

2002

ANNUAL REPORT

# PUTTING CFIDS FIRST

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

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

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

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

## WHAT IS CFIDS?

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# Letter from the Chairman of the Board and the President & CEO

Any organization can look like a winner in good times. But it is in the face of adversity that great organizations distinguish themselves.

2002 was arguably the most difficult year in a decade for The CFIDS Association of America. At a time when our organization found itself stronger and more capable than ever to advance progress toward its mission, the weakened economy and a pervasive societal uncertainty hit the Association hard.

Across the charitable sector, donors reflected the mood; they made smaller gifts and oftentimes, postponed planned gifts and annual contributions.

We are grateful, however, that many of our supporters, like you, continued to make The CFIDS Association one of their top philanthropic priorities. We are especially thankful for your generosity during a year which, we realize, was as challenging for the individual as it was for the Association, other non-profit organizations, corporations, communities and our nation.

2002 will ultimately be remembered for the ways in which we stretched our human and financial resources to sustain vital education, advocacy and research programs. We kept up the fight for a future free of chronic fatigue and immune dysfunction syndrome (CFIDS).

The pages that follow report what we accomplished in a year when we were tested to do more with less. We move forward buoyed by the potential we have to bring remarkable progress to people with CFIDS.

Research due to be released by the Centers for Disease Control and Prevention will document that the financial impact of CFIDS on the economy now rivals the devastating physical and emotional toll it takes on the individual. Visibility like this will help build awareness and public support. It will give us opportunities to drive ground-breaking research, increase federal funding and educate health care providers.

At the same time, we are keenly aware that pursuing promising new initiatives requires a corresponding increase in funding, funding over and above the capital necessary to maintaining the momentum of core programs. An increased investment in our efforts is essential if we are to meet our shared mission.

Thank you for being part of a movement with the ability to make a lasting impact. Thank you for supporting The CFIDS Association of America, a charitable organization whose existence, integrity, experience and work really matters.

Thank you for putting CFIDS first.



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

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



*Jonathan B. Sterling*



*K. Kimberly Kenney*

# CFIDS Awareness & Education...First

**T**he general public and far too many health care professionals are not sufficiently familiar with CFIDS — a devastating illness that affects more Americans than multiple sclerosis (MS), AIDS or lung cancer.

As a result, over 800,000 people nationwide suffer the stigma associated with a misunderstood and marginalized illness. Additionally, studies estimate that 85% of those men, women and children go undiagnosed and without treatment, many drifting from one health care provider to another until some drop out of the health care system altogether, either out of frustration and hopelessness or due to dwindling financial resources.

Raising awareness will help ensure that CFIDS is as recognized and cared about as other illnesses, and it will help attract the financial and intellectual resources necessary to conquer it.

Improving patient care through medical education has become one of the Association's most important and relevant initiatives on behalf of the CFIDS community. Preliminary studies indicate that for CFIDS, as with other chronic conditions, early detection, diagnosis and treatment ultimately yield better health outcomes.



## **Building Awareness**

In early 2002, the Association released the first national public service announcement (PSA) on CFIDS for television, featuring former U.S. Surgeon General Dr. David Satcher. The PSA emphasized CFIDS as a serious, complex medical disorder that can affect people of all races and from all walks of life. Dr. Satcher validates the illness saying, “We may not know the cause of [CFIDS], but the pain and suffering are real.”

We worked with NewsProNet, a service that supplies broadcast footage to TV stations across the country, to create a compelling story on pediatric CFIDS. The piece included Association President & CEO, Kim Kenney, Dr. William Reeves from the Centers for Disease Control and Prevention (CDC) and respected CFIDS clinician Dr. David Bell of Lyndonville, N.Y.



Terri Lupton, BSS, RN, the Association's Coordinator for Educational Opportunities, authored an article for the December 2002 issue of *Nursing Spectrum*. The piece addressed the importance of provider-patient partnership and the need for informed and compassionate nursing care.

Other Association-led media efforts resulted in CFIDS-related articles in *The Smithsonian*, *Association Management* and *BioPeople*, a radio “CFIDS Health Alert” broadcast on over 312 stations nationwide and an hour-long segment covering a range of CFIDS issues on National Public Radio program “The Infinite Mind.”

In today's information-cluttered environment, making CFIDS a mainstream medical concern is increasingly difficult. Negotiating our "place" demands targeted communications and messages that resonate — The CFIDS Association is uniquely positioned to tackle this challenge and to turn passive support into action.

**Educating those on the front lines of patient care**

The Association successfully secured continuing funding from CDC for its multi-dimensional provider education project titled, "Chronic Fatigue Syndrome: A Diagnostic & Management Challenge." At the core of the project is a curriculum developed by CFIDS experts from around the country designed to teach health care providers how to better recognize and manage the illness.

As of November 2002, print-, video- and Web-based self-study courses were approved for continuing education credits through the CDC. And at year-end the curriculum went "live" on *www.cfids.org*, giving medical professionals 24-7 access to information on CFIDS diagnosis and treatment.

We also took our message — and a dynamic exhibit — directly to the medical masses at seven national professional conferences. At these events, Terri Lupton interacted with health care professionals from multiple disciplines, answering their questions and stimulating interest in CFIDS and its complexities.

In its third year, the Association's *CFS Research Review* continued to spread the message about CFIDS to health care professionals in all fields. The publication covered a wide range of topics — from primary care basics and the potential connection between brain abnormalities and persistent pain, to sleep dysfunction in CFIDS and information on selecting and utilizing fatigue rating scales.

The *Review* moved from a quarterly to a semi-annual schedule in 2003 to reduce costs associated with its production and distribution and ensure our continuing ability to offer this valuable resource, at no cost, to thousands of health care professionals.



**Best-selling author (and person with CFIDS) Laura Hillenbrand as featured in the December 2002 issue of *The Smithsonian*.**



**Kristine Healy, PA-C, MPH and Terri Lupton, RN, BSS educate providers at a national medical conference.**



**Leonard Jason, PhD and Charles Lapp, MD present the CFIDS curriculum at a train-the-trainer workshop.**

**The Association participated in the following medical conferences in 2002:**

- American Medical Women's Association (AMWA)
- National AHEC (Area Health Education Centers) Organization
- National Organization of Social Security Claimants Representatives (NOSSCR)
- American Academy of Family Physicians (AAFP)
- Infectious Disease Society of America (IDSA)
- Primary Medicine (Pri-Med)
- Nurse Practitioner Associates for Continuing Education (NPACE)

# CFIDS Public Policy...First

Over the years, The CFIDS Association of America has established itself as a highly respected advocate for sound and compassionate CFIDS-related public policy.

And our efforts have brought victories to people with CFIDS. Following a six-year paper trail, the Association exposed a funding scandal at the Centers for Disease Control & Prevention (CDC), helped secure full restoration of the diverted research dollars and jump-started a more enthusiastic and dedicated CFIDS research effort at the agency. Today, research conducted at CDC holds real promise for unlocking the mysteries of the illness that have eluded us for so many years (see page 7).

In 2002, three of the CFIDS community's fiercest and most effective advocates, Mary Beth Buchholz and Tom Sheridan of The Sheridan Group and Association President & CEO Kim Kenney worked vigorously inside the beltway, on both sides of the aisle and with top federal agency brass.



*(Left to right) Mark Peterson, Vicki Walker, Tom Peterson and Margaret Peterson gather on the steps of the Cannon Building following meetings at the offices of Rep. JoAnn Davis (R-VA) and Rep. Thomas Davis (R-VA).*

One of their most important successes was securing a new federal CFIDS committee, a significant achievement when numerous existing committees were being disbanded. The new advisory committee, designed to provide top public health officials with guidance on CFIDS-related issues, will be housed with the Department of Health and Human Services Office of Disease Prevention and Health Promotion under the direction of Dr. Larry Fields, Senior Advisor to the Assistant Secretary for Public Health and Science.

At the National Institutes for Health (NIH), however, we have not achieved the same success, nor have we seen research applications and awards increase despite a multi-disciplinary program announcement in December 2001. The Association continues to meet with top NIH staff to boost NIH-funded CFIDS research using time-tested, pro-active strategies.

Over the course of the year, the Association and The Sheridan Group worked closely with CDC officials including Dr. William Reeves, chief of the Viral Exanthems & Herpesvirus Branch, Dr. James LeDuc, Director of the Division of Viral and Rickettsial Diseases, and Bill Gimson, Chief Operating Officer, to secure support for the continued expansion of the agency's growing CFIDS research program.



*Advocates Diane Buckley and Robert Miller of Nev. participate in Lobby Day training to prepare for their meetings on Capitol Hill.*

Grassroots advocates continue to play a vital role in Association-led CFIDS public policy efforts. The largest group ever joined the Association in Washington, DC for its 11th annual Lobby Day in March 2002. Participants walked the halls of Congress, meeting with their Representatives, Senators and health staff. Key requests included calling for increased funding for CFIDS research at the NIH, accelerated research efforts at CDC and for every member of Congress to make

CFIDS a priority given its magnitude and its impact on the communities they represent. Lobby Day 2002 concluded as it traditionally does, with a well-attended reception at the home of Tom Sheridan, giving participants an opportunity to share experiences, renew friendships and celebrate what most call “an exhilarating day” of empowerment.

Looking ahead, research soon to be released from the CDC will document the severe financial impact of CFIDS on our nation’s economy. With help from The Sheridan Group, the Association is poised to utilize this opportunity to mobilize strong support from new Congressional CFIDS champions and ultimately increase federal funding for CFIDS research.

In today’s changed environment, new tactics and strategies will be necessary in order to secure greater attention to CFIDS-related issues on Capitol Hill. People with CFIDS can count on The CFIDS Association to continue to be their voice and advance our cause.



*At a meeting of Association supporters in Chicago, Ill., Ted Van Zelst (Louann Van Zelst seated) stresses the importance of a vigorous CFIDS public policy program.*



*Above left: Lobby Day participants Phyllis Amdurer, Suzanne Glaser, Barbara Steinberg and Sandy Kazlow.*

*Above right: Kim Almond and Sharon Greenspan at a post-Lobby Day reception.*



*Left: Mary Beth Buchholz, Tom Sheridan and Kim Kenney prepare to meet with Dr. Elias Zerhouni, Director of the National Institutes of Health.*

# CFIDS Research...First

**T**he path to a cure is charted one step at a time. Each study takes us a bit further along that path, answering some questions, raising new ones. The mysteries that continue to puzzle scientists who've been studying CFIDS for many years are now piquing the curiosity of researchers just entering this critical field of exploration. And we are making strides in understanding this serious and complex illness. It is a hopeful time for CFIDS research.

The CFIDS Association of America stands as the nation's largest not-for-profit source of funds for scientists studying CFIDS. Since 1987, we've directly invested over \$4.3 million in CFIDS research efforts.

In 2002, the Association continued to improve its track record of attracting qualified researchers to the study of CFIDS science and increasing the quantity of cutting-edge studies in the research pipeline.

The work of two talented researchers is currently being funded by the Association with more than \$155,000 in research grant dollars. Theodore C. Friedman, MD, PhD of the UCLA School of Medicine is exploring the possible causes behind the decreased blood flow to the brain that occurs in some people with CFIDS. This phenomenon could be due to a decreased ability to produce a hormone called renin. Renin is made in the kidneys and stimulates the production of other hormones that help conserve salt in the body. Initial data found defects in renin production in 19 of 21 study subjects.

The second Association-funded study, conducted by Giris Jacob, MD, DSc of Rambam Medical Center in Haifa, Israel, is examining the possible link between a persistently overactive immune system and CFIDS and also takes a rare look at individuals in the earliest stages of illness.



*Ted Nilson (second from right), President of the New Jersey CFS Association, presents a check to Association-funded researcher Dr. Dimitris Papanicolaou.*





*Left: CDC's Dr. Suzanne Vernon observes as Dr. Dominique Rollin prepares nucleic acids for gene expression experiments.*



*Right: Drs. Mangalathu Rajeevan and Martin Steinau of CDC assess differences between a person with CFIDS and a healthy control as shown by scanned images from an experiment using the cutting-edge technology of differential display polymerase chain reaction (DD-PCR).*

Both projects were chosen using a peer-review process that began with the evaluation of 37 letters of intent and 11 full applications. In 2003, the Association hopes to encourage further innovation by providing a source of seed funding for smaller novel projects with theoretical support, but little existing data. The Association will issue its Request for Applications for 2004 CFIDS Research Grants this fall.

Research efforts underway at CDC should also bring hope to the CFIDS community. Until recently, much of their efforts emphasized surveillance. Today they've enlisted over 70 people with CFIDS identified through their surveillance program in Wichita, Kan. (and approximately 300 matched controls) and will study them in a clinical setting. Volunteers will undergo a battery of neuroendocrine, immune and mental function studies as well as formal sleep testing.

At the heart of CDC's program are a series of exciting studies that take advantage of cutting-edge gene expression microarray technology. Differences in gene expression profiles and patterns can help to distinguish between people who have CFIDS and those who do not. This important work may ultimately lead to a routine diagnostic test for the illness.

In collaboration with Emory University researchers, CDC is supporting a separate study using functional magnetic resonance imaging (fMRI) to examine changes occurring in the brain over time, giving researchers a closer look at brain activity in PWCs.

Only continued rigorous scientific research will provide the tools needed to effectively diagnosis, treat, manage and, one day, cure and prevent CFIDS. The CFIDS Association of America is committed to driving the research that will translate into real results, and improved health, for the 800,000 men, women and children who suffer.



*Dr. William Reeves, principal investigator for CFS Studies at CDC.*

# People with CFIDS...First

**W**hat are the latest treatment options? How can I better understand my illness so I can ask my doctor the most appropriate questions? My wife is so sick — what can I do to help her cope with her illness and the effects it has had on our lives? How will CFIDS impact my child's school experience?

Whatever your questions about CFIDS are, The CFIDS Association of America can play a role in helping you find answers. We are committed to providing current, comprehensive and trusted information and resources to people with CFIDS and those who care about them.

The Association's flagship publication, *The CFIDS Chronicle*, provides coverage of a broad spectrum of CFIDS issues. In 2002, the quarterly magazine featured an interview with Barry Hurwitz, PhD, the principal investigator in the Procrit-CFIDS study. Procrit increases the body's production of oxygen-carrying red blood cells and is currently being used on people who have undergone chemotherapy and people who are on kidney dialysis. Because some of the symptoms of CFIDS (fainting, dizziness, light-headedness) may be caused by decreased red blood cell volume, Procrit is being studied as a possible treatment. The *Chronicle* also covered the name change debate, disability issues, worldwide research efforts and complementary and alternative therapies.

To help people with CFIDS share their stories, a special "Snapshots of CFIDS" supplement, featuring poetry, prose, artwork and photographs, was included in the fall 2002 *Chronicle*. In response to readers' warm reception, "Snapshots" is now slated to run in every winter and summer edition of the *Chronicle*.

Technology keeps accelerating the spread of information and "real time" is now the rule instead of the exception. In 2002 the Association improved its communications mix to bring you more of the reliable news you need, faster. We launched an electronic newsletter, *CFIDS Link*, and we continue to update and improve the offerings available on our Web site, [www.cfids.org](http://www.cfids.org). Today, with the click of a mouse, these resources put a wealth of timely, relevant CFIDS information at your fingertips.

To connect people with CFIDS with local support groups, the Association maintains state-by-state listings of CFIDS support groups and contacts. The Association also sponsors The CFIDS Support Network (CSN), an organization that helps group leaders facilitate positive and productive meetings. Although the primary goal for most CFIDS support groups is to help members "live" with CFIDS, many groups also work to educate the public, raise funds for research and focus state and national policy makers' attention on this devastating illness.



Chronicle Editor Mark Giuliucci

## People who care...



*Above left: Volunteer Margaret Cannon (far left) with Association staff members (left to right) Nova Bouknight, Lois Infanti and Gloria Smith.*

*Above center: Julie Carothers and Kasia Faryna*

*Above right: Jon Sterling with Association supporter Henry Levin.*

*Right: Sheila Sterling, Jane Perlmutter and Dr. Evi Gianakakou gather at an Association event at the Essex Hotel in New York City.*



*Above left: Alan and Jane Cornell (seated) hosted an evening for Association friends and supporters at their home in Boca Raton, Fla.*

*Above center: Association volunteers Tricia Yerkes and Annie Sullivan.*

*Above right: Support Group leaders Sue Alexander and Glenda Yakel help educate people about CFIDS at a conference in Reno, Nev.*

*Far left: Luke Sheets, lead singer of Jordan's Wake, performs at a CFIDS benefit.*

*Left: Association staff members join band members of Jordan's Wake to celebrate the success of their 60-concert, 30-day tour to raise awareness of CFIDS.*



# CFIDS First...

*A dynamic partnership between 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 greatest impact possible with programs aimed at advancing the Association's mission.*

## Board of Directors, Standing Committees of the Board, Professional Staff and selected Advisory Committees (current as of June 1, 2003)

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Director of Development  
& Chief Operating Officer

Kristina P. Hopkins,  
Controller

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Coordinator for Educational  
Opportunities

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Central Florida CFIDS Support Group,  
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*Rick Baldwin*



*Patti Schmidt*



*John Trussler speaks at a meeting of Association friends and benefactors in Chicago, Ill.*



*Far left: Adrienne Ryan (left) and Jon Sterling (right) with advocate Jacqueline Niederle of N.J.*

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

*Below: Joe Lane and Jane Perlmutter prepare for meetings on Capitol Hill.*

Renee Wilkins,  
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The CFIDS Association of America



**Beth Levine**



**Barbara Comerford**



**Mark Peterson**

## Controller's Report



*Kristina P. Hopkins*  
Controller

During 2002, the Association experienced the effects of the tumultuous economic times and saw total revenue and support decline for the first time since 1994. Revenue and support totaled \$1,518,143 in 2002 compared with \$2.06 million in 2001 and \$1.86 million in 2000. Yet at the same time, the need for our programs and services held steady. To protect vital core programs, the Association implemented rigorous cost-cutting measures and restructured project plans.

Our thanks to the individual donors (including estate gifts), corporations and foundations who, in 2002, sustained their support of our work. Those who wished to be acknowledged are recognized beginning on page 20.

The CFIDS Association of America is proud of its 16-year record of accomplishments and continuing ability to be a good steward of the funds it raises and distributes. Combined, our general and management expenses, and fundraising and development expenses accounted for less than 15% of the total spending in 2002. Mission-related activities, including grants for CFIDS research accounted for over 85% of our total annual spending.

Moving forward, we must build a stronger financial foundation so the Association can effectively respond to the challenges presented by CFIDS and seize emerging opportunities. Equally important is the organization's ability to weather changing economic conditions and maintain the integrity of programmatic efforts.

The statements that follow have been prepared in conformity with generally accepted accounting principles. I invite you to review the financial results of 2002 and to look forward with us to 2003 and beyond. Working together we will accomplish our mission — to conquer CFIDS.

## Report of Independent Certified Public Accountants



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, 2002, 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 Notes 1 and 9, the prior year summarized comparative information has been derived from the Association's 2001 financial statements; and in our report dated January 17, 2002, 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, 2002, and the results of its operations, changes in net assets, and its cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America.

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

Charlotte, North Carolina  
February 3, 2003

## Statement of Financial Position — December 31, 2002

(With Comparative Totals for Year Ended December 31, 2001)

	December 31, 2002			December 31, 2001
	Unrestricted	Temporarily Restricted	Totals	
<b>Assets</b>				
<b>Current assets</b>				
Cash and cash equivalents	\$ 370,464	\$ 254,516	\$ 624,980	\$ 847,486
Pledges receivable	10,000	107,241	117,241	3,000
Other receivables	64,490	—	64,490	328,508
Inventories	956	—	956	13,168
Prepaid expenses	9,252	—	9,252	24,785
<b>Total current assets</b>	<b>455,162</b>	<b>361,757</b>	<b>816,919</b>	<b>1,216,947</b>
Property and equipment				
Office furniture and fixtures	67,574	—	67,574	59,968
Computers and related equipment	99,074	—	99,074	106,039
Leasehold improvements	25,872	—	25,872	42,504
	192,520	—	192,520	208,511
Less accumulated depreciation	(146,083)	—	(146,083)	(147,042)
<b>Net property and equipment</b>	<b>46,437</b>	<b>—</b>	<b>46,437</b>	<b>61,469</b>
Cash surrender value of life insurance	—	17,209	17,209	—
<b>Total assets</b>	<b>\$ 501,599</b>	<b>\$ 378,966</b>	<b>\$ 880,565</b>	<b>\$ 1,278,416</b>
<b>Liabilities and Net Assets</b>				
<b>Current liabilities</b>				
Accounts payable	39,050	—	39,050	46,237
Accrued payroll and payroll taxes withheld	29,028	—	29,028	31,569
Unearned dues revenue	92,840	—	92,840	126,490
Current obligation under capital lease	3,821	—	3,821	—
<b>Total current liabilities</b>	<b>164,739</b>	<b>—</b>	<b>164,739</b>	<b>204,296</b>
<b>Other liabilities</b>				
Obligation under capital lease less current portion	7,019	—	7,019	—
<b>Net assets</b>				
Unrestricted				
Undesignated	165,062	—	165,062	504,926
Designated	164,779	—	164,779	261,756
Total unrestricted	329,841	—	329,841	766,682
Temporarily restricted	—	378,966	378,966	307,438
<b>Total net assets</b>	<b>329,841</b>	<b>378,966</b>	<b>708,807</b>	<b>1,074,120</b>
<b>Total liabilities and net assets</b>	<b>\$ 501,599</b>	<b>\$ 378,966</b>	<b>\$ 880,565</b>	<b>\$ 1,278,416</b>

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

## Statement of Activities and Changes in Net Assets — December 31, 2002

(With Comparative Totals for Year Ended December 31, 2001)

	December 31, 2002			December 31, 2001
	Unrestricted	Temporarily Restricted	Totals	
<b>Support and revenues</b>				
<b>Public support</b>				
Contributions and grants	\$ 595,557	\$ 643,016	\$ 1,238,573	\$ 1,745,387
<b>Revenues</b>				
Membership dues	245,148	—	245,148	275,554
Educational material sales	27,440	—	27,440	15,968
Card sales, shirt sales	—	—	—	9
Advertising revenue	—	—	—	600
Interest and other	6,982	—	6,982	30,241
	279,570	—	279,570	322,372
<b>Assets released from restrictions</b>				
Satisfaction of donor restrictions	571,488	(571,488)	—	—
<b>Total support and revenues</b>	<b>1,446,615</b>	<b>71,528</b>	<b>1,518,143</b>	<b>2,067,759</b>
<b>Expenses and losses</b>				
<b>Program services</b>				
Research	376,162	—	376,162	254,054
Public Policy	298,270	—	298,270	384,777
Education	918,620	—	918,620	968,709
<b>Supporting services</b>				
Management and general	136,354	—	136,354	165,775
Fund raising and development	139,302	—	139,302	190,597
	1,868,708	—	1,868,708	1,963,912
Loss on assets disposed	14,748	—	14,748	312
<b>Total expenses and losses</b>	<b>1,883,456</b>	<b>—</b>	<b>1,883,456</b>	<b>1,964,224</b>
Change in net assets	(436,841)	71,528	(365,313)	103,535
<b>Net assets</b>				
Beginning of year	766,682	307,438	1,074,120	970,585
End of year	\$ 329,841	\$ 378,966	\$ 708,807	\$ 1,074,120

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



## Statement of Functional Expenses — December 31, 2002

(With Comparative Totals for Year Ended December 31, 2001)

	Year Ended December 31, 2002						Year Ended December 31, 2001 Totals
	Program Services			Supporting Services		Totals	
	Research	Public Policy	Education	Management and General	Fund-Raising and Development		
Contract services	\$ 1,413	\$ 185,546	\$ 129,881	\$ 2,206	\$ 1,422	\$ 320,468	\$ 342,556
Salaries	61,857	72,842	447,070	96,560	62,226	740,555	765,405
Payroll taxes	4,812	5,666	28,395	7,511	4,840	51,224	50,242
Printing and postage	2,284	2,878	125,567	2,342	34,761	167,832	239,975
Repairs and maintenance	640	753	4,074	998	643	7,108	15,088
Supplies	975	1,148	6,041	1,522	981	10,667	21,497
Educational materials/ cost of sales	—	—	27,780	—	—	27,780	7,760
Research symposium	7,045	—	—	—	—	7,045	141,211
Travel expenses	1,913	6,809	7,212	413	6,883	23,230	28,109
Insurance	501	589	2,954	781	504	5,329	3,895
Telephone	2,962	1,924	11,603	2,355	1,580	20,424	38,113
Occupancy costs	7,170	8,443	42,310	11,192	7,213	76,328	77,067
Depreciation	2,684	3,160	15,836	4,189	2,700	28,569	27,188
Miscellaneous	3,982	8,512	41,788	6,285	15,549	76,116	96,241
Direct grants	277,924	—	28,109	—	—	306,033	109,565
<b>Total expenses</b>	<b>\$ 376,162</b>	<b>\$ 298,270</b>	<b>\$ 918,620</b>	<b>\$ 136,354</b>	<b>\$ 139,302</b>	<b>\$1,868,708</b>	<b>\$1,963,912</b>
Management and general expenses						\$ 136,354	\$ 165,775
Fundraising and development expenses						139,302	190,597
<b>Total management and general, and fundraising and development expenses</b>						<b>\$ 275,656</b>	<b>\$ 356,372</b>
<b>Total support and revenue</b>						<b>\$1,518,143</b>	<b>\$2,067,759</b>
<b>Supporting services ratio</b>						<b>18.16%</b>	<b>17.23%</b>

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

## Statement of Cash Flows — December 31, 2002

(With Comparative Totals for Year Ended December 31, 2001)

	Year Ending December 31,	
	2002	2001
<b>Cash flows from operating activities</b>		
Change in net assets	\$ (365,313)	\$ 103,535
Adjustments to reconcile increase (decrease) in net assets to net cash used in operating activities:		
Depreciation	28,569	27,188
Loss on disposal of assets	14,748	312
(Increase) decrease in operating assets:		
Pledges and other receivables	149,777	(298,780)
Inventories	12,212	8,935
Prepaid expenses	15,533	(17,917)
Cash value annuity insurance contract	(17,209)	—
Decrease in operating liabilities:		
Accounts payable	(7,187)	(46,909)
Accrued payroll and payroll taxes withheld	(2,541)	(12,546)
Unearned dues revenues	(33,650)	(12,504)
<b>Net cash used in operating activities</b>	<b>(205,061)</b>	<b>(248,686)</b>
<b>Cash flows from investing activities</b>		
Purchases of property and equipment	(16,511)	(44,348)
<b>Cash flows from financing activities</b>		
Principal reduction of obligation under capital lease	(934)	—
<b>Net decrease in cash and cash equivalents</b>	<b>(222,506)</b>	<b>(293,034)</b>
<b>Cash and cash equivalents</b>		
Beginning of year	847,486	1,140,520
End of year	\$ 624,980	\$ 847,486

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

## Notes to Financial Statements

### Note 1 — Summary of significant accounting policies

#### Description of operations

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

#### Basis of accounting

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

#### 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.

*Temporarily restricted net assets* — Net assets subject to donor-imposed stipulations that may or will be met, either by actions of the Association and/or the passage of time. When a restriction expires, that is when a stipulated time restriction ends or purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions. If a restriction is fulfilled in the same time period in which the contribution is received, the contribution is reported as unrestricted.

*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. At December 31, 2002, the Association has no permanently restricted net assets.

#### 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 Statement of Financial Accounting Standards (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 SFAS No. 136, Transfers of Assets to a Not-for-Profit Organization or Charitable Trust That Raises or Holds Contributions for Others, the Association recognizes contribution revenue from assets held by a recipient organization for the sole benefit of the Association. At December 31, 2002, 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 2002 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	\$ 244,173	\$ 55,545
Grassroots Lobbying	\$ 65,836	\$ 9,727

### 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, 2002.

### 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, 2001, from which the summarized information was derived.

### Note 2 — Pledges receivable

Unconditional promises are expected to be realized in the following periods as of December 31, 2002:

In one year or less	\$ 70,000
Between one year and five years	<u>50,000</u>
	120,000
Less: discount	<u>(2,759)</u>
	<u>\$ 117,241</u>

Unconditional promises to give expected to be realized in more than one year are reflected at the present value of estimated future cash flows using a discount rate of 5.25%. A pledge receivable in the amount of \$110,000 at December 31, 2002 is restricted for use in Association public policy efforts while the remaining pledge receivable of \$10,000 is unrestricted.

### Note 3 — Grants

In 2002, the Association was awarded \$2,830,150 in federal funds from The Centers for Disease Control and

Prevention 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. Total funds expended in 2002 were \$88,253. The funds were received by the Association on a reimbursement basis. At December 31, 2002, \$62,176 is included in other receivables. 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

During 2002, the Association acquired equipment under a capital lease. Property and equipment includes equipment under capital leases with a cost basis of \$11,774 and accumulated depreciation of \$2,355. 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, 2002.

2003	\$	4,141
2004		4,141
2005		<u>3,106</u>
		11,388
Less amount representing interest		<u>(548)</u>
Present value of net minimum lease payments		10,840
Current maturities		<u>(3,821)</u>
Noncurrent maturities	\$	<u>7,019</u>

#### Note 5 — Temporarily restricted net assets

Temporarily restricted net assets are available for the following purposes as of December 31, 2002:

Research activities	\$	194,540
Public policy activities		143,380
Educational activities		23,837
Donor specified		<u>17,209</u>
	\$	<u>378,966</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, 2002 as follows:

Purpose restrictions accomplished:		
Research grants, symposia, and related expenditures	\$	315,806
Government grants		169,226
Public policy activities		48,930
Educational activities		32,085
Donor specified		<u>5,441</u>
	\$	<u>571,488</u>

#### Note 7 — Commitments

As discussed in Note 1, the Association awards grants for medical research and funds such projects contingent upon research contributions received and cash flow. At December 31, 2002, the Board of Directors had approved funding for the following research projects to be disbursed during 2003:

Giris Jacob, MD, DSc	\$	75,250
Theodore Friedman, MD, PhD		<u>79,996</u>
Total	\$	<u>155,246</u>

The Association retains the services of The Sheridan Group, a professional government relations firm in Washington, D.C., through an annual contract. The Sheridan Group represents the interests of the Association with Congress, the Executive Branch, and other federal governmental agencies. The total contractual obligation to The Sheridan Group for the year 2003 is \$120,000 payable in monthly installments. The services of The Sheridan Group in 2002 amounted to \$183,881.

#### 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 and computers under leases expiring in 2003.

Future minimum lease commitments under the above operating leases are as follows at December 31, 2002:

Year ending December 31,	
2003	\$ 52,866
2004	52,176
2005	52,176
2006	52,176
2007	<u>21,740</u>
	<u>\$ 231,134</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 \$82,536 for the year ended December 31, 2002.

#### 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 2002, the Association made contributions into this plan amounting to \$19,797.

## PUTTING CFIDS FIRST

Thank you for supporting The CFIDS Association of America. However you choose to invest in the battle to conquer CFIDS, know that your donation accelerates vital CFIDS education and awareness, sound CFIDS-related public policy and promising CFIDS research.

Today the work of the Association is increasingly supported through bequests and other planned gifts. To learn more, please contact the Association's Director of Development at 704-364-0466, [jldavis@cfids.org](mailto:jldavis@cfids.org) or visit the Association's Web site at [www.cfids.org](http://www.cfids.org).

*Gifts to The CFIDS Association are tax-deductible to the full extent allowed by law. Many gift opportunities may also provide additional tax benefits to the donor.*

*The CFIDS Association of America does not provide legal or financial advice. Please consult your attorney, financial planner or accountant regarding the specific tax and financial implications of your charitable contributions.*

We invite you to explore the many ways you can put CFIDS first and make a significant contribution to the campaign to conquer one of the most prevalent and devastating chronic illnesses of our time.

- Remember the Association in your will
  - Make a gift in honor or in memory of a friend or loved one
  - Name The CFIDS Association as a beneficiary of your trust, life insurance policy or individual retirement account
  - Write a personal check to The CFIDS Association of America
- Join The Chairman's Circle monthly giving program
- Ask your friends to send donations to the Association in lieu of birthday gifts this year
- Make a gift of stock or appreciated (or depreciated) securities
- Host an event and introduce your friends to the Association's important work
- Join the distinguished President's Club with your gift of \$50,000 or more
- Participate in your employer's matching gift program
- Donate a percentage of your company's profits to the Association
- Visit [www.cfids.org](http://www.cfids.org) and make a secure online donation
- Select The CFIDS Association as the recipient of your workplace campaign contributions
- Federal employees can designate the Association (#2515) in the Combined Federal Campaign
- Earmark your United Way gift for The CFIDS Association

#### WHAT IS THE CFIDS ASSOCIATION OF AMERICA?

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

The Association plays a principal role in focusing mainstream attention on this serious public health concern, advocating for people with CFIDS and accelerating the pace of ground-breaking CFIDS research.

Since its founding in 1987, the Association has invested \$14 million in direct support of its mission to bring an end to the suffering caused by CFIDS.

The Association works toward its mission on five important fronts:

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

Through these and all its efforts, the Association strives to eradicate CFIDS.

THE CFIDS ASSOCIATION OF AMERICA, INC.

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