

The Promise of Tomorrow



If not us,  
**who?**

If not now,  
**when?**

# The Promise of Tomorrow

As the largest and most active CFS organization in the world, the CFIDS Association of America works tirelessly to fulfill our simple but powerful mission: *To conquer CFS.*

Founded in 1987, the CFIDS Association of America is a national, voluntary nonprofit health organization which depends heavily upon individual gifts to serve the CFS community. In fact, excluding government grants for specific awareness-building projects, **gifts from individual donors comprised 87% of the Association's operating income in 2007.** Membership dues remain an important but small source of revenue, but cover only the costs of producing the quarterly magazine, the *CFIDS Chronicle*.

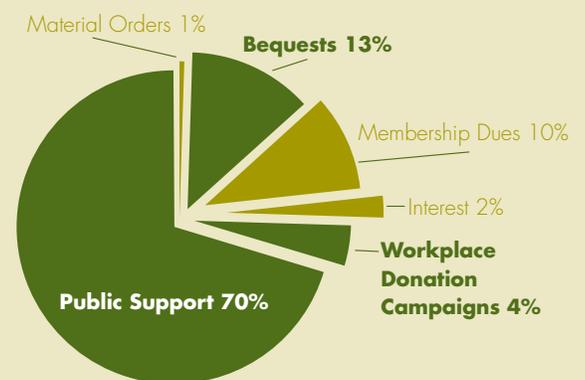
While accelerating the scientific investigation into the causes of CFS, the Association actively pursues its other core programs of public policy advocacy, public awareness and education, provider education and patient support.

For example, in 2007 the Association has...

- Sent the traveling photo exhibit, "The Faces of Chronic Fatigue Syndrome," to 14 consumer venues and 4 medical conferences in more than a dozen cities in the United States. Estimated traffic figures provided by these venues indicate that as many as 5.1 million consumers and 14,000 health care providers were exposed *directly* to the photo exhibit.
- Held three more Education and Empowerment ("kNOw MORE CFS") seminars in New Brunswick, New Jersey, Houston, Texas and Denver, Colorado for patients and caregivers, bringing the series total to six.
- Distributed more than 82,000 sheets from the CFS Toolkit for Health Care Professionals to doctors and other providers across the country, educating them about diagnosing and managing chronic fatigue syndrome.
- Produced 12 *CFIDSLink* online newsletters, published four issues of the *CFIDS Chronicle* and a commemorative magazine, *Defining Moments: 20 Years of Making CFS History*, and maintained an active website, [www.cfids.org](http://www.cfids.org), visited an average of 98,000 times per month.

## 2007 Sources of Revenue

Excluding government grants for specific projects



*"(After getting sick in 1977) I've been fortunate to earn a living and even put together a shadow life. What that allowed me to do is to have the resources to fight CFS through you. What the Association has been able to accomplish makes me feel like I am giving to the right people. This is how I am part of the fight."*

– Hal Rubinstein, Pittsburgh, PA

*"Having CFS is a heartbreaking family legacy. It may be too late for some of us, but we can do better for our kids and for our grandkids. That's why I give."*  
 – Julia Kelly, Albuquerque, NM



*"I first became ill in 1983. (Except for one brief period of recovery) I have been living with CFS ever since. That's not the same as being well, however, and I'm ever hopeful that research will eventually lead to significant breakthroughs...In the meantime, I support the CFIDS Association of America because they are the leaders in providing: 1) CFS education for patients, families and the medical community; 2) education and advocacy in the general media; 3) advocacy in Congress and the federal government and 4) funding for research. That's why I'm a member of the Chairman's Circle and why I'll make an additional unrestricted gift to further these very important activities that benefit all of us who live with CFS."*

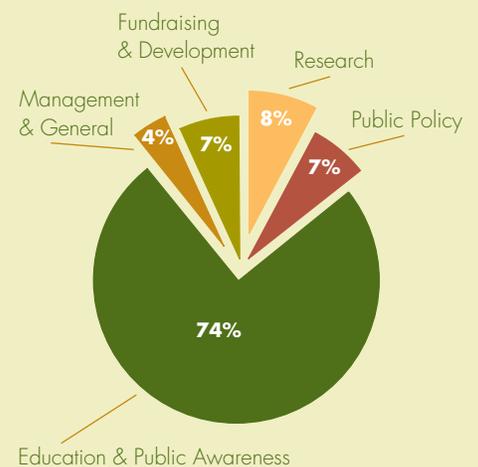
– Lisa Karpf, Long Beach, CA

- Generated more than 400 stories about CFS in the mainstream media, including stories in the *New York Times*, *Boston Globe*, *Washington Post*, *Arizona Republic*, *Philadelphia Tribune*, *Los Angeles Times* and Fox TV network. Stories also appeared in several national consumer magazines, including *Woman's Day*, *Parade*, *Fitness*, *Working Mother*, *First for Women*, *Prevention*, *Consumer Reports on Health and Remedy*.

- Garnered 9,346 more plays of the television public service announcement (PSA), bringing the total number of plays so far during the public awareness campaign to 12,478 TV and 24,898 radio PSAs. This is more than \$2.2 million in free commercial airtime for CFS.
- Generated journal articles in the medical press including coverage of CFS in the *ACP Observer*, *OB.GYN News*, *Arthritis Today*, the *AMA's Morning Rounds*, *Arthritis Practitioner* and other journals and newsletters. Outreach to medical and health care organizations also resulted in updated information about CFS being posted on WebMD, the Mayo Clinic website, the Department of Health and Human Services National Women's Health Center online newsletter, *MedicalNewsToday.com* and other key medical websites for consumers.
- Sought educational opportunities with a major focus on medical schools with top-rated family medicine programs, resulting in a total of 22 presentations provided for 10 universities/sponsoring institutions, reaching a mixed audience of more than 1,142 students, faculty and clinical professionals.
- Facilitated 6,000 contacts to lawmakers, policymakers and media contacts on CFS matter through the Grassroots Action Center during the 2007 4<sup>th</sup> Annual Virtual Lobby Day.
- Fielded an average of 600 e-mail and 125 telephone inquiries per month from CFS patients and others seeking information about the illness, including those recently diagnosed.
- Mailed thousands of free brochures and packets to CFS patients on topics such as choosing a doctor, finding a support group, qualifying for Social Security disability and dealing with pediatric CFS.

And the list goes on and on.

**2007 Use of Funds**



## HOW DO THESE ACTIVITIES BENEFIT YOU?

When your doctor researches CFS either online or on paper, it's likely he or she accesses information developed by the federal Centers for Disease Control and Prevention (CDC) and the Association.

When you learn about new treatment options or gain insights on how to cope with some of your symptoms, chances are you learned it from material developed by the Association.

When a friend or family member has an "Aha!" moment about your illness, chances are he or she gained new appreciation from an article or interview orchestrated by the Association.

When you see an ad in a magazine about CFS, or hear of a new CFS study being supported by the National Institutes of Health, or read testimony given to an official CFS watchdog committee on Capitol Hill, it's the result of advocacy efforts in Washington by the Association.

When you need the support of other people who understand what you're going through, chances are you call on the Association.

When you want to feel empowered, to feel that you're not alone in your struggle, to feel that there is promise that we *will find new cures and will conquer CFS*, chances are you reach out to the Association.

*"Having ME/CFS is such an isolating, life changing, and demoralizing experience. Finding others who understand its depths can be difficult. The CFIDS Association of America did that for me. I was no longer alone in this fight. The Association gave me hope. I want them to be there for other patients. That is why I donate."*

– Sister Sandra Duma, Frankfort, IL

*"I donate to the CFIDS Association because every dollar given means we are one step closer to a cure. We must support the Association that tirelessly supports us."*

--Christine Atherton, Arlington, VA

*"I give to CFIDS because I feel so helpless for my daughter, who has struggled with this disease that has robbed her of an abundant life since she was 13. She is now 26. By contributing to the CFIDS Association I'm helping raise awareness about the disease, educating the public and providing money for research which I hope will lead to a cure. In the early days of dealing with her CFS we had to battle with doctors to get them to even admit that it was a real disease and not a psychological problem. I would do anything to help my daughter."*

--Janet Aylsworth, Sugar Land, TX

## RESEARCH REPORT CARD

*"CFS hollows out a person. (She) looks just fine from the outside, but inside she is battered and hurting. As the father of a young CFS patient, it is maddening and incredibly frustrating to see her restricted and tied down in this way. At a time of life that should be full of energy, exploration, spontaneity, (my daughter) is instead severely limited... I don't have a lot of money to give, but when I do, I give out of anger and frustration. I also give with the expectation that we can get the ball rolling and build a lot more momentum towards understanding CFS and, eventually, cures."*

– Jia Shu, San Marino, CA

*I am one of the lucky ones with this disease who is able to work, so I feel it is important for me to be a voice for those of us who are too weak to speak. I donate because I believe in the mission of the CFIDS Association.*

– Alyson Butcher, Houston, TX



**The Campaign to Accelerate CFS Research**

is the biggest single fundraising campaign ever undertaken by the CFIDS Association of America. Literally hundreds of individual donors will support this effort, making it the first time a non-government entity has ever pumped \$1 million into CFS research in one year.

**At the top of the agenda we plan to seed several new laboratory and clinical studies.**

Our aim is to advance the discovery of biomarkers and methods for early detection, objective diagnosis and effective treatment of CFS.

In preparation of the 2008 research grant cycle, the Association overhauled its application process and made the competition for grants tighter and more robust. The Association's Executive Committee will make the final decisions based on scientific merit, strategic factors and the amount of funds available. Watch for an announcement of these grants in the fall of 2008.

**And that's just the beginning.**

Parallel to the grant-making process, the Association is doing much more to bring about meaningful progress in other ways. Under the expert guidance of our scientific director, Dr. Suzanne Vernon, an experienced CFS researcher with a PhD in microbiology, the CFIDS Association is taking the lead to...

- Foster new collaborations among investigators and other potential funding sources.
- Capitalize on the minds and discoveries of gifted scientists in other fields of medical research.
- Recruit new investigators to the CFS field.
- Promote regular, vigorous communication within the scientific community to maximize results.

In short, through this comprehensive approach the Association is "connecting the dots" in the field of CFS research **worldwide**, and improving scientific citizenship to accelerate the quest for answers. No other organization in the world is serving the CFS community in this vital capacity.

The \$1 million raised through **The Campaign to Accelerate CFS Research** will be earmarked specifically for our **research** program; none of those funds may be spent for any other purpose.

This million-dollar milestone is not an endpoint by any means. But it can be a springboard to boost the Association's other services to the CFS community – and to renew hope.

**We're committed to finding cures. The momentum is building!**



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The CFIDS Association of America, Inc., is a national nonprofit health agency.

Support for its work comes primarily from donations from individuals like you.

Gifts are fully deductible for tax purposes.

*Parting thoughts...*

*Bequests are often an overlooked way to support the causes which matter to you the most, and yet many Americans die without a will – the most important document you'll probably ever make. A will assures that your assets are disbursed according to your wishes, and can save your estate a significant amount of taxes. Consult with an attorney, accountant or other legal advisor on a plan that's right for you.*

*You may also want to consider a gift of stock. Please call the Association's Director of Development at 704-364-0016, ext. 101, for transfer details.*

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