

2003 ANNUAL REPORT



THE CFIDS ASSOCIATION OF AMERICA INC.

the power
of one

What is CFIDS?

Chronic fatigue and immune dysfunction syndrome (CFIDS, also widely recognized as chronic fatigue syndrome or CFS) is a serious and debilitating illness that affects the brain and multiple body systems.

It is characterized by crushing 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 (MS), fibromyalgia (FM), Lyme disease, post-polio syndrome and autoimmune diseases such as lupus.

CFIDS strikes people of all age, ethnic and socioeconomic groups—an estimated 800,000 U.S. adults suffer from CFIDS.

Despite nearly two decades 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.

CFIDS is a complex illness, but learning about it has never been easier. Contact the CFIDS Association of America.



McCleary



Sterling

Letter from the Chairman of the Board and the President & CEO	1
Board of Directors, Committees and Staff.....	10
Independent Auditors' Report	12
Financial Tables.....	13
Notes to Financial Statements	17
Donors	20
Guide to Giving.....	inside back cover

the power of one

Our organization was founded by one man with a single mission—to find a cure for the devastating illness that was ravaging his life and turning his family’s world upside down.

He knew there were others who must also be suffering.

The Force of Many

A handful of passionate and visionary volunteers joined Marc Iverson. At a time when CFIDS was demeaned as the “yuppie flu” by the media, its existence questioned by the medical community, CFIDS patients who had been loosely organized around the country found common ground at the Association.

News of the organization spread. From an extra room above Marc’s garage, CFIDS information was amassed and distributed. A small but determined staff was engaged. Contributions were solicited and received. And the CFIDS Association began making progress for people with CFIDS (PWCs).

The Association entered the research arena making its first grant of \$15,000 to Dr. Paul Cheney. At the same time, another man’s belief in the potential of the Association’s fledgling efforts on Capitol Hill became an inaugural investment in our advocacy program.

Today, 17 years later, the CFIDS Association of America is the nation’s largest and most active charitable organization dedicated to ending CFIDS.

Our strategies have developed and matured, informed by years of work and the counsel of many. Our office space has changed—though still modest—to accommodate the professional staff and volunteer leaders who power our organization. And our programs are flexible by design so we can be responsive to emerging opportunities and the needs of the hundreds of thousands of people we now represent.

The CFIDS Association believes that public complacency about CFIDS must be vigorously countered by sustained information that this illness is a serious and debilitating medical disorder that destroys health, lifestyles, careers and families. CFIDS is an illness that warrants public attention. We have earned the respect of key lawmakers and agency officials and direct a dynamic public policy program that focuses federal attention on the most important issues faced by PWCs. We pursue science-based solutions to the illness, funding and fostering innovative, promising research studies that will speed progress toward better diagnostics and treatments. And we provide health care professionals, people with CFIDS and those who care about them accurate, trusted CFIDS information through continuing medical education efforts, conferences, workshops, our website and widely accessible print and e-publications.

The CFIDS Association is driven by one prevailing and unifying vision—conquering CFIDS.

We are proud to be part of the community working to end the pain and disability caused by CFIDS. We are profoundly grateful to each of the individuals, families, corporations and foundations who have supported this mission over the years as well as the nearly 3,500 who made generous gifts ranging from \$1 to \$95,000 in 2003. The Association also extends its thanks to those who donated their time and talents—your support is invaluable.

The power of one person, one idea, one vision, permeates everything we do and what we stand for. But it is the force of many that will enable us to accomplish our mission and restore good health to people with CFIDS.

Thank you for your extraordinary support.



K. Kimberly McCleary, President & CEO



Jonathan B. Sterling, Chairman of the Board

From start to finish, 2003 was an important year for the CFIDS community.

With media attention sparked by a beautifully written book and the compelling personal battle of one woman, the voices of 800,000 men, women and children echoed across the country. Laura Hillenbrand courageously shared her CFIDS story in hundreds of print, radio and TV interviews, drawing parallels to the lives of the three lost men and the crook-legged racehorse she wrote about in her award-winning and beloved book, *Seabiscuit: An American Legend*.

Although Laura didn't expect to become a "celebrity" or a spokesperson for people with CFIDS (PWCs), she was instrumental in helping to reshape the perception of the illness.

Perhaps the most powerful example of Laura's courage, compassion and tenacity on behalf of the CFIDS community is her essay published in the July 7, 2003 issue of *The New Yorker* magazine. "A Sudden Illness" is a moving account of her battle with CFIDS. Laura has remarked that this deeply personal piece of writing means more to her than her book. This year, Laura received the prestigious National Magazine Award for her essay. The judges' citation reads "In this essay about her long, nearly unfathomable fight with chronic fatigue syndrome, Laura Hillenbrand delivers rich, suspenseful, cinematic details and imagery that transport the reader deep into the heart of her nightmare until it seems you are experiencing her claustrophobic and horrific reality. 'A Sudden Illness' champions the importance of respecting personal experience as valid (despite an army of 'authorities' who work to discredit it) and creates an inspiring testament to the will to live and create."

Gifted writer and PWC Floyd Skloot was also recently recognized for his work. His book, *In the Shadow of Memory*, an intimate self-exploration about the devastating life changes brought about by a disordered brain

(due to CFIDS), received national acclaim winning the distinguished PEN Center USA Literary Award in Creative Nonfiction and the 2004 Independent Publishers Book Award in Creative Non-Fiction/Essay. A longtime friend of the Association, Floyd generously crafted "A Patient's Perspective" for the opening page of *Snapshots of CFIDS*, an Association publication created to "personalize" and broaden understanding of CFIDS.

The CFIDS Association's persistence in the public awareness arena paid dividends in 2003. The Association provided thousands of pages of resource material, story ideas and coordinated contacts and interviews for numerous media outlets. Association President & CEO Kim McCleary and documentary filmmaker and PWC Kim Snyder were guests on CNN's *The Flipside*. During the 12-minute segment, Ms. McCleary effectively conveyed the seriousness of the illness, its economic impact and pressing funding issues related to CFIDS research.

Readers of newspapers across the country, from the *Boston Herald* to the *Des Moines Register* to the *Daily-Times Call* of Gunbarrel, Colo., learned a great deal more about CFIDS last year. And an Association-produced camera-ready article about CFIDS research findings generated coverage in nearly 270 newspapers with a combined readership of more than 6.3 million.

We redesigned our website in 2003, improving its look and feel, navigation and readability. www.cfids.org receives an average of 57,000 visitors per month. *CFIDS Link*, the Association's e-publication, significantly expanded its reach last year to 15,683 monthly subscribers.

Not to be outdone, the Association's flagship publication, the *CFIDS Chronicle*, continues to receive kudos from readers. The *Chronicle* covered a broad spectrum of CFIDS-related topics in 2003 ranging from Q & A's with prominent CFIDS researchers, to navigating the disability insurance maze to insights in complementary therapies.

The Power of One Event

The fight against CFIDS hit the silver screen on July 28, 2003 when nearly 400 celebrities, politicians, scientists and friends of the CFIDS Association gathered in Washington, DC, for a special screening of the movie *Seabiscuit*. The benefit event, organized and sponsored by the Association, featured a rare public appearance by Laura Hillenbrand, author of *Seabiscuit: An American Legend*, the best-selling book about the 1930s racehorse that inspired the motion picture.

Hillenbrand's success—and her willingness to speak out about her illness on behalf of her fellow CFIDS sufferers—has helped our cause immensely.

ESPN's Tony Kornheiser was the event's honorary chairman. He praised Hillenbrand's efforts, as did U.S. Senator Harry Reid and Dr. Julie Gerberding, director of the U.S. Centers for Disease Control and Prevention (CDC). NBC's and HBO's Bob Costas was also in attendance, as was radio personality Diane Rehm, *Washington Post* writer Andrew Beyer, DC-area entertainment reporter Arch Campbell, *Inside Edition*'s Les Trent, actress Mary McDonough and Kornheiser's TV co-host, *Washington Post* sports columnist Michael Wilbon.

Dr. Gerberding said the evening was all about “C-words”: Celebration, commitment and collaboration. “Hopefully, this leads to the last c-word which is ‘cure,’” she said. Dr. Gerberding then surprised the crowd, announcing that the CDC would provide an additional \$100,000 to the Association's physician education program.

But the star of the night was Hillenbrand. With longtime boyfriend Borden Flanagan by her side, Laura walked slowly to the front of the theatre to a standing ovation from a grateful audience.

Sportswriter, humorist and TV personality Tony Kornheiser with the evening's guest of honor, Laura Hillenbrand.



Above: Kim McCleary (left) with CDC director Dr. Julie Gerberding and CFIDS lobbyist Tom Sheridan.

Below: A full house awaits the benefit screening of *Seabiscuit*. The Association extends special thanks to Universal Pictures/DreamWorks Pictures/Spyglass Entertainment, Random House, Neiman Marcus and Kay Unger New York for their generous support of this special event.



The Power of One Medium

According to Harris Interactive, the busiest medical practitioners are most likely to go online looking for information and the vast majority of those doctors report that the information they find online has an impact on medical decisions about diagnosis and treatment. To ensure that CFIDS information is readily available and accessible, the Association “went live” in 2003 with a Web-based self-study course for busy health care professionals. (CFIDS self-study opportunities are also available in print, DVD and video formats.)

A powerful combination of technology and human resources, the project connects health care providers to vital CFIDS information. 548 providers registered for the online course last year. Clearly more work needs to be done before all people struggling with CFIDS can find a CFIDS-savvy physician, however, feedback continues to be encouraging. Dr. Michael Sills, MD, FACP, recently completed the course and noted, “While the source of the syndrome remains a mystery, knowing how to be compassionate toward those who suffer from it does not have to be.”



Good patient care begins with good information.

The Association’s medical education project is about enhanced understanding of CFIDS, earlier detection and diagnosis, better patient-to-doctor and doctor-to-patient communication and improved illness management. And it’s about empowering patients.

The Association’s provider education program was conceived in 1997 and piloted in 2000 by the U.S. Centers for Disease Control & Prevention, the U.S. Health Resources and Services Administration (HRSA) and Illinois Health Consortium. Today, the program has grown to include Grand Rounds presentations, a myriad of continuing education opportunities, exhibits at national provider conferences and scientific meetings and a multidisciplinary teaching curriculum.

The primary component of the program is an educational course, *Chronic Fatigue Syndrome: Diagnosis and Management*, a collaborative project between the CDC and the CFIDS Association. With full accreditation from CDC, the program offers health care providers who successfully complete trainings or self-study courses the opportunity to earn free continuing education credits (CME, CEU and CNE).

Terri Lupton, BSS, RN, the Association’s Coordinator for Education Opportunities, opened doors to—and the minds of—thousands of medical professionals with a thought-provoking exhibit. In 2003, the Association exhibited at seven major national medical conferences:

- » **American Academy of Pain Management**, Denver, Co.
- » **American Academy of Physician Assistants**, New Orleans, La.

- » **American Association of Chronic Fatigue Syndrome**, Chantilly, Va.
- » **American College of Nurse Practitioners**, Cincinnati, Ohio
- » **American College of Physicians/American Society of Internal Medicine**, San Diego, Calif.
- » **American Public Health Association**, San Francisco, Calif.
- » **National Medical Association**, Philadelphia, Pa.

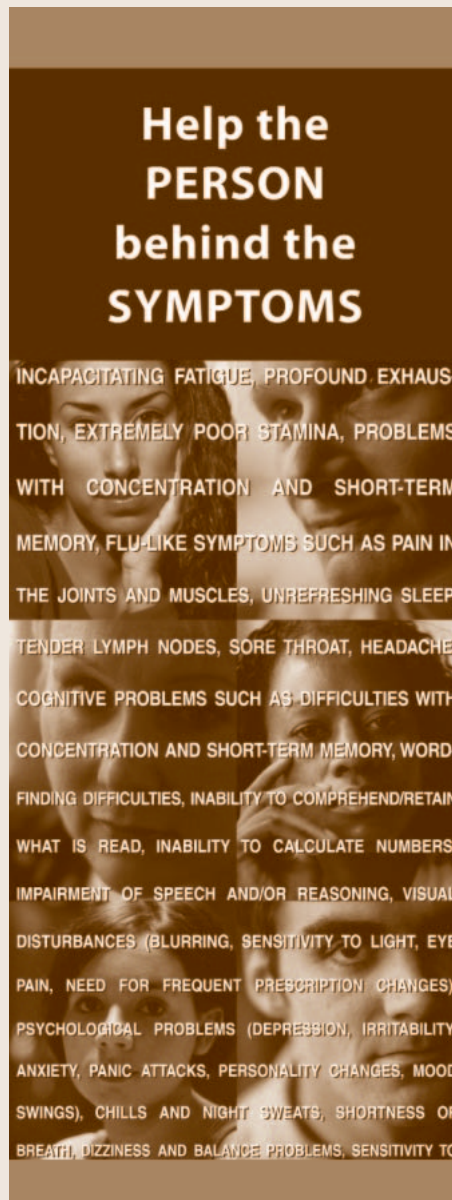
The Power of Information

The Association introduced a powerful new tool in 2003—the *CFS Pocket Resource Guide*. This compact, laminated, tri-fold brochure is an excellent reference guide for health care professionals and includes a diagnostic decision-making model and clear, concise information on illness management and disability documentation.

Since its introduction in November 2003, more than 5,000 copies of the resource guide have been distributed to clinicians, nurses, physician assistants and interested others across the country. We anticipate requests for tens of thousands of this important new informational guide over the next 12 months. Copies of the *CFS Pocket Resource Guide* are available by sending a request to resourceguide@cfids.org.



Glenda Yakel, Lois McPherson, Terri Lupton and Sue Alexander at the American Academy of Pain Management Clinical Meeting in Denver, Colorado, September 2003.



The medical education exhibit utilizes striking images and bold text to capture the attention of health care providers. The display has sparked booth traffic, initiated discussions and led the way to instructional opportunities that are invaluable to the provider education project's mission.

The watchwords for the most vigorous CFIDS advocates... remaining relevant.

The CFIDS Association, and longtime partners at The Sheridan Group, lead an array of activities aimed at forging and fostering vital, productive relationships with key Congressional decision makers and enhancing the political influence of the CFIDS community.

Regardless of the tactics employed—a meeting with Dr. Elias Zerhouni, director of the National Institutes of Health (NIH); discussions with Senators Judd Gregg (R-NH and Chairman of the Senate HELP committee) and Harry Reid (D-NV and Minority Whip); participation in the meetings of the Department of Health and Human Services (DHHS) CFS Advisory Committee; or effective, steady communication with leaders and scientists at the U.S. Centers for Disease Control & Prevention (CDC)—the priority of the Association’s public policy program is to keep CFIDS relevant.

Lawmakers and bureaucrats have the power to decide which causes get funded and which ones don’t. And they count on the apathetic advocate and the inattentive organization that will let them “off the hook.” Vigorous Association-led advocacy and a consistent presence in Washington, DC is necessary to secure the research funding, recognition and policy changes we seek. The Association relies on grassroots advocates to help demonstrate that the issues we bring to the Hill have a real, human dimension. Of significance in 2003 was our ability to mobilize a stronger and more active cadre of grassroots advocates bolstering the interests of people with CFIDS on Capitol Hill.

The Association is grateful to the many PWCs, their family members and friends who continue to make CFIDS-related public policy their priority.

The Power of One Volunteer

For Jonathan Stein, the last minute decision by the government to close federal offices on September 18, 2003 due to a predicted hurricane—effectively canceling the Association’s 12th Annual Lobby Day planned for the same day—wasn’t enough to douse his plans to meet with Sen. Arlen Specter (R-Pa.), share his daughter’s story and ask for greater federal resources for CFIDS.

As soon as Stein returned home from Washington, DC, he used materials and tips he obtained at the Lobby Day training session to connect with Specter’s office. Through persistent follow-up, Stein and his daughter Rachel were invited to meet with Sen. Specter, chairman of the Senate Health and Human Services Appropriations Subcommittee.

The meeting was brief but productive. Rachel, a graduate of Yale and Princeton, shared her personal story. She has been totally disabled by CFIDS for four years since the sudden onset of the illness while she was working as a consultant for KPMG. The two gave Specter updated prevalence figures and spoke about the personal and collective economic toll the illness exacts.

Since the meeting, staff from Specter’s office followed up with the Association’s lobbyists at The Sheridan Group to obtain more detailed information about the Steins’ request for increased spending and accountability by the NIH on CFIDS.

The Power of Persistence

For almost three years, the CFIDS Association worked steadily with Congress and staff at the Department of Health and Human Services (DHHS) to manage the formation of a committee “established” when the DHHS announced, in January 2001, its intention to transform the existing CFS Coordinating Committee into a formal advisory committee governed by the Federal Advisory Committee Act. CFIDS Association leaders balanced persistence with patience as they pushed for progress while the committee charter stalled due to an administration change and competing federal priorities, including 9-11, bioterrorism and other national crises.

There was little fanfare as the new CFS Advisory Committee finally met for the first time on September 29, 2003. But the calm belied the significance of the committee charged with providing expert advice and recommendations to the Secretary for Health and Human Services on a broad range of issues pertaining to CFIDS. Moving forward, the Association will use the opportunities the committee creates to assess federal efforts, express concerns and make policy recommendations as they relate to CFIDS.

Blending the resources of our federal government with progressive Association-funded pilot research is a powerful combination that will give us a commanding advantage over an illness that has been a formidable opponent.

The CFIDS Association is grounded in CFIDS science.

Solid biomedical research is fundamental to understanding CFIDS, its causes and prevalence. It is central to finding a diagnostic marker, effective treatment and a cure.

For almost two decades, the Association's research program has filled an important need in the CFIDS research arena, identifying gaps in current knowledge, defining the top areas for future exploration and providing seed funding for innovative pilot research projects. In fact, outside of the federal government, the Association is the nation's largest source of funds for scientists studying CFIDS, investing more than \$4 million in CFIDS research over the past 17 years.

The Power of Partnership

The Association works closely with leaders and scientists at the Centers for Disease Control & Prevention (CDC) to monitor and help shape their CFIDS research program, now the most diverse and promising CFIDS research effort in the world. Today, the agency is pioneering gene expression microarray technology—important work that may lead to a routine diagnostic test for CFIDS.

CDC also recently published a landmark study which documents the enormous toll CFIDS takes on the individual and the country. The study, based upon a phone survey of 56,000 persons in Wichita, Kan., followed by thorough medical evaluations of those who complained of unusual fatigue lasting a month or more, reports that CFIDS costs the United States more than \$9 billion annually in lost productivity. According to the study authors, "The extent of the burden indicates that continued research to determine the cause of and potential therapies for CFIDS could provide substantial benefit both for individual patients and for the nation."

A committee of respected scientists peer-reviewed nine applications from investigators invited to submit full proposals during the Association's 2004 research grants cycle. We are pleased to announce over \$317,000 in research awards in support of the following projects:

HERV-K18 as a risk factor for CFIDS; Brigitte Huber, PhD, Tufts University School of Medicine, Boston, Mass. This study seeks to identify the possible differential distribution of HERV-K18 allele and genotype frequencies in CFIDS patients when compared to healthy controls, opening new avenues for the development of clinical treatments of this chronic disease.

Pilot study of the effects of corticotrophin-releasing hormone (CRH) on cortisol and interleukin-6 concentrations, and adipose tissue interleukin-6 production in patients with CFS; Dimitris Papanicolaou, MD, Emory University School of Medicine, Atlanta, Ga. Dr. Papanicolaou will investigate the role of corticotrophin-releasing hormone (CRH) as the stimulus for interleukin-6 (IL-6) secretion, which has been implicated in the pathogenesis of CFS.

H MRS Neurometabolites as Diagnostic Markers for Chronic Fatigue Syndrome; Dikoma Shungu, PhD, Weill Medical College of Cornell University, New York, N.Y. This study will test the hypothesis that CFS is associated with changes in the levels of specific brain chemicals, and that such changes are measurable by hydrogen magnetic resonance spectroscopic imaging (H MRSI), thus serving as diagnostic markers of CFS.

Using an Exercise Challenge to Investigate the Pathophysiology of CFIDS; Christopher Snell, PhD and J. Mark Van Ness, PhD, University of the Pacific, Stockton, Ca. Drs. Snell and VanNess will examine the physical cognitive responses of CFIDS patients to exercise using multiple assessment strategies aimed at identifying abnormalities that might point to the origins of many CFIDS symptoms and provide reliable markers for diagnosis and disease severity.

In 2003, the Association supported the work of Giris Jacob, MD and Theodore Friedman, MD, PhD. Dr. Jacob and his team at Rambam Medical Center in

Haifa, Israel, are examining the possible link between a persistently over-active immune system and CFIDS. Their work has been delayed due to the tragic events in the Middle East.

Dr. Friedman, UCLA School of Medicine, is looking into possible causes behind the decreased blood flow to the brain that occurs in subsets of CFIDS patients. Friedman's preliminary data shows that a large percentage of patients with CFIDS have defects in their renin-aldosterone axis, representing a discrete, previously unrecognized disease entity, with its own pathophysiology and functional characteristics. This subset of patients should benefit from unique treatment options aimed at correcting their mineralocorticoid deficiency.

As Association-funded pilot studies have explored cutting-edge concepts and expanded promising theories, we have also worked vigorously to attract the best and brightest scientific minds to the study of CFIDS, foster collaborative research teams and increase the quantity (and quality) of new studies in the research pipeline.

The CFIDS Association is committed to advancing scientific research that will translate into real results, and improved health, for the hundreds of thousands of people with CFIDS.

This past year, neuroendocrine and immunology symposia papers, generated by the Association's research symposia series were accepted by *Neuroimmunomodulation*. Additionally, results from a large population-based CDC study of CFS patients were published in the *Archives of Internal Medicine*, concluding that "chronic fatigue syndrome constitutes a major public health problem."

The Power of One Meeting

Cellular and molecular mechanisms of unexplained fatigue was the focus of discussion and debate at the prestigious Banbury Center of the Cold Spring Harbor Laboratory in N.Y. CFIDS was the focus of several presentations—Association President & CEO Kim McCleary, and Eleanor Hanna, PhD of the National Institutes of Health, co-chaired a session on the search for a biological marker for CFIDS. Experts from other fields provided context and insight into how fatigue in other conditions is being investigated using new technologies and animal models.

The meeting provided an excellent opportunity to raise the visibility of CFIDS in the broader scientific community and to draw attention to the intellectual challenges its study poses. Researchers left the meeting with new consideration for ongoing and planned studies; those from other fields acknowledged a greater appreciation for the complexity of CFIDS and interest in launching or collaborating on CFIDS-related projects.



The Power of Cooperation

Collaborative efforts between Association volunteers and staff is a critical component in the fight to eradicate CFIDS. Volunteers contribute their time and talents and help the professional staff make the most impact possible with programs aimed at advancing the Association's mission.

Board of Directors, Professional Staff and selected Advisory Committees

(current as of June 23, 2004)

Board of Directors

Officers

Jonathan B. Sterling, Chairman, Oradell, N.J.

Joseph Lane, Vice Chairman, Buffalo, N.Y.

Patti Schmidt, Secretary, Philadelphia, Pa.

Jane Perlmutter, Treasurer, New York, N.Y.

Directors

R. Richard Baldwin, Newark, Del.

Susan Jacobs, JD, Providence, R.I.

K. Kimberly McCleary, Charlotte, N.C.

Mark Peterson, DDS, Chesapeake, Va.

Lynn Royster, PhD, JD, Chicago, Ill.

Adrienne B. Ryan, Oldwick, N.J.

John Trussler, Grants Pass, Ore.

Professional Staff

K. Kimberly McCleary,
President & Chief Executive Officer

Jamie L. Davis,
Director of Development & Chief Operating Officer

Kristina P. Hopkins, Controller

Terri Lupton, BSS, RN,
Coordinator for Educational Opportunities

Marcia Harmon, Director of Communications

Kim Almond, Development Project Coordinator
Nova L. Bouknight,
CSN Membership Services Coordinator
Gloria Smith, Front Office Manager
Lois J. Infanti, Accounting & Personnel Assistant
Julie Carothers, Information Technology Specialist
Kasia Faryna, Marketing Associate

Primary Care Provider Education Project Advisory Committee

Julie Barroso, PhD, ANP, CS,
University of North Carolina at Chapel Hill,
Chapel Hill, N.C.
Kristine Healy, MPH, PA-C,
Midwestern University, Downers Grove, Ill.
Leonard Jason, PhD,
DePaul University, Chicago, Ill.
James Jones, MD, CDC
Charles Lapp, MD,
Director, The Hunter-Hopkins Clinic, Charlotte, N.C.
Rosane Neisenbaum, PhD, CDC
Dimitris Papanicolau, MD,
Emory University, Atlanta, Ga.
William Reeves, MD, CDC
Dieter Wagner, PhD, CDC

CFS Research Review Editorial Advisory Board

Mary Ann Fletcher, PhD,
University of Miami School of Medicine, Miami, Fla.
Terry Hedrick, PhD, Cobb Island, Md.
Leonard Jason, PhD, DePaul University, Chicago, Ill.
Charles Lapp, MD,
Director, The Hunter-Hopkins Clinic, Charlotte, N.C.

Paul H. Levine, MD,
The George Washington School of Medicine,
Washington, D.C.

Nancy Reichenbach,
Temple University School of Medicine,
Philadelphia, Pa.

Charles Shepherd, MD,
Medical Director, ME Association, Essex, England

Scientific Advisory Committee

Joseph Cannon, MD,
Medical College of Georgia, Augusta, Ga.
Frank Cerny, PhD, East Aurora, N.Y.
Richard Drake, PhD,
Eastern Virginia Medical School, Norfolk, Va.
Eleanor Z. Hanna, PhD, ORWH,
National Institutes of Health, Bethesda, Md.
Terry Hedrick, PhD, Cobb Island, Md.
Frank G. Hillary, PhD,
Kessler Medical Rehabilitation Research and
Education Corporation, West Orange, N.J.
Joseph John, MD,
Ralph H. Johnson Veterans Administration Medical Center,
Charleston, S.C.
Joseph Lane, MBPA,
University of Buffalo (SUNY), Amherst, N.Y.
Graeme F. Mason, PhD,
Yale University Magnetic Resonance Research Center,
New Haven, Ct.
Rosane Nisenbaum, PhD,
CDC, Division of Viral & Rickettsial Diseases,
Atlanta, Ga.
Donald W. Pfaff, PhD,
Rockefeller University, New York, N.Y.
Jonathan Sterling, Oradell, N.J.
Linda A. Toth, DVM, PhD,
Southern Illinois University, Springfield, Ill.



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, 2003, 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 2002 financial statements; and in our report dated February 3, 2003, 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, 2003, 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.

In accordance with Government Auditing Standards, we have also issued our report dated March 26, 2004 on our consideration of the Association's internal control over financial reporting and on our tests of its compliance with certain provisions of laws, regulations, contracts, and grants. That report is an integral part of an audit performed in accordance with Government Auditing Standards and should be read in conjunction with this report in considering the results of our audit.

The accompanying schedule of expenditures of federal awards is presented for purposes of additional analysis as required by U.S. Office of Management and Budget Circular A-133, Audits of States, Local Governments, and Non-Profit Organizations, and is not a required part of the financial statements. Such information has been subjected to the auditing procedures applied in the audit of the financial statements and, in our opinion, is fairly stated, in all material respects, in relation to the financial statements taken as a whole.

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

Charlotte, North Carolina
March 26, 2004

Statement of Financial Position — December 31, 2003

(With Comparative Totals for Year Ended December 31, 2002)

	December 31, 2003			December 31, 2002
	Unrestricted	Temporarily Restricted	Totals	
Assets				
Current assets				
Cash and cash equivalents	\$ 635,606	\$ 186,870	\$ 822,476	\$ 624,980
Pledges receivable	2,500	67,241	69,741	117,241
Government Grant receivable	174,692	—	174,692	62,176
Other receivables	4,950	—	4,950	2,314
Inventories	742	—	742	956
Prepaid expenses	9,248	—	9,248	9,252
Total current assets	827,738	254,111	1,081,849	816,919
Property and equipment				
Office furniture and fixtures	69,709	—	69,709	67,574
Computers and related equipment	108,605	—	108,605	99,074
Leasehold improvements	25,872	—	25,872	25,872
	204,186	—	204,186	192,520
Less accumulated depreciation	(168,146)	—	(168,146)	(146,083)
Net property and equipment	36,040	—	36,040	46,437
Cash surrender value of life insurance	—	16,790	16,790	17,209
Total assets	\$ 863,778	\$ 270,901	\$ 1,134,679	\$ 880,565
Liabilities and Net Assets				
Current liabilities				
Accounts payable	72,511	—	\$72,511	\$39,050
Accrued payroll and payroll taxes withheld	24,046	—	24,046	29,028
Unearned dues revenue	79,806	—	79,806	92,840
Current obligation under capital lease	3,958	—	3,958	3,821
Total current liabilities	180,321	—	180,321	164,739
Other liabilities				
Obligation under capital lease less current portion	3,061	—	3,061	7,019
Net assets				
Unrestricted				
Undesignated	513,735	—	513,735	165,062
Designated	166,661	—	166,661	164,779
Total unrestricted	680,396	—	680,396	329,841
Temporarily restricted	—	270,901	270,901	378,966
Total net assets	680,396	270,901	951,297	708,807
Total liabilities and net assets	\$ 863,778	\$ 270,901	\$ 1,134,679	\$ 880,565

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

Statement of Activities and Changes in Net Assets — December 31, 2003

(With Comparative Totals for Year Ended December 31, 2002)

	December 31, 2003			December 31, 2002
	Unrestricted	Temporarily Restricted	Totals	
Support and revenues				
Public support				
Contributions and grants	\$ 827,284	\$ 169,753	\$ 997,037	\$ 1,069,347
Federal funds				
Government grants	—	667,905	667,905	169,226
Revenues				
Membership dues	193,540	—	193,540	245,148
Educational material sales	12,622	—	12,622	27,440
Advertising revenue	—	—	—	—
Interest and other	3,317	—	3,317	6,982
	209,479	—	209,479	279,570
Assets released from restrictions				
Satisfaction of donor restrictions	945,723	(945,723)	—	—
Total support and revenues	1,982,486	(108,065)	1,874,421	1,518,143
Expenses and losses				
Program services				
Research	254,113	—	254,113	376,162
Public Policy	236,031	—	236,031	298,270
Education	871,518	—	871,518	918,620
Supporting services				
Management and general	96,547	—	96,547	136,354
Fund raising and development	172,832	—	172,832	139,302
	1,631,041	—	1,631,041	1,868,708
Loss on assets disposed	890	—	890	14,748
Total expenses and losses	1,631,931	—	1,631,931	1,883,456
Change in net assets	350,555	(108,065)	242,490	(365,313)
Net assets				
Beginning of year	329,841	378,966	708,807	1,074,120
End of year	\$ 680,396	\$ 270,901	\$ 951,297	\$ 708,807

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

Statement of Functional Expenses — December 31, 2003

(With Comparative Totals for Year Ended December 31, 2002)

	Year Ended December 31, 2003						Totals	Year Ended December 31, 2002 Totals
	Program Services			Supporting Services				
	Research	Public Policy	Education	Management and General	Fund-Raising and Development			
Contract services	\$ 2,217	\$ 140,099	\$ 107,387	\$ 2,671	\$ 10,751	\$ 263,125	\$ 317,293	
Speaker honoraria	—	—	15,000	—	—	15,000	1,500	
Salaries	53,591	56,568	344,615	64,575	63,724	583,073	740,555	
Payroll taxes	5,203	5,492	19,812	6,269	6,186	42,962	51,224	
Printing and postage	1,753	4,205	97,490	1,727	54,723	159,898	167,832	
Repairs and maintenance	498	525	2,856	600	592	5,071	7,108	
Supplies	648	684	4,102	781	770	6,985	10,667	
Educational materials/ cost of sales	—	—	22,497	—	—	22,497	27,780	
Research symposia	—	—	—	—	—	—	7,045	
Travel expenses	2,330	838	47,213	928	3,639	54,948	23,230	
Exhibit Fees	—	—	19,062	—	—	19,062	7,825	
Curriculum development meetings	—	—	3,053	—	—	3,053	—	
Awareness and curriculum promotion	—	—	91,765	—	—	91,765	9,242	
Event Sponsorship	—	—	22,895	—	—	22,895	—	
Insurance	597	631	2,275	720	710	4,933	5,329	
Telephone	1,684	1,903	6,967	2,010	2,137	14,701	20,424	
Occupancy costs	7,164	7,562	27,281	8,632	8,519	59,158	76,328	
Depreciation	3,032	3,200	11,546	3,654	3,605	25,037	28,569	
Miscellaneous	3,973	3,506	13,724	3,980	17,476	42,659	60,724	
Direct grants	171,423	10,818	11,978	—	—	194,219	306,033	
Total expenses	\$ 254,113	\$ 236,031	\$ 871,518	\$ 96,547	\$ 172,832	\$ 1,631,041	\$ 1,868,708	
Management and general expenses						\$ 96,547	\$ 136,354	
Fundraising and development expenses						172,832	139,302	
Total management and general, and fundraising and development expenses						\$ 269,379	\$ 275,656	
Total support and revenue						\$ 1,874,421	\$ 1,518,143	
Supporting services ratio						14.37%	18.16%	

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

Statement of Cash Flows — December 31, 2003

(With Comparative Totals for Year Ended December 31, 2002)

	Year Ending December 31,	
	2003	2002
Cash flows from operating activities		
Change in net assets	\$ 242,490	\$ (365,313)
Adjustments to reconcile increase (decrease) in net assets to net cash used in operating activities:		
Depreciation	25,037	28,569
Loss on disposal of assets	890	14,748
(Increase) decrease in operating assets:		
Pledges and other receivables	(67,652)	149,777
Inventories	214	12,212
Prepaid expenses	4	15,533
Cash value annuity insurance contract	419	(17,209)
Decrease in operating liabilities:		
Accounts payable	33,461	(7,187)
Accrued payroll and payroll taxes withheld	(4,982)	(2,541)
Unearned dues revenues	(13,034)	(33,650)
Net cash provided by (used in) operating activities	216,847	(205,061)
Cash flows from investing activities		
Purchases of property and equipment	(15,530)	(16,511)
Cash flows from financing activities		
Principal reduction of obligation under capital lease	(3,821)	(934)
Net increase (decrease) in cash and cash equivalents	197,496	(222,506)
Cash and cash equivalents		
Beginning of year	624,980	847,486
End of year	\$ 822,476	\$ 624,980

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

Notes to Financial Statements — Year Ended December 31, 2003

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

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*.

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.

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.

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.

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, 2003, the Association has no assets held by recipient organizations which are considered material.

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.

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 2003 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.

	<u>Allowable</u>	<u>Actual</u>
Direct Lobbying	\$ 231,305	\$ 41,910
Grassroots Lobbying	\$ 59,402	\$ 1,661

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, 2003.

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, 2002, from which the summarized information was derived.

Note 2 — Pledges Receivable

Individual pledge receivables at December 31, 2003 are designated as follows: \$60,000 is restricted for use in Association public policy efforts; \$10,000 is restricted for use in Association public policy and research efforts; \$2,500 is unrestricted. Unconditional promises are expected to be realized in 2004.

Note 3 — Grants

In 2002, the Association was awarded \$2,830,150 in federal funds from the Centers for Disease Control and Prevention (the “CDC”) over a five year period (October 2002–September 2007) as follows: \$538,890 year one, \$561,205 year two, \$605,007 year three, \$546,218 year four and \$578,830 year five. During 2003, the

Association was awarded an amendment for an additional \$100,000 to each of the first two years. Total funds expended in 2003 relating to year one and year two were \$431,960 and \$151,579, respectively, and \$84,366 of the amendment was also expended. The funds were received by the Association on a reimbursement basis. At December 31, 2003, \$174,692 is in the Government Grant receivable. These funds are being used to educate multidisciplinary health care providers about CFIDS to enable timely detection and management of the illness, ultimately resulting in improved care for CFIDS patients.

Note 4 — Capital Leases

At December 31, 2003, property and equipment includes equipment under capital leases with a cost basis of \$11,774 and accumulated depreciation of \$6,123. Amortization of assets under capital lease is included in depreciation expense.

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, 2003.

2004	\$ 4,141
2005	<u>3,106</u>
	7,247
Less amount representing interest	<u>(228)</u>
Present value of net minimum lease payments	7,019
Current maturities	<u>(3,958)</u>
Noncurrent maturities	<u>\$ 3,061</u>

Note 5 — Temporarily restricted net assets

Temporarily restricted net assets are available for the following purposes as of December 31, 2003:

Public Policy activities	\$ 136,450
Research activities	78,995
Donor specified	<u>55,456</u>
	<u>\$ 270,901</u>

Note 6 — Net assets released from restrictions

Net assets were released from restrictions by incurring expenses satisfying the purpose during the year ended December 31, 2003 as follows:

Purpose restrictions accomplished:

Government Grants	\$ 668,322
Research grants, symposia, and related expenditures	168,056
Public policy activities	75,077
Educational activities	32,514
Donor specified	<u>1,754</u>
	<u>\$945,723</u>

Note 7 — Commitments

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 2004 is \$120,000 payable in monthly installments. The services of The Sheridan Group in 2003 amounted to \$137,759.

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 including increases based upon the Consumer Price Index. The Association also leases office equipment under leases expiring in 2005

Future minimum lease commitments under the above operating leases are as follows at December 31, 2003

	Year ending December 31
2004	\$ 53,472
2005	53,472
2006	53,472
2007	<u>22,280</u>
	<u>\$182,696</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 \$61,376 for the year ended December 31, 2003.

Note 9 — 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 2003, the Association made contributions into this plan amounting to \$12,219.

the power of your gift

Your primary reason for making a gift to the CFIDS Association of America is your commitment to ending the pain and disability caused by CFIDS.

But your donation may have other tangible personal benefits which vary depending on how you choose to make your gift.

Gifts of Cash The simplest and most common way to give, cash gifts are typically deductible up to 50% of your adjusted gross income for the taxable year.

Gifts of Securities A donation of appreciated securities can also be made quickly and easily and provides a twofold income tax benefit—you can deduct the full fair market value of the securities if owned for more than one year and save again by avoiding capital gains taxes on their “paper profit.” If you own stock that has declined in value, consider selling the stock and contributing the proceeds to the CFIDS Association. You will receive a gift deduction in addition to a capital loss deduction.

To donate stocks, bonds or mutual funds, you can instruct your broker to transfer the securities to the Association’s account (2114-5761) at Wachovia Securities, DTC Number 0141. For additional information, please contact Jamie Davis at the CFIDS Association, 704-364-0466, or Roger Fuller, Jr. at Wachovia Securities, 800-929-0972.

Gifts of Individual Retirement Accounts Naming the Association as a beneficiary of assets in your qualified retirement plan is wise tax planning. If left to individuals other than a spouse, up to 80% of the remaining assets could be consumed by taxes. Estate and income taxes are generally not incurred if a charitable organization is named as beneficiary.

Life Insurance Gifts An asset not often considered as a gift is the cash value of a life insurance policy no longer needed for its original purpose. Many policies also issue dividends—direct your insurance company to pay your dividends directly to the Association and you can deduct them as a charitable contribution. Talk to your financial planner about these and the many other ways to make a gift of life insurance.

Gifts that Pay Income Charitable remainder trusts allow you to make a gift to the CFIDS Association and enable you or others to enjoy enhanced income for your lifetimes(s) or for a specified term of years. When the remainder trust ends, the principal in the trust passes to the Association. The reverse is true in a charitable lead trust where the trust pays out income to the Association for a specified number of years. When the trust ends, the principal goes to your family. Savings on capital gains, estate and gift taxes vary depending on the trust you create.

A Gift through your Will A bequest is the most common method of making a planned gift. Many donors have expressed that their gift by will is simply a continuation of the support they had given during their lifetime.

There are several types of bequests that you can easily include in a new will or add to your existing will.

General bequests specify that the Association will receive a predetermined percentage of your estate or a designated sum. A **specific bequest** designates a specific piece of property, including securities, real estate or personal property, such as art. A **residuary bequest** names the Association as recipient of all or a percentage of your estate after all costs and general and specific bequests are satisfied.

Be sure to include the Association’s legal designation: The CFIDS Association of America, Inc., a 501(c)(3) tax-exempt organization incorporated by the laws of the State of North Carolina. Federal Tax ID, 56-1683450.

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

For more information about these and other ways to give, please contact the Association’s Director of Development at 704-364-0466 or jldavis@cfids.org.

THE CFIDS ASSOCIATION AT A GLANCE

The CFIDS Association of America is the largest and most active 501(c)(3) charitable organization dedicated to conquering chronic fatigue and immune dysfunction syndrome (CFIDS, also widely known as chronic fatigue syndrome or CFS).

Since its founding in 1987, the Association has invested over \$15.2 million in support of its mission to bring an end to the pain, disability and suffering caused by CFIDS.

The Association is proud to lead national efforts in CFIDS education, awareness, public policy and research and we are grateful to those who support our vital work.

Our mission is shared by many. The scientists striving to understand the cause and progression of CFIDS, identify diagnostic markers and discover effective treatments. The health care professionals working to provide appropriate care to their CFIDS patients. The donors who generously fund the Association's programs. The grassroots advocates—CFIDS sufferers and their family members—who provide the compelling evidence that CFIDS warrants a swift and strong federal response. The support groups that ease the transition for the newly diagnosed patient and provide emotional support to others in their ongoing struggle with the disease. And the staff and volunteers working everyday on behalf of 800,000 American men, women and children and countless others around the globe.

The CFIDS Association of America is committed to conquering CFIDS. Thank you for your faith in and support of this important mission.

The CFIDS Association of America, Inc.

PO Box 220398

Charlotte, NC 28222-0398

Resource Line: 704-365-2343

Fax: 704-365-9755

Toll-free Voice Mail: 800-442-3437

Home Page: www.cfids.org

E-mail: cfids@cfids.org