

THE CFIDS ASSOCIATION OF AMERICA
2004 Annual Report

FOCUSING ATTENTION

FINDING ANSWERS

FUNDING RESEARCH

FOSTERING UNDERSTANDING

WHAT IS CFIDS?

Chronic fatigue and immune dysfunction syndrome (CFIDS, also called chronic fatigue syndrome or CFS) is a complex and serious illness characterized by crushing fatigue (experienced as profound exhaustion and extremely poor stamina), debilitating cognitive impairment, flu-like symptoms, widespread muscle and joint pain, dizziness, nausea, sleep disorders and numerous other symptoms.

CFIDS is often misdiagnosed or unrecognized, and can resemble other disorders including multiple sclerosis (MS), fibromyalgia (FM), post-polio syndrome, chronic Lyme disease and autoimmune diseases such as lupus.

CFIDS strikes people of all age, ethnic and socioeconomic groups. Women account for the majority of cases, but it afflicts hundreds of thousands of men and children as well. Researchers estimate that more than 800,000 U.S. adults have CFIDS, yet fewer than 15 percent have been properly diagnosed.

Twenty years of research have uncovered defects in the immune, endocrine and nervous systems of CFIDS patients, although the cause of the illness remains unknown. Current treatment is aimed at symptom relief and improved function.

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

The CFIDS Association of America, Inc.

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Charlotte, NC 28222-0398

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www.cfids.org

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THE CFIDS ASSOCIATION OF AMERICA

Conquering Chronic Fatigue and Immune Dysfunction Syndrome

The phrase “conquering CFIDS” is more than just a couple of words.

It’s our mission — the driving force behind what we do, why we’re here and where we focus our resources.

This simple yet powerful phrase guides the Association’s battle against a destructive illness that has damaged hundreds of thousands of lives.

The CFIDS Association of America leads the battle to end CFIDS on many fronts: in the research labs where we fund cutting-edge CFIDS science; on Capitol Hill where we work to focus government attention on the needs and concerns of the CFIDS community; in the doctors’ offices where CFIDS patients seek care and support; and among the general public where we strive to foster greater understanding of CFIDS and compassion for those who suffer from it.

We are profoundly grateful to each of the individuals, families, corporations and foundations that have supported our work over the years, as well as the nearly 3,300 individuals who made generous gifts ranging from \$1 to \$120,000 in 2004. We also extend thanks to those who made in-kind gifts and the volunteers who donated their time and talents — your support is invaluable.

On the pages that follow, you’ll read about what was accomplished with your support and how we will build on these successes.

The CFIDS Association is the largest and most active charitable organization working to conquer CFIDS. Be assured that we will continue to prioritize, channel our resources into the most promising projects and programs and effectively utilize the precious funds you entrust to us.

On behalf of the Association’s Board of Directors and professional staff, we extend our deepest appreciation for your support in 2004. Thank you for everything you have helped us to achieve and for what we will accomplish together as we work to speed progress toward improved health for people with CFIDS.



Jacobs



McCleary

Susan Jacobs
Susan L. Jacobs
Chairman of the Board

Kimberly McCleary
K. Kimberly McCleary
President & CEO

CONQUERING CFIDS

2004... AT A GLANCE

JANUARY

Kim McCleary, president & CEO of the CFIDS Association, and Tom Sheridan, president of the Sheridan Group, meet with top officials at the Centers for Disease Control & Prevention (CDC) to discuss the urgent need to improve the public's understanding of CFIDS as a serious and life-altering illness.



Kim McCleary and Tom Sheridan

The CFIDS Association distributes a feature article about pediatric CFIDS, "Children CAN get Chronic Fatigue Syndrome," to hundreds of newspapers across the U.S. through the North American Precis Syndicate, reaching over 27 million readers.

HEALTH AWARENESS

Children CAN Get Chronic Fatigue Syndrome

(NAPS)—Chronic fatigue syndrome, also called chronic fatigue and immune dysfunction syndrome (CFIDS), is a serious medical condition that can affect children as well as adults. Children as young as five years old have been found to have CFIDS, although the onset is more common in puberty.

Physical and cognitive problems. Children with CFIDS exhibit symptoms similar to adults—including severe exhaustion, problems with concentration and memory, sore throat, tender lymph nodes, muscle pain and headaches—but children more commonly report dizziness, abdominal pain, rash and fever. The majority of children with CFIDS have an acute onset—symptoms appear suddenly within a few days or weeks, usually with a flu or mononucleosis-like illness.

High rate of misdiagnosis. While the physical symptoms may be similar in children and adults, a child's difficulty in effectively expressing how he feels can make it more challenging to identify and diagnose the illness. Often CFIDS in children is mistaken as a behavioral or emotional problem, in particular school phobia. The cognitive difficulties, including short-term memory loss and confusion, produced by CFIDS may be mistaken for attention deficit disorder (ADD). Failure to make a proper diagnosis can lead to isolation, insecurity, sense of failure, family stress and even long-term intellectual development problems.

Educational impact. The vast majority of children with CFIDS experience difficulty with school performance due to the physical and cognitive symptoms imposed by the illness. Many must be home-schooled because they are too ill to attend classes. Children with CFIDS who cannot attend school miss out on important social and intellectual opportunities, affecting friendships, plans and dreams for the future.

The CFIDS Association of America offers a Web site on CFIDS youth issues, referrals to local support groups and other resources of interest to children (and adults) with CFIDS, their families, health care providers and advocates.

For more information, contact The CFIDS Association of America, PO Box 220308, Charlotte, NC 28222-0308 or visit www.cfids.org.



FEBRUARY

Close to 100 Association friends and benefactors attend the Association's Oscar night gala in New York City honoring Laura Hillenbrand, the award-winning author of *Seabiscuit: An American Legend*, for her courage and tenacity in fighting CFIDS. The benefit event raised nearly \$100,000 — through sponsorships, tickets sales and in-kind support — for Association-led efforts to expand CFIDS research.

MARCH

CFIDS Association leaders participate in the third meeting of the Department of Health and Human Services' CFS Advisory Committee (CFSAC).

The Association updates its brochure, "Social Security Disability and CFIDS," a free resource designed to help people navigate the complex process of pursuing disability benefits.

APRIL

Association staff members Terri Lupton, B.S.S., R.N. and Kasia Faryna exhibit at the annual conference of the American College of Physicians/American Society of Internal Medicine, speaking with hundreds of health care providers about the diagnosis and management of CFIDS.

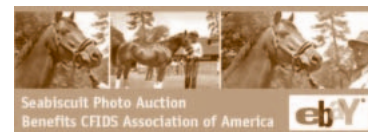
Grassroots Action Center



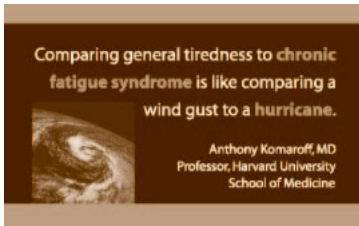
The Association launches an online Grassroots Action Center to help people with CFIDS and those who care about them direct messages about CFIDS to members of Congress, top health policymakers and the media.

MAY

Association staff members Jamie Davis and Marcia Harmon meet with Laura Hillenbrand to receive a collection of vintage Seabiscuit photographs and discuss plans to auction the photographs to raise money to support activities in CFIDS awareness and research.



The Association participates in a CFS/FM conference hosted by the Organization for Fatigue and Fibromyalgia Education and Research (OFFER) and held in Salt Lake City, Utah.



JUNE

Nine CFIDS research proposals are reviewed by the Association's Scientific Advisory Committee. Based on their expert recommendations, the Executive Committee of the Association's Board of Directors approves four projects, totaling more than \$317,000, for funding.

The Association exhibits at the national conferences of the American Academy of Physician Assistants and the American Physical Therapy Association.

JULY

CFIDSLink, the Association's free monthly electronic newsletter reaches more than 18,000 readers.

Kim McCleary and Jamie Davis represent the CFIDS community at the Revolutionary Women event in Boston, Massachusetts, sharing information about CFIDS with advocates and thought-leaders.

AUGUST

Leonard Jason, Ph.D. and Fred Friedberg, Ph.D. present an educational seminar on CFS at the American Psychological Association's annual conference. Terri Lupton staffs the CFIDS Association's educational exhibit at the conference.

SEPTEMBER

The Association kicks off its Annual Fund campaign, raising more than \$336,000 for CFIDS education, public policy and research.

Analysis of the National Institutes for Health (NIH) CFS research funding from FY99–03 is completed by the Association and presented by Kim McCleary to the CFSAC. The 75-page report shows that NIH has overreported its CFIDS funding by 20 percent.

Ms. McCleary represents the Association at a CFS think tank organized by the CDC and held at the Banbury Center of Cold Spring Harbor Laboratories.

OCTOBER

More than 600 CFIDS advocates use the Association's Grassroots Action Center to send letters to NIH director Dr. Elias Zerhouni about their concern over the lack of CFIDS-related research funded by NIH.



A panel moderated by Dr. William Reeves was convened at the national conference of the American Association of CFS to discuss the pros and cons of a proposed central research network for CFS. Panelists included Dr. Nancy Klimas, Dr. Tony Komaroff, Dr. Birgitta Evengard and Kim McCleary. Not pictured are Dr. Leonard Jason and Dr. Kenny De Meirleir.

NOVEMBER

The third and final consensus statement from the CFIDS Association's research symposia series is published in *Neuroimmunomodulation*.

A presentation about the Association's partnership with the Centers for Disease Control & Prevention (CDC) on health care provider education is made at the American Public Health Association's annual conference.

The Association organizes a Grand Rounds at Harvard School of Nursing.



Dr. Sue Levine, Dr. Dikoma Shungu and Dr. Sanjay Mathew

DECEMBER

Along with his collaborators, Dr. Dikoma Shungu of Weill Medical College of Cornell University shares an update on his Association-funded research study, "H MRS Neurometabolites as Diagnostic Markers for CFS," with the Association's director of development Jamie Davis and the Association benefactor fully funding his work.

NIH's issuance of a Program Announcement soliciting CFS research applications is widely publicized by the Association within the research community.

FOSTERING UNDERSTANDING

INFORMATION CAN EMPOWER. It can provide comfort, encourage, validate and motivate. The CFIDS Association is committed to meeting the varied information needs of people with CFIDS (PWCs) and the other audiences we serve — caregivers, medical professionals, members of the media and general public, legislators and public health officials.

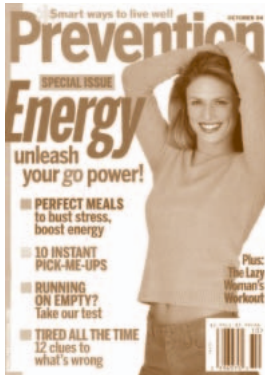


Since publishing our first issue of the *CFIDS Chronicle* in 1987, the CFIDS Association has become one of the nation's most trusted sources of information about CFIDS. In 2004 we redesigned the *Chronicle*, winning praise from readers for its relevancy and visual appeal. The *Chronicle* covered a broad spectrum of CFIDS-related topics last year, featuring articles about how to file a successful disability claim, joint hypermobility and its link with CFIDS, the search for a bio-marker, complementary therapies and beating the high cost of prescription drugs.

Focusing attention on the real-life struggles and experiences of PWCs is a critical part of the education and awareness process, both for the patient community and for the general public. This year the Association significantly expanded the number of compelling and frank personal stories included in the *Chronicle* and in our free monthly e-newsletter, *CFIDSLink*.

Current, reliable information about CFIDS is available 24/7 on the Association's website, www.cfids.org. The website is continuously updated and expanded to support and promote the Association's mission. Visits to www.cfids.org soared to more than 703,000 in 2004. Most frequently accessed areas included the "Do I Have CFIDS?" health assessment tool, the Grassroots Action Center, as well as the sections for newly diagnosed patients and caregivers.

The Association provided thousands of pages of resource material, generated story ideas and coordinated interviews for numerous media outlets to help improve the public's understanding of CFIDS and the tremendous



toll it takes on the individual and the nation's economy. *Advance for Nurse Practitioners, Body & Soul, Fibromyalgia AWARE, MDNet Guide* and *Prevention* magazines, *AWARE* Talk Radio, UPI (a leading provider of information to media outlets, businesses, governments and researchers worldwide), Lifetime Television's website and the *New York Times* were just a few of the numerous print and broadcast outlets that covered CFIDS and PWCs last year.

To help determine how the general public and the provider community really feel about CFIDS and the people who have it, the Association commissioned market research. The results of the focus groups and omnibus survey, published in 2004, provided a wealth of information to assist the Association in crafting future education and awareness initiatives and in broadening our outreach efforts in 2005 and 2006.

GOOD PATIENT CARE BEGINS WITH GOOD INFORMATION. Five years ago the Association and the Centers for Disease Control and Prevention (CDC) partnered to improve health care providers' knowledge of CFIDS. To further this important effort, we created a provider-specific website, www.cfids.org/treatcfs, in 2004. There, medical professionals can access a web-based curriculum, *CFS: Diagnosis and Management*, designed to enhance their understanding of CFIDS, promote earlier detection and diagnosis and improve illness management. With full accreditation from the CDC, the program offers free continuing education credits (CME, CNE and CEU) to providers who successfully complete the course.

Program materials are currently being adapted for behavioral health and rehabilitation professionals, including physical and occupational therapists. We expect these materials to be available in the next six months.

In 2004 the Association exhibited at eleven major national medical conferences and reached out to smaller, regional provider audiences at their conferences and meetings.

Keeping up-to-date on CFIDS research used to be a fairly simple task. Today, CFIDS research spans the globe and across many different disciplines. In June the Association introduced an online annotated bibliography reflecting the latest in CFIDS research. Nearly 800 medical professionals have downloaded the bibliography since it became available.

ADVANCES IN HEALTH CARE PROVIDER EDUCATION — Advertisements like this appeared in numerous professional journals, publications and conference materials throughout 2004, promoting the availability of educational courses about CFS. More than 900 health care providers requested the print, video or DVD version of the CFS self-study curriculum in 2004. Nearly 600 providers participated in the web-based version of the course.

Help the PERSON behind the SYMPTOMS

INDIGESTING FATIGUE, PROFOUND EXHAUSTION, EXTREMELY POOR STAMINA, PROBLEMS WITH CONCENTRATION AND SHORT-TERM MEMORY, FLU-LIKE SYMPTOMS, PULSING PAIN IN THE JOINTS AND MUSCLES, UNREFRESHING SLEEP, TENDER LYMPH NODES, SORE THROAT, HEADACHE, COGNITIVE PROBLEMS SUCH AS DIFFICULTIES WITH CONCENTRATION AND SHORT-TERM MEMORY, WORD-FINDING DIFFICULTIES, UNABILITY TO COMPREHEND WHAT'S BEING SAID, INABILITY TO CALCULATE NUMBERS, MIND-BLANK OF SPEECH AND/OR REASONING, MULTIPLE DISTRACTIONS

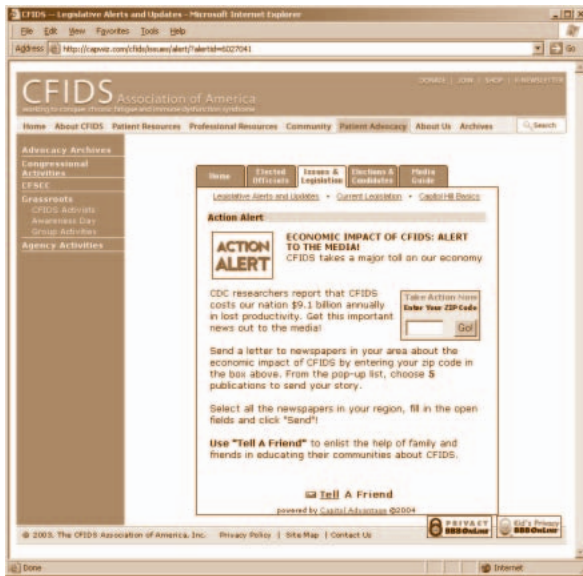
Chronic Fatigue Syndrome: Diagnosis and Management

Chronic fatigue syndrome (CFS) affects at least 800,000 U.S. adults and an unknown number of teens with debilitating pain, exhaustion and cognitive problems. Studies show that 80% of people with CFS have not been properly diagnosed by a medical professional. Even fewer receive appropriate medical care.

Earn Free Continuing Education Credits from CDC

Self-study courses about diagnosing and managing CFS are available in Web-, print-, or DVD-based formats. The CDC is an accredited provider of continuing education credits for various professions.

For more information:
 704-364-0486 · meded@cfids.org · www.cfids.org/treatcfs
 Supported by the Centers for Disease Control and Prevention (CDC) and the CFIDS Association of America



JUNE 21, 2004 — CDC researchers report that CFS costs the U.S. economy \$9.1 billion per year in lost productivity. The Association urged its members and donors to use the Grassroots Action Center at www.cfids.org to spread the news of this study to the media and help send a message to the public about the serious toll CFIDS takes on the individual and our economy.

FOCUSING ATTENTION



SINCE 1992 THE CFIDS ASSOCIATION HAS MAINTAINED A CONSISTENT PRESENCE in Washington, D.C., representing the health care concerns and medical research interests of people with CFIDS to policy makers and agency officials.

The primary issue shaping our current advocacy agenda is the erosion of CFIDS research at the National Institutes of Health (NIH). The CFIDS Association became increasingly concerned about the NIH's questionable CFIDS research portfolio when our discussions with agency representatives, two Freedom of Information Act requests and a personal meeting with Dr. Elias Zerhouni, director of the NIH, failed to produce a meaningful accounting of the agency's CFIDS research-related efforts.

The Association intensified its scrutiny of CFIDS research activities at NIH in late 2003, culminating in an eye-opening report presented by Association president & CEO Kim McCleary to the Department of Health and Human Services' CFS Advisory Committee on September 27, 2004. The report revealed that NIH has considerably overstated the amount of CFIDS research it funded over a five-year period. Twenty-one studies, totaling almost \$6 million, were misclassified as CFIDS-related. Adjusting for these misclassified projects dropped the cumulative amount of NIH-funded research from \$31.6 million to only \$25.8 million for the past five years and less than \$4 million in FY2003, little more than the amount spent on CFIDS by the NIH in 1992, and not enough for an illness that severely impacts the health and quality of life of hundreds of thousands of women, men and children.

The Association's report included specific recommendations for boosting NIH efforts, including the release of a well-funded Request for Applications and the creation of clinical and research Centers for Excellence. To ensure that funding for CFIDS research doesn't suffer further erosion, the Association is meeting with key congressional leaders, enlisting the support of grassroots advocates and initiating efforts to work with other organizations equally concerned about NIH transparency, funding and accountability.

The importance of making our voices heard in the halls of Congress should not be underestimated. The Association encourages PWCs, their family members and friends to contact their elected officials, share their stories and demonstrate that there are a lot of real people (and voters) who live with and care about this issue.

Breaking new ground, the Association launched an online Grassroots Action Center in 2004, linking advocates to their members of Congress, agency officials and members of the media. Through the Action Center, CFIDS advocates can easily and actively engage in efforts aimed at securing a more dedicated federal response to CFIDS simply by logging on to their computers. Over the past 12 months, the Grassroots Action Center helped advocates send more than 20,000 targeted messages to lawmakers and media. The unique tool gives everyone touched by, or interested in, CFIDS a voice on Capitol Hill.

Shifting federal budgetary priorities do not change the fact that 800,000 U.S. adults and teens nationwide suffer from CFIDS. The Association will continue to work vigorously, every day, to focus federal attention on CFIDS and to ensure that the federal government is using its ample resources to find answers for people with CFIDS.

THE CFIDS ASSOCIATION IS THE LEADING CHARITABLE ORGANIZATION dedicated to biomedical research on CFIDS. We have invested more than \$4.7 million in CFIDS research efforts, second only to the federal government. The Association aggressively pursues an entrepreneurial research strategy, funding innovative, scientifically sound pilot studies that often lack the preliminary data required by more traditional grant sources.

Since 1987 the Association’s research program has filled a unique niche for investigators studying CFIDS, providing funds for projects that demonstrate promise for accelerating the rate at which scientific knowledge translates into improvements in the daily lives of PWCs. The program is informed and guided by a Scientific Advisory Committee, a group of leading CFIDS experts and respected researchers and clinicians from related fields.

Current Association-funded researchers are making strides in the understanding of CFIDS.

Brigitte Huber, Ph.D., Tufts University School of Medicine, Boston, Massachusetts; HERV-K18 as a Risk Factor for CFIDS; Dr. Huber has shown that Epstein-Barr virus (EBV) infection and treatment with interferon-alpha (IFN-a) activate transcription of the envelope gene of a human endogenous retrovirus, HERV-K18. This retroviral gene encodes a superantigen, a class of proteins capable of dysregulating the immune system.

FINDING ANSWERS



THE SEARCH FOR A BIOMARKER — Suzanne Vernon, Ph.D. (right), is the team leader of the CDC’s Molecular Epidemiology Program. She works with a team of 24 intramural and extramural researchers who are integrating genomics with proteomics to understand the pathogenesis of CFIDS and develop therapeutic and prevention strategies for CFIDS.

FUNDING RESEARCH

To date, Dr. Huber and her research team have generated a genomic DNA bank using patient samples from Dr. Susan Levine, a CFIDS clinician in New York City, and Dr. Andrew Miller of Emory University. They are also pursuing collaboration with Dr. Andrew Lloyd of the University of South Wales in Sydney, Australia. Huber's team has continued to refine a highly sensitive real-time PCR assay for the HERV-K18 allele typing. Dr. Huber hopes that this research will establish whether a differential distribution of HERV-K18 allele and genotype frequencies exists in CFIDS patients as compared to healthy controls, something which would open new avenues for the development of clinical treatments.

Christopher Snell, Ph.D. and J. Mark VanNess, Ph.D., University of the Pacific, Stockton, California; Using an Exercise Challenge to Investigate the Pathophysiology of CFIDS; Drs. Snell and VanNess are examining the physical and cognitive responses of CFIDS patients to exercise to obtain a comprehensive picture of the body processes involved in the production and supply of energy. Their objective is to identify abnormalities that might point to the origins of many CFIDS symptoms and provide reliable markers for diagnosis and disease severity.

Exercise testing has concluded and all pre- and post-exercise data has been collected for patients and controls, including physical, cognitive, immune, metabolic, cardiovascular and neuroendocrine profiles of each subject.

Drs. Snell and VanNess hope to clarify the biological basis for CFIDS symptoms and suggest interventions directed at treating the causes of these symptoms rather than merely treating the symptoms themselves.

Midyear reports from two other Association-funded researchers, **Dr. Dikoma Shungu of Weill Medical College, Cornell University, "H MRS Neurometabolites as Diagnostic Markers for CFS"** and **Dr. Frances Abbott of McGill University, "Neuroactive Progesterone Metabolites in CFS,"** are forthcoming.

The Association is examining its role in fostering the research that will have a meaningful impact on the daily lives of PWCs. With assistance from an ad hoc committee — to be comprised of CFIDS clinicians, researchers and other stakeholders — the Association will explore means of stimulating and providing greater support for treatment-based research as well as other areas of research with the highest probability of returning results. We are also investigating new ways to attract talented investigators to the field of CFIDS science and dedicated clinicians to the care of CFIDS patients.

The Association is determined to advance the science and pursue the research promising effective diagnosis, improved therapies and ultimately a cure for people living with CFIDS.

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Report of Independent Auditors

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

We have audited the accompanying statement of financial position of the CFIDS Association of America, Inc. (the Association) as of December 31, 2004, 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 2003 financial statements; and in our report dated March 26, 2004, 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, 2004, 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 April 6, 2005, 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 agreements and other matters. The purpose of that report is to describe the scope of our testing of internal control over financial reporting and compliance and the results of that testing and not to provide an opinion on the internal control over financial reporting or on compliance. That report is an integral part of an audit performed in accordance with *Government Auditing Standards* and should be considered in assessing 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
April 6, 2005

Statement of Financial Position — Year Ended December 31, 2004

(With Comparative Totals for Year Ended December 31, 2003)

	Year Ended December 31, 2004			Totals	Year Ended December 31, 2003
	Unrestricted	Temporarily Restricted	Permanently Restricted		
ASSETS					
Current assets					
Cash and cash equivalents	\$ 829,800	\$ 444,295	\$ -	\$ 1,274,095	\$ 819,293
Contributions receivable	—	35,000	—	35,000	69,741
Government grants receivable	80,940	—	—	80,940	174,692
Other receivables	3,498	—	—	3,498	4,950
Inventories	1,017	—	—	1,017	742
Investments	4,637	887	5,400	10,924	3,183
Prepaid expenses	12,722	—	—	12,722	9,248
Total current assets	932,614	480,182	5,400	1,418,196	1,081,849
Property and equipment					
Office furniture and fixtures	88,548	—	—	88,548	69,709
Computers and related equipment	113,543	—	—	113,543	108,605
Leasehold improvements	25,872	—	—	25,872	25,872
	227,963	—	—	227,963	204,186
Less accumulated depreciation	(177,746)	—	—	(177,746)	(168,146)
Net property and equipment	50,217	—	—	50,217	36,040
Cash surrender value of life insurance	—	16,144	—	16,144	16,790
Total assets	\$ 982,831	\$ 496,326	\$ 5,400	\$ 1,484,557	\$ 1,134,679
LIABILITIES AND NET ASSETS					
Current liabilities					
Accounts payable	\$ 36,434	\$ —	\$ —	\$ 36,434	\$ 72,511
Accrued payroll and payroll taxes withheld	11,385	—	—	11,385	24,046
Unearned dues revenue	70,660	—	—	70,660	79,806
Obligation under capital lease — current portion	6,171	—	—	6,171	3,958
Total current liabilities	124,650	—	—	124,650	180,321
Other liabilities					
Obligation under capital lease less current portion	20,057	—	—	20,057	3,061
Total liabilities	144,707	—	—	144,707	183,382
Net assets					
Unrestricted					
Undesignated	665,920	—	—	665,920	513,735
Designated	172,204	—	—	172,204	166,661
Total unrestricted	838,124	—	—	838,124	680,396
Temporarily restricted	—	496,326	—	496,326	270,901
Permanently restricted	—	—	5,400	5,400	—
Total net assets	838,124	496,326	5,400	1,339,850	951,297
Total liabilities and net assets	\$ 982,831	\$ 496,326	\$ 5,400	\$ 1,484,557	\$ 1,134,679

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

Statement of Activities and Changes in Net Assets — Year Ended December 31, 2004

(With Comparative Totals for Year Ended December 31, 2003)

	Year Ended December 31, 2004			Totals	Year Ended
	Unrestricted	Temporarily Restricted	Permanently Restricted		December 31, 2003
SUPPORT AND REVENUES					
Public support					
Contributions and grants	\$ 673,960	\$ 482,833	\$ 5,400	\$ 1,162,193	\$ 997,037
Federal funds					
Government grants	—	587,463	—	587,463	667,905
Revenues					
Membership dues	162,231	—	—	162,231	193,540
Educational material sales	7,087	—	—	7,087	12,622
Interest and other	7,158	887	—	8,045	3,317
	176,476	887	—	177,363	209,479
Assets released from restrictions					
Satisfaction of donor restrictions	845,758	(845,758)	—	—	—
Total support and revenues	1,696,194	225,425	5,400	1,927,019	1,874,421
EXPENSES AND LOSSES					
Program services					
Research	167,663	—	—	167,663	254,113
Public Policy	209,031	—	—	209,031	236,031
Education	869,290	—	—	869,290	871,518
Supporting services					
Management and general	97,252	—	—	97,252	96,547
Fund raising and development	196,004	—	—	196,004	172,832
	1,539,240	—	—	1,539,240	1,631,041
Loss (gain) on assets disposed	(774)	—	—	(774)	890
Total expenses and losses	1,538,466	—	—	1,538,466	1,631,931
Change in net assets	157,728	225,425	5,400	388,553	242,490
NET ASSETS					
Beginning of year	680,396	270,901	—	951,297	708,807
End of year	\$ 838,124	\$ 496,326	\$ 5,400	\$ 1,339,850	\$ 951,297

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

Statement of Functional Expenses — Year Ended December 31, 2004

(With Comparative Totals for Year Ended December 31, 2003)

	Year Ended December 31, 2004						Totals	Year Ended December 31, 2003 Totals
	Program Services			Supporting Services				
	Research	Public Policy	Education	Management and General	Fund-Raising and Development			
Contract services	\$ 2,628	\$ 137,355	\$ 103,343	\$ 2,820	\$ 19,587	\$ 265,733	\$ 263,125	
Speaker honoraria	—	—	5,000	—	—	5,000	15,000	
Salaries	58,006	41,036	398,404	62,245	65,632	625,323	583,073	
Payroll taxes	6,160	4,357	20,342	6,610	6,969	44,438	42,962	
Printing and postage	4,228	1,321	107,995	1,476	43,241	158,261	177,088	
Repairs and maintenance	1,334	944	6,243	1,432	1,509	11,462	5,071	
Supplies	1,631	1,154	10,153	1,750	1,845	16,533	6,985	
Educational materials/cost of sales	—	—	8,763	—	—	8,763	5,307	
Travel expenses	2,106	1,683	43,544	2,054	13,010	62,397	54,948	
Exhibit Fees	—	—	39,130	—	—	39,130	19,062	
Curriculum development meetings	—	—	705	—	—	705	3,053	
Awareness and curriculum promotion	—	—	43,466	—	—	43,466	91,765	
Event sponsorship	—	—	21,075	—	—	21,075	22,895	
Event in-kind donations	—	—	—	—	16,375	16,375	—	
Insurance	624	442	2,062	670	706	4,504	4,933	
Telephone	2,948	1,466	7,028	2,084	2,258	15,784	14,701	
Occupancy costs	8,389	5,935	27,707	9,002	9,492	60,525	59,158	
Depreciation	3,891	2,752	12,849	4,175	4,402	28,069	25,037	
Miscellaneous	2,766	2,086	11,481	2,934	10,978	30,245	42,659	
Direct grants	72,952	8,500	—	—	—	81,452	194,219	
Total expenses	\$167,663	\$209,031	\$869,290	\$97,252	\$196,004	\$1,539,240	\$1,631,041	
Management and general expenses						\$ 97,252	\$ 136,354	
Fundraising and development expenses						196,004	139,302	
Total management and general, and fundraising and development expenses						\$ 293,256	\$ 275,656	
Total support and revenue						\$ 1,927,019	\$ 1,874,421	
Supporting services ratio						15.22%	14.71%	

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

Statement of Cash Flows — Year Ended December 31, 2004

(With Comparative Totals for Year Ended December 31, 2003)

	Year Ended December 31,	
	2004	2003
Cash flows from operating activities		
Change in net assets	\$ 388,553	\$242,490
Adjustments to reconcile increase (decrease) in net assets to net cash used in operating activities:		
Depreciation	28,069	25,037
Loss (gain) on disposal of assets	(774)	890
Amortization of contributions receivable discount	(2,759)	—
In-kind contribution of investments	(10,045)	(3,183)
Reinvestment of investment earnings	(879)	—
Cash value annuity insurance contract	646	419
(Increase) decrease in operating assets:		
Pledges and other receivables	132,704	(67,652)
Inventories	(275)	214
Prepaid expenses	(3,474)	4
Decrease in operating liabilities:		
Accounts payable	(36,077)	33,461
Accrued payroll and payroll taxes withheld	(12,661)	(4,982)
Unearned dues revenues	(9,146)	(13,034)
Net cash provided by operating activities	473,882	213,664
Cash flows from investing activities		
Purchases of property and equipment	(17,985)	(15,530)
Proceeds from disposal of asset	1,000	—
Proceeds from sale of investments	3,183	—
Net cash used in investing activities	(13,802)	(15,530)
Cash flows used in financing activities		
Principal reduction of obligation under capital lease	(5,278)	(3,821)
Net increase in cash and cash equivalents	454,802	194,313
Cash and cash equivalents		
Beginning of year	819,293	624,980
End of year	\$ 1,274,095	\$ 819,293
Supplemental disclosure of cash flow information		
Noncash transaction:		
Issuance of capital lease for acquisition of equipment	\$ 30,856	\$ —

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

Notes to Financial Statements — Year Ended December 31, 2004

Note 1 — Organization and Summary of Significant Accounting Policies

Description of operations

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

Basis of accounting

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

Classes of net assets

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

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

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

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

Revenue recognition

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

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*. The Association did, however, receive contributions of certain supplies and investments during the year ended December 31, 2004. In-kind contributions are included in contribution income in the accompanying statement of activities and are detailed as follows for the year ended December 31, 2004:

Investments	\$ 10,045
Special event catering and supplies	<u>16,375</u>
Total in-kind	<u>\$ 26,420</u>

Research grants

The Association awards grants for medical research projects in the field of CFIDS. To ensure that the most worthy and promising research projects are funded, the Association periodically convenes a Scientific Advisory Committee that advises the Association's Executive Committee of its Board of Directors. The Association's Executive Committee, heavily weighing the recommendations of this advisory committee, makes all funding decisions. Members of the Scientific Advisory Committee include internationally respected researchers and clinicians. Because these grants are contingent upon research contributions received and the Association's cash flow, these grants are not recognized as expenditures until payment occurs. However, at December 31, 2004, the Association had approved grants of \$244,758 that are available for disbursement in subsequent years.

Cash equivalents

For purposes of the statement of cash flows, the

Association considers all highly liquid debt instruments with maturity of three months or less when purchased as cash equivalents.

Investments

Investments are recorded in accordance with the provisions of SFAS No. 124, *Accounting for Certain Investments Held by Not-for-Profit Organizations*. Under SFAS No. 124, investments in marketable securities with readily determinable fair values are valued in the statement of financial position at their fair value. Fair value is determined by reference to exchange or dealer-quoted market prices. If a quoted market price is not available, fair value is estimated using quoted market prices for similar investment securities. Changes in the fair value of securities are reflected as investment gains or losses in the accompanying statements of activities and changes in net assets.

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 or at fair value at the date of donation, if contributed. Expenditures for acquisitions, renewals and betterments are capitalized, whereas maintenance and repair costs are expensed as incurred. Depreciation is charged to expense over the estimated useful lives of the assets principally using accelerated methods.

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, 2004, the Association has assets held by recipient organizations totaling \$9,956. This balance is included in investments on the accompanying statement of financial position.

Cash surrender value of life insurance

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

the year ended December 31, 2004, the decrease in the cash surrender value of life insurance was \$646.

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.

Reclassifications

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

Concentrations of credit risk

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

The Association, similar to other organizations of its nature and size, periodically receives large contributions and grants from a relatively small number of individuals and/or organizations. The continued support of large donors cannot be determined with certainty. No individual contribution represented more than twenty percent (20%) of public support for the year ended December 31, 2004, however, thirty percent (30%) of the Association's support and revenue is derived from its contracts with the Centers for Disease Control and Prevention (CDC).

Prior year summarized information

The financial statements include certain prior-year summarized comparative information in total but not by net asset class. Such information does not include sufficient detail to constitute a presentation in conformity with accounting principles generally accepted in the United States of America. Accordingly, such information should be read in conjunction with the Association's financial statements for the year ended December 31, 2003, from which the summarized information was derived.

Estimates

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

Note 2 — Contributions receivable

Individual contributions receivable at December 31, 2004, are designated as follows: \$35,000 is restricted for use in Association public policy efforts. Unconditional promises are expected to be received in 2005.

Note 3 — Grants

The Association was awarded a contract of federal funds from the CDC for the purpose of educating multidisciplinary health care providers about CFIDS to enable timely detection and management of the illness, ultimately resulting in improved care for CFIDS patients. The Association also has a contract with CDC to provide public awareness of the existence of CFIDS. The funds for both of these contracts are received by the Association on a reimbursement basis. At December 31, 2004, \$80,940 is in the government grants receivable.

Note 4 — Investments

Investments are recorded at fair market value and include investments held in the Association's brokerage and beneficial interest account. The following is a summary of investments at December 31, 2004:

Equity securities	\$ 968
Mutual funds	9,956
	<u>\$ 10,924</u>

Note 5 — Capital leases

At December 31, 2004, property and equipment includes equipment under capital leases with a cost basis of \$30,856 and accumulated depreciation of \$6,171. Amortization of assets under capital lease is included in depreciation expense. The lease is interest free and interest has not been imputed as the amount is immaterial. The following is a schedule by year of future minimum lease payments under capital leases together with the present value of net minimum lease payments as of December 31, 2004.

2005	\$ 6,171
2006	6,171
2007	6,171
2008	6,171
2009	1,544
	<u>26,228</u>
Less amount representing interest	—
Present value of	
net minimum lease payments	26,228
Current maturities	(6,171)
Noncurrent maturities	<u>\$ 20,057</u>

Note 6 — Net assets**Unrestricted, board designated**

Unrestricted net assets that have been designated by the Association's board of directors for future goals are comprised of the following at December 31, 2004:

Undistributed endowment earnings	
in endowment fund	\$ 3,669
Cash reserve for future years	168,535
	<u>\$ 172,204</u>

Temporarily restricted

Temporarily restricted net assets are available for the following purposes as of December 31, 2004:

Public policy activities	\$ 83,589
Research activities	297,871
Education	97,835
Endowment	887
Other donor specified	16,144
	<u>\$ 496,326</u>

Permanently restricted

Permanently restricted net asset is comprised of contributions made to the Association's endowment fund. These assets are held under an interest in a beneficial trust. At December 31, 2004, the principal balance of the endowment was \$5,400.

Note 7 — Net assets released from restrictions

Net assets were released from restrictions by incurring expenses satisfying the purpose during the year ended December 31, 2004, as follows:

Purpose restrictions accomplished:	
Government grants	\$ 587,463
Research grants, symposia, and related expenditures	68,062
Public policy activities	106,782
Educational activities	2,000
Donor specified	81,451
	<u>\$ 845,758</u>

Note 8 — Leases

The Association leases office space used in its operations under an operating lease that expires in June 2007. The lease initially provides for a monthly rental of \$4,348 and is subject to annual increases including increases based upon the Consumer Price Index. The Association also leases office equipment under leases expiring in 2006

Future minimum lease commitments under the above operating leases are as follows at December 31, 2004

Year ending December 31,	
2004	\$ 55,302
2005	52,276
2006	23,498
2007	27,498
	<u>\$ 158,574</u>

Rental expense incurred under operating leases was \$53,995 for the year ended December 31, 2004.

Note 9 — Financial instruments

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

The following methods and assumptions were used by the Association in estimating the fair value of its financial instruments. Fair value approximates carrying value for the following financial instruments due to their short-term nature: cash and cash equivalents, investments, various receivables and accounts payable. The fair value of capital lease payable is estimated

by discounting future cash flows using interest rates available to the Association with similar terms and maturities.

	Carrying Amount	Fair Value
Capital leases payable	\$ 26,228	\$ 23,462

Note 10 — Benefit plan

The Association sponsors a cafeteria plan whereby employees may select from a list of available qualified benefits or additional wages up to ten percent (10%) of their annual gross compensation. Included in this cafeteria plan is an election that can be made by employees to have a designated amount contributed into their 403(b) Plan accounts. The Association's 403(b) retirement plan covers substantially all employees meeting certain service and age requirements. This plan is a defined contribution plan with voluntary employee participation. During 2004, the Association made contributions into this plan amounting to \$9,523.

Note 11 — Limits on nontaxable lobbying expenditures

The Association is covered under Section 501(h) of the Internal Revenue Code that permits a limited amount of nontaxable lobbying expenditures based upon varying percentages of total exempt purpose expenditures. This code section also imposes a ceiling (upper limit) for lobbying expenditures, above which 501(c)(3) organizations may be subject to revocation of tax-exempt status. The ceiling amounts are 150 percent of nontaxable lobby expenditures computed over a four-year averaging period. Both the ceiling and nontaxable amounts apply to direct and grassroots lobbying expenditures. The nontaxable amounts and the actual amounts spent by the Association for 2004 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	\$ 226,962	\$ 32,716
Grassroots lobbying	\$ 56,741	\$ 2,316

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 more than \$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 a higher level of 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 every day on behalf of people with CFIDS everywhere.

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

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