

With improved public and media awareness of CFS and promising research advances on many fronts, now is the time to spur scientific progress that will translate to better care for CFS patients.

Accelerating Research: Our Future

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AT-A-GLANCE ►►

- **The CFIDS Association has launched a campaign to raise \$1 million for CFS research by the end of 2008.**
- **In March a Request for Applications (RFA) went out to 500 researchers, soliciting proposals for studies that will advance the discovery of biomarkers and methods for early detection, objective diagnosis and effective treatment.**
- **The Association plans to fund more studies, increase collaboration among researchers and advocate for better government funding and policies.**

The search for answers to basic questions about CFS has lasted more than 20 years. What causes CFS? How can it be objectively diagnosed? How can it be effectively treated? When will it be cured? How can it be prevented?

CFS researchers—a growing group of committed investigators from around the world—have made scientific progress over the past two decades. We know quite a lot about the body systems CFS affects and some of the complex biologic mechanisms involved in the illness. But answers to the basic questions above still elude us. CFS patients, like my daughter, await healthier days and fuller lives.

Since its inception in 1987, the CFIDS Association of America has supported CFS research, continuously seeking the routes most likely to accelerate progress and strategically applying our efforts there (see story on page 14). At the same time, we've advanced public policy, educated health care professionals and the media, and kept CFS in the public spotlight.

Now, with public awareness about the illness at an all-time high and advances in research technology offering a broad array of possibilities, we must apply leverage to move into a new era of scientific progress on CFS. And the Association is ready and uniquely qualified to be that force. That's why we've launched *The Campaign to Accelerate CFS Research* and set an unprecedented \$1 million fundraising goal for 2008.

This marks the largest independent initiative ever undertaken by the Association—and the largest, most concentrated effort ever undertaken by a nongovernmental entity to discover biomarkers, diagnostics and treatments for this illness.

If not us, who?

Since the beginning, the CFS community has brought about its own change—funded research initiatives, formed support groups, defined policy priorities. Noted CFS physician Dr. David Bell has said, “Nearly everything good

that has come to people with CFS has come via the support of the community.” As a result of its full engagement on all these fronts, the community has become a knowledgeable and powerful force.

The CFIDS Association has been on the leading edge of change in many of these areas, particularly at the national level.

Driven by the mission to conquer chronic fatigue syndrome, the CFIDS Association has grown to be the world’s largest and most active nonprofit organization dedicated to this cause. With 21 years of continuous service to the CFS community, a visionary Board of Directors and the recent addition of a full-time scientific director to our seasoned staff, we can leverage our experience, our relationships and our collective knowledge to propel the CFS research field to the next level.

Put simply, the CFIDS Association is in the best position to be *the* catalyst for scientific advances that translate into better care for CFS patients. With your help, we believe we can change the pace of progress. We can accelerate CFS research.

What’s the plan?

Only through a multifaceted strategy will we build the scientific momentum necessary to transform CFS into a condition that is treatable, preventable and curable.

That means providing more funding for high-quality CFS studies, fostering increased collaboration among CFS researchers and pushing the federal government to make CFS a greater priority.

The Association issued a Request for Applications (RFA) on March 3, 2008, to nearly 500 researchers. To increase visibility for CFS and expand the pool of applicants, the announcement was also posted to *Science* magazine’s website. The first in a series, this RFA solicited research proposals for studies that will advance the discovery of biomarkers and methods for early detection, objective diagnosis and effective treatment. Proposals meeting rigorous review standards will be granted awards this fall based on scientific merit and strategic importance. Donations permitting, we expect to support six to eight new studies,

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closely monitoring progress and tracking performance of the investigators we fund. In the end, we will fund as many well-designed, pertinent research proposals as we can with the funds available; the more support we receive, the more promising studies we can green-light.

Concurrent with the exacting grantmaking process, the Association is leading activities to foster meaningful progress in other ways. Under the expert guidance of our scientific director, Dr. Suzanne Vernon, a CFS specialist with a PhD in microbiology, the Association is

- Encouraging the application of cutting-edge technology to analyze existing data in new ways;
- Fostering collaborations among investigators and other potential funding sources;
- Drawing on the knowledge of gifted scientists in other fields of medical research;
- Recruiting new scientific talent to the CFS field;
- Aggressively promoting regular, vigorous communication within the scientific community to maximize results.

In short, we’re striving to build the capacity of the scientific community to fully understand this illness. Our goal is to translate current and future scientific findings into better diagnostics, better treatments and even cures—and to do so more quickly than the traditional pace of the past.

With a full-time scientific director on staff, the CFIDS Association is in a unique position to maintain a comprehensive overview of all aspects of the investigation into

The Campaign to **Accelerate****CFS**
Research*If not us, who?*
If not now, when?

THE CFIDS ASSOCIATION OF AMERICA

The CFIDS Association of America is absolutely committed to research that will reveal what causes CFS and how it can be treated and ultimately prevented or cured. But such an uncommon commitment takes an uncommon investment. We need your gift to succeed.

Use the envelope enclosed in this magazine to make your gift to support *The Campaign to Accelerate CFS Research*. To donate online, visit <https://secure.cfids.org>.

CFS—both in and out of the laboratory—and to “connect all the dots.” No other organization in the world is serving the field of CFS in this vital capacity.

If not now, when?

In many ways, events have been building to a point of convergence for the CFS community. Through years of advocacy this community, led by the CFIDS Association, has grown to be an effective health lobby—gaining supporters in Congress and helping to influence discussions about this illness. Public and media awareness of CFS is higher now than ever as a result of the national CFS public awareness campaign. And in the research arena, we’ve discovered key facts about how CFS affects the body, even as advances in technology are opening yet more doors of exploration. The time is right to try to initiate more rapid progress toward earlier diagnosis, more effective treatment and a cure.

We recognize our \$1 million fundraising goal is not an endpoint, and we will not discover all the answers to CFS in one year. Indeed, research will need to be a top priority into the foreseeable future. However, by raising \$1 million by the end of 2008, we hope to generate unprecedented momentum, marking the beginning of the end of this complex, debilitating illness. It’s a bold vision, but necessary if we expect to effect more rapid change.

Looking forward

The Campaign to Accelerate CFS Research is the most ambitious undertaking in the history of the CFIDS Association of America. In fact, we believe this watershed campaign will reshape the future and direction of CFS research and the Association itself. It’s a defining moment

in which circumstances have presented a purpose, time and vision for significantly improving the lives of the millions of patients and families that experience the devastating effects of this illness.

Personally, I can’t wait for the day when I no longer have reason to serve on the Association’s board because the organization has no need to exist. I look forward to the day when my daughter is out in the world, living a full life and pursuing her dreams. For me this is personal. It’s probably personal for you, too. We can make CFS history. If not us, who? If not now, when? ■

Bruce Allshouse is an experienced executive who is now the principal of a consulting firm that works with companies to plan and manage major strategic transitions. Bruce has served on the Association’s Board of Directors since 2005. Bruce’s adult daughter, Cari, has CFS.

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You can help. Donate now.