

# Fostering Research: Our Foundation

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One of the first tasks I was assigned when I joined the Association's staff 17 years ago was to assemble a set of policies to guide our research funding program. The assignment was prompted by the IRS, a condition of approval of our application for permanent tax-exempt status. The agency asked for documentation that we demonstrated reasonable care in making grants and following our grantees' progress. We formalized a Scientific Advisory Committee and modeled our grantmaking policies after those of the American Cancer Society and the American Foundation for AIDS Research. In response, the IRS approved our 501(c)(3) application late that year, 1991.

Since then, our research program has evolved considerably to meet the changing dynamics within the field of CFS and philanthropy in general. We've focused on different disciplines as ideas about the root(s) of CFS have expanded, and we've invested in building a more robust research field. We've also tightened our accountability measures to make sure we fund the best studies possible and that grantees make the most of our support. Here's a look at the stages of evolution of the Association's research program as we've sought the ways to best foster progress for people with CFS.

## Seeding the pioneers

In the earliest years, 1987-1989, the Association raised funds and distributed support for the clinicians who were seeing CFS patients. This handful of physicians was reviewing charts for commonalities and comparing test results in search of a common illness marker. Their case reports were often delivered at patient-sponsored conferences rather than through the peer-reviewed

**How does an organization support meaningful research in a complex field as it evolves over two decades? By adapting its strategies to maximize opportunities and fill voids.**

medical and scientific literature. Yet these reports caught the interest of a few virus hunters who began to engage in the search for a novel virus that might be causing CFS.

The influence of the discovery of HIV as the cause of AIDS was hard to ignore, and hopes were high that the same kind of progress could be made for CFS, even with just a handful of researchers. Ultimately, by 1995 support for these studies waned, with the researchers unable to show meaningful differences between the CFS cases they studied and results from healthy control subjects.

## Broadening the scope

Around this same time, high prevalence of orthostatic intolerance (poor blood pressure control during upright posture) in teens with CFS was being reported by researchers at Johns Hopkins University. This finding spurred interest from a whole new set of scientists and began studies of treatments to improve associated symptoms.

The Association joined the search and funded several new studies of the autonomic nervous system to complement those being supported by the National Institutes of Health (NIH) and other organizations. Although initial hopes that treatments like fludrocortisone or fluid-loading would be the "magic bullet" to relieve CFS didn't pan out, this approach to treatment has provided supportive therapy to many who experience dysautonomia associated with their CFS symptoms.

Perhaps as important, these studies also opened new avenues of investigation and promoted closer inspection of the relationship between abnormalities in the immune, autonomic nervous and endocrine systems.

## Bolstering the field

In late 1999 a peer review committee assembled by the Association reviewed the only four research grant proposals

Years of  
continuous  
research  
support: 22



Number of  
investigators  
supported:  
38

we received. Not one passed muster. The low number of applications submitted and the lack of scientific rigor among them raised strong concerns about the “potency” of the field. Instead of simply supporting less-than-credible requests just to maintain our active support of research, we decided it was time to take a different tack.

Over a period of 18 months, we organized a series of three scientific symposia, one focused on each of the three most promising areas of research—the autonomic nervous system, the HPA axis and the immune system. We asked experts from each of these fields who had little direct experience with CFS to hear the evidence from those who were CFS experts. In a “scientific court” format, this data was presented and challenged. Consensus papers were published after each symposium in the peer-reviewed journal *Neuroimmunomodulation*, documenting a kind of roadmap for the field.

In 2002 we issued a request for applications and hoped the scientific community would respond. In contrast to the 4 proposals received in 1999, we were delighted with 27 applications, many of which came from investigators new to the study of CFS.

### Supporting scientific diversity

In 2002 our policies were updated to reflect a more rigorous review process and stricter reporting requirements. We engaged a broader range of experts in helping evaluate the relatively large number of studies proposed. That year, funding for five new studies exploring diverse theories about CFS was approved. Over the next three years, more than a dozen new studies would be approved, many of them following the path laid by the symposia series, with some investigators attracting support from the NIH to expand their studies.

### Accelerating momentum

In early 2007 the growth of the field of CFS research was evident at the International Association of CFS/ME (IACFS/ME) biennial research conference held in Fort Lauderdale, Florida. Also evident was the complexity of the condition, revealed by the number and diversity of disciplines represented among those who presented data. The remarkable similarity of conclusions reached about CFS, regardless of discipline and body system studied, was evident too.

In light of this progress, it seemed a waste to allow another two years to pass waiting for the next IACFS/ME conference, for researchers to connect with one another and share data and ideas. We promptly sought ways to foster a more constant exchange of information and shape the next phase of research grantmaking to leverage the progress of the field. We also recognized that we needed more internal capacity at the Association to fully understand and communicate about the breadth of CFS studies being conducted worldwide.

From these needs, the concept of hiring a full-time, experienced scientific director was born. Support from benefactors was immediate, and within a few months we had recruited Suzanne Vernon, PhD, formerly of the CDC, to our staff.

*The Campaign to Accelerate CFS Research* was launched within days of Dr. Vernon’s November 1, 2007, start date, and now we’re two-thirds of the way to reaching the ambitious \$1 million fundraising goal for 2008. We’ve also issued our first international Request for Applications (RFA) and are now reviewing the dozens of letters of intent received from researchers; we’ve hosted meetings of investigators interested in forming mini-networks and we’ve visited with the large research group studying CFS in Japan.

To reflect the continued evolution of our research program and current trends in health nonprofits, we’ve again updated our research policies, tightening requirements for measurable outcomes and reinforcing accountability measures. This time we’ve looked to the myriad “venture philanthropy” organizations funding medical research to define our standards. The investigators whose studies are funded later this year—after our most rigorous application and review process yet—will help fulfill the promise of accelerated progress in the search for biomarkers, objective means of diagnosis and effective treatment. We’ve never been better positioned to achieve the mission of the CFIDS Association of America: to conquer CFS. ■



Total  
research  
funded  
to date:  
\$4.8 million