

THE CFIDS ASSOCIATION OF AMERICA, INC.

2001 ANNUAL REPORT



15 YEARS  
LEADING THE FIGHT AGAINST CFIDS

**WHAT IS CFIDS?**

Chronic fatigue and immune dysfunction syndrome (CFIDS) is a serious and complex illness that affects the brain and multiple body systems. It is characterized by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), problems with information processing and memory, flu-like symptoms, pain in the joints and muscles, dizziness, nausea, sleep disorders, and numerous other symptoms. CFIDS can be severely debilitating and can last for many years.

CFIDS is often misdiagnosed. It can resemble other disorders including mononucleosis, multiple sclerosis, fibromyalgia, Lyme disease, post-polio syndrome and autoimmune diseases such as lupus. CFIDS is also known by the names chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME).

CFIDS strikes people of all age, ethnic and socioeconomic groups. Carefully designed studies have yielded estimates that more than 800,000 U.S. adults suffer from CFIDS. Although the illness is most prevalent in women, the illness afflicts men and children as well. In women, CFIDS is more common than multiple sclerosis, lupus, HIV infection and lung cancer.

Despite over a decade of research, the cause of the illness is not yet known, there is still no definitive diagnostic test and treatment is aimed primarily at symptom relief.

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As The CFIDS Association of America marks its 15th year of service to the CFIDS community, we are pleased to reflect over the Association’s past, sharing highlights of progress that’s been achieved in the last decade and a half. From humble beginnings as a local Charlotte support group, the Association’s growth has been guided by committed volunteers, and since 1990, a dedicated professional staff. Today The CFIDS Association of America stands as the largest, most active and most dynamic organization working to end chronic fatigue and immune dysfunction syndrome (CFIDS, also known as chronic fatigue syndrome or CFS).



**Jonathan B. Sterling,  
Chairman of the Board**



**K. Kimberly Kenney,  
President &  
Chief Executive Officer**

There is great satisfaction in reviewing the numerous achievements from the past year and the past 15 years. All of these activities were made possible thanks to the tremendous generosity and support of the Association’s benefactors, donors and members. Those giving \$50 or more in 2001 are listed in this Annual Report. Those who wished to remain anonymous or whose support was at a lower, though no less important level are acknowledged as well.

While we share our enthusiasm for what we as an organization of individuals have accomplished together, let us be clear that we have no intention to rest on our laurels. With each page and paragraph we are reminded of how much more work remains to be done, of how many needs remain unmet. And most of all, we recall how many people are in pain and despair because this disease lacks effective treatment and widespread acceptance as a serious and debilitating condition. So, as this Annual Report presents the Association’s financial and operations results from 2001, it also serves as a symbol of our unwavering commitment to build the resources and expand the programs necessary to defeat CFIDS.

We have learned a great deal since 1987, about the illness and about the actions required to overcome CFIDS. As our organization has matured, so has our appreciation for the complexity of generating and maintaining momentum in education, public policy and research activities. The road ahead promises to be long and winding. However, we are more capable of overcoming challenges than ever before and we see meaningful progress on the horizon. For all of us united in the mission to conquer CFIDS, hope for a healthier tomorrow sustains our journey. Your continued support is vital. Let’s celebrate the satisfaction of reaching our goal, together.

With deep appreciation,

Jonathan B. Sterling  
Chairman of the Board  
The CFIDS Association of America

K. Kimberly Kenney  
President & Chief Executive Officer  
The CFIDS Association of America

# 15 YEARS: AN ASSOCIATION RETROSPECTIVE

## THE BEGINNING

Dedicated to finding a cure for their debilitating illness, Marc M. Iverson and another Charlotte, NC business executive set out to build an organization to fund CFIDS research. At a time when the medical community and general public demeaned the illness as the “yuppie flu,” they saw an opportunity to help themselves and the thousands of others they knew must be suffering as they were. In 1987, Marc Iverson founds The CFIDS Association of Charlotte and the Association supports its first research project with a \$15,000 grant to Dr. Paul Cheney.

### The Early Years 1988 to 1990

News of the Association spreads; patients who had been loosely organized around the country now share a common mission and common “home.” The Association dedicates itself to providing the most current and accurate information on CFIDS and publishes its first issue of *The CFIDS Chronicle*. CFIDS begins moving out of the shadows — top-five TV show “The Golden Girls” features a two-part episode on Dorothy’s (Bea Arthur) mysterious illness and CFIDS makes the cover of *Newsweek* magazine becoming 1990’s highest-selling issue.

### Independence, Leadership & Expansion 1991 to 1993

The Association adds “of America” to its name; receives its non-profit status from the IRS; hires K. Kimberly Kenney as its first Executive Director; forms a Scientific Advisory Committee, initiating a peer-reviewed grants program; and takes responsibility for advocacy efforts previously led by volunteers. With its focus shifting to include urging the federal government to aggressively fund CFIDS research, the Association ramps up its grassroots advocacy efforts, forms a Public Policy Advisory Committee and hires lobbyist Tom Sheridan. An analysis of federal research funding finds that money is missing from agency budgets, triggering the beginning of what would become a six-year Association-led effort to document and hold the Centers for Disease Control & Prevention (CDC) accountable for the diversion of CFS funds to other agency programs.

### Opportunities, Accomplishments & Hope 1994 to 1996

The Association forms The CFIDS Support Network (CSN), the CFIDS Youth Alliance and the CFIDS Public Relations (CPR) Team. The advocacy investment begins paying dividends as the Social Security Administration (SSA) admits to the Association that some people with CFIDS (PWCs) have been unfairly denied benefits. *The CFIDS Chronicle* exposes deceptive tactics of long-term disability carriers. Science moves in a new direction as Johns Hopkins University publishes a report linking CFIDS with neurally mediated hypotension. The Association begins funding Dr. Robert Suhadolnik’s antiviral pathway research aimed at a protein marker for CFIDS. Nine divisions of the National Institutes of Health (NIH) issue a program announcement indicating an interest in funding CFIDS research.

## MOVING FORWARD — 2001 AND BEYOND

The Association moves forward a more mature and stronger organization, but one still singularly committed to the vision it was built upon in 1987. CFIDS is one of the most prevalent chronic illnesses of our time. The realities and challenges this tenacious foe continues to present demand more innovative research, necessitates a greater level of collaboration with the medical community, the federal government, the general public and people with CFIDS and requires more financial and intellectual resources. We understand these realities and will meet these challenges. The battle to conquer CFIDS is one we fully intend to win. This purpose is at the heart of The CFIDS Association of America.

### Growth & Growing Pains 1997 to 1998

The Association secures representation on the federal CFS Coordinating Committee, which advises the Secretary for Health and provides a forum for advocates to interact with senior public health officials. Lobby day, in its sixth year, attracts three times more advocates than before. As the Association aggressively pursues its programs while holding fast to its commitment to immediately invest every dollar received in the fight against CFIDS, year-end fundraising efforts fail. The organization sinks to its most vulnerable point ever, but is soon buoyed as friends affirm the Association’s value to the CFIDS community through their words of support and contributions. Back on its feet, the Association scrutinizes every program, every activity and reflects on its core values and mission.

### Reaping Rewards for People with CFIDS 1999 to 2000

With the addition of a Director of Communications, the organization’s dedication to winning recognition for CFIDS as a mainstream medical concern gains steam. Positive stories about CFIDS are featured in major media outlets, including *USA Today*, *The Washington Post* and on ABC’s *20/20*. A DePaul University prevalence study sheds light on the actual number of U.S. adults suffering from CFIDS and helps debunk myths about the illness. SSA issues a ruling stating CFIDS can be a disabling impairment for which patients are entitled to federal disability benefits. A report from the Inspector General confirms that \$12.9 million allocated for CFIDS research had been misappropriated by the CDC — the Association successfully secures full restoration of these funds. In a bold move to reinvigorate CFIDS science, the Association invests in an effort to recruit investigators from diverse disciplines to the field through a series of research symposia. And efforts to improve patient care take hold with the launch of a health care provider program complete with CFIDS curriculum, outreach to medical professionals and the debut of a new Association publication, *The CFS Research Review*.

# FIGHTING MYTH AND BUILDING AWARENESS

## WHAT THE MEDIA IS SAYING ABOUT CFIDS

The Association worked with the medical and general media to send important messages about the illness in 2001.



**"CFS is now known to be a very real and disabling disorder than can hit children as well as adults."**  
*Redbook* magazine, June 2001



**"CFS is an illness so debilitating that its 800,000 victims — most of them women — cannot perform the most basic daily tasks."**  
*Ladies' Home Journal*, November 2001



**"Raising awareness about the nature of the disease, advocates say, is as important as funding research and improving treatment."**  
CNN.com, December 2001



**"As debilitating as the disorder may be, dealing with skeptics is just as traumatic."**  
*The Boston Globe*, September 2001

**"[CFS] patients often deal with doctors who do not understand their condition."**  
Good Morning America, August 2001

The Association uses a number of communications tools and strategies to build recognition of CFIDS as a serious, widespread medical disorder and to raise awareness about the Association and its important mission. Active participation in the public relations arena is vital to securing the financial and intellectual resources necessary to effectively fight this illness.

In 2001, a generous gift from Association benefactor Jennifer Small enabled The CFIDS Association to hire Manning, Selvage & Lee, one of the nation's leading public relations firms, and undertake unique and proactive projects to capture the media's attention.

The Association conducted its first survey of medical professionals' attitudes and beliefs about CFIDS in 2001. More than 8,000 physicians, nurses and other health care practitioners were asked about barriers to diagnosis and treatment (see page 11). Press materials from the survey, which generated significant media coverage, were posted on the Association's Web site for patients to use in their own awareness-raising efforts. Another proactive project, an article on CFIDS sent to local newspapers across the country through the North American Precis Syndicate (NAPS), resulted in more than 200 placements reaching 24 million readers.

The Association worked one-on-one with top media outlets such as CNN.com, Good Morning America and *Redbook* magazine to secure coverage that enhanced understanding of CFIDS. An interview with the Association in *Vitality*, a magazine nearly 30% of all Fortune 500 companies provide to their employees, helped inform the American workforce about the illness. Celebrity Laura Hillenbrand, a person with CFIDS (PWC) and author of the best-seller "Seabiscuit: An American Legend," further increased the Association's outreach and gave the illness a more public profile by granting interviews that showcased her experience with CFIDS.



The Association continued to battle misperceptions about the illness in 2001, including mitigating negative or misleading media. Following confirmation that a controversial review of CFIDS treatments was about to be released in the *Journal of the American Medical Association*, the Association moved quickly to launch a counter attack, releasing a statement and giving media interviews warning that misinterpretation of the findings could be harmful to PWCs. The

Association also corrected misinformation about CFIDS on media Web sites and educated prominent CFIDS detractors.



The Association's first camera-ready print article appeared in more than 50 newspapers in 22 different states and on the Web site of General Mills, a well-respected Fortune 500 company.

**"CFIDS has long been marginalized, misunderstood and disrespected. The CFIDS Association is leading the fight to raise awareness that this illness is an overwhelming public health problem and must be addressed."**

Renée Brehio, Director of Communications (right) pictured with Leah Moseley

**F**ifteen years ago, federal spending on CFIDS research was negligible. Congress, like other institutions, had no clue and no concern about the government's response to CFIDS. And public health officials struggling with the growing AIDS epidemic paid no attention to reports of clustered and sporadic cases of CFIDS in communities across the country. Today, although per patient research spending ranks near the bottom, the government's CFIDS research effort has grown to \$18 million per year. Congress may be preoccupied with homeland security but there is broad, bipartisan support for accelerating federal CFIDS activities. And at the height of anthrax and bioterrorism scares, U.S. Surgeon General David Satcher recorded a public service announcement about CFIDS for television.

**"The tenacity and credibility The CFIDS Association has displayed over the years is nothing short of awesome. I am proud of my work for them and inspired to continue this fight until the government uses all of its resources to find the cause of and cure for CFIDS — to do less is not an option."**

Tom Sheridan, founder of The Sheridan Group



One of the decisions that has most influenced the history of and contributed to progress by The CFIDS Association of America was hiring Washington lobbyist Thomas Sheridan. The 10-year partnership between The Sheridan Group and The CFIDS Association has produced meaningful results in expanded research funding, tighter accountability for federal activities and broader respect for the role of CFIDS advocates in developing public policy. The Sheridan Group's strong and continuous presence on Capitol Hill and with federal health agencies is one of the CFIDS community's greatest assets.

At the end of 2000 the CFIDS community lost one of its most staunch and influential advocates — Representative John E. Porter (R-IL) retired from Congress and his visible post as chairman of the appropriations subcommittee on Labor, Health and Human Services, Education and Related Agencies. Through his relationship with constituent Theodore Van Zelst, Rep. Porter developed a thorough understanding of the seriousness and impact of CFIDS. During the six years that he chaired the L/HHS subcommittee, Mr. Porter ensured that government funds for CFIDS research grew and that federal agencies were responsive to the CFIDS community. The Association has been working to identify a group of CFIDS champions within Congress to replace the legislative leadership formerly provided by Rep. Porter. New sources of bi-partisan support have been located through events

like the Association's annual lobby day and meetings with advocates living in congressional districts home to powerful health lawmakers.

#### Lobby Day 2001

Dozens of CFIDS advocates from across America joined in Washington, D.C. on June 21 for the Association's 10th annual Lobby Day event. Participants met with Congressmen, Senators and staff members to stress the need for greater federal funding and support for CFIDS research. Lobby Day is a crucial tool for raising CFIDS awareness on Capitol Hill, especially as the Association seeks new Congressional champions for the CFIDS cause. Association members from 19 states and the District of Columbia participated in the 2001 event. Many came to advocate for themselves and said although they paid a physical price for their experience, they left Washington with a new feeling of empowerment — and new contacts to pursue in the ongoing fight against CFIDS. Others came to speak on behalf of a friend or family member too ill to make the trip and noted they left Lobby Day with new respect for the process that can significantly strengthen funding for CFIDS research and expand patient access to needed social services.



Kim Kenney as she testifies before the House of Representatives Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee on behalf of persons with CFIDS.



Pat Golemme, Diane Turner and Jamie Davis visit with Rep. William D. Delahunt (D-MA).

# DRIVING HIGH QUALITY CFIDS RESEARCH

**A**s many as 800,000 women, men and children of all age, ethnic and socioeconomic backgrounds suffer from CFIDS. Their greatest hopes for the future lie with research. The CFIDS Association of America takes a multi-dimensional, multi-disciplinary approach to fostering new and promising research theories and translating them into real results for patients. Our program to drive high quality research includes efforts to attract the best and brightest scientific minds to the study of CFIDS; seed grant support of innovative research; and work with Congress and the federal research community to urge increased federal support of CFIDS research at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and other agencies.

The Association's campaign to generate excitement around CFIDS research kicked into high gear in 2001. Two scientific symposia were held: "Neuroendocrine Aspects of CFS" in March and "Immunologic Aspects of CFS" in October. The goals of these meetings — to establish current knowledge, identify the top areas for future exploration, and, most importantly, introduce a new group of scientists to CFIDS research — were met. Several non-CFIDS researchers came to the meetings as skeptics, but emerged with a new understanding of CFIDS, as well as plans to apply their expertise to CFIDS. Although this venture

seemed risky at the outset, reaching beyond the CFIDS community's circle will increase the quantity and quality of CFIDS research funded by the NIH and other organizations, bring answers to the many compelling questions surrounding this complex illness and ultimately, conquer CFIDS.

## Association awards CFIDS research grants

In 2001, the Association re-opened its peer-reviewed CFIDS research grants program and attracted a record number of applications, demonstrating growing scientific interest in the illness. Twenty-five scientists made preliminary funding inquiries, 15 were invited to submit full applications and four studies were approved for funding in 2002. A total of \$276,461 was granted to Jian Ding, MD, PhD of the University of Minnesota, Sidney Grossberg, MD of the Medical College of Wisconsin, Dimitris Papanicolaou, MD of Emory University and Ronald Schondorf, MD, PhD of McGill University. In June 2002, the Association will issue its Request for Applications for 2003 CFIDS Research Grants, with a specific call for proposals on the immunology of CFIDS.

In 2001, the Association provided a \$10,000 grant to Dr. Leonard Jason as part of its ongoing effort to find a better name for "chronic fatigue syndrome." Dr. Jason's study, "Attributions about CFS," measured health care providers' opinions of the proposed "chronic neuroendocrine-immune dysfunction syndrome" name and concept. Current CFIDS clinicians and researchers were polled by mail and medical trainees were surveyed in focus groups. A manuscript describing the results of the study is now being reviewed by a medical journal.

The National Institutes of Health (NIH) sent a message to scientists and the CFIDS community that it is interested in funding CFIDS research with the December publication of the agency's first CFIDS grant announcement since 1996. This Program Announcement is sponsored by 11 NIH divisions and invites applications on dozens of diverse topics such as treatment, sleep and cognitive symptoms, etiology, genetics, biological tests, neuroimaging and environmental factors. It is expected that this new announcement will further drive renewed scientific interest in CFIDS research. Visit the Association's Web site at [www.cfids.org/resources/research-grants.asp](http://www.cfids.org/resources/research-grants.asp) for this and other CFIDS grant announcements.



Drs. Gerhard Krueger, Nahid Mohaghehpour and Dimitris Papanicolaou

Above: Drs. Dimitris Papanicolaou, Ron Herberman, Gerhard Krueger, Nahid Mohaghehpour and Terry Hedrick (clockwise from top center) come to consensus on the immunological aspects of CFS at the Association's October 2001 symposium.



**"Scientists from different disciplines working together provide the greatest hope for advancing the CFIDS research agenda. I'm driven by my conviction that this will bring an end to CFIDS."**

Vicki Walker, Research and Public Policy Project Manager

# EDUCATING THOSE ON THE FRONT LINES OF PATIENT CARE

**I**n 2001, the Association continued to vigorously pursue efforts to change patient care for the better. The primary care provider education project, “CFS: A Diagnostic & Management Challenge,” educated over 1,200 health care providers. Fifty-two providers participated in intensive two-day workshops, led by CFS experts Leonard Jason, PhD and Charles Lapp, MD, then returned to their home areas to educate their colleagues through workshops and grand rounds. The Association took its CFS exhibit to seven national conferences, reaching professionals from multiple disciplines, including internal medicine physicians, physician assistants, nurse practitioners and psychologists. Video-, Web- and print-based self-study modules of the CFS curriculum were developed to provide broad access to this important information. All three modules are scheduled for implementation in 2002 and will offer continuing medical education credits.

“The skeptical attitude of health care professionals about CFIDS is changing. They are interested in how to make the diagnosis and deal with the puzzling array of symptoms. Creating opportunities to teach providers about CFIDS has been a very rewarding experience. We still have a long way to go, but we’re moving in the right direction.”



Terri Lupton, Coordinator for Educational Opportunities

Support from the Faith and James Knight Foundation added considerable impact to the provider-education project. An educational “ad” published in *School Nurse News* magazine, which has a readership of 14,000, helped to educate school health professionals about CFS and the effect it has on its youngest victims. Promotional ads in the American Academy of Pediatrics’ conference guide and daily newsletters stimulated interest in the CFS exhibit and afforded the Association’s health educator, Terri Lupton, BSS, RN, an opportunity to interact with this important group of specialists. Scholarships awarded to six family practice medical students and

residents, enabled them to attend their national conference. A keynote speaker and community service award were also sponsored for this event, generating increased attendance at the CFS exhibit and enhancing interaction with meeting participants.

In its second year, *The CFS Research Review* continued to spread the message about CFIDS to health care professionals in all fields. The *Review* covered a wide range of topics — from the neuroendocrine and genetic aspects of CFIDS to possible breakthroughs in immunotherapy treatments. A number of internationally recognized CFIDS experts contributed articles, including Roberto Patarca-Montero, MD, PhD

and David J. Torpy, MBBS, PhD, FRACP. The *Review* is published quarterly, and has a circulation of nearly 25,000. It is mailed to all Association members; each member may elect to add two health care professionals to the *Review* mailing list.

Thanks to aggressive outreach, medical practitioners were also educated about CFIDS through their professional literature. The Association built relationships with medical specialty magazines and trade publications that resulted in positive, influential coverage of the illness. Medical publications and Web sites that ran comprehensive stories on CFIDS included *American Medical News*, the American Medical Association’s weekly newspaper for more than 200,000 physicians, *Nursing Spectrum*, *Advance for Physical Therapists*, *Internal Medicine News* and WebMD.com.



Terri Lupton interacts with an interested medical student at the American Academy of Family Physicians national conference for Family Practice Residents and Medical Students in Kansas City, Mo.

## PHYSICIAN SURVEY RESULTS

The CFIDS Association’s survey of medical professionals generated media coverage and increased understanding of the illness. Findings included:

- » 75% of respondents believe CFIDS is as or more disabling than other chronic diseases such as lupus or multiple sclerosis.
- » 83% cited impaired memory or concentration as the most common non-fatigue related symptom.
- » When respondents were asked what symptom other than fatigue would make them most likely to suspect CFIDS, the most common answer was post-exertional malaise.
- » Approximately half of the respondents felt the general public is not very well informed about CFS.



(From left to right) Saul Ferdan, Pat Ferdan, Emily Weston, Stacey and Stefanie Heminger, Jack Werner, Vivien Haynes and Robert Ferdan of the San Joaquin CFIDS/ME/FM Support Network at their spring meeting.

**T**he more fully people understand their illness, the better equipped they are to deal with its effects. The Association's flagship publication, *The CFIDS Chronicle*, provides coverage of a broad spectrum of CFIDS issues. In 2001, the quarterly magazine won praise from readers for stories on medical issues such as visual dysfunction in people with CFIDS, plus updates on research efforts worldwide. The *Chronicle* also kept members abreast of the CDC's payback of misspent CFIDS research funds and advocacy efforts such as Lobby Day and CFIDS Awareness Day. Most importantly, readers received vital advice on coping with CFIDS concerns ranging from disability benefits to handling the after-shock of the terrorist attacks of Sept. 11. The *Chronicle* is mailed to all Association members. Archived editions are available online at the Association's Web site.

The Association's Web site, [www.cfids.org](http://www.cfids.org), re-launched in May 2001, now welcomes more than 45,000 visitors each month. The expanded site provides concise, timely information to patients, caregivers, researchers and medical professionals. It was designed primarily to provide people with CFIDS, and those who think they may have the illness, the resources they need to combat it.

Living with CFIDS requires adapting to an entirely new way of life. People with

CFIDS (PWCs) often feel alone with their disease and with the everyday struggles this illness brings to their lives and the lives of family members and friends. Support groups ease the transition for the newly diagnosed patient and provide emotional support in the ongoing struggle with the disease. Knowing that others share their journey offers comfort and reassurance. Sometimes the best words a CFIDS patient can hear is "I understand" from someone who really does.

To connect PWCs with local support groups, the Association maintains state-by-state listings of CFIDS support groups and contacts. The Association also sponsors The CFIDS Support Network (CSN), a support group member organization that strives to help group leaders facilitate positive and productive meetings. CSN is one of the few programs of the Association led by a committee made up entirely of CFIDS patients. Formed to help guide CSN activities, the CSN Advisory Committee (CSNAC) is a group of dedicated members of the CFIDS support community who understand the unique challenges faced by group leaders and their members. Current CSNAC projects include hosting free monthly conference calls for group leaders, updating the Association's support group leader handbook and developing a resource directory for the CFIDS community.

**Priscilla deLeon (second from left) and Georgia Bowen (second from right) visit with staff from the offices of Arlen Specter (R-PA) and Rick Santorum (R-PA).**



**"Information and understanding — they go a long way in the battle against CFIDS."**

Mark Giuliucci, editor of *The CFIDS Chronicle* and *The CFS Research Review*

Although the primary goal for most CFIDS support groups is to help members "live" with CFIDS, many groups also seek to educate the public, raise funds for CFIDS research and focus state and national policy makers' attention on this devastating illness.

# BUILDING A STRONG TEAM

A dynamic partnership between volunteers and staff is a critical component in the fight to eradicate CFIDS. Volunteers — from Board members and scientists, to support group leaders and patients — contribute their time and talents and help the professional staff make the most impact possible with programs aimed at advancing the Association's mission.

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(continued on following page)



Above: Jane Perlmutter articulates the Association's requests for increased research funding by federal agencies during a meeting with a Congressional aide at Lobby Day.



Top right: John Trussler



Bottom right: Adrienne Ryan



Above: Patti Schmidt, Rick Baldwin and Jon Sterling join Kim Kenney (2nd from right) in NYC as she is honored by Redbook magazine for her outstanding efforts on behalf of people with CFIDS.



Inset left: Mac Sasser



Inset right: Beth Levine



Left: (from left to right) John Ginsberg relaxes with Patrick Holaday and Brett Holaday at a post-Lobby Day reception.

# BUILDING A STRONG TEAM

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James Baraniuk, MD, Georgetown University, Washington, DC  
 George Chrousos, MD, National Institutes of Health, Bethesda, Md.  
 Donald S. Ciccone, MD, University of Medicine and Dentistry of New Jersey, Newark, N.J.

Firdaus S. Dhabhar, PhD, Ohio State University, Columbus, Ohio

Bret A. Hassel, PhD, University of Maryland, Baltimore, Md.

Terry Hedrick, PhD, Cobb Island, Md.

Robert Hill, PhD, Palo Alto, Calif.

Joseph F. John, Jr., MD, Medical University of South Carolina, Charleston, S.C.

Nancy Klimas, MD, University of Miami, Miami, Fla.

Susan Levine, MD, New York, N.Y.

Roderick Mahurin, MD, University of Washington, Seattle, Wash.

Lee Meisel, MD, Boca Raton, Fla.

Marc Ovadia, MD, University of Illinois, Chicago, Ill.

Peter C. Rowe, MD, Johns Hopkins University, Baltimore, Md.

Robert Shapiro, MD, PhD, University of Vermont, Burlington, Vt.

Jon Sterling, Oradel, N.J.

Alexandros N. Vgontzas, MD, Pennsylvania State University, Hershey, Pa.

K. Kimberly Kenney, The CFIDS Association of America, Charlotte, N.C.

Vicki C. Walker, The CFIDS Association of America, Charlotte, N.C.

All current as of May 8, 2002

## TREASURER'S REPORT



R. Richard Baldwin, Treasurer

On behalf of the Board of Directors, I wish to express the Association's special thanks to the thousands of friends who support our cause, especially those who have given so generously for many years. In 2001, your contributions helped us mark a milestone — Association revenue topped the \$2 million mark for the first time in its 15 year history.

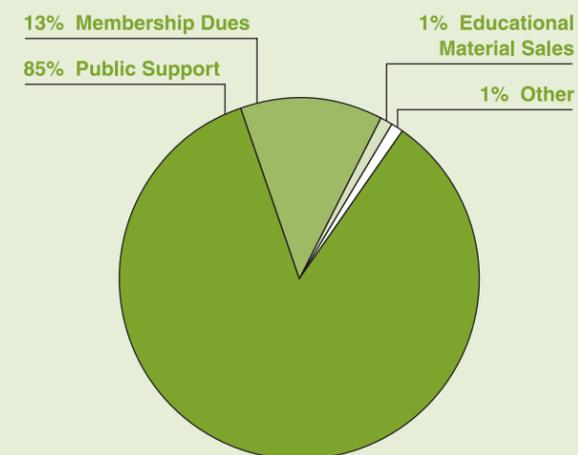
The generosity of individual contributors (including estate gifts), corporations and foundations enabled the Association to make significant progress in CFIDS education, public policy and research programs. In total, \$1,963,912 was invested in the fight against CFIDS in 2001.

At the same time, I'm pleased to report that the Association was able to maintain a supporting services ratio at 17.23% of total support and revenue, a percentage well below the 25% acceptable threshold and one that compares very favorably with other national organizations of similar size and mission.

The financial statements on the following pages present the financial results of fiscal year 2001 with comparative figures for 2000.

We are proud of these financial results and the work they made possible in 2001. Thank you for your continued support and commitment to strengthening the programmatic, development and leadership efforts necessary to accomplishing our shared mission, conquering CFIDS.

### Sources of Funds



### 12 Years of Progress





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, 2001, and the related statements of activities and changes in net assets, of functional expenses, and of cash flows for the years 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 Notes 1 and 9, the prior year summarized comparative information has been derived from the Association's 2000 financial statements; and in our report dated February 9, 2001, we expressed an unqualified opinion on those financial statements.

We conducted our audit in accordance with auditing standards generally accepted in the United States. 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, 2001, and its changes in net assets and cash flows for the year then ended in conformity with accounting principles generally accepted in the United States.

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

Charlotte, North Carolina  
January 17, 2002

## STATEMENT OF FINANCIAL POSITION

December 31, 2001

(With Comparative Totals for Year Ended December 31, 2000)

	Unrestricted	Temporarily Restricted	2001 Totals	2000 Totals
<b>Assets</b>				
<b>Current assets</b>				
Cash and cash equivalents	\$ 521,048	\$ 326,438	\$ 847,486	\$ 1,140,520
Pledges receivable	2,000	1,000	3,000	1,500
Other receivables	328,508	—	328,508	31,228
Inventories	13,168	—	13,168	22,103
Prepaid expenses	24,785	—	24,785	6,868
<b>Total current assets</b>	<b>889,509</b>	<b>327,438</b>	<b>1,216,947</b>	<b>1,202,219</b>
<b>Property and equipment</b>				
Office furniture and fixtures	59,968	—	59,968	36,008
Computers and related equipment	106,039	—	106,039	118,974
Leasehold improvements	42,504	—	42,504	22,918
	208,511	—	208,511	177,900
Less accumulated depreciation	(147,042)	—	(147,042)	(133,279)
<b>Net property and equipment</b>	<b>61,469</b>	<b>—</b>	<b>61,469</b>	<b>44,621</b>
	<b>\$ 950,978</b>	<b>\$ 327,438</b>	<b>\$ 1,278,416</b>	<b>\$ 1,246,840</b>
<b>Liabilities and Net Assets</b>				
<b>Current liabilities</b>				
Accounts payable	\$ 26,237	\$ 20,000	\$ 46,237	\$ 93,146
Accrued payroll and payroll taxes withheld	31,569	—	31,569	44,115
Unearned dues revenue	126,490	—	126,490	138,994
<b>Total current liabilities</b>	<b>184,296</b>	<b>20,000</b>	<b>204,296</b>	<b>276,255</b>
<b>Net assets</b>				
Unrestricted				
Undesignated	504,926	—	504,926	428,740
Designated	261,756	—	261,756	311,041
Total unrestricted	766,682	—	766,682	739,781
Temporarily restricted	—	307,438	307,438	230,804
<b>Total net assets</b>	<b>766,682</b>	<b>307,438</b>	<b>1,074,120</b>	<b>970,585</b>
	<b>\$ 950,978</b>	<b>\$ 327,438</b>	<b>\$ 1,278,416</b>	<b>\$ 1,246,840</b>

The accompanying notes are an integral part of these financial statements.

## STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

Year Ended December 31, 2001

(With Comparative Totals for Year Ended December 31, 2000)

	Unrestricted	Temporarily Restricted	2001 Totals	2000 Totals
<b>Support and revenues</b>				
<b>Public support</b>				
Contributions and grants	\$ 1,093,597	\$ 651,790	\$ 1,745,387	\$ 1,489,586
<b>Revenues</b>				
Membership dues	275,554	—	275,554	314,654
Educational material sales	15,968	—	15,968	19,422
Card sales, shirt sales	9	—	9	18
Advertising revenue	600	—	600	1,500
Interest and other	30,241	—	30,241	37,925
	322,372	—	322,372	373,519
<b>Assets released from restrictions</b>				
Satisfaction of donor restrictions	575,156	(575,156)	—	—
<b>Total support and revenues</b>	<b>1,991,125</b>	<b>76,634</b>	<b>2,067,759</b>	<b>1,863,105</b>
<b>Expenses and losses</b>				
<b>Program services</b>				
Research	254,054	—	254,054	107,877
Public policy	384,777	—	384,777	319,152
Education	968,709	—	968,709	800,220
<b>Supporting services</b>				
Management and general	165,775	—	165,775	167,898
Fund-raising and development	190,597	—	190,597	221,380
	1,963,912	—	1,963,912	1,616,527
Loss on assets disposed	312	—	312	758
<b>Total expenses and losses</b>	<b>1,964,224</b>	<b>—</b>	<b>1,964,224</b>	<b>1,617,285</b>
Increase in net assets	26,901	76,634	103,535	245,820
<b>Net assets</b>				
Beginning of year	739,781	230,804	970,585	724,765
<b>End of year</b>	<b>\$ 766,682</b>	<b>\$ 307,438</b>	<b>\$ 1,074,120</b>	<b>\$ 970,585</b>

The accompanying notes are an integral part of these financial statements.

## STATEMENT OF FUNCTIONAL EXPENSES

Year Ended December 31, 2001

(With Comparative Totals for Year Ended December 31, 2000)

	Program Services			Supporting Services		2001 Totals	2000 Totals
	Research	Public Policy	Education	Management and General	Fund-Raising and Development		
Contract services	\$ 1,967	\$ 224,866	\$ 110,207	\$ 3,447	\$ 2,069	\$ 342,556	\$ 192,729
Salaries	65,158	104,947	412,563	114,186	68,551	765,405	634,426
Payroll taxes	4,277	6,889	27,081	7,495	4,500	50,242	40,583
Printing and postage	6,058	8,517	138,531	3,951	82,918	239,975	200,269
Repairs and maintenance	1,284	2,069	8,133	2,251	1,351	15,088	13,179
Supplies	2,868	2,204	12,587	2,398	1,440	21,497	22,789
Educational materials/cost of sales	—	—	7,760	—	—	7,760	8,089
Travel expenses	796	6,106	16,342	1,043	3,822	28,109	50,225
Insurance	332	534	2,099	581	349	3,895	3,864
Telephone	3,737	4,418	22,819	4,283	2,856	38,113	26,824
Symposia series	141,211	—	—	—	—	141,211	40,463
Occupancy costs, including utilities	6,561	10,567	41,540	11,497	6,902	77,067	55,759
Depreciation	2,314	3,728	14,654	4,056	2,436	27,188	25,797
Miscellaneous	7,491	9,932	54,828	10,587	13,403	96,241	135,866
Direct grants	10,000	—	99,565	—	—	109,565	165,665
<b>Total expenses</b>	<b>\$ 254,054</b>	<b>\$ 384,777</b>	<b>\$ 968,709</b>	<b>\$ 165,775</b>	<b>\$ 190,597</b>	<b>\$1,963,912</b>	<b>\$1,616,527</b>
Management and general expenses						\$ 165,775	\$ 167,898
Fund-raising and development expenses						190,597	221,380
<b>Total management and general, and fund-raising and development expenses</b>						<b>356,372</b>	<b>389,278</b>
<b>Total support and revenue</b>						<b>\$2,067,759</b>	<b>\$1,863,105</b>
<b>Supporting services ratio</b>						<b>17.23%</b>	<b>20.89%</b>

The accompanying notes are an integral part of these financial statements.

**STATEMENT OF CASH FLOWS**

Year Ended December 31, 2001

(With Comparative Totals for Year Ended December 31, 2000)

	2001	2000
<b>Cash flows from operating activities</b>		
Increase in net assets	\$ 103,535	\$ 245,820
Adjustments to reconcile increase in net assets to net cash provided (used) by operating activities:		
Depreciation	27,188	25,797
Loss on disposal of assets	312	758
(Increase) decrease in operating assets:		
Pledges and other receivables	(298,780)	(26,972)
Inventories	8,935	(8,757)
Prepaid expenses	(17,917)	5,501
Increase (decrease) in operating liabilities:		
Accounts payable	(46,909)	(80,753)
Accrued payroll and payroll taxes withheld	(12,546)	12,270
Unearned dues revenues	(12,504)	(17,818)
<b>Net cash provided (used) by operating activities</b>	<b>(248,686)</b>	<b>155,846</b>
<b>Cash flows from investing activities</b>		
Purchases of property and equipment	(44,348)	(33,556)
<b>Net cash used by investing activities</b>	<b>(44,348)</b>	<b>(33,556)</b>
<b>Net increase (decrease) in cash and cash equivalents</b>	<b>(293,034)</b>	<b>122,290</b>
<b>Cash and cash equivalents</b>		
Beginning of year	1,140,520	1,018,230
End of year	\$ 847,486	\$ 1,140,520

The accompanying notes are an integral part of these financial statements.

**NOTES TO FINANCIAL STATEMENTS**

December 31, 2001

**Note 1 — 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.

**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.

**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.

**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 stipulated by donors for specific operating purposes.

*Permanently restricted net assets* — Net assets consisting of contributions received from donors whose use by the Association is limited by permanent donor-imposed stipulations. At December 31, 2001, the Association has no permanently restricted net assets.

**Inventories**

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

**Property and equipment**

Property and equipment items are stated at cost. Depreciation is charged to expense over the estimated useful lives of the assets using principally accelerated methods.

**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 donation. 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*.

**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 grants are recognized as revenue when received, except for pledges, which are recognized as revenue at the time the pledge is received.

**Research grants**

The Association awards grants for medical research projects in the field of chronic fatigue and immune dysfunction syndrome. 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 research contributions received and the Association's cash flow, these grants are not recognized as expenditures until payment occurs (See Note 4).

#### 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 held by a recipient organization for the sole benefit of the Association. At December 31, 2001, the Association has no assets held by recipient organizations which are considered material and warrant inclusion in the accompanying financial statements (see Note 2).

#### 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.

#### 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 2001 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	\$ 248,211	\$ 77,561
Grassroots Lobbying	\$ 67,856	\$ 30,712

#### 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.

#### 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, 2000, from which the summarized information was derived. Certain information reported in the comparative totals for 2000 has been reclassified in order to conform to the 2001 presentation.

#### Note 2 — Change in accounting principles

In December 1994, the Association made an irrevocable gift to the Foundation for the Carolinas hereinafter referred to as recipient organization, in the amount of \$5,000. This gift was for the establishment of a permanent endowment fund, the earnings of which are for the benefit of the Association. On January 1, 2001, the Association adopted Statement of Financial Accounting Standards (SFAS) No. 136, *Transfers of Assets to a Not-for-Profit Organization or Charitable Trust That Raises or Holds Contributions for Others*. As a result, the Association would be required to change its method of accounting for material contributions received by a recipient organization that are specified for the Association. Previously, the Association recorded contribution revenue as it was notified of distributions to be made by the recipient organization. Under the new accounting method, the Association recognizes the assets held by the recipient organization for the sole benefit of the Association. As of December 31, 2001, the Association had \$8,578 in assets held by the recipient organization, which is considered insignificant for financial statement purposes.

#### Note 3 — Temporarily restricted net assets

Temporarily restricted net assets are available for the following purposes:

Research activities	\$ 296,087
Educational activities	11,351
	<u>\$ 307,438</u>

#### Note 4 — Net assets released from restrictions

Net assets were released from restrictions by incurring expenses satisfying the purpose as follows:

Purpose restrictions accomplished:	
Research grants, symposia, and related expenditures	\$ 202,609
Educational activities	336,941
Public policy activities	35,606
	<u>\$ 575,156</u>

#### Note 5 — Commitments

As discussed in Note 1, the Association awards grants for medical research and funds such projects contingent upon research contributions received and cash flow. At December 31, 2001, the Board of Directors had approved funding for the following research projects to be disbursed during 2002:

Jian M. Ding, MD, PhD	\$ 79,947
Sidney E. Grossberg, MD	79,120
Ronald Schondorf, MD, PhD	58,594
Dimitris A. Papanicolaou, MD	66,800
	<u>\$ 284,461</u>

The Association retains the services of The Sheridan Group, a professional government relations firm in Washington, D.C., through an annual contract. The Sheridan Group represents the interests of the Association with Congress, the Executive Branch, and other federal governmental agencies. The total contractual obligation to The Sheridan Group for the year 2002 is \$174,000 payable in monthly installments. The services of The Sheridan Group in 2001 amounted to \$221,698.

#### Note 6 — Leases

The Association leases office space used in its operations under an operating lease that expires in June 2002. The lease initially provides for a monthly rental of \$5,432 and is subject to annual increases including increases based upon the Consumer Price Index. The Association also leases office equipment and computers under leases expiring in 2003.

Future minimum lease commitments under the above operating leases are as follows at December 31, 2001:

Year ending December 31	
2002	\$ 27,720
2003	690
	<u>\$ 28,410</u>

Additionally, the Association leases certain storage areas under operating leases with terms typically less than one year.

Rental expense incurred under all operating leases was \$79,737 for the year ended December 31, 2001.

#### Note 7 — Concentrations of credit risk

Financial instruments, which potentially subject the Association to concentrations of credit risk, consist principally of pledges receivable and cash. The Association receives pledges from various entities and individuals located throughout the United States for various fund raising drives. Since these pledges 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, 2001.

#### Note 8 — Benefit plan

The Association has a 403(b) retirement plan in place covering substantially all employees meeting certain service and age requirements. This plan is a defined contribution plan with voluntary employee participation. During 2001, the Association made contributions into this plan amounting to \$22,301.



The CFIDS Association of America invites you to explore the many opportunities by which you can leave your mark on the future and make a significant and enduring contribution to the campaign against CFIDS. Your generosity will accelerate efforts aimed at finding the cause of and cure for CFIDS and provide a legacy of hope to the hundreds of thousands who suffer the devastating effects of this cruel illness.

### **CRAFTING A TRIBUTE**

Honorary and memorial donations are a wonderful way to recognize someone in life or pay tribute to someone's memory. Consider making a contribution to the Association to honor the strength of your spouse or child, to thank a supportive caregiver or doctor or to remember a friend or loved one. The Association will notify the individual acknowledged, or their family, of your generous gift.

### **LEAVING A LEGACY**

Include The CFIDS Association of America in your will and leave a lasting legacy. You can direct gifts to be made in a specific amount, a percentage of your estate or the remainder of your estate. As with other donations, bequests may be earmarked for the Association's education, public policy and/or research programs or for The CFIDS Endowment Fund.

The CFIDS Association of America's correct legal designation is: 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.

For additional information, contact the Association's Director of Development at:

The CFIDS Association of America

PO Box 220398

Charlotte, NC 28222-0398

Tel.: 704-364-0466

Fax: 704-365-9755

E-mail: [jldavis@cfids.org](mailto:jldavis@cfids.org)

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

## WHAT IS THE CFIDS ASSOCIATION OF AMERICA?

The CFIDS Association of America is the nation's leading charitable organization dedicated to conquering chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME).

Funded by charitable contributions from individuals, foundations and corporations, the Association has directly invested over \$12 million in support of its mission. Through effective programs devoted to CFIDS education, advocacy and research, the Association plays a catalytic role in focusing mainstream attention on this serious public health concern, achieving public policy victories for people with CFIDS and accelerating the pace of cutting-edge CFIDS research.

The Association battles CFIDS on five important fronts:

- » 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.

Tremendous progress has been made in these areas since the Association was founded in 1987, but the ultimate goal, conquering CFIDS, still lies ahead. For all those committed to the mission of The CFIDS Association of America, the end will not come until we know the cause of and find a cure for this debilitating, life changing illness.

The CFIDS Association of America, Inc.  
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