

The Promise of Tomorrow



If not us,
who?

If not now,
when?

A request from Jennie Spotila, J.D., Chairman
Board of Directors, The CFIDS Association of America



What a *promising* time to be a part of the Association.

This year we've focused our energy on research. With the help of the CFS community, **The Campaign to Accelerate CFS Research** has been a resounding success. Thank you! As a result the Association is poised to propel CFS discovery to the next level. *Read a "report card" on accomplishments in research elsewhere in this booklet.*

But as a national nonprofit health organization, the CFIDS Association of America serves you and members of the CFS community in so many other ways besides research – through public awareness and education, policy advocacy in Washington, provider education, and patient education and support.

These services are not possible without the ongoing financial commitment of donors like you.

Unrestricted gifts enable the Association to provide all these services, which impact everyone in the CFS community.

In fact, last year **gifts from individual donors like you made up 87% of our income** (excluding government grants for specific awareness-building projects). Membership dues represent only a fraction of our budget, and primarily cover the costs of producing our quarterly magazine, the *CFIDS Chronicle*.

That's why I'm appealing to you today – to ask you to make a generous gift so we can continue our fight to conquer this debilitating illness. So we can maintain hope. So we can realize **The Promise of Tomorrow.**

Because of the CFIDS Association of America, you're not alone.

I should know; I have CFS. This illness ended my career and left me unable to earn a living. Like you, I'm depending upon the Association to lead me to the day when I get my health back.

*"(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

The Promise of Tomorrow
THE CFIDS ASSOCIATION'S
2008 ANNUAL FUND DRIVE

*If not us, **who?** If not now, **when?***

A request from Jennie Spotila, J.D., continued

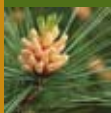
As chairman of the Board, I can say without qualification that the Association is in the best position to accomplish this goal for me and the four million other Americans who suffer from CFS. We shall settle for nothing less.

The CFIDS Association has the professional expertise and the dedication. We now need your unrestricted gifts to continue our vital work. *The section titled "Where Your Money Goes" on the next page lists some of the ways the Association serves your interests.*

As a CFS patient since 1994, I know that NOW is the time to propel **all** of our programs forward. The research campaign has proven that the CFS community *can* stretch itself and succeed. With your gift today, **we have the opportunity to build the same unprecedented momentum in other areas that we're creating in research.**

"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

By raising \$750,000 in unrestricted money by December 31, we – all of us in the CFS community – can do just that. Ambitious? You bet, but don't we all want...

- Our friends to understand and empathize with our condition?
- Wider public understanding about CFS?
- More government funding for CFS research?
- More physicians with the knowledge and compassion to treat CFS?
- Our good health – our lives – back?

Therefore, I'm asking you to join me and the Board of Directors in making a gift to the CFIDS Association of America. Please fill out the enclosed reply card or donate at www.cfids.org today.

There's new energy surrounding this cause. We're stepping up the pace for answers. We CAN keep **The Promise of Tomorrow** – restored health for all of us who suffer with CFS every day.

If not us, who? With our tax-deductible gifts, regardless of their amount, we're investing in a future free of CFS. When we contribute to this cause, we're *empowered*. We're not waiting for anyone else to fix it.

If not now, when? Only with your gift to the CFIDS Association right now can we keep up the momentum and serve the increasing needs of CFS patients.

Thank you for sharing this vision – and for your generosity. My fellow directors and I are deeply grateful for your faith in our stewardship.

Jennie Spotila, J.D.

P.S. You might want to consider enrolling in the Chairman's Circle, the Association's monthly giving program. It's easy: On the enclosed reply card or at the Chairman's Circle secure page at www.cfids.org, simply authorize a fixed amount to be drafted from your bank account each month. I've found it's an ideal way to spread my gift over the entire year and help provide the Association with a steady source of operating funds.

Where Your Money Goes

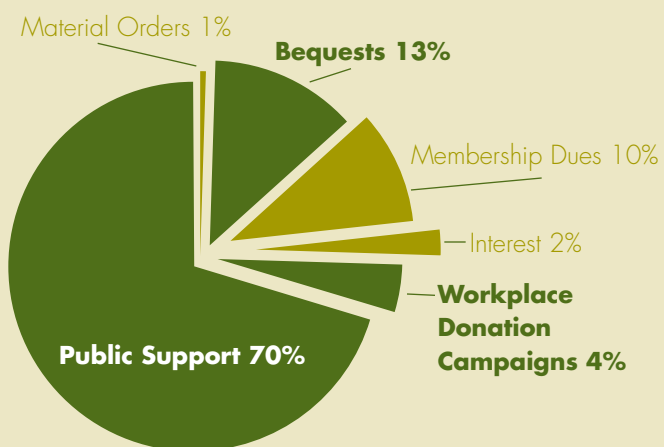
As the largest and most active CFS organization in the world, the CFIDS Association of America works tirelessly to fulfill our simple but powerful mission: *To conquer CFS.*

Founded in 1987, the CFIDS Association of America is a national, voluntary nonprofit health organization that depends heavily upon individual gifts to serve the CFS community. In fact, excluding government grants for specific awareness-building projects, **in 2007 gifts from individual donors like you combined for a total of 87% of the Association's program support.** Membership dues remain an important but small source of revenue, covering 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.

2007 Sources of Revenue

Excluding government grants for specific projects



"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

For example, in the last 12 months the Association has...



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

- Held a congressional briefing to deepen legislative staff members' appreciation for the scientific opportunity in the field of CFS research and impress on them the burden of illness represented by CFS on the individual, the community and the nation.
- Sent the traveling photo exhibit, "The Faces of Chronic Fatigue Syndrome," to 17 more cities, bringing the total number of venues so far to 38.
- Held two more Education and Empowerment ("kNOw MORE CFS") seminars in Denver and Tampa for patients and caregivers, bringing the series total to eight.
- Distributed more than 95,000 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, visited an average of 98,000 times per month.
- Generated more than 400 stories about CFS in the mainstream media, including stories in the *New York Times*, *Arizona Republic*, *Philadelphia Tribune*, *Los Angeles Times* and Fox TV network.

Where Your Money Goes, continued

- Garnered 4,781 more plays of the television public service announcement (PSA), bringing the total number of plays so far during the public awareness campaign to 14,091 TV and 25,093 radio PSAs. This is more than \$2.3 million in free commercial airtime for CFS.
- Generated journal articles in the medical press, including coverage of CFS in the *Journal of the Academy of Physician Assistants*, *Clinical Advisor*, *Arthritis Practitioner* and *Cortlandt Forum*.
- Facilitated 4,045 contacts to lawmakers, policymakers and media contacts on CFS matters through the Grassroots Action Center during the 2008 5th 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.
- Held a free online webinar, "The Science of CFS, Past, Present and Future," conducted by our scientific director and President & CEO Kim McCleary. The presentation was later posted on the Association's

website and may be downloaded by going to <http://www.cfids.org/webinar/sciencecfs-video.asp>.

And the list goes on and on.

"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

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 this 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.

Your gift, regardless of the amount, matters. Please give generously today!

"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



The Campaign to Accelerate CFS Research was the biggest single fundraising campaign ever undertaken by the CFIDS Association of America. By the time you read this message, we expect to have reached our groundbreaking \$1 million goal.

We couldn't have accomplished this milestone without gifts from donors like YOU. To all of you, our most profound thanks.

Literally hundreds of individual donors supported this effort, making it the first time a nongovernment entity has ever pledged \$1 million for an expanded CFS research program 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.

This year the Association overhauled its application process and made the competition for grants tighter and more robust. Twenty-one detailed proposals are now under peer review. 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 later this fall.

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 has taken the lead to...

- Foster new collaborations among investigators and other potential funding sources. Several of the proposals we received represent new mini-research networks, leveraging talent and discovery in new ways.

- Capitalize on the minds and discoveries of gifted scientists in other fields of medical research. For example, we have engaged 44 scientists from around the world from diverse disciplines to help evaluate the research proposals, bringing them closer to the CFS field.
- Recruit new investigators to the CFS field. Ten of the 21 – half of the – principal investigators who submitted proposals are experienced researchers making their first application for CFS funding.
- Promote regular, vigorous communication within the scientific community to maximize results. For example, earlier this month the Association co-sponsored a conference in Okinawa, Japan, where 300 investigators from throughout the world gathered to discuss the science of fatigue and CFS.

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** has been 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!

*"For me to support an organization, I need to know that it is not only on the front lines of the medical issues surrounding CFIDS, but that it is also on the front line of the **social/emotional** issues that affect us, because the emotional fall-out of this disease is just as harmful physically as the disease itself. While my greatest anchor is my faith, the CFIDS Association has become an important anchor because it has opened up to the public new paths for **learning, for discussion, and on the most basic level, for becoming acquainted with the harsh reality of CFIDS.**"*

– Evelyn Walpus, Temple City, CA



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2008 ANNUAL FUND DRIVE

*If not us, **who?** If not now, **when?***

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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