroots advocates to contact their elected officials, share their stories and demonstrate that there are a lot of real people (and voters) who live with and care about this issue.

- >> The Association hosted its 13th annual Lobby Day in Washington, DC. 58 advocates representing 22 states attended a half-day training session on May 11, then spread out across Capitol Hill for meetings with 80 Congressional offices on May 12, 2005. Advocates informed members of Congress and their staff about CFS and the tremendous toll it takes on the individual and the national economy. They also made specific requests for expanded research funding for CFS and a more dedicated federal response to the illness.
- >> We held our first-ever "Virtual Lobby Day" event in tandem with lobby day, allowing those unable to travel to Washington, DC the opportunity to participate in grassroots lobbying

efforts. Using the Association's Grassroots Action Center, individuals were able to send letters to their senators and representatives, the Secretary of Health and appropriations committee members, echoing the messages carried by those visiting Capitol Hill. Online advocates sent more than 3,000 letters to specified targets.

- >> In response to requests made by advocates during 2005 Lobby Day activities, 12 members of Congress, led by Rep. Sue Myrick (R-NC) and Rep. Frank Pallone (D-NJ), signed on to an August 8, 2005 letter expressing concern about federal programs for CFS. They asked Secretary of Health Michael Leavitt to act on a set of 11 recommendations submitted by the CFSAC in August 2004. Using the Grassroots Action Center, advocates pressed for Senate follow through and in November, Senators Rick Santorum (R-PA) and Orrin Hatch (R-UT) sent a letter to Secretary Leavitt asking him to take action on the set of recommendations made by his own advisory committee. Later in the month, the Secretary heard from Senate Minority leader, Sen. Harry Reid (D-NV) who also expressed his support for the CFS Advisory Committee's recommendations to expand funding and the scope of CFS research.

A strong advocacy program is critical to winning — and maintaining — the federal funding and policy changes the CFS community seeks.



Vivian  
THE EXPLORER & EVANGELIST

“ I used to work 15-hour days in the film industry. Then CFS hit and dismantled my life. For 3 of the 13 years I've been ill, I was bedridden. Severe relapses occur periodically, and I still struggle daily with short-term memory loss and oppressive exhaustion. Now, on the days I'm an explorer, I use all the energy I can muster to learn about conquering this illness. On the days I'm an evangelist, I educate everyone who will listen about this devastating illness. ”

# Hope

## Bringing hope for improved health

CFS can cause feelings of frustration, isolation and confusion. People with CFS often feel alone with their illness and the everyday struggles it brings to their lives and the lives of their family members and friends. Sometimes the best words a person with CFS can hear are, “I understand how you feel” or “I care” from someone who really does.

- >> The Association’s Resource Line, 704-365-2343, is a valuable source of information, encouragement and crucial “one on one” communication for many people who choose to contact our organization. Because of the varied nature of the questions callers pose, the Resource Line is staffed by an experienced and knowledgeable Association employee for 32 hours each week.
- >> Support groups can make a real difference in the lives of people with CFS. They can ease the transition for the newly diagnosed patient and provide essential emotional support in the ongoing struggle with the disease. They can provide opportunities for people with CFS to get involved and fight back against their illness. Knowing that others share this journey offers comfort and reassurance. The Association maintains a state-by-state listing of support groups and also has a variety of online and print

materials and resources which are available to support group leaders to help them help others.

- >> The Association launched its **KNOW MORE CFS Education and Empowerment Seminar Series** in 2005 as a way to provide information resources to people with CFS and their family and friends. Working in partnership with local and regional support organizations, these half-day programs feature nationally recognized experts in CFS research and care and cover a wide range of high-interest topics. In addition to hearing current and credible information about CFS, these programs provide attendees an opportunity to identify local resources and meet others facing some of the same challenges of living with CFS. Programs are hosted around the country, with various speakers. To date, seminars have been held in Reston, Va., Charlotte, N.C. and Akron, Ohio. The next CFS seminar will take place in Sacramento, Ca. in October 2006.
- >> People living with CFS have valuable knowledge that can benefit someone else. The Association publishes personal stories in the *CFIDS Chronicle* and the *CFIDSLink* to allow people to share their experiences and speak candidly about how CFS has impacted their life as a means to inspire, enlighten and encourage others.

**Since 1987, the CFIDS Association of America has invested \$18.4 million in CFS education, awareness, public policy and research.**

**Through all of its efforts, the Association is determined to defeat CFS and to hasten progress toward the day when CFS is preventable, curable, a thing of the past. And we will with your help.**



“ I was lucky to have been diagnosed fairly soon after becoming ill. From that point on, I made it my business to learn all I could about CFS, to recruit others to search for its cause and cure, and to build a business dedicated to serving people with CFS and other chronic illnesses. Information has been the primary weapon in my fight against a disease that's stolen so much from me and from more than one million fellow Americans. ”

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(current as of July 1, 2006)

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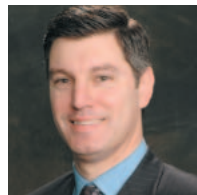
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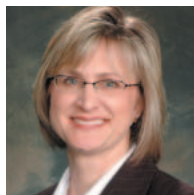
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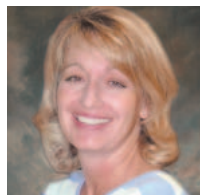
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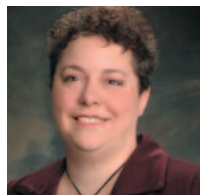
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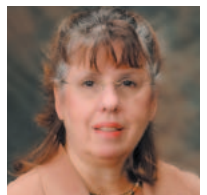
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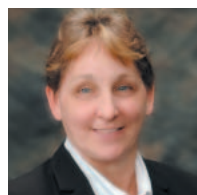
Stovall



Bouknight



Smith



Infanti



Faryna



Baldwin



Perlmutter



Berne



Converse



Ryan



Spotila

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(current as of July 1, 2006)

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## Report of Independent Auditors

The Board of Directors  
The CFIDS Association of America, Inc.  
Charlotte, North Carolina

We have audited the accompanying statement of financial position of The CFIDS Association of America, Inc. (the Association) as of December 31, 2005, and the related statements of activities and changes in net assets, functional expenses, and cash flows for the year then ended. These financial statements are the responsibility of the Association's management. Our responsibility is to express an opinion on these financial statements based on our audit. As described in Note 1, the prior year summarized comparative information has been derived from the Association's 2004 financial statements; and in our report dated April 6, 2005, we expressed an unqualified opinion on those financial statements.

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of The CFIDS Association of America, Inc. as of December 31, 2005, and the changes in its net assets, and its cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America.

*Cherry, Bekaert & Holland, L.L.P.*

Charlotte, North Carolina  
April 14, 2006

## Statement of Financial Position

### Year Ended December 31, 2005

(With Comparative Totals for Year Ended December 31, 2004)

|  | Year Ended December 31, 2005 |                           |                           | Totals              | Year Ended<br>December 31,<br>2004 |
|--|------------------------------|---------------------------|---------------------------|---------------------|------------------------------------|
|  | Unrestricted                 | Temporarily<br>Restricted | Permanently<br>Restricted |                     |                                    |
| <b>Assets</b>  |                              |                           |                           |                     |                                    |
| <b>Current assets</b>                                  |                              |                           |                           |                     |                                    |
| Cash and cash equivalents                              | \$ 887,207                   | \$ 177,532                | \$ —                      | \$ 1,064,739        | \$ 1,274,095                       |
| Contributions receivable, net                          | —                            | 190,000                   | —                         | 190,000             | 35,000                             |
| Government grants receivable                           | 199,251                      | —                         | —                         | 199,251             | 80,940                             |
| Other receivables                                      | 3,647                        | —                         | —                         | 3,647               | 3,498                              |
| Inventories  | 299                          | —                         | —                         | 299                 | 1,017                              |
| Investments  | 5,782                        | 708                       | 5,400                     | 11,890              | 10,924                             |
| Prepaid expenses                                       | 12,757                       | —                         | —                         | 12,757              | 12,722                             |
| <b>Total current assets</b>                            | <b>1,108,943</b>             | <b>368,240</b>            | <b>5,400</b>              | <b>1,482,583</b>    | <b>1,418,196</b>                   |
| <b>Property and equipment</b>                          |                              |                           |                           |                     |                                    |
| Office furniture and fixtures                          | 84,568                       | —                         | —                         | 84,568              | 88,548                             |
| Computers and related equipment                        | 100,483                      | —                         | —                         | 100,483             | 113,543                            |
| Leasehold improvements                                 | 25,872                       | —                         | —                         | 25,872              | 25,872                             |
|  | 210,923                      | —                         | —                         | 210,923             | 227,963                            |
| Less accumulated depreciation                          | (181,896)                    | —                         | —                         | (181,896)           | (177,746)                          |
| <b>Net property and equipment</b>                      | <b>29,027</b>                | <b>—</b>                  | <b>—</b>                  | <b>29,027</b>       | <b>50,217</b>                      |
| <b>Cash surrender value of life insurance</b>          | <b>—</b>                     | <b>15,262</b>             | <b>—</b>                  | <b>15,262</b>       | <b>16,144</b>                      |
| <b>Total assets</b>                                    | <b>\$ 1,137,970</b>          | <b>\$ 383,502</b>         | <b>\$ 5,400</b>           | <b>\$ 1,526,872</b> | <b>\$ 1,484,557</b>                |
| <b>Liabilities and Net Assets</b>                      |                              |                           |                           |                     |                                    |
| <b>Current liabilities</b>                             |                              |                           |                           |                     |                                    |
| Accounts payable                                       | \$ 112,100                   | \$ —                      | \$ —                      | \$ 112,100          | \$ 36,434                          |
| Accrued payroll and<br>payroll taxes withheld          | 14,458                       | —                         | —                         | 14,458              | 11,385                             |
| Unearned dues revenue                                  | 63,906                       | —                         | —                         | 63,906              | 70,660                             |
| Obligation under capital lease<br>— current portion    | 6,171                        | —                         | —                         | 6,171               | 6,171                              |
| <b>Total current liabilities</b>                       | <b>196,635</b>               | <b>—</b>                  | <b>—</b>                  | <b>196,635</b>      | <b>124,650</b>                     |
| <b>Other liabilities</b>                               |                              |                           |                           |                     |                                    |
| Obligation under capital lease<br>less current portion | 13,885                       | —                         | —                         | 13,885              | 20,057                             |
| <b>Total liabilities</b>                               | <b>210,520</b>               | <b>—</b>                  | <b>—</b>                  | <b>210,520</b>      | <b>144,707</b>                     |
| <b>Net assets</b>                                      |                              |                           |                           |                     |                                    |
| <b>Unrestricted</b>                                    |                              |                           |                           |                     |                                    |
| Undesignated   | 751,009                      | —                         | —                         | 751,009             | 665,920                            |
| Designated   | 176,441                      | —                         | —                         | 176,441             | 172,204                            |
| <b>Total unrestricted</b>                              | <b>927,450</b>               | <b>—</b>                  | <b>—</b>                  | <b>927,450</b>      | <b>838,124</b>                     |
| Temporarily restricted                                 | —                            | 383,502                   | —                         | 383,502             | 496,326                            |
| Permanently restricted                                 | —                            | —                         | 5,400                     | 5,400               | 5,400                              |
| <b>Total net assets</b>                                | <b>927,450</b>               | <b>383,502</b>            | <b>5,400</b>              | <b>1,316,352</b>    | <b>1,339,850</b>                   |
| <b>Total liabilities and net assets</b>                | <b>\$ 1,137,970</b>          | <b>\$ 383,502</b>         | <b>\$ 5,400</b>           | <b>\$ 1,526,872</b> | <b>\$ 1,484,557</b>                |

## Statement of Activities and Changes in Net Assets Year Ended December 31, 2005

(With Comparative Totals for Year Ended December 31, 2004)

|  | Year Ended December 31, 2005 |                           |                           | Totals           | Year Ended<br>December 31,<br>2004 |
|--|------------------------------|---------------------------|---------------------------|------------------|------------------------------------|
|  | Unrestricted                 | Temporarily<br>Restricted | Permanently<br>Restricted |                  |                                    |
| <b>Support and revenues</b>              |                              |                           |                           |                  |                                    |
| Public support:                          |                              |                           |                           |                  |                                    |
| Contributions and grants                 | \$ 615,471                   | \$ 268,130                | \$ —                      | \$ 883,601       | \$ 1,162,193                       |
| Federal funds:                           |                              |                           |                           |                  |                                    |
| Government grants                        | —                            | 1,131,939                 | —                         | 1,131,939        | 587,463                            |
| Revenues:                                |                              |                           |                           |                  |                                    |
| Membership dues                          | 149,137                      | —                         | —                         | 149,137          | 162,231                            |
| Educational material sales               | 12,587                       | —                         | —                         | 12,587           | 7,087                              |
| Interest and other                       | 14,348                       | —                         | —                         | 14,348           | 8,045                              |
|  | 176,072                      | —                         | —                         | 176,072          | 177,363                            |
| <b>Assets released from restrictions</b> |                              |                           |                           |                  |                                    |
| Satisfaction of donor restrictions       | 1,512,893                    | (1,512,893)               | —                         | —                | —                                  |
| <b>Total support and revenues</b>        | <b>2,304,436</b>             | <b>(112,824)</b>          | <b>—</b>                  | <b>2,191,612</b> | <b>1,927,019</b>                   |
| <b>Expenses and losses</b>               |                              |                           |                           |                  |                                    |
| Program services:                        |                              |                           |                           |                  |                                    |
| Research                                 | 323,091                      | —                         | —                         | 323,091          | 167,663                            |
| Public Policy                            | 228,087                      | —                         | —                         | 228,087          | 209,031                            |
| Education                                | 1,382,860                    | —                         | —                         | 1,382,860        | 869,290                            |
| Supporting services:                     |                              |                           |                           |                  |                                    |
| Management and general                   | 97,548                       | —                         | —                         | 97,548           | 97,252                             |
| Fund raising and development             | 183,502                      | —                         | —                         | 183,502          | 196,004                            |
|  | 2,215,088                    | —                         | —                         | 2,215,088        | 1,539,240                          |
| Loss (gain) on assets disposed           | 22                           | —                         | —                         | 22               | (774)                              |
| <b>Total expenses and losses</b>         | <b>2,215,110</b>             | <b>—</b>                  | <b>—</b>                  | <b>2,215,110</b> | <b>1,538,466</b>                   |
| <b>Change in net assets</b>              | <b>89,326</b>                | <b>(112,824)</b>          | <b>—</b>                  | <b>(23,498)</b>  | <b>388,553</b>                     |
| <b>Net assets</b>                        |                              |                           |                           |                  |                                    |
| Beginning of year                        | 838,124                      | 496,326                   | 5,400                     | 1,339,850        | 951,297                            |
| End of year                              | \$ 927,450                   | \$ 383,502                | \$ 5,400                  | \$ 1,316,352     | \$ 1,339,850                       |

## Statement of Functional Expenses Year Ended December 31, 2005

(With Comparative Totals for Year Ended December 31, 2004)

|   | Year Ended December 31, 2005 |                   |                     |                              |                                    |                     | Totals              | Year Ended<br>December 31,<br>2004 |
|---|------------------------------|-------------------|---------------------|------------------------------|------------------------------------|---------------------|---------------------|------------------------------------|
|   | Program Services             |                   |                     | Supporting Services          |                                    |                     |                     |                                    |
|   | Research                     | Public Policy     | Education           | Management<br>and<br>General | Fund-Raising<br>and<br>Development |                     |                     |                                    |
| Contract services   | \$ 4,652                     | \$ 145,283        | \$ 424,955          | \$ 5,912                     | \$ 10,002                          | \$ 590,804          | \$ 265,733          |                                    |
| Honoraria   | —                            | —                 | 3,700               | —                            | —                                  | 3,700               | 5,000               |                                    |
| Salaries  | 43,802                       | 44,549            | 510,514             | 55,675                       | 70,367                             | 724,907             | 625,323             |                                    |
| Payroll taxes   | 6,463                        | 6,573             | 23,134              | 8,215                        | 10,382                             | 54,767              | 44,438              |                                    |
| Printing and postage  | 1,710                        | 2,734             | 111,842             | 2,198                        | 54,898                             | 173,382             | 158,261             |                                    |
| Repairs and maintenance   | 840                          | 855               | 6,309               | 1,068                        | 1,350                              | 10,422              | 11,462              |                                    |
| Supplies  | 1,144                        | 1,163             | 6,159               | 1,454                        | 1,837                              | 11,757              | 16,533              |                                    |
| Educational materials/cost of sales   | —                            | —                 | 2,852               | —                            | —                                  | 2,852               | 8,763               |                                    |
| Travel expenses   | 1,918                        | 8,201             | 32,391              | 1,406                        | 2,050                              | 45,966              | 62,397              |                                    |
| Exhibit Fees  | —                            | —                 | 27,102              | —                            | —                                  | 27,102              | 39,130              |                                    |
| Patient education seminars  | —                            | —                 | 15,049              | —                            | —                                  | 15,049              | —                   |                                    |
| Curriculum development meetings   | —                            | —                 | —                   | —                            | —                                  | —                   | 705                 |                                    |
| Awareness and curriculum promotion  | —                            | —                 | 53,429              | —                            | —                                  | 53,429              | 43,466              |                                    |
| Event sponsorship   | —                            | —                 | 40,700              | —                            | —                                  | 40,700              | 21,075              |                                    |
| Event in-kind donations   | —                            | —                 | —                   | —                            | —                                  | —                   | 16,375              |                                    |
| Insurance   | 538                          | 547               | 1,926               | 684                          | 864                                | 4,559               | 4,504               |                                    |
| Telephone   | 1,356                        | 1,278             | 5,344               | 1,520                        | 1,982                              | 11,480              | 15,784              |                                    |
| Occupancy costs   | 7,338                        | 7,463             | 26,267              | 9,327                        | 11,790                             | 62,185              | 60,525              |                                    |
| Depreciation  | 2,788                        | 2,836             | 9,980               | 3,544                        | 4,479                              | 23,627              | 28,069              |                                    |
| Miscellaneous   | 5,450                        | 6,605             | 16,262              | 6,545                        | 13,501                             | 48,363              | 30,245              |                                    |
| Direct grants   | 245,092                      | —                 | 64,945              | —                            | —                                  | 310,037             | 81,452              |                                    |
| <b>Total expenses</b>   | <b>\$ 323,091</b>            | <b>\$ 228,087</b> | <b>\$ 1,382,860</b> | <b>\$ 97,548</b>             | <b>\$ 183,502</b>                  | <b>\$ 2,215,088</b> | <b>\$ 1,539,240</b> |                                    |
| Management and general expenses   |                              |                   |                     |                              |                                    | \$ 97,548           | \$ 97,252           |                                    |
| Fundraising and development expenses  |                              |                   |                     |                              |                                    | 183,502             | 196,004             |                                    |
| <b>Total management and general, and fundraising and development expenses</b> |                              |                   |                     |                              |                                    | <b>\$ 281,050</b>   | <b>\$ 293,256</b>   |                                    |
| <b>Total support and revenue</b>  |                              |                   |                     |                              |                                    | <b>\$ 2,191,612</b> | <b>\$ 1,927,019</b> |                                    |
| <b>Supporting services ratio</b>  |                              |                   |                     |                              |                                    | <b>12.82%</b>       | <b>15.22%</b>       |                                    |

## Statement of Cash Flows

### Year Ended December 31, 2005

(With Comparative Totals for Year Ended December 31, 2004)

|  | Year Ending December 31, |                     |
|--|--------------------------|---------------------|
|  | 2005                     | 2004                |
| <b>Cash flows from operating activities</b>  |                          |                     |
| Change in net assets   | \$ (23,498)              | \$ 388,553          |
| Adjustments to reconcile increase (decrease) in net assets to net cash used in operating activities: |                          |                     |
| Depreciation   | 23,627                   | 28,069              |
| Loss (gain) on disposal of assets  | 22                       | (774)               |
| Amortization of contributions receivable discount  | —                        | (2,759)             |
| In-kind contribution of investments  | (22,314)                 | (10,045)            |
| Reinvestment of investment earnings  | (708)                    | (879)               |
| Cash value annuity insurance contract  | 882                      | 646                 |
| (Increase) decrease in operating assets:   |                          |                     |
| Pledges and other receivables  | (273,460)                | 132,704             |
| Inventories  | 718                      | (275)               |
| Prepaid expenses   | (35)                     | (3,474)             |
| Decrease in operating liabilities:   |                          |                     |
| Accounts payable   | 75,666                   | (36,077)            |
| Accrued payroll and payroll taxes withheld   | 3,073                    | (12,661)            |
| Unearned dues revenues   | (6,754)                  | (9,146)             |
| <b>Net cash provided (used) by operating activities</b>  | <b>(222,781)</b>         | <b>473,882</b>      |
| <b>Cash flows from investing activities</b>  |                          |                     |
| Purchases of property and equipment  | (2,459)                  | (17,985)            |
| Proceeds from disposal of asset  | —                        | 1,000               |
| Proceeds from sale of investments  | 22,056                   | 3,183               |
| <b>Net cash provided (used) in investing activities</b>  | <b>19,597</b>            | <b>(13,802)</b>     |
| <b>Cash flows used in financing activities</b>   |                          |                     |
| Principal reduction of obligation under capital lease  | (6,172)                  | (5,278)             |
| <b>Net increase (decrease) in cash and cash equivalents</b>  | <b>(209,356)</b>         | <b>454,802</b>      |
| <b>Cash and cash equivalents</b>   |                          |                     |
| Beginning of year  | 1,274,095                | 819,293             |
| End of year  | <b>\$ 1,064,739</b>      | <b>\$ 1,274,095</b> |
| <b>Supplemental disclosure of cash flow information</b>  |                          |                     |
| Noncash transaction:   |                          |                     |
| Issuance of capital lease for acquisition of equipment   | \$ —                     | \$ 30,856           |

## Notes to Financial Statements — Year Ended December 31, 2005

### Note 1: Organization and summary of significant accounting policies

#### Description of operations

The CFIDS Association of America, Inc. (the Association) is a non-profit corporation whose purpose is to conquer chronic fatigue and immune dysfunction syndrome (CFIDS). The Association works toward its mission by building recognition of CFIDS as a serious widespread medical disorder; securing a meaningful response to CFIDS from the federal government; stimulating high quality CFIDS research; improving health care providers' abilities to detect, diagnose and manage CFIDS; and providing information to persons with CFIDS and enabling the CFIDS community to speak with a collective voice. Substantially all of the Association's revenue is derived from membership dues, contributions from members and other interested parties, grants from foundations and government agencies, and sales of educational materials.

#### Basis of accounting

The accompanying financial statements are prepared on the accrual basis of accounting.

#### Classes of net assets

The financial statements report amounts separately by net assets classification. A summary of these classifications follows.

*Unrestricted net assets* are those currently available for use in the day-to-day operations of the Association and those resources invested in property and equipment. It is the policy of the Board of Directors to review its plans for future expansion and other future monetary requirements. From time-to-time, the Board of Directors will designate appropriate sums to assure adequate funds are available to assist in those estimated future monetary requirements. Such amounts are presented as designated net assets in the statement of financial position.

*Temporarily restricted net assets* are those implied or explicitly stipulated by donors for purpose or timing.

*Permanently restricted net assets* — Net assets consisting of contributions received from donors whose use by the Association is limited by permanent donor-imposed stipulations. The restrictions are for the donated assets to remain in perpetuity, and the Association does not have the right to invade the original principal.

#### Revenue recognition

Membership dues are recognized as revenue over the applicable membership period. The Association waives membership dues for individuals experiencing financial hardships. All contributions and private grants are recognized as revenue at the time the contributions are unconditionally promised.

Generally, federal grant funds made available to the Association are utilized to accomplish specific objectives of the grantor and the Association. Such grants contain specific criteria governing the expenditure of such funds. As a condition of the grants, the Association agrees to utilize the funds in a manner as prescribed by the underlying grant agreement. Accordingly, revenue is recognized as funds are expended.

#### Donated services and assets

The Association periodically receives donated services for certain functions and donated assets. The assets are stated at their fair market value at time of dona-

tion. No amounts have been reflected in the financial statements for the services since they do not meet the criteria for recognition under SFAS No. 116, *Accounting for Contributions Received and Contributions Made*. The Association did, however, receive contributions of investments, valued at \$22,314, during the year ended December 31, 2005.

#### Research grants

The Association awards grants for medical research projects in the field of CFIDS. To ensure that the most worthy and promising research projects are funded, the Association periodically convenes a Scientific Advisory Committee that advises the Association's Executive Committee of its Board of Directors. The Association's Executive Committee, heavily weighing the recommendations of this advisory committee, makes all funding decisions. Members of the Scientific Advisory Committee include internationally respected researchers and clinicians. Because these grants are contingent upon researchers submitting a claim for reimbursement, these grants are not recognized as expenditures until payment occurs. However, at December 31, 2005, the Association had approved grants of \$6,667 that are available for disbursement in subsequent years.

#### Cash equivalents

For purposes of the statement of cash flows, the Association considers all highly liquid debt instruments with maturity of three months or less when purchased as cash equivalents.

#### Contributions receivable

Contributions, including unconditional promises, are recognized as revenues in the period received. Conditional promises are not recognized until they become unconditional, that is, when the conditions on which they depend are substantially met. Contributions of assets other than cash are recorded at their estimated fair value at the date of the contribution. Management of the Association periodically evaluates its contributions receivable for collectibility and delinquent contribution receivables are written off when that the amount is deemed to be uncollectible. At December 31, 2005, management considers \$20,000 of outstanding contributions to be uncollectible.

Gifts of land, buildings and equipment are presented as unrestricted support unless explicit donor stipulations specify how the donated assets must be used. Gifts of long-lived assets with explicit restrictions that specify how the assets are to be used and gifts of cash or other assets that must be used to acquire long-lived assets are reported as restricted support. Absent explicit donor stipulations about how long those long-lived assets must be maintained, the Association reports expirations of donor restrictions when the donated or acquired long-lived assets are placed in service.

#### Inventories

Inventories, which consist of educational materials, are recorded at the lower of cost (first-in, first-out) or market.

#### Investments

Investments are recorded in accordance with the provisions of SFAS No. 124, *Accounting for Certain Investments Held by Not-for-Profit Organizations*. Under SFAS No. 124, investments in marketable securities with readily determinable fair values are valued in the statement of financial position at their fair value. Fair value is determined by reference to exchange or dealer-quoted market prices. If a quoted market price

is not available, fair value is estimated using quoted market prices for similar investment securities. Changes in the fair value of securities are reflected as investment gains or losses in the accompanying statements of activities and changes in net assets.

#### **Property and equipment**

Property and equipment items are stated at cost or at fair value at the date of donation, if contributed. Expenditures for acquisitions, renewals and betterments are capitalized, whereas maintenance and repair costs are expensed as incurred. Depreciation is charged to expense over the estimated useful lives of the assets principally using accelerated methods. When assets are retired or disposed of, the cost and accumulated depreciation thereon are removed from the accounts and any gains or loss are included in unrestricted revenue. These assets are reviewed for impairment whenever changes in circumstances indicate the carrying value of an asset may not be recoverable.

#### **Beneficial interest in trust**

In accordance with Statement of Financial Accounting Standards No. 136, *Transfers of Assets to a Not-for-Profit Organization or Charitable Trust That Raises or Holds Contributions for Others*, the Association recognizes contribution revenue from assets donated to a recipient organization held for the sole benefit of the Association. At December 31, 2005, the Association has assets held by recipient organizations totaling \$10,664. This balance is included in investments on the accompanying statement of financial position.

#### **Cash surrender value of life insurance**

The Association is the named beneficiary of a life insurance policy that covers a donor and his spouse. The policy has a face value of \$1,000,000 and is payable to the Association upon the death of the donor and his spouse. The policy continues to decrease in value as the policy matures, at which time, an additional premium will be payable from the Association in order to maintain the policy. For the year ended December 31, 2005, the decrease in the cash surrender value of life insurance was \$882.

#### **Advertising expense**

The Association expenses advertising costs as they are incurred. Total advertising costs related to provider education for the year ended December 31, 2005, were \$45,555.

#### **Tax status**

The Association is a not-for-profit voluntary health agency, exempt from federal and state income tax under Section 501(c)(3) of the Internal Revenue Code and Sections 105-125 and 105-130.11(a)(3) of the General Statutes of North Carolina. The Association has been designated as a "publicly supported" charity under Sections 509(a)(1) and 107(b)(1)(A)(vi) of the Internal Revenue Code.

#### **Conflict of interest**

All members of the Association's Board of Directors, committees of the board, and advisory committees to the Association are governed by a conflict-of-interest policy. This policy precludes members from voting on motions with respect to which they may have a conflict of interest. Conflict of interest is deemed to exist if the member would directly benefit, personally or professionally, from a motion that has been made.

#### **Concentrations of credit risk**

Financial instruments, which potentially subject the Association to concentrations of credit risk, consist principally of contributions receivable and cash. The

Association receives contributions from various entities and individuals located throughout the United States for various fund raising drives. Since these contributions are unsecured, the Association has no guarantee that these monies will be received. The Association places its cash with various financial institutions. The Federal Deposit Insurance Corporation (FDIC) insures these balances for up to \$100,000. Periodically, the Association maintains cash balances in excess of the amount insured by the FDIC.

The Association, similar to other organizations of its nature and size, periodically receives large contributions and grants from a relatively small number of individuals and/or organizations. The continued support of large donors cannot be determined with certainty. No individual contribution represented more than twenty percent (20%) of public support for the year ended December 31, 2005, however, fifty-two percent (52%) of the Association's support and revenue is derived from its contracts with the Centers for Disease Control and Prevention (CDC).

#### **Prior year summarized information**

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with accounting principles generally accepted in the United States of America. Accordingly, such information should be read in conjunction with the Association's financial statements for the year ended December 31, 2004, from which the summarized information was derived.

#### **Reclassifications**

Certain reclassifications have been made to the prior year comparative totals in order to comply with the current year financial statement presentation. Such reclassifications had no effect on total net assets.

#### **Estimates**

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

#### **Note 2: Contributions receivable**

Individual contributions receivable at December 31, 2005, are designated as follows: \$160,000 is restricted for CFIDS research grants; \$35,000 is restricted for use in Association public policy efforts; and \$15,000 is restricted for Association education efforts. The Association maintains an allowance for Contributions receivable of \$20,000. Unconditional promises are expected to be received in 2006.

#### **Note 3: Grants**

The Association was awarded a contract of federal funds from the CDC for the purpose of educating multidisciplinary health care providers about CFIDS to enable timely detection and management of the illness, ultimately resulting in improved care for CFIDS patients. The Association also has a contract with CDC to provide public awareness of the existence of CFIDS. The funds for both of these contracts are received by the Association on a reimbursement basis. At December 31, 2005, \$199,251 is in the government grants receivable.

**Note 4: Investments**

Investments are recorded at fair market value and include investments held in the Association's brokerage and beneficial interest account. The following is a summary of investments at December 31, 2005:

|                   |                  |
|-------------------|------------------|
| Equity securities | \$ 1,226         |
| Mutual funds      | 10,664           |
|                   | <u>\$ 11,890</u> |

**Note 5: Capital leases**

At December 31, 2005, property and equipment includes equipment under capital leases with a cost basis of \$30,856 and accumulated depreciation of \$16,045. Amortization of assets under capital lease is included in depreciation expense. The lease is interest free and interest has not been imputed, as the amount is immaterial. The following is a schedule by year of future minimum lease payments under capital leases together with the present value of net minimum lease payments as of December 31, 2005.

|   |                  |
|---|------------------|
| 2006  | \$ 6,171         |
| 2007  | 6,171            |
| 2008  | 6,171            |
| 2009  | 1,543            |
|   | <u>20,056</u>    |
| Less amount representing interest           | —                |
| Present value of net minimum lease payments | 20,056           |
| Current maturities                          | (6,171)          |
| Noncurrent maturities                       | <u>\$ 13,885</u> |

**Note 6: Net assets**

**Unrestricted, board designated**

Unrestricted net assets designated by the Association's board of directors for cash reserve for future years at December 31, 2005 total \$176,441.

**Temporarily restricted**

Temporarily restricted net assets are available for the following purposes as of December 31, 2005:

|                          |                   |
|--------------------------|-------------------|
| Research activities      | \$ 292,458        |
| Educational activities   | 56,441            |
| Public policy activities | 18,633            |
| Other donor specified    | 15,262            |
| Endowment earnings       | 708               |
|                          | <u>\$ 383,502</u> |

**Permanently restricted**

Permanently restricted net asset is comprised of contributions made to the Association's endowment fund. These assets are held under an interest in a beneficial trust. At December 31, 2005, the principal balance of the endowment was \$5,400.

**Note 7: Net assets released from restrictions**

Net assets were released from restrictions by incurring expenses satisfying the purpose during the year ended December 31, 2005, as follows:

|  |                     |
|--|---------------------|
| Purpose restrictions accomplished:       |                     |
| Government grants expended               | \$ 1,132,482        |
| Research grants and related expenditures | 244,719             |
| Educational activities                   | 68,075              |
| Public policy activities                 | 66,555              |
| Donor specified                          | 1,062               |
|  | <u>\$ 1,512,893</u> |

**Note 8: Leases**

The Association leases office space used in its operations under an operating lease that expires in June

2007. The lease initially provides for a monthly rental of \$4,348 and is subject to annual increases based upon the Consumer Price Index. The Association also leases office equipment under leases expiring in 2006.

Future minimum lease commitments under the above operating leases are as follows at December 31, 2005:

|                          |                  |
|--------------------------|------------------|
| Year ending December 31, |                  |
| 2006                     | 53,185           |
| 2007                     | 23,914           |
|                          | <u>\$ 77,099</u> |

Rental expense incurred under operating leases was \$55,364 for the year ended December 31, 2005.

**Note 9: Financial instruments**

SFAS No. 107, *Disclosures about Fair Value of Financial Instruments*, requires disclosure of the fair value of all financial instruments, including both assets and liabilities recognized and not recognized in the statement of financial position, for which it is practicable to estimate fair value.

The following methods and assumptions were used by the Association in estimating the fair value of its financial instruments. Fair value approximates carrying value for the following financial instruments due to their short-term nature: cash and cash equivalents, investments, various receivables and accounts payable. The fair value of capital lease payable is estimated by discounting future cash flows using interest rates available to the Association with similar terms and maturities.

|                        |                 |            |
|------------------------|-----------------|------------|
|                        | Carrying Amount | Fair Value |
| Capital leases payable | \$ 20,057       | \$ 14,811  |

**Note 10: Benefit plan**

The Association sponsors a cafeteria plan whereby employees may select from a list of available qualified benefits or additional wages up to ten percent (10%) of their annual gross compensation. Included in this cafeteria plan is an election that can be made by employees to have a designated amount contributed into their 403(b) Plan accounts. The Association's 403(b) retirement plan covers substantially all employees meeting certain service and age requirements. This plan is a defined contribution plan with voluntary employee participation. During 2005, the Association made contributions into this plan amounting to \$10,281.

**Note 11: Limits on nontaxable lobbying expenditures**

The Association is covered under Section 501(h) of the Internal Revenue Code that permits a limited amount of nontaxable lobbying expenditures based upon varying percentages of total exempt purpose expenditures. This code section also imposes a ceiling (upper limit) for lobbying expenditures, above which 501(c)(3) organizations may be subject to revocation of tax-exempt status. The ceiling amounts are 150 percent of nontaxable lobby expenditures computed over a four-year averaging period. Both the ceiling and nontaxable amounts apply to direct and grassroots lobbying expenditures. The nontaxable amounts and the actual amounts spent by the Association for 2005 are listed below. The majority of the Association's public policy expenses are incurred in its monitoring of federal agencies, not on lobbying for specific legislation.

|                     |            |           |
|---------------------|------------|-----------|
|                     | Allowable  | Actual    |
| Direct lobbying     | \$ 259,791 | \$ 34,013 |
| Grassroots lobbying | \$ 64,948  | \$ 4,500  |

## Ways to Support the CFIDS Association of America

The CFIDS Association needs and appreciates your support as we work to: deepen understanding of CFS and diminish the suffering it causes; secure a meaningful response to CFS from the federal government; provide hope to people with CFS and their families; improve patient care; and advance the CFS research that will lead to new and improved treatments, and one day, a cure.

Some of the many ways in which you can provide support for our important work are outlined below. For further information, please contact the Association's Director of Development, Jamie Davis, at 704-364-0466 or [jdavis@cfids.org](mailto:jdavis@cfids.org). Or send an email to [development@cfids.org](mailto:development@cfids.org) and request a copy of our brochure, **A Guide to Giving**.

### Donations

Please send your check to:  
**The CFIDS Association of America**  
**PO Box 220398**  
**Charlotte, NC 28222-0398**

To make an online contribution, visit our secure website at [www.cfids.org/ecommerce/online-donations.asp](http://www.cfids.org/ecommerce/online-donations.asp).

To make a gift with your credit card, call us at 704-365-2343 or visit us online.

### Gifts of Stock

A donation of marketable securities that have appreciated in value can be made quickly and easily. Your bank or broker will need the following information in order to transfer stock to the Association.

DTC # **0141**  
Brokerage Firm: **Wachovia Securities**  
CFIDS Association Account # **2114-5761**  
Federal Tax ID # **56-1683450**

If you have further questions, please contact: Roger Fuller, Jr. at Wachovia Securities, 800-929-0972 or 704-442-6300, or the Association's Director of Development at 704-364-0466.

If you own stock that has declined in value, consider selling the stock (in order to establish a tax loss) and contributing the proceeds to the Association.

### Monthly Giving

A regular monthly gift is a wonderful way to provide consistent support for the Association's work. To join the Chairman's Circle, call us at 704-365-2343 or send an email to [ChairmansCircle@cfids.org](mailto:ChairmansCircle@cfids.org). Information is also available on our website at [www.cfids.org/support/chairmans-circle.asp](http://www.cfids.org/support/chairmans-circle.asp).

### Bequests

Including the Association in your will through a bequest is the easiest and most common way to make a planned gift. To do so, your attorney or financial planner will need the Association's correct legal designation: The CFIDS Association of America, Inc., a 501(c)(3) tax-exempt organization incorporated by the laws of the State of North Carolina. Federal Tax Identification Number 56-1683450.

### Life Insurance Gifts

Talk to your financial planner or life insurance provider about naming the Association as primary or contingent beneficiary on your life insurance policy.

### Commemorative Gifts

Honor the memory of a loved one or celebrate the life and accomplishments of a friend or family member with a gift to the CFIDS Association. The Association will inform the individual honored, or the family of the memorialized individual, of your generosity.

### Matching Gifts

Many businesses offer programs through which an employee's or retiree's charitable gift can be matched dollar-for-dollar. Ask your employer if there is such a program at your workplace.

## **Credits and Thanks**

This report was published by the CFIDS Association of America in collaboration with Lisa Weedman Graphic Design. The photographs appearing on the inside front cover, page 1 and pages 3–13 were taken by George Lange. Photographs on pages 2, 14 and 15 by Robert East.

Special thanks to the many Association friends who submitted their photos for pages 25 through 31 of the Annual Report. We regret that we were not able to include every photo we received.

Thanks also to Brian Bernard, Dr. David Bell, Rich Carson, Wilhelmina Jenkins, Dr. Anthony Komaroff, Jacqueline Niederle, Meaghan Peterson, Kathy Rabin, Adrienne Ryan and Vivian Treves whose portraits and words are part of the traveling CFS photography exhibit and this Annual Report. “The Faces of Chronic Fatigue Syndrome” photo exhibit is just one element of the first national CFS public awareness campaign — the exhibit will travel to cities across the country throughout 2006 and 2007. To learn more about the awareness campaign, please visit [www.cfids.org/sparkcfs](http://www.cfids.org/sparkcfs).

The mission of the **CFIDS Association of America** is to conquer chronic fatigue syndrome (CFS). We are deeply committed to the community we serve — people suffering from CFS and all those who care about them — and to the efforts in CFS education, awareness, public policy and research that we carry out on their behalf.

The CFIDS Association of America, Inc.  
PO Box 220398  
Charlotte, NC 28222-0398  
Resource Line: 704-365-2343  
Fax: 704-365-9755

Home Page: [www.cfids.org](http://www.cfids.org)  
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