

# 2000 Annual Report



# Table of Contents

Chairman's Message .....	1
What is CFIDS? .....	1
President & Chief Executive Officer's Report.....	2
Strategies .....	3
Controller's Report .....	8
Independent Auditor's Report .....	10
Financial Tables .....	11
Notes to Financials.....	15
Board of Directors, Committees, and Professional Staff .....	18
2000 Annual Donors .....	20

# Chairman's Message

The CFIDS Association of America has raised and invested over \$3.7 million in CFIDS research efforts. In fact, outside of the federal government, the Association is the largest provider of CFIDS research grants in the United States.

In 2000, however, we did not solicit nor receive any grant applications for research. Alternatively, we worked to refine and improve the program and we launched a series of scientific symposia aimed at defining the limits of existing knowledge of specific CFIDS research topics, developing consensus about the most promising avenues for research in those areas, and increasing the overall quantity and quality of CFIDS research.

Today, I'm delighted to announce the re-opening of our peer-reviewed CFIDS research grants program.

Invigorated by knowledge gained from our on-going symposia series and strengthened by a planned increase in the Association's direct investment in pioneering research, I am confident this revitalized program and an aggressive, proactive approach to CFIDS research have tremendous potential to bring answers to the many compelling questions surrounding this illness.

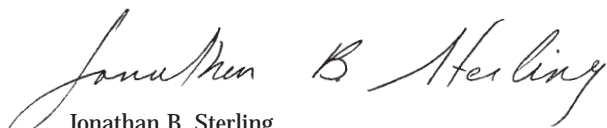
But such aggressive tactics necessitate equally vigorous fundraising efforts.

The Association's Board and professional staff are firmly committed to the important role that The CFIDS Association plays in battling CFIDS and endorse the research-driven plan. But let me assure you that by doing so, we've not lost sight of the equally important work we must accomplish in the public policy arena, in CFIDS education, and in raising awareness.

Many in the scientific community have responded to the critical need to foster CFIDS research by participating in an Association-led research symposium. Thousands more have made a commitment to ensuring better care for people with CFIDS by reading *The CFS Research Review*.

Today, I challenge you to help the Association speed progress in CFIDS research progress without sacrificing or diminishing our vital efforts in other important program areas. Please, continue to generously support The CFIDS Association of America.

Thank you for everything you've helped us achieve and for what we'll accomplish together on behalf of the CFIDS community.



Jonathan B. Sterling  
Chairman of the Board

CHALLENGE:  
TO CONQUER CFIDS

## What is CFIDS?

Chronic fatigue and immune dysfunction syndrome (CFIDS) is a complex illness that affects the brain and multiple body systems. It is characterized by disabling 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. Despite more than a decade of research, the cause of the illness is not yet known, there is no definitive diagnostic test, and treatment is aimed primarily at symptom relief.

CFIDS strikes women, men, and children of all age, ethnic, and socioeconomic groups. A recent study published in the *Archives of Internal Medicine* reports that as many as 800,000 U.S. adults suffer from CFIDS. The study also found that less than 10% of individuals with CFIDS had been diagnosed, leaving hundreds of thousands with no understanding of their illness and no treatment. And although few studies of CFIDS among children and teenagers have been done, it is known that the lives of thousands of young people have been forever changed by CFIDS.

# President & Chief Executive Officer's Report

When I joined the staff of The CFIDS Association of America in 1990, the name of the Association was regularly followed by this tag line: Advocacy, Information, Research, and Encouragement for the CFIDS Community. There have been many changes in the Association over the past decade — our programs have dramatically multiplied and expanded; our staff has grown and become more expert; and our financial position has strengthened and become more stable. Yet, the tag line introduced over 10 years ago still reflects the core strategies we employ today to achieve the Association's mission: to conquer CFIDS.

In our 2000 Annual Report, we present not only last year's programmatic highlights and financial results; we also attempt to convey a sense of the momentum that is building in virtually every aspect of the Association's work. In 2000, we launched exciting initiatives in our research program, through our symposia series, and in our medical education efforts, through the creation of a vibrant traveling educational exhibit and realization of plans to deliver a CFIDS curriculum to primary care providers. Our advocacy efforts intensified, securing the restoration of \$13 million in CFIDS research funds misspent by one federal agency (Centers for Disease Control and Prevention) and generating a more dedicated and diverse approach to CFIDS research by another (National Institutes of Health). *Snapshots of CFIDS*, a new publication that captures the essence of the CFIDS experience, joined *The CFIDS Chronicle* and *The CFS Research Review* as another means of meeting the varied information needs of the many audiences the Association now serves: persons with CFIDS, their family members and caregivers, medical and media professionals, legislators and public health officials, and interested members of the public. And, just a few weeks ago, many months of work culminated in the launch of the Association's all-new web site, [www.cfids.org](http://www.cfids.org), providing a critical tool to reach members of each of those audiences who rely on the Internet for health information, news, and support.

The accomplishments listed above and those described in more detail on the following pages were made possible by the generosity of our members and donors. This annual report recognizes all those who supported our programs: the 1,169 donors who contributed \$50 or more and chose to be named are listed beginning on page 20. Nearly 800 donors wished to remain anonymous and are acknowledged first within each appropriate giving level. We also wish to thank 2,748 donors whose smaller, yet no less generous, gifts provided a significant source of support for the Association's programs. Members of The Founder's Circle, who make monthly donations, are thanked too. We also introduce two new, and very special, groups of benefactors — The Iverson Society, comprised of individuals whose lifetime gifts exceed \$500,000, and the President's Club, recognizing those whose lifetime gifts total to \$50,000-\$499,999. We remain deeply grateful for every single person who has chosen to support the Association's work with a gift, regardless of its size.

In the same way the "Advocacy, Information, Research, and Encouragement" tag line has stood the test of time, so has a refrain I first heard in 1990, when I was just learning about the Association. A woman with CFIDS told me that, to her, the Association was a "lifeline" and an invaluable source of information and hope. I am gratified by the fact that during each of the nearly 550 weeks I've been with the Association, I have heard from at least one, and often scores, of people who express this same feeling about the work we do.

Two other constants deserve mention. The first is that the challenges ahead, then as now, are intimidating. The second is that those who continue to drive this Association share a resolve to overcome challenge, a resolve that only deepens with time.

The constancy of your support of the Association is essential if we are to capitalize on the momentum generated over the past year, and to speed meaningful improvements in the daily lives of all persons with CFIDS. Together we will make our 2001 Annual Report an even more robust record of achievement for The CFIDS Association of America and the community it serves.



K. Kimberly Kenney  
President & Chief Executive Officer

For more than a decade, the effort to defeat CFIDS has been driven by individuals directly affected by the illness. However, their knowledge of the worthiness and importance of this cause is not enough — to conquer CFIDS we must secure support from those beyond the CFIDS community. To turn this tide, the Association's dynamic education and media activities are directed to the general public, in particular those people who are not sufficiently familiar with an illness four times more common than HIV infection in women and 15 times more common in women than lung cancer. An illness affecting 800,000 Americans and countless others around the world cannot be ignored. Through heightened CFIDS awareness, we will attract the financial and intellectual resources necessary to defeat this devastating illness.

**Strategy**  
**Build recognition**  
**of CFIDS as a**  
**serious, widespread**  
**medical disorder.**



Jane Stockman shares her CFIDS experience with *Lifetime Live* viewers.



Dana Reeve interviews Kim Kenney.

## CFIDS in the News

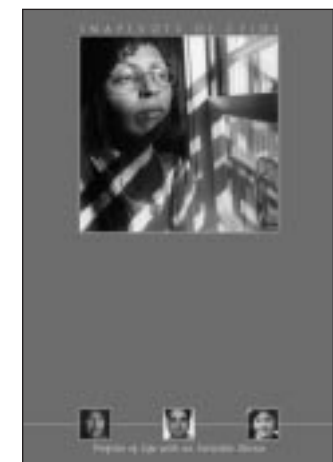
In 2000, the Association worked vigorously to gain media coverage for the illness. As a direct result of our efforts, positive stories about CFIDS were featured in some of the nation's leading media outlets, including *USA Today*, one of the highest circulation newspapers in the world; *Lifetime Live*, the popular women-oriented cable network's news show; and "Focus on the Family," a syndicated Christian radio program heard on nearly 3,000 stations. The Association also helped shape coverage of emerging issues, including working with ABC's *20/20* to ensure fair, balanced reporting on neurosurgery as a treatment for CFIDS and fibromyalgia.

## Media to Fuel Advocacy Efforts

Media was important to building recognition of CFIDS issues on Capitol Hill. A front page article in *The Washington Post* informed more than a million people, including key legislators, of the widespread abuses within the Centers for Disease Control and Prevention (CDC) that led to funds being diverted from CFIDS and other research programs. This coverage, aggressively pursued by the Association, brought about expanded legislative hearings that put CDC in the "hot seat," a call for a more comprehensive General Accounting Office investigation of the agency, and improved attention to CFIDS as a serious public health issue.

## Patient Profile Publication

Most people will not become interested in an illness until they can imagine what it must be like to have it. In 2000, The CFIDS Association created a new publication, *Snapshots of CFIDS: Profiles of Life with an Invisible Illness*, to help people do just that. Through its compelling words and portraits, *Snapshots of CFIDS* introduces seven courageous men and women whose lives have been derailed by this tragic illness and paints an accurate picture of the wide range of age, race, and socioeconomic boundaries CFIDS crosses.





Mary Ellen Jacobs, Allison Baldwin, Rep. Joe Hoeffel (Pa.), Patti Schmidt, Priscilla deLeon, and Rick Baldwin

57 advocates reached 132 Congressional offices. Our issues and requests were met with overwhelming support and Lobby Day participants reported a sense of empowerment and excitement after spending a day on the Hill.

### Misappropriated CFS Funds Restored

In 2000, the Centers for Disease Control and Prevention (CDC) began its restitution of the \$12.9 million in CFIDS funds diverted to other programs between 1995 and 1998. Led by President & CEO Kim Kenney, The CFIDS Association of America played a central role in uncovering the scandal and securing Congressional support for full restoration of research funds. Several Congressional appropriations hearings in early 2000 focused on the agency's false reports to Congress about its CFS activities, and the story was covered by *The Washington Post* and other news agencies (see page 3).



A group from San Antonio at Lobby Day training

### Lobby Day a Success

For the ninth consecutive year, persons with CFIDS and healthy family members and close friends met with Congressional staff and members of Congress to educate and urge a stronger federal response to CFIDS. On June 22, 2000, armed with the just-released General Accounting Office (GAO) report, which noted a series of deficiencies in the federal CFS program,



**Strategy**  
Secure a meaningful response to CFIDS from the federal government.

CFIDS advocacy is a smart investment. In a single year, the federal government has the ability to appropriate millions of dollars for the battle against CFIDS, far more money than The CFIDS Association could hope to raise in the same amount of time. For that reason, the Association leads strategic efforts to garner support for CFIDS issues from legislators and public health officials and to hold them accountable for their response to the illness. A vigorous and effective public policy program will strengthen research funding; lift the funding burden from patient community; expand patient access to social services; and significantly improve the way CFIDS is viewed by lawmakers, the medical community, the media, and the public.

**Strategy**  
Stimulate high quality CFIDS research.

### Driving CFS Research

Months of careful planning culminated in the Association's first research symposium, "Chronic Fatigue Syndrome: What Role Does Dysautonomia Play in the Pathophysiology of this Complex Illness?" held December 3-5, 2000 in Washington, D.C. Following a proven format of a "scientific court," expert panelists representing diverse disciplines heard a full day of scientific presentations, then worked late into the night and all the next day to evaluate evidence, draw on findings from related fields, and craft a consensus statement outlining the boundaries of existing knowledge and promising research directions. The resulting statement is being submitted to top-notch peer-reviewed journals for publication.



### Respected CFS Researcher Leads Panel

Nancy G. Klimas, M.D., an immunologist at the University of Miami and one of the country's foremost CFIDS experts, spoke at the Association's December 2000 symposium which explored the role of the autonomic nervous system (ANS) in CFS, with special emphasis on the interactions between ANS dysfunction and identified abnormalities in the immune and endocrine systems of CFS patients.

Other presenters and panelists at this symposium included: David Bell, MD, Timothy Gerrity, PhD, Georgetown University Medical Center, Peter Rowe, MD, Johns Hopkins University Hospital, and Julian Stewart, MD, PhD, New York Medical College.

Further symposia focus on the neuroendocrine aspects of CFS (March 2001), the immunologic aspects of CFS (October 2001), and promising diagnostic processes and tools (2002).

### Research Grants Program

Funding priorities for The CFIDS Association of America's Research Grants program lie in the following four specific areas of study, which the Association believes to be the most essential areas of CFIDS investigation: diagnostic markers or possible causes; underlying pathophysiology; efficacious treatments for the disease; and epidemiology, natural history, and pathophysiology in adolescents and children.

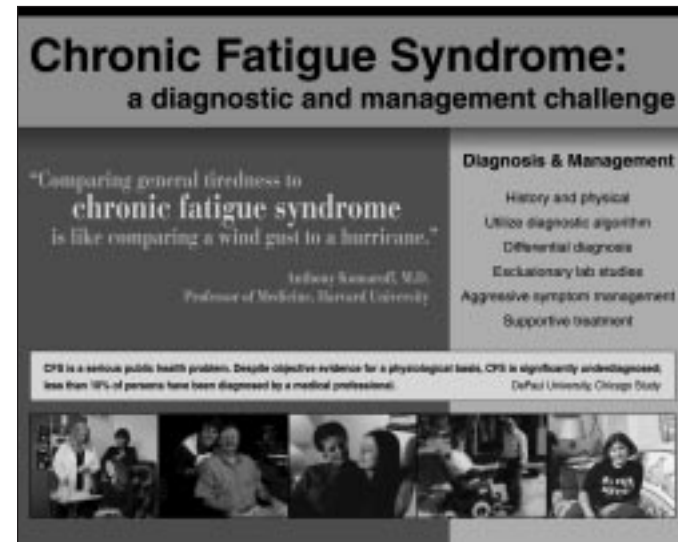


## Association Debuts New Medical Publication

Since its launch in spring 2000, *The CFS Research Review* has quickly become one of the world's most widely acclaimed CFS publications and is now considered by many "de rigueur" for health care professionals. Currently, the *Review* reaches over 7,000 physicians, government scientists, and allied health professionals each quarter free-of-charge. It is also distributed to Association members along with *The CFIDS Chronicle*. A letter from Dr. Philip Lee, former U.S. Assistant Secretary of Health, and Dr. Anthony Komaroff, Professor of Medicine at Harvard Medical School, was mailed with the summer issue urging health care professionals to educate themselves about CFIDS in order to improve the care their patients receive.

## "Chronic Fatigue Syndrome: A Diagnostic & Management Challenge"

In partnership with the Illinois Area Health Education Center (AHEC), the Association launched an ambitious health care provider-training program to educate those on the front lines of CFIDS/CFS diagnosis and treatment. Educational components of the project include, a teaching curriculum, train-the-trainer workshops, video- and web-based self-study modules (with an opportunity for continuing education credit), and a conference exhibit. Health educator Terri Lupton, BSS, RN joined the Association's staff in July 2000 and serves as project coordinator. Charles Lapp, MD and Leonard Jason, PhD function as master trainers, and an expert advisory committee works to ensure the success of this exciting project, which holds significant promise for increasing provider awareness and understanding of CFS diagnosis and treatment.



Education is the foundation of The CFIDS Association. Through our two quarterly publications, brochures, all-new Web site, Resource Line, and participation in educational and support group events, we offer the most comprehensive, trusted, and accurate information about CFIDS to our members, donors, the patient community, and interested others. We also work to reach the 90% of CFIDS sufferers who've slipped through the cracks of the medical system and are struggling with symptoms and an illness they may not even know exists. Simply stated, The CFIDS Association is here to help people find the information and answers they need. We endeavor to empower individuals to make informed choices about their healthcare, arm them as better advocates for themselves and for others, connect them with the broader CFIDS community, and help them more effectively cope with a complex and serious illness.

**Strategy**  
Provide information to persons with CFIDS and enable the CFIDS community to speak with a collective voice.

for on-line donations, memberships, and material orders; and links to outside resources of interest to people with CFIDS.

## The CFIDS Support Network (CSN)

CSN provides information, materials, resources, and assistance to support group leaders in order to help them facilitate positive, productive meetings, and better serve the needs of their members. In 2000, the CSN stood 185 support groups strong. Each year through its CSN ACTION Awards, CSN members recognize the efforts of individuals who give of themselves to help others cope with this debilitating illness.

A special Certificate of Appreciation went to Sheila Stevens of the Miami/Coral Gables CFIDS Support Group. Sheila, who recently retired as her group's leader, has been an active member of the CSN since its inception in 1994. She and her group also won an ACTION award in 1999.



Flanked by Dr. Nancy Klimas and group member Bonnie Mayer, Sheila Stevens accepts her award.



## The CFIDS Association's Web Site

The redesign of www.cfids.org began mid-2000 and launched to an enthusiastic welcome on May 7, 2001. The goals of the project were to present the most up-to-date CFIDS and Association information in a dynamic format and engage visitors more effectively. The new site, shaped by program and development staff, with design and technical help from ettain, inc., focuses primarily on the interests and needs of people with CFIDS and their families. Sections of the site are also tailored to the specific information needs of medical professionals and the media. New Web site features include: an interactive questionnaire for people who think they might have CFIDS; an area dedicated to the unique concerns of women; search-able *Chronicle* and *CFS Research Review* archives; a secure environment

**Strategy**  
Improve health care providers' abilities to detect, diagnose, and manage CFIDS.

We can change patient care for the better. CFIDS certainly presents a considerable challenge for health care professionals in its diagnosis and treatment. Not only is the cause of the illness unknown, a recent DePaul University study reported that less than 10% of individuals suffering with CFIDS have even been diagnosed. Despite these facts, we can vastly improve the lives of persons with CFIDS. By educating those on the front lines of patient care about the detection, diagnosis, and management of CFIDS and by stimulating interest and curiosity in its complexities, we can effect positive change in the day-to-day health of those who suffer from this debilitating illness.

# Controller's Report

The year 2000 opened with The CFIDS Association of America in its best financial position ever and ended the fiscal year with a record \$1,863,105 in total revenue and \$970,585 in total net assets. Annual support and revenue (see graph at right) has risen steadily since 1990.

As shown on the Sources of Funds graph, public support accounted for 80% of the Association's revenue in 2000, a 5% increase over 1999 and an 86% increase in public support over the past four years. However, other areas of support showed decreases except for interest and other revenue.

The generosity of members, donors, corporations, and foundations enabled us to invest \$800,000 in CFIDS education efforts aimed at the general public, members of the medical community, the media, persons with CFIDS, and their families and friends. This increase of \$180,000 over the 1999 education investment is due largely to increased focus on health care provider education.

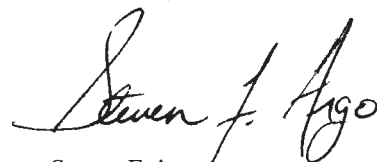
The Association remains firmly committed to expanding federal CFIDS research initiatives and holding the government accountable for its response to CFIDS. In 2000, the Association invested over \$319,000 in its CFIDS public policy program. Limited earmarked public policy contributions meant that the majority of the Association's investment in this critical effort came from its unrestricted fund.

2000 was an atypical, yet successful, year for the Association's CFIDS research program. The Association did not solicit or receive research grant applications. Instead, as planned, the Association invested \$107,000 in launching its CFS Research Symposia Series to re-invigorate interest in the critical study of CFIDS science and increase the number and scope of future CFIDS research projects. The Association's CFIDS research grants program reopened in spring 2001.

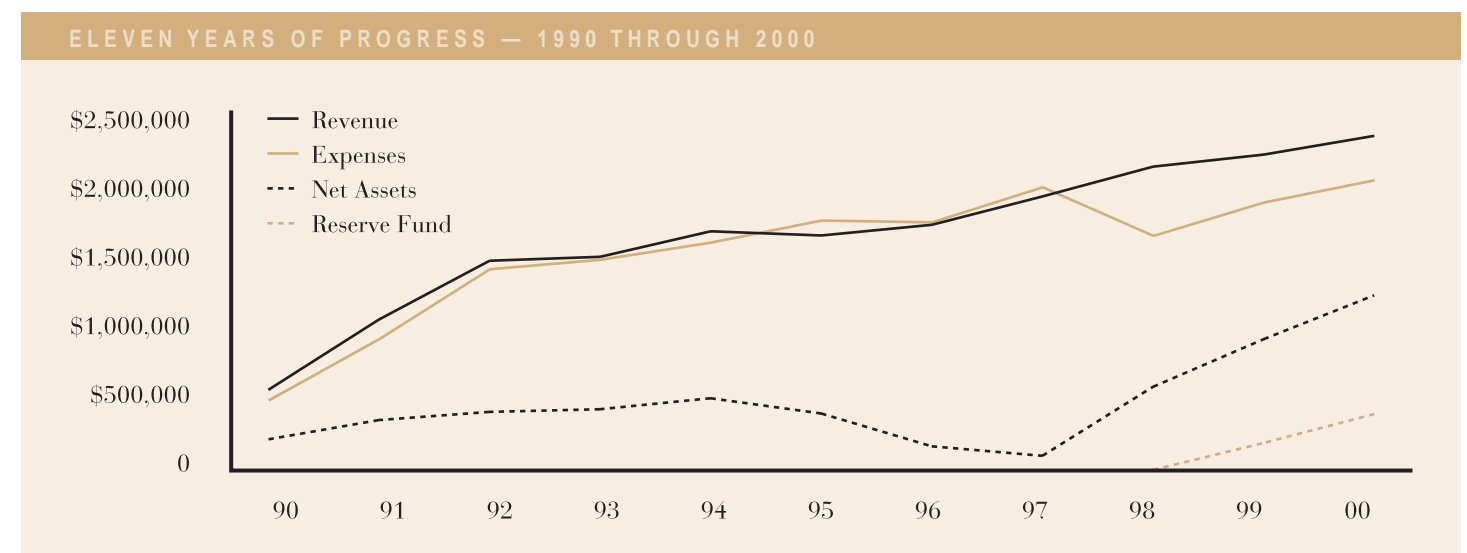
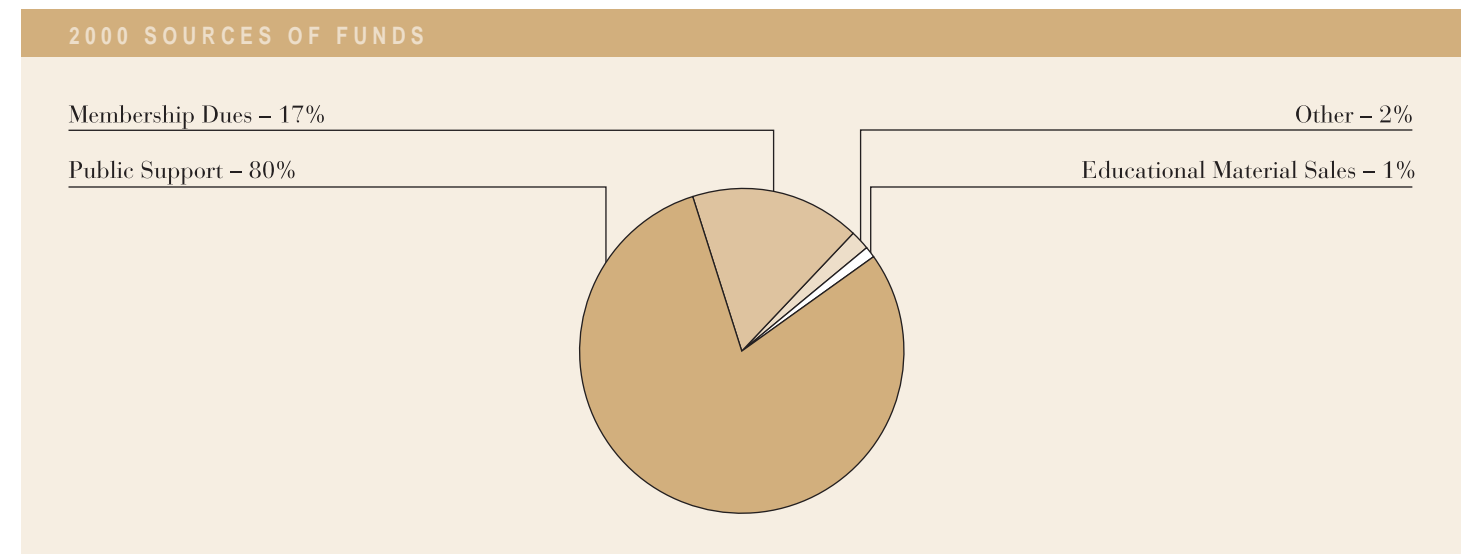
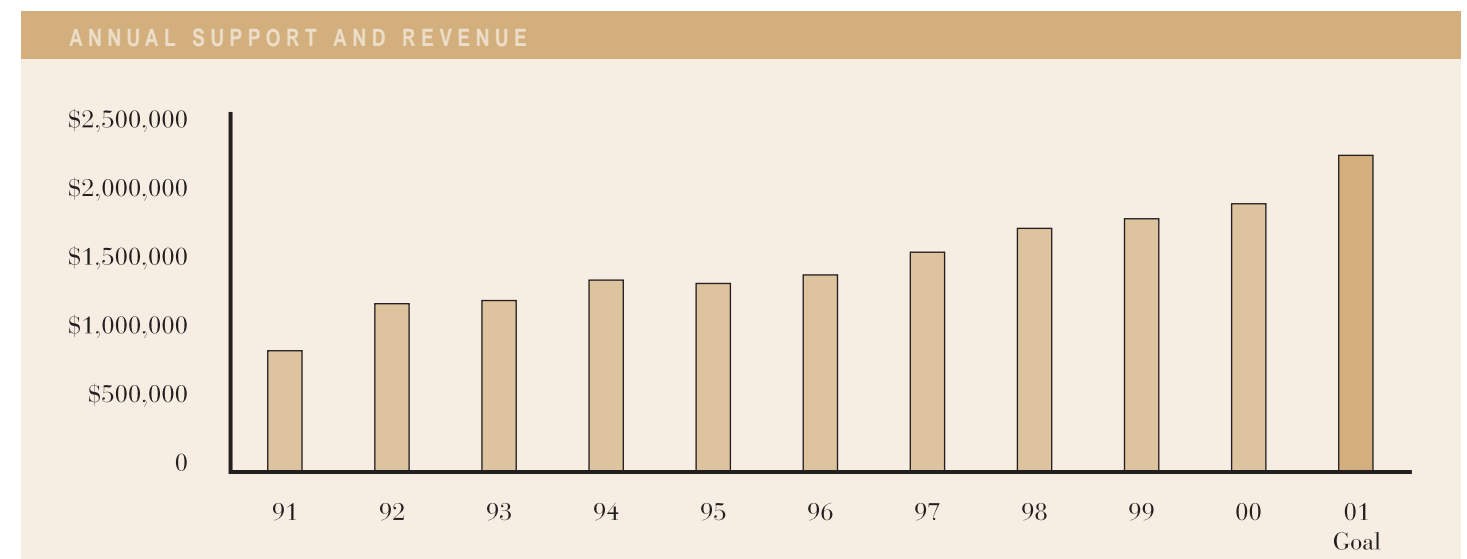
In total, \$1,616,527 was invested in the fight against CFIDS in 2000. Management and general expenses and fund-raising and development activities (known as supporting services costs) represented 20.9% of total support and revenue, well below the standard 25% threshold and comparable with national organizations of similar size and mission. At year-end, the Association added \$150,000 to the Reserve Fund (see graph at right), which now holds a balance of over \$311,000. The CFIDS Association of America takes great pride in its continuing ability to prudently manage operations while directing the vast majority of its resources to the vital activities that advance our mission.

The financial success of 2000, and the CFIDS education, public policy, and research programs it helped accelerate, is due to the incredible generosity and vision of all Association members and donors. We thank you for your steadfast support and are committed to strengthening the programmatic, development, and leadership efforts that will move us closer to accomplishing our mission: to conquer CFIDS.

Respectfully submitted,



Steven F. Argo  
Controller



# 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, 2000, and the related statements of activities and changes in net assets, of functional expenses, and of cash flows for the years then ended. These financial statements are the responsibility of the Association's management. Our responsibility is to express an opinion on these financial statements based on our audit. As described in Notes 1 and 9, the prior year summarized comparative information has been derived from the Association's 1999 financial statements; and in our report dated February 8, 2000, we expressed an unqualified opinion on those financial statements.

We conducted our audit in accordance with generally accepted auditing standards. 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, 2000, and its changes in net assets and cash flows for the year then ended in conformity with generally accepted accounting principles.

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

Charlotte, North Carolina  
February 9, 2001

# Statement of Financial Position

December 31, 2000

(With Comparative Totals for December 31, 1999)

	Unrestricted	Temporarily Restricted	2000 Totals	1999 Totals
<b>Assets</b>				
<b>Current assets</b>				
Cash and cash equivalents	\$ 877,716	\$ 262,804	\$ 1,140,520	\$ 1,018,230
Pledges receivable	1,500	—	1,500	2,000
Other receivables	31,228	—	31,228	3,756
Inventories	22,103	—	22,103	13,346
Prepaid expenses	6,868	—	6,868	12,369
<b>Total current assets</b>	<b>939,415</b>	<b>262,804</b>	<b>1,202,219</b>	<b>1,049,701</b>
<b>Property and equipment</b>				
Office furniture and fixtures	36,008	—	36,008	43,790
Computers and related equipment	118,974	—	118,974	85,051
Leasehold improvements	22,918	—	22,918	22,918
Total property and equipment	177,900	—	177,900	151,759
Less accumulated depreciation	(133,279)	—	(133,279)	(114,139)
<b>Net property and equipment</b>	<b>44,621</b>	<b>—</b>	<b>44,621</b>	<b>37,620</b>
<b>\$ 984,036</b>	<b>\$ 262,804</b>	<b>\$ 1,246,840</b>	<b>\$ 1,087,321</b>	
<b>Liabilities and Net Assets</b>				
<b>Current liabilities</b>				
Accounts payable	\$ 61,146	\$ 32,000	\$ 93,146	\$ 173,899
Accrued payroll and payroll taxes withheld	44,115	—	44,115	31,845
Unearned dues revenue	138,994	—	138,994	156,812
<b>Total current liabilities</b>	<b>244,255</b>	<b>32,000</b>	<b>276,255</b>	<b>362,556</b>
<b>Net assets</b>				
<b>Unrestricted</b>				
Undesignated	428,740	—	428,740	466,068
Designated	311,041	—	311,041	150,000
Total unrestricted	739,781	—	739,781	616,068
Temporarily restricted	—	230,804	230,804	108,697
<b>Total net assets</b>	<b>739,781</b>	<b>230,804</b>	<b>970,585</b>	<b>724,765</b>
<b>\$ 984,036</b>	<b>\$ 262,804</b>	<b>\$ 1,246,840</b>	<b>\$ 1,087,321</b>	

See notes to financial statements.

# Statement of Activities & Changes in Net Assets

Year Ended December 31, 2000

(With Comparative Totals for Year Ended December 31, 1999)

	Unrestricted	Temporarily Restricted	2000 Totals	1999 Totals
<b>Support and revenues</b>				
<b>Public support</b>				
Contributions and grants	\$ 1,174,640	\$ 314,946	\$ 1,489,586	\$ 1,335,825
<b>Revenues</b>				
Membership dues	314,654	—	314,654	360,286
Educational material sales	19,422	—	19,422	36,108
Card sales, shirt sales	18	—	18	1,879
Advertising revenue	1,500	—	1,500	2,925
Interest and other	37,925	—	37,925	21,551
	373,519	—	373,519	422,749
<b>Assets released from restrictions</b>				
Satisfaction of donor restrictions	192,839	(192,839)	—	—
<b>Total support and revenues</b>	<b>1,740,998</b>	<b>122,107</b>	<b>1,863,105</b>	<b>1,758,574</b>
<b>Expenses and losses</b>				
<b>Program services</b>				
Research	107,877	—	107,877	278,645
Public policy	319,152	—	319,152	258,853
Education	800,220	—	800,220	618,203
<b>Supporting services</b>				
Management and general	167,898	—	167,898	140,015
Fund-raising and development	221,380	—	221,380	197,637
	1,616,527	—	1,616,527	1,493,353
Loss on disposal of assets	758	—	758	—
<b>Total expenses and losses</b>	<b>1,617,285</b>	<b>—</b>	<b>1,617,285</b>	<b>1,493,353</b>
Increase in net assets	123,713	122,107	245,820	265,221
<b>Net assets</b>				
Beginning of year	616,068	108,697	724,765	459,544
End of year	\$ 739,781	\$ 230,804	\$ 970,585	\$ 724,765

See notes to financial statements.

# Statement of Functional Expenses

Year Ended December 31, 2000

(With Comparative Totals for Year Ended December 31, 1999)

	Program Services			Supporting Services		2000 Totals	1999 Totals
	Research	Public Policy	Education	Management and General	Fund-Raising and Development		
Contract services	\$ 651	\$ 161,129	\$ 19,039	\$ 1,857	\$ 10,053	\$ 192,729	\$ 180,745
Salaries	38,975	96,413	316,187	111,164	71,687	634,426	439,224
Payroll taxes	2,493	6,167	20,226	7,111	4,586	40,583	26,849
Printing and postage	1,627	9,494	100,807	5,296	83,045	200,269	186,188
Repairs and maintenance	810	2,003	6,568	2,309	1,489	13,179	14,298
Supplies	1,909	3,285	10,774	3,788	3,033	22,789	15,938
Educational materials/cost of sales	—	—	8,089	—	—	8,089	27,394
Travel expenses	7,525	8,623	14,016	1,307	18,754	50,225	23,904
Insurance	237	587	1,926	677	437	3,864	4,290
Telephone	1,775	4,501	13,506	4,135	2,907	26,824	44,232
Symposia	40,463	—	—	—	—	40,463	—
Occupancy costs, including utilities	3,425	8,474	27,789	9,770	6,301	55,759	54,181
Depreciation	1,585	3,920	12,857	4,520	2,915	25,797	19,388
Miscellaneous	6,402	14,556	82,771	15,964	16,173	135,866	56,547
Direct grants	—	—	165,665	—	—	165,665	400,175
<b>Total expenses</b>	<b>\$ 107,877</b>	<b>\$ 319,152</b>	<b>\$ 800,220</b>	<b>\$ 167,898</b>	<b>\$ 221,380</b>	<b>\$ 1,616,527</b>	<b>\$ 1,493,353</b>
Management and general expenses						\$ 167,898	\$ 140,015
Fund-raising and development expenses						221,380	197,637
<b>Total management and general, and fund-raising and development expenses</b>						<b>389,278</b>	<b>337,652</b>
<b>Total support and revenue</b>						<b>\$ 1,863,105</b>	<b>\$ 1,758,574</b>
<b>Supporting services ratio</b>						<b>20.89%</b>	<b>19.20%</b>

See notes to financial statements.

# Statement of Cash Flows

Year Ended December 31, 2000

(With Comparative Totals for Year Ended December 31, 1999)

	2000	1999
<b>Cash flows from operating activities</b>		
Increase in net assets	\$ 245,820	\$ 265,221
Adjustments to reconcile increase in net assets to net cash provided by operating activities:		
Depreciation	25,797	19,388
Loss on disposal of assets	758	—
(Increase) decrease in operating assets:		
Pledges and other receivables	(26,972)	939
Inventories	(8,757)	8,469
Prepaid expenses	5,501	(3,771)
Increase (decrease) in operating liabilities:		
Accounts payable	(80,753)	165,152
Accrued payroll and payroll taxes withheld	12,270	19,638
Unearned dues revenues	(17,818)	(15,606)
<b>Net cash provided by operating activities</b>	<b>155,846</b>	<b>459,430</b>
<b>Cash flows from investing activities</b>		
Proceeds from sale of equipment	—	450
Purchases of property and equipment	(33,556)	(30,487)
<b>Net cash used by investing activities</b>	<b>(33,556)</b>	<b>(30,037)</b>
<b>Net increase in cash and cash equivalents</b>	<b>122,290</b>	<b>429,393</b>
<b>Cash and cash equivalents</b>		
Beginning of year	1,018,230	588,837
End of year	\$ 1,140,520	\$ 1,018,230

See notes to financial statements.

# Notes to Financial Statements

December 31, 2000

## 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, and sales of educational materials.

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

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

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

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

*Unrestricted net assets* are those currently available for use in the day-to-day operations of the Association and those resources invested in property and equipment. It is the policy of the Board of Directors to review its plans for future expansion and other future monetary requirements. From time-to-time, the Board of Directors will designate appropriate sums to

assure adequate funds are available to assist in those estimated future monetary requirements. Such amounts are presented as designated net assets in the statement of financial position.

*Temporarily restricted net assets* are those stipulated by donors for specific operating purposes.

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

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

**Donated services and assets** The Association periodically receives donated services for certain functions and donated assets. The assets are stated at their fair market value at time of donation. No amounts have been reflected in the financial statements for the services since they do not meet the criteria for recognition under SFAS No. 116, Accounting for Contributions Received and Contributions Made.

**Revenue recognition** Membership dues are recognized as revenue over the applicable membership period. The Association waives membership dues for individuals experiencing financial hardships. All contributions are recognized as revenue when cash payments are received, except for pledges, which are recognized as revenue at the time the pledge is received. Grants are recognized as revenue when the Association is notified of the award of the grant.

**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 CFIDS researchers and clinicians. Because these grants are contingent upon research contributions received and the Association's cash flow, these grants are not recognized as expenditures until payment occurs (See Note 4).

**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 2000 are listed below. The majority of the Association's public policy expenses are incurred in its monitoring of federal agencies, not on lobbying for specific legislation.

	<u>Allowable</u>	<u>Actual</u>
Direct Lobbying	\$ 226,739	\$ 59,776
Grassroots Lobbying	\$ 59,182	\$ 10,690

**Estimates** The preparation of financial statements in conformity with generally accepted accounting principles 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 generally accepted accounting principles. Accordingly, such information should be read in conjunction with the Association's financial statements for the year ended December 31, 1999, from which the summarized information was derived. Certain information reported in the comparative totals for 1999 has been reclassified in order to conform to the 2000 presentation.

### Note 2 — Temporarily restricted net assets

**Temporarily restricted net assets are available for the following purposes:**

Research grants	\$ 228,657
Educational activities	2,109
Public policy activities	<u>38</u>
	<u>\$ 230,804</u>

### Note 3 — Net assets released from restrictions

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

Purpose restrictions accomplished:	
Research grants and related expenditures	\$ 19,901
Educational activities	165,656
Public policy activities	<u>7,282</u>
<b>Total restrictions released</b>	<b><u>\$ 192,839</u></b>

### Note 4 — 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, 2000, the Executive Committee had not approved funding for any research projects.

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 and the Executive Branch, including federal governmental agencies, and performs public policy work for the Association including proposing strategies for advancing the goals of the Association, monitoring new developments and regulations related to

CFIDS, and preparing reports for public relations among other professional services. The total contractual obligation to The Sheridan Group for the year 2001 is \$199,980 payable in monthly installments. The services of The Sheridan Group in 2000 amounted to \$159,518.

In July 2000, the Association contracted with a provider of Internet consulting and development services for redesign of their website including front-end development and application development. The contract is not to exceed \$75,460 and should be completed by June 2001. As of December 31, 2000, the Association recorded expenses of \$55,050 relating to this contract.

### Note 5 — Leases

The Association leases office space used in its operations under an operating lease that expires in April 2002. The lease initially provides for a monthly rental of \$3,723 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, 2000:

<b>Year ending December 31</b>	
2001	\$ 57,073
2002	22,334
2003	<u>690</u>
	<b><u>\$ 80,097</u></b>

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 \$63,875 for the year ended December 31, 2000.

### Note 6 — 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 of public support for the year ended December 31, 2000.

### Note 7 — Income derived from funds by others

In December 1994, the Association made an irrevocable gift to the Foundation for the Carolinas in the amount of \$5,000. This gift was for the establishment of a permanent endowment fund, the earnings of which are for the benefit of the Association. The nature of this gift made necessary a change in the recognition of the endowment and the related earnings, which was made at December 31, 1996. Consequently, these funds are no longer reflected in the net assets of the Association. The balance of the Endowment as of December 31, 2000 was \$8,873, and the related earnings for the year then ended have been added to the principal of the Endowment at the election of the Association.

### Note 8 — Benefit plan

The Association has a 403(b) retirement plan in place covering substantially all employees meeting certain service and age requirements. This plan is a defined contribution plan with voluntary employee participation. During 2000, the Association made contributions into this plan amounting to \$16,789.

### Note 9 — Reclassifications

Certain temporarily restricted net assets as reflected on the 1999 financial statements (\$56,200) have been reclassified as designated unrestricted net assets.



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**Beth Levine**  
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**Adrienne Ryan**  
New York, N.Y.



**Charles McBrayer  
Sasser, JD**  
Charlotte, N.C.

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Patti Schmidt, Chairman

#### Long-Range Strategic

#### Planning Committee

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Patti Schmidt, Chairman

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The CFIDS Association of America

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Association of America

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Policy Project Manager, The CFIDS  
Association of America

Gail Herzenberg, MPA, Health Research  
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University School of Medicine,  
Philadelphia, Pa.

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

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

The CFIDS Association of America, Inc., a 501(c)(3) tax-exempt organization incorporated by the laws of the State of North Carolina. Federal Tax Identification Number 56-1683450.

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

The CFIDS Association of America  
PO Box 220398  
Charlotte, NC 28222-0398  
Tel.: 704/364-0466  
Fax: 704/365-9755  
E-mail: [jldavis@cfids.org](mailto:jldavis@cfids.org)

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

## Leaving a Legacy

A bequest in your will or trust is a meaningful, yet easy way to make a legacy gift in support of The CFIDS Association of America's efforts to conquer chronic fatigue and immune dysfunction syndrome (CFIDS). As with gifts of cash and appreciated securities, a bequest may be earmarked for the Association's education, public policy and/or research programs or for The CFIDS Endowment Fund. Your bequest may also enable you to enjoy a number of tax-saving benefits.

## Crafting a Tribute

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

## Shaping the Future

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

## 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 (M.E.).

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

Since its founding in 1987, The CFIDS Association of America has invested over \$12 million in CFIDS education, public policy, and research programs in its efforts to bring an end to the suffering caused by CFIDS.

The Association wages battle against CFIDS on five important fronts:

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

Through these and all its efforts, The CFIDS Association of America strives to eradicate CFIDS.

The Association is governed by an elected Board of Directors comprised of dedicated men and women who volunteer their time, knowledge, and breadth of experience to help advance the campaign to conquer CFIDS.

**The CFIDS Association of America, Inc.**  
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