The CFIDS Association of America, Inc.

2011 ANNUAL REPORT

Dear Friend,

Many times over the 25-year history of the CFIDS Association of America we have shared news about new research grants funded under a traditional nonprofit model. We raised money from supporters, vetted various project proposals and then gave the money to someone else. Many times our hopes were realized, like with the last round of grants (2009–2010) that have already yielded nearly $5 million in follow-on funding, seven times the original grant award total. But we aren't satisfied with outcomes that don't have more immediate impact on patients' lives.

In February 2012 we announced the creation of the **Research Institute Without Walls** — representing a different way of working to accelerate the answers that will change patients' lives. Business as usual in research doesn't always work well for patients: the incentives and barriers in the system make it a slow, hard, frequently random process with no guarantee of results. The Association's approach with the Research Institute Without Walls systematically tears down each of those old walls, one by one:

Research Institute Without Walls

- It forces scientists to collaborate across disciplines, so that new insights are created. For example, the grant to Dr. Dane Cook is a collaboration arising from grants funded in 2009–10.
- It requires information sharing on a common platform, so that approved researchers can access information and make constructive use of it.
- It promotes the use of standard sampling methods and data standards, so that study findings "speak the same language" and are more comparable, better understood and more readily replicated.
- It harvests assets of the SolveCFS BioBank, a wealth of information and samples collected from well-characterized (rather than simply labeled) patients and healthy controls, so that researchers can test new hypotheses and validate past findings.
- It reflects projects chosen for strategic merit, not just scientific merit. Our intent is to drive progress toward disease-modifying treatment, rather than allowing the science to simply drift.
- It will leverage the powerful data mining system, LogosOmix, to scour the existing research literature to identify potential biomarkers to direct future research.

With the Research Institute Without Walls, the Association, our grantees and CFS patients and their families are all becoming partners in research. **Patient Participation** is fueling the Association's transformative research program through the SolveCFS BioBank and The Catalyst Fund.

To everyone — the 458 consented participants in the SolveCFS BioBank, the 2,032 donors to The Catalyst Fund, those who have shared links to our Research**1st** or Facebook posts, retweeted our messages or invited a friend to support the cause we share — we express our deepest, most sincere thanks for making this paradigm shift and active partnership possible.

Sincerely,

K. Kimberly McCleary
President & CEO
The CFIDS Association of America

Acceleration to Transformation

The CFIDS Association was founded in 1987 and our first dollar was invested in research. Over the first 20 years of service to the community, you helped us fund $4.6 million in research grants, host three research symposia and support numerous conferences and meetings. Over those first two decades, our approach to research followed a traditional model and the studies we funded contributed to a knowledge base of 4,000 small studies.

In 2007, we carefully evaluated the gaps and opportunities. Three important themes emerged from this review:

- The literature was essentially a collection of "one and done" studies with few attempts to validate early observations or extend findings. These had limited benefit for improving patient care.
- Studies were hampered by the use of multiple case definitions and the lack of standardized ways of collecting data about patients or samples from them.
- Research priorities were driven by "in vogue" hypotheses, with few organized efforts to connect the dots or link findings from one study to another.

We knew there was a better way to approach research, and so did you.

In 2008, we added a full-time scientific director, Suzanne D. Vernon, Ph.D., to our staff and we asked you to help us:

- fund innovative studies;
- leverage existing data;
- strengthen international collaborations;
- recruit new talent to the field; and
- expand communication among scientists to share ideas, knowledge and data.

You came through and helped us accelerate the pace of CFS research.

Now we want to transform it.

Over the next seven pages, we report on how we have delivered on the promises made in 2008 and what we propose to do next with your participation and support. It is an exciting and pivotal time, with many opportunities to seize. We hope you agree!

Returning On Your Investment

The research grants funded by the CFIDS Association of America in 2009–2010 supported six principal investigators and their projects that were evaluated to have the highest scientific and strategic merit among the 24 submitted during our 2008 cycle. Funding totaling $647,940 was awarded to support these research studies, thanks to the generosity of our donors.

Gordon Broderick, PhD of University of Alberta

Molecular patterns of persistent immune activation in a post-infectious adolescent cohort

Objective:

To use network analysis of gene expression and endocrine measures to identify biomarkers that describe the events from infectious mononucleosis (IM) to post-infection CFS.

Preliminary Outcomes:

Funding: Three new federal awards totaling more than $3.5 million

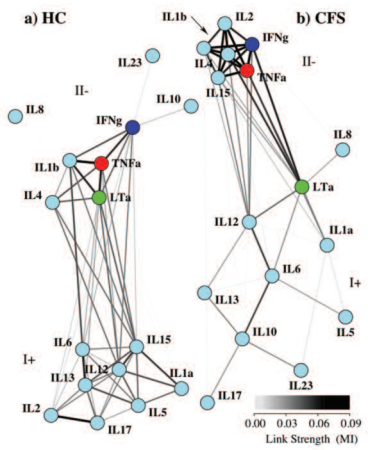
Publications:

- Cytokine expression as a potential prog-nostic indicator in post-infectious fatigue. *Cytokine*. 2010; 52(1–2): SS11–7,81.
- Plasma neuropeptide Y: a biomarker for symptom severity in CFS. *Behavioral and Brain Functions*. 2010 Dec 29;5:76.
- A pilot study of immune network remodeling under challenge in Gulf War illness. *Brain, Behavior and Immunity*. 2011 Feb; 25(2): 302–13.

"What has the Association's support meant to my group and our CFS research? So many things that it's actually difficult to put into words.

First and foremost, the Association has been and continues to be our essential portal to the patient population. The Association offers a clear rallying point around which researchers can congregate and begin to organize as a community. This is essential if we are to deploy a clear research strategy, one that avoids unnecessary duplication and maximizes the delivery of tangible results to the patient population and their families. Through the Association and its supporters, we are slowly becoming one much larger and much better coordinated virtual research laboratory, one with clear goals and where our roles and interactions as scientists, clinicians and educators are beginning to crystallize. This sense of community has been a vital motivator and has kept our group engaged and focused, enabling us to weather the criticism of more traditional academia and the comparatively barren funding landscape.

"All of this gives CFIDS Association funding a very special meaning. With every dollar being contributed by patients and their families, these projects represent a sacred trust if there ever were one. Looking back, the impact that these donations have



This figure shows the differences between "communication networks" of immune proteins in healthy controls (left) and CFS patients (right).

had is nothing short of inspiring. They have changed the research landscape for CFS. Key preliminary findings were made possible as a direct result of the patients, their families and the governance of the Association. In turn, these findings have given us a solid scientific beachhead from which to apply for much larger grants. Indeed, results generated with Association-directed patient donations have allowed us to leverage $125,000 in seed funding into three multi-year operating grants from the Department of Defense (DOD) and the National Institutes of Health (NIH) totaling over $3.5 million. None of this would have been possible without preliminary research supported by patient donations administered under the stewardship of the Association.

"Also important is the role of this funding in training future clinicians in an area of practice sorely lacking in first-line care providers. Through its support of summer studentships in our laboratory, the Association has contributed to the research training of five undergraduate medical students and two post-doctoral research staff in the endocrine and immune abnormalities associated with CFS. The medical students alone went on to publish three papers in well-respected scientific journals, with two more currently in preparation. Finally, and perhaps most importantly, these patient-funded seed projects are promoting important changes in government research policy, the inclusion of CFS as a research topic in the recent U.S. Department of Defense funding mechanisms being only one example."

Kathleen Light, PhD of University of Utah

Novel ion channel-based biomarkers in CFS

Objective:
Evaluate post-exercise increases in acid-sensing and ion channel receptors on blood cells.

Preliminary Outcomes:
Funding: Support from a pharmaceuticalcompany to conduct a treatment trial of FDA-approved medications. Supplemental support from organizations supporting MS and fibromyalgia research to include additional comparison groups. Several NIH applications are under review, one pending an award notice.

Publications:

- Moderate exercise increases expression for sensory, adrenergic and immune genes in CFS but not in normal subjects. *Journal of Pain*. 2009.
- Gene expression alterations at baseline following moderate exercise in patients with CFS and fibromyalgia syndrome. *Journal of Internal Medicine*. May 26, 2011.
- Evidence for a heritable predisposition to CFS. *BMC Neurology*. May 27, 2011.
- Additional manuscripts in preparation and under review.

"Support from the CFIDS Association for our research program on blood-based biomarkers of CFS/ME was vital in keeping this program alive. The data obtained using this support made it clear that we can use post-exertional gene expression for selected markers to differentiate patients with CFS from those with other disorders involving daily fatigue, like multiple sclerosis, as well as from healthy individuals. With this evidence in hand, we are also able to obtain a very strong review for our next grant application with NIH, which we expect to be funded in a few months; this new NIH R01 grant will assess whether our post-exertional biomarkers can differentiate CFS from clinical depression. Objective biomarkers for CFS will be valuable in diagnosis and to help individualize treatments for specific patients. Thank you to the CFIDS Association and its generous donors for this very important support."

Marvin Medow, MD of New York Medical College

Splanchnic vasoconstriction is impaired by microbiomic nitric oxide production reducing cerebral blood flow in CFS

Objective: To determine if upright posture causes neurocognitive deficits as a result of impaired cerebral blood flow and modulation of nitric oxide and reactive oxygen species.

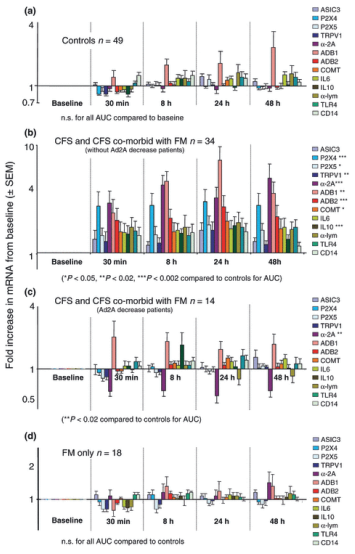
Preliminary Outcomes:
Funding: Application to NIH pending review.

Publications (selected):

- Decreased upright cerebral blood flow and cerebral autoregulation in normocapnic postural tachycardia syndrome. *AJP Heart and Circulatory Physiology*, 2009.
- Respiration drives phase synchronization between blood pressure and RR interval following loss of cardiovagal baroreflex during vasovagal syncope. *AJP Heart and Circulatory Physiology*. Nov. 12, 2010.

- Reactive oxygen species from NADPH and xanthine oxidase modulate the cutaneous local heating response in healthy humans. *Journal of Applied Physiology*. March 24, 2011.
- Cutaneous constitutive nitric oxide synthase activation in POTS with splanchnic hyperemia. *AJP Heart and Circulatory Physiology*. June 3, 2011.
- Increasing orthostatic stress impairs neurocognitive functioning in chronic fatigue and POTS and is not related to cerebral blood flow velocity. In preparation.
- Additional data being analyzed; manuscripts in preparation.

"In addition to the obvious benefits of receiving financial support from the CFIDS Association that helps to defray the cost of conducting research on CFS, my research has allowed me to interact with many CFS subjects during these studies, which has put a 'personal face' on this syndrome. This has increased my appreciation for the need to provide answers to the many unanswered questions about the cause of and the mechanisms that underlie symptoms of CFS. I have also enjoyed providing information about CFS through our scientific publications, and the webinars and scientific meetings arranged by the Association. Lastly, the interactions that I have had with other health care professionals I have met through the Association have provided useful insights into CFS beyond the scope of my own investigations."



This figure from the *Journal of Internal Medicine* compares gene expression increases following moderate exercise in patients with CFS and FM.

Bud Mishra, PhD of New York University School of Medicine

Translate science to a cure for CFIDS

Objective: To build a knowledgebase for CFS that combines published literature with experimental data.

Preliminary Outcomes:

Creation of a digital library of 250,000 full-text articles on CFS, 14 commonly co-occurring conditions of CFS and relevant biomedical literature to help decipher CFS pathophysiology.

Publications:

- Metamorphosis: the coming transformation of translational systems biology, *Queue*, 7(9):40–52, ACM, 2009.
- Reverse engineering dynamic temporal models of biological processes and their relationships, *Proceedings of the National Academy of Science*, 107(28): 12511–6, 2010.

"The main focus of this research program was to develop novel 'systems biological' tools focusing on understanding the causes of CFS. The NYU tools can be categorized into two groups: tools that generate novel hypotheses using data on how various genomics and related information vary over time and how they differ from patient and patient (the subject of a student's PhD thesis); and tools that filter known hypotheses about the progression of the disease by data-mining the published literature. By using principled and rigorous approaches, such tools identify causal bases of CFS that go beyond anecdotal explanations of the syndrome. Since the results can be visualized on a computer, researchers thus have the ability to further examine the most significant hypotheses carefully and design new studies. In this way, the NYU team's research has enabled the CFS community to move into the state-of-the-art genomics and systems biology arena, which would not have been possible without the Association's funding."

Sanjay Shukla, PhD of Marshfield Clinic Research Foundation

Metagenomics approach to study CFS patients

Objective:

Determine if there is an altered ratio of gut commensal and pathogenic bacteria in CFS and if exercise increases microbe translocation to cause post-exertion symptoms.

Preliminary Outcomes:

- Secured supplementary funding of from Univ. of Wisconsin-Madison to expand sample size.
- Study data is currently being analyzed and prepared for publication.

"I am really excited to explore the potential role of the gut microbiome in explaining some aspects of CFS and I thank the CFIDS Association for funding this exciting project. Several recent research studies have suggested a role for the gut microbiome in modulating chronic diseases from diabetes to obesity to ulcerative colitis. With awareness of those findings, I am really excited to explore the potential role of the gut microbiome, especially gut permeability, in explaining at least some aspects of CFS."

Dikoma Shungu, PhD of Weill Medical College of Cornell University

MR neuroimaging assessment of cerebral metabolic substrates and regional blood flow in CFS

Objective: Use magnetic resonance spectroscopy (MRS, an advanced MRI method) to measure specific brain chemicals. The investigators build upon preliminary evidence showing elevated lactate in CFS patients. Examine chemicals in blood and brain that are indicators of oxidative stress and mitochondrial dysfunction.

Preliminary Outcomes:

Funding: NIH award in collaboration with Benjamin Natelson, M.D., with total funding of $379,000. Another NIH application has been submitted.

Publications:

- Ventricular cerebrospinal fluid lactate is increased in chronic fatigue syndrome compared with generalized anxiety disorder: an in vivo 3.0 T (1)H MRS imaging study. *NMR in Biomedicine*. April 2009.
- Increased ventricular lactate in chronic fatigue syndrome measured by H MRS imaging at 3.0 T. II: comparison with major depressive disorder. *NMR in Biomedicine*. July 2010.

"As is amply clear, the continuing skepticism that CFS is not a 'real' disease will not abate until there is foolproof scientific evidence that this debilitating illness is a distinct medical entity with biological or organic causes. To achieve this objective will require funding of high-quality, groundbreaking research, which is scarce and dwindling. The largest source of medical research funding is the National Institutes of Health (NIH). However, because research funds are limited, it is nearly impossible to compete for NIH funding without having strong preliminary data that support the validity of new research ideas or hypotheses about a disease that one wishes to investigate. This even harder for CFS, which has no known causes. That is where small research funds that are provided by dedicated organizations like the CFIDS Association of America assume critical importance. With the support of the Association, my collaborators and I have been able to conduct small but high-quality and critically important pilot studies that have enabled us to test the validity of some of our ideas about the causes of CFS, and then to use the generated preliminary data to compete effectively for larger NIH grants to pursue those ideas. Case in point: using preliminary data obtained in a small pilot study supported by the Association, we submitted a grant application to the NIH to test ideas that could show that CFS was not a psychiatric disease, and were very recently informed that this application has been funded by the National Institute of Neurological Disorders and Stroke and the NIH Office of the Director, with total support of $379,000 for the collaborative effort led jointly by Dr. Benjamin Natelson at Beth Israel Medical Center and Dr. Nora Weiduschat in my laboratory at Weill Cornell. In addition, we just submitted another NIH grant application, based on data generated with funding from the Association, to test a drug that we postulate could alleviate some of the disability associated with CFS. In short, without the type of funding that caring organizations such as the Association can provide, high-quality research into the biological causes of CFS by dedicated researchers would be virtually impossible due to lack of federal support. We and all those affected by this illness owe the contributors to the Association's research funds a debt of gratitude." ■

10 Ways the Association Has Readied to Transform Research

1. We narrowed our focus to execute the following strategy: "To stimulate research aimed at the early detection, objective diagnosis and effective treatment of CFS through expanded public, private and commercial investment."
2. We deepened our expertise with the addition of a Scientific Advisory Board.
3. We have learned from and collaborated with other innovative organizations working to end suffering caused by common and rare diseases.
4. We developed a rigorous review process to select the strongest research proposals based on scientific and strategic merit.
5. We networked our funded investigators and required them to work together.
6. We worked closely with our grantees to ensure their projects yielded results.
7. We established a patient registry and biobank for clinical data and samples —the SolveCFS BioBank.
8. We conducted our first collaborative BioBank study and enrolled 458 active participants.
9. We engaged researchers, policy makers and patients around the world.
10. We have become the leading resource for credible research information.

Expanding Research:
Looking to the Future

The changes we've made over the past three years have transformed our organization and our approach to CFS research. The traditional model, marked by passive support of research grants, is appropriate for disease states for which there exist large government- and industry-supported research portfolios that can be augmented through private philanthropy. As you know, this is not the case for CFS.

To inform our transition beyond the traditional role, we have learned from other organizations that leverage their investment in research to get more from academia, government and industry. We have benefited tremendously from innovative research programs developed by the Myelin Repair Foundation (working on myelin repair therapies for M.S.), the Michael J. Fox Foundation (working for better therapies and a cure for Parkinson's disease), the Susan B. Love Army of Women (giving all women the opportunity to partner with researchers and take breast cancer beyond a cure), FasterCures (an "action tank" that works to improve the medical research system) and others.

Now, we look to the future and the opportunity to build on our dynamic program in four major areas by:

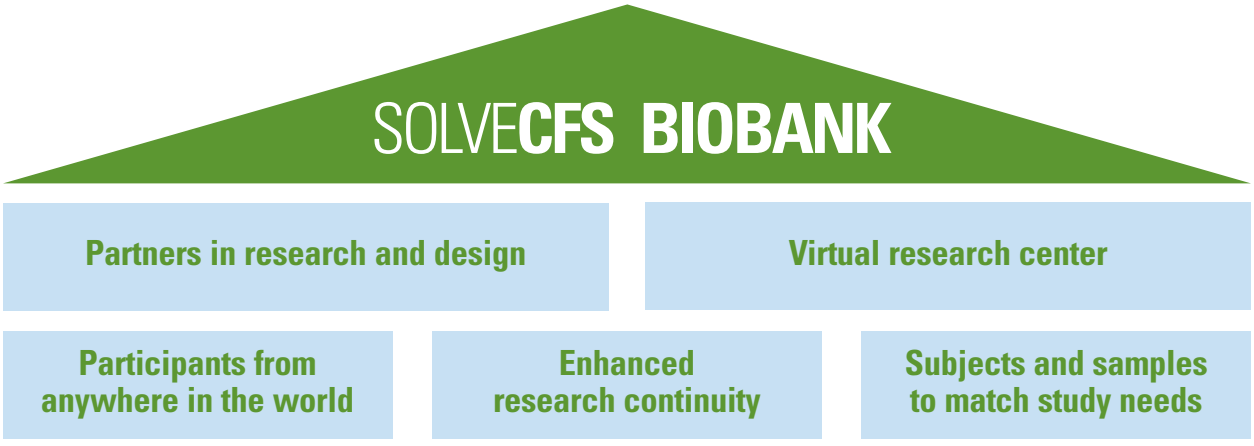
- Funding five **new grants** from our 2011 Request for Applications;
- building a larger, **more valuable SolveCFS BioBank**;
- developing a **biomarker "hit list"** to drive future research priorities; and
- **expanding collaborations** and networks of investigators working in the field.

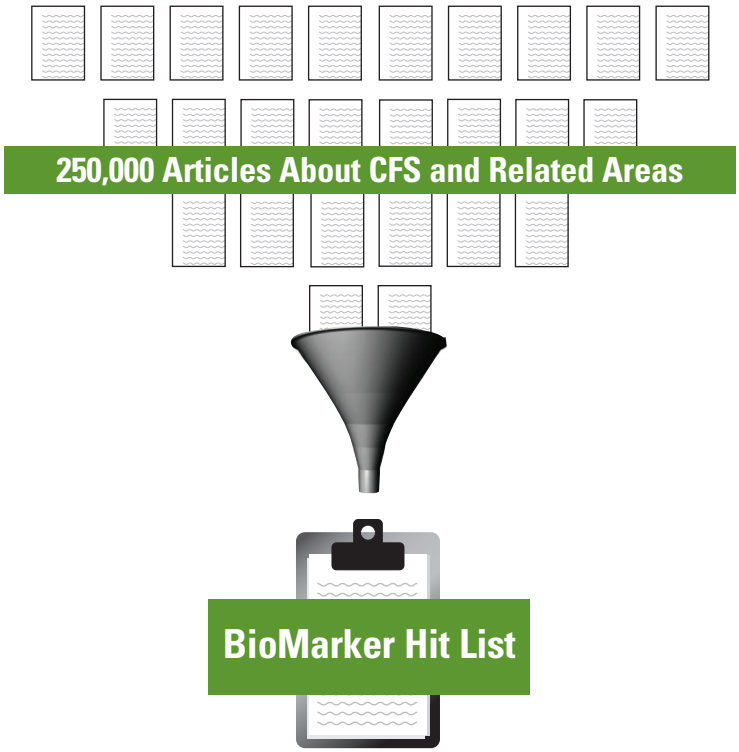
New Grants:

In April 2011, we widely circulated a new Request for Applications that generated 36 letters of intent. Full proposals were invited from 27 investigators with projects responsive to our emphasis on advancing objective diagnosis and effective treatment. All applicants (and their institutions) agreed to revised policies that strengthen the Association's data-sharing and intellectual property policies. Proposals were reviewed on two levels: 10 measures of scientific merit by peers in related disciplines, and nine measures of strategic merit judged by reviewers familiar with the CFS literature and the field. Five projects were selected for funding.

More Valuable BioBank:

In March 2010, we announced the launch of the SolveCFS BioBank, the first combined patient registry and biorepository of its kind. In its first 18 months of operation, the BioBank enrolled 449 participants (including well-characterized CFS patients and healthy controls) and we completed our first collaborative study. Results from that study are being analyzed and prepared for publication. We are now ready to expand the BioBank and can engage participants anywhere in the world, matching subjects and samples to the needs of individual investigators. BioBank participants contribute to multiple studies and form the basis of study by various investigators focusing on different aspects of CFS, creating a "virtual center" in which we are





partners in the design and conduct of research studies. Through the BioBank, we can deepen understanding of results obtained for individuals, subgroups and the population as a whole. It also helps provide continuity as individual investigators enter and exit the field.

Biomarker Hit List:

One of the products of the projects funded in 2009–2010 is the knowledgebase generated from 250,000 articles about CFS and related areas of science. Dr. Bud Mishra's team at New York University built this knowledgebase and the text mining tools that will enable us to use these assets to build a data-driven target list of biomarkers. We will then "shop" this list with academic centers and biotech companies to stimulate validation of these target biomarkers using samples from the BioBank or other clinical populations, accelerating the pace of moving from theoretical to practical applications for diagnostics and treatments.

Expanding Collaborations:

In 2009 we networked our funded investigators, bringing them together to discuss their study designs, data collection and subject recruitment — before their studies got started. The network was expanded to include NIH-funded investigators and has yielded new collaborations and greater sharing of resources, data and ideas. We are now working with NIH and several academic groups to establish a secure data-sharing platform and to standardize ways of defining cases and collecting and analyzing data to improve comparability of research across all settings and to provide a more formal infrastructure for collaboration and networking.

These new initiatives will truly transform the way that CFS research is conducted — not just for studies conducted with Association support, but for the field as a whole. This approach reflects an integrated strategy to overcome the barriers of the past and accelerate the pace of discovery and implementation for the future. ■

The CFIDS Association of America

BOARD OF DIRECTORS

Hi-Fi Sci-Di: Dr. Suzanne Vernon Orchestrates High-Fidelity Research

Our scientific director, Suzanne D. Vernon, PhD, has dedicated the majority of her professional career to studying CFS and bridging gaps in our scientific understanding of it. It's more than just an occupation for Suzanne, it's a personal passion. From the podium at scientific meetings to the steep and narrow trail at a 24-hour bike race organized to solve CFS, her leadership of the Association's research program is recognized and lauded by researcher-colleagues, patients and advocates alike. Here is a brief summary of some of ways in which Suzanne has been orchestrating transformation over the past year.

Sponsored Research Program

- Closely monitored grantees' performance milestones and outcomes.
- Developed and widely circulated new Request for Applications (RFA).
- Explored various data-sharing platforms and policies and other institutions' policies on intellectual property to foster discovery and development of promising findings.
- Reviewed Letters of Intent and issued invitations and declinations to investigators who submitted letters of intent.
- Distributed revised policies and addressed questions from invited applicants and their respective institutions.
- Recruited dozens of qualified reviewers to evaluate the scientific and strategic merit of proposals submitted by Sept. 30.

SolveCFS BioBank

- Oversaw the conversion of the collection of extensive medical history and clinical data from BioBank participants from a paper-based system to a secure online system.
- Completed the first collaborative study using BioBank resources, data for which is being analyzed and prepared for publication.
- Received two new applications to utilize BioBank resources; both were reviewed and approved by the Medical Research Advisory Committee.

Other Collaborations

- Served as a member of the NIH ME/CFS State of the Knowledge Workshop planning group. Participated in several group discussions as follow-up to the need for a centralized data-sharing platform.
- Participated in two XMRV-related working groups; CEO Kim McCleary participates in two other XMRV-related working groups.
- Consulted with a biotech company to develop a biomarker proposal in response to the Department of Defense Congressionally Directed Medical Research Program (CDMRP).
- Developed five research funding proposals submitted to other institutions, all of which are collaborations with other investigators and organizations.
- Helped identify clinical collaborators for a Phase II clinical trial of a promising therapy being planned by an academic center.
- Served as a peer-reviewer for several CFS-related grant applications and manuscripts.

Presentations and Meetings

- Participated in the meeting of collaborators for the study of XMRV being led by Dr. Ian Lipkin. (Dec. 20, 2010)
- Provided an overall summary of research, existing gaps, areas of agreement and needed next steps at the ME/CFS State of the Knowledge Workshop. (April 7–8)
- Delivered public testimony at the DHHS CFS Advisory Committee meeting, along with CEO Kim McCleary and Board members Jennifer M. Spotila, J.D., and Amy Squires. (May 10–11)
- Gave a presentation on CFS and chaired a session at the 6th Annual TMJ Association Scientific Meeting on Co-Morbid Conditions. (June 5–7)
- Spoke to participants, volunteers, donors and sponsors about CFS at the second annual 24 Hours in the Enchanted Forest. (June 17–19)
- Delivered three presentations on biobanking at the Genetic Alliance 25th Annual Conference. (June 23–26)
- Gave a series of presentations in Sweden, including a half-day seminar with other CFS experts at the Ministry of Health and a program for doctoral students at the University of Umea. (Aug. 22–26)
- Provided more than a dozen media interviews and authored numerous articles for Association publications. ■

The CFIDS Association of America, Inc.
Statement of Financial Position

For the Year Ended December 31, 2011 (with comparative totals for the year ended December 31, 2010)

	Year Ended December 31, 2011				Year Ended
	Unrestricted	Temporarily Restricted	Permanently Restricted	Totals	December 31, 2010
Assets					
Current assets					
Cash and cash equivalents	$ 967,493	$ 57,517	$ –	$ 1,025,010	$ 906,526
Contributions receivable	45,930	–	–	45,930	53,762
Pharmaceutical contract receivable	–	–	–	–	23,753
Other receivables	1,893	–	–	1,893	1,946
Inventories	706	–	–	706	418
Beneficial interest	–	6,631	5,400	12,031	12,462
Prepaid expenses	8,096	–	–	8,096	11,148
Total current assets	1,024,118	64,148	5,400	1,093,666	1,010,015
Property and equipment					
Office furniture and fixtures	77,642	–	–	77,642	89,466
Computers and related equipment	100,393	–	–	100,393	91,389
Leasehold improvements	25,872	–	–	25,872	25,872
	203,907	–	–	203,907	206,72
Less accumulated depreciation	(177,134)		–	(177,134)	(197,986)
Net property and equipment	26,773	–	–	26,773	8,741
Accumulated policy value of life insurance	–	13,149	–	13,149	13,592
Total assets	$ 1,050,891	$ 77,297	$ 5,400	$ 1,133,588	$ 1,032,348
Liabilities and Net Assets					
Current liabilities					
Accounts payable	$ 7,260	$ –	$ –	$ 7,260	$ 18,407
Accrued payroll expeses	21,438	–	–	21,438	23,324
Capital lease obligation, current	3,642	–	–	3,642	7,365
Total current liabilities	32,340	–	–	32,340	49,096
Other liabilities					
Capital lease obligation, noncurrent	21,358	–	–	21,358	1,227
Total liabilities	53,698	–	–	53,698	50,323
Net assets					
Unrestricted					
Undesignated	811,675	–	–	811,675	681,661
Designated	185,518	–	–	185,518	184,852
Total unrestricted	997,193	–	–	997,193	866,513
Temporarily restricted	–	77,297	–	77,297	110,112
Permanently restricted	–	–	5,400	5,400	5,400
Total net assets	997,193	77,297	5,400	1,079,890	982,025
Total liabilities and net assets	$ 1,050,891	$ 77,297	$ 5,400	$ 1,133,588	$ 1,032,348

The CFIDS Association of America, Inc.
Statement of Activities

For the Year Ended December 31, 2011 (with comparative totals for the year ended December 31, 2010)

	Year Ended December 31, 2011				Year Ended December 31, 2010
	Unrestricted	Temporarily Restricted	Permanently Restricted	Totals	
Support and revenues					
Public support:					
Contributions and grants	$ 1,089,380	$ 107,532	$ –	$ 1,196,911	$ 1,102,145
Federal funds:					
Government grants	–	–	–	–	142,428
Revenues:					
Pharmaceutical contracts	5,605	–	–	5,605	77,855
Research subcontracts	14,671	–	–	14,671	–
Educational material sales	1,449	–	–	1,449	2,404
Interest and other	1,275	–	–	1,275	3,053
	23,000	–	–	23,000	83,312
Net assets released from restrictions	140,348	(140,348)	–	–	–
Total support and revenues	1,252,728	(32,816)	–	1,219,911	1,327,885
Expenses					
Program services:					
Research	759,958	–	–	759,958	940,419
Public Policy	–	–	–	–	253,585
Communications	169,791	–	–	169,791	158,349
Supporting services:					
Management and general	58,276	–	–	58,276	72,916
Fund raising and development	131,620	–	–	131,620	148,904
Total program and supporting services expenses	1,119,645	–	–	1,119,645	1,574,173
Loss (gain) on assets disposed	2,401	–	–	2,401	–
Change in net assets	130,680	(32,816)	–	97,865	(246,288)
Net assets					
Beginning of year	866,513	110,112	5,400	982,025	1,228,313
End of year	$ 997,193	$ 77,297	$ 5,400	$ 1,079,890	$ 982,025

The CFIDS Association of America, Inc.
Statement of Functional Expenses

For the Year Ended December 31, 2011 (with comparative totals for the year ended December 31, 2010)

	Year Ended December 31, 2011					
	Program Services		Supporting Services			
	Research	Communications	Management and General	Fundraising and Development	Totals	Year Ended December 31, 2010
Contract services	$ 145,113	$ 47,745	$ 6,869	$ 18,096	$ 217,823	$ 327,648
Salaries and benefits	422,861	83,600	36,916	72,688	616,065	638,479
Payroll taxes	26,131	8,852	3,909	7,695	46,587	44,715
Printing and postage	7,865	5,480	240	9,624	23,209	32,002
Repairs and maintenance	1,691	573	252	498	3,014	3,928
Supplies	2,593	834	368	800	4,595	4,764
Educational materials cost of sales	–	546	–	–	546	882
Travel expenses	39,251	1,956	913	4,180	46,300	31,108
Event and exhibit fees	10,415	–	–	–	10,415	1,365
SolveCFS BioBank Costs	28,874	–	–	–	28,874	142,001
Insurance	3,531	1,196	528	1,040	6,295	6,086
Telephone	3,927	895	413	831	6,066	5,405
Occupancy costs	34,703	11,756	5,191	10,221	61,871	61,084
Depreciation	6,580	2,229	984	1,938	11,731	6,761
Miscellaneous	13,420	4,130	1,693	4,008	23,251	15,064
Direct grants	13,003	–	–	–	13,003	252,881
Total program and supporting services expenses	$ 759,958	$ 169,791	$ 58,276	$ 131,620	$ 1,119,645	$ 1,574,173
Management and general expenses					$ 58,276	$ 72,916
Fundraising and development expenses					131,620	148,904
Total management and general, and fundraising and development expenses					$ 189,896	$ 221,820
Total support and revenue					$ 1,219,911	$ 1,327,885
Supporting services ratio					15.6%	16.7%