

SOLVE CFS

In 2009, CFS commanded the world's attention with the landmark research published in *Science* by researchers at the Whittemore Peterson Institute (WPI), National Cancer Institute and the Cleveland Clinic. Many important events and milestones were marked in the past year, too. Here's a month-by-month recap of some of the CFIDS Association's contributions to the movement from 2009.



January 2009

- As the year began, the **Board of Directors** welcomed four new directors and the staff adjusted to the loss of 5 staff positions forced in early December (2008) by the sharp economic downturn and impact of the Madoff scandal on several Association benefactors.
- In December 2008 the CFIDS Association of America announced research funding decisions following an intensive set of grant reviews for scientific and strategic merit. Six studies will be supported, providing total new funding of \$647,940 to six teams of investigators in the U.S. and Canada. To kick off these projects and the **first-ever strategically coordinated CFS research network** the studies now form, the Association hosted the first investigators meeting in Charlotte on January 19-20, 2009. Against the backdrop of the inauguration of President Barack Obama, the Association's scientific director, Dr. Suzanne Vernon, led a jam-packed agenda to enable the scientists and clinicians to get to know one another, understand the aims and designs of one another's studies, agree on standardized information to be collected on all study participants across sites, and to begin the process of data sharing and marker validation. The Association's president & CEO Kim McCleary also took part in the two-day meeting, providing the group with an understanding of the Association's funding strategy and its expectations as the studies get under way.
- *PLoS Computational Biology* selected the paper, "**Model-based therapeutic correction of HPA axis dysfunction**" by Drs. Amos Ben-Zvi, Suzanne D. Vernon and Gordon Broderick (one of the Association's funded investigators) as one of the most important in its January issue. The press release generated media coverage in Canada and the U.S.



February 2009

- The winter issue of the **CFIDS Chronicle**, focused on research, was mailed to members. As announced in its pages, it would be the final magazine-style issue; this change was made to reduce publication costs and respond to the growing number of member requests for online formats and “greener” communications vehicles.
- On Feb. 10, Suzanne sent a letter requesting that the U.S. Centers for Disease Control & Prevention (**CDC**) **share its CFS data** with the newly formed network of funded investigators and others, under President Obama’s Jan. 21 directive requiring broader release of government data. The response received a month later indicated that they were working toward this and would address it in their research plan.
- Suzanne and CEO Kim McCleary delivered a **two-hour briefing** to the newly designated federal officer for the CFS Advisory Committee (CFSAC), Dr. Wanda Jones, and other members of the Office of Public Health and Science staff about CFS and the Association on Feb. 24. They discussed CFSAC meeting attendance by the community and ways to make meetings more accessible to patients.
- While in Washington for the briefing with Dr. Jones, Suzanne and Kim met with **key Congressional staffers** about CFS research and policy.
- With the February issue of *CFIDSLink*, the Association initiated a **series of reader surveys** to develop reader profiles, seek input on topics of greatest interest and help tweak the format of the Association’s free monthly e-newsletter.
- As a means to connect members of the community with one another and more directly with the Association, the Association launched a **Facebook** page (www.facebook.com/CFIDSAssn) on Feb. 28. It has 4,410 fans from 20 countries and content is updated daily with posts and links from the Association and/or its fans.



March 2009

- The Association joined with five organizations representing conditions that frequently overlap with CFS to form the **Overlapping Conditions Alliance**. An information website (www.overlappingconditions.org) was launched on March 1.
- Health Radio Network’s syndicated radio program “Ask Dr. DeSilva” devoted an hour to CFS on March 5 with guests Suzanne and Kim. **Media listings** at www.cfids.org/sparkcfs/media-coverage.asp are updated at least twice weekly.
- “The Faces of CFS” exhibit was featured at the Meadowood Mall in **Reno, Nevada**, March 9-15. Media outreach conducted by the Association’s Public Relations & Events Manager, Sara Collins, also drew attention to the IACFS/ME conference.
- On March 11, Kim McCleary sent a heavily footnoted seven-page letter to **acting CDC director Dr. Richard Besser** about the urgent need to strengthen the CDC’s CFS research program. Text of the letter is available at www.cfids.org/cfidslink/2009/050607d.pdf.
- The IACFS/ME convened its eighth annual **international research and clinical conference** in Reno on March 12-15. Kim and Suzanne represented the CFIDS Association at the various sessions and informal meetings with collaborators and researchers new to the field. Suzanne presented a **three-hour workshop** for clinicians and researchers on March 12 and was **honored for research excellence**.



April 2009

- Following an intensive long-range planning process, the Board of Directors announced new statements of **mission, strategy and core values** in the April edition of *CFIDSLink*.

Our Mission:

For CFS to be widely understood, diagnosable, curable and preventable.


Our Strategy:

To stimulate research aimed at the early detection, objective diagnosis and effective treatment of CFS through expanded public, private and commercial investment.

Our Core Values:

To lead with integrity, innovation and purpose.

These statements now guide all of the Association's plans and programs and will be reinforced in the communications sent to supporters, researchers, legislators, public health officials, health care professionals, media professionals and members of the public.

- The Association submitted a research grant application to the Department of Defense's **Congressionally Directed Medical Research Program**. The CDMRP is a peer-reviewed Department of Defense program that funds research on a variety of disease topics important both to the military and U.S. public health. The Association's application focused on determining if vaccination and natural infection can trigger an autoimmune response that causes and sustains CFS. Joining the CFIDS Association on this application were the Weizmann Institute of Science, University of Alberta, University of Utah Health Sciences Center and Walter Reed Army Medical Center. Unfortunately the study was not approved for funding. 
- The CFIDS Association partnered with Drs. Sanjay Shukla and Steve Yale of the Marshfield Clinic Research Foundation on a **"Challenge" grant application** titled, "Interaction of Genetic Susceptibility Markers and Intestinal Microbiome in Interstitial Cystitis/Painful Bladder Syndrome and Overlapping Clinical Syndromes" to National Institutes of Health (NIH) in response to the first major research initiative announced under ARRA. The crux of the proposal was that CFS, chronic urologic pain syndromes, fibromyalgia and irritable bowel syndrome are described by similar symptoms of fatigue and pain because of shared genetic and infectious features. The study would examine genetic variation in genes important for modulating healthy immune, serotonergic and metabolic responses, as well as to document the ratio of "good" to "bad" gut microbes. NIH received an unprecedented number of applications, and the Association's application was among those that did not receive funding for this round.
- Media outreach in **St. Louis** generated numerous quality television, radio, print and online stories about CFS featuring local experts and patients as "The Faces of CFS" exhibit was on display at St. Louis Mills from April 23-26.
- Kim attended a **public meeting at the CDC** on April 27, delivering testimony about the shortcomings of the CDC draft research outline. In weeks prior to the meeting, the Association requested that CDC make the meeting accessible and that it accept public statements via audioconference, which it did. Kim's testimony is available at www.cfids.org/cfidslink/2009/050607b.pdf.

May 2009

- In conjunction with an in-person meeting of the Board of Directors, the Association hosted a **Research Roundtable in Chicago** for Association supporters featuring two of its funded investigators, Gordon Broderick, PhD, of University of Alberta and Sanjay Shukla, PhD, of Marshfield Clinic Research Foundation.
- The Association submitted a **"Grand Opportunity" grant application** to NIH in response to one of the funding opportunities created under the American Recovery and Reinvestment Act (ARRA). In response to the GO announcement, the CFIDS Association recruited several top-notch co-investigators in an attempt to both expand the Association's CFS Research Network as well as explore the relevance of autoimmunity in CFS. Investigators at Walter Reed Army Medical Center, Oklahoma Medical Research Foundation, New York University, Harvard University, University of Washington, University of Chicago and University of Miami joined the CFIDS Association on this application. This team of investigators proposed to measure autoantibodies that are present in serum against several thousand proteins to generate autoantibody repertoires. It was hypothesized that these autoantibody repertoires will identify CFS subtypes and may also indicate how CFS is caused (for example, by infection, vaccination, etc). This proposal received excellent reviews, but was not among those selected for funding.
- The May 11-17 exhibit of "The Faces of CFS" at Mayfair Mall near **Milwaukee, Wis.**, provided additional exposure for CFS/ME Awareness Day on May 12.
- The fifth annual **Virtual Lobby Day**, launched on May 12 through the Association's Grassroots Action Center, generated 4,222 letters to lawmakers, public health officials and media contracts.
- Association-funded researcher **Dr. Dikoma Shungu** received attention from New York-Presbyterian Hospital's publications for his research that has found elevated levels of lactate in the brains of CFS patients.
- At the conclusion of a request for proposals and review of proposals received, the Association engaged new representation for its federal public policy work through **B&D Consulting** and began an intensive process of briefing firm staff about past challenges and successes and future opportunities.
- Kim participated in the May 28-29 **CFS Advisory Committee meeting** and again gave testimony focused on the lack of productivity in CDC's research program. This was the first CFSAC meeting that was webcast online. Jennie Spotila, Chairman of the Association's Board of Directors, provided testimony to the committee which is available at www.cfids.org/cfidslink/2009/060309b.pdf.
- The May edition of *CFIDSLink* included a request for readers to participate in an anonymous **research survey** about illness onset triggers and perpetuating factors. Responses were capped at 1,200 participants and were reported in the August and September issues of *CFIDSLink*.



June 2009

- Our new-format print publication, ***SolveCFS: The Chronicle of the CFIDS Association of America***, made its debut with a mailing to Association supporters. Changes to the Association's membership program were announced in its pages, eliminating the often-confusing distinction between members and donors. An online version was made available a month later.
- **Dr. Marvin Medow**, one of the Association's funded researchers, was among the authors of a June 5 study published in the *American Journal of Physiology - Heart and Circulatory Physiology* describing "slow flow" in patients with postural orthostatic tachycardia syndrome (POTS), many of whom meet the case definition for CFS. His Association-funded study explores these symptoms in CFS.



- Suzanne and Kim continued to provide background and to discuss strategic opportunities with Dave Zook, JD, Debra Lappin, JD and Jenny Carey at B&D Consulting. On June 8, they **met with several Congressional staffers** about CFS research and education needs on behalf of the CFS community.
- Kim represented the Association at the National Heart, Lung and Blood Institute's **(NHLBI) annual Public Interest Group meeting** on June 9, connecting with other nonprofit leaders and gathering information about changes at NHBLI and the NIH.
- The 41st display of "The Faces of CFS" took place at the Westfield Meriden mall near **Hartford, Conn.**, from June 15-21, yielding coverage of CFS in regional print, broadcast and online media.
- The Association received notice of a **\$35,000 award from the NIH** to host a meeting of funded research investigators at the Banbury Conference Center of Cold Spring Harbor Laboratories in September.
- In response to CDC's request for input, on June 26, the Association submitted **detailed written recommendations to CDC** based on its draft research plan for the CFS program. Read more about the Association's recommendations at www.cfids.org/temp/research-plan-response.pdf
- The Association joined the **Alliance for Taxpayer Access** that promotes "barrier-free access to taxpayer-funded research." An advocacy alert was issued to generate support for the Federal Research Public Access Act (FRPAA) sponsored by the Alliance. 388 letters were sent through the Association's Grassroots Action Center to U.S. senators in support of the bill.



July 2009

- An **Action Alert** issued through the Association's Grassroots Action Center to generate additional support for the Association's recommendations to CDC yielded more than 1,000 messages sent to the CDC planners.
- A second **Research Roundtable** was hosted for Association supporters in Denver, Col., on July 12, featuring presentations from Dr. Marvin Medow of New York Medical College and Dr. Lucinda Bateman of the Fatigue Consultation Clinic in Salt Lake City. The Association's Board also met in person in Denver.
- **Association-funded researcher Alan R. Light, PhD**, and his team at the University of Utah Health Sciences Center published a study that identified genes that increase in activity following moderate exercise in CFS patients. The paper was e-published in the *Journal of Pain* ahead of print.
- **Dr. Ben Katz** of Northwestern University, an Association-funded collaborator, published results from a study of teens followed for two years after the onset of mononucleosis in the July 2009 issue of *Pediatrics*.
- "The Faces of CFS" was displayed at the **American Academy of Family Physicians Students & Residents National Conference** in Kansas City, Mo., from July 30 until Aug. 1. Association Board members Christoph Bausch, PhD, and Brian Smith, a pre-med student, talked with physicians-in-training about CFS.



August 2009

- The August edition of *CFIDSLink* included **profiles from two Japanese women**, Kazue Hirano and Motoko Habara, with CFS, wrapping up a series of first-hand stories from people in countries outside the U.S. sharing their challenges of living with CFS.



- The August CFIDSLink invited readers to share information about their everyday lives through a 25-item **Profile Survey**. The top 10 responses to question #22, **"What is the one thing you'd like your family/friends to really understand about CFS?"** were reported in the September issue of the CFIDSLink, and accounted for one of the most popular Link articles of the entire year. Read the results of the survey at www.cfids.org/cfidslink/2009/090201.asp.
- The Association established a relationship with the NIH-funded initiative **Biomedical Information Research Network (BIRN)**, as a model for an effective research network and a partner in building a more robust CFS research network.
- Suzanne attended the **NIH Family History State of the Science conference** Aug. 23-26 to gain a stronger understanding of the value of and tools for collecting appropriate family medical histories in studying complex conditions.
- **Detroit-area** residents were able to learn about CFS through area media outreach and "The Faces of CFS" exhibit when it was displayed at Eastland Center in Harper Woods from Aug. 24-30.

September 2009

- With co-sponsor NIH, the Association hosted a meeting of funded CFS researchers and selected experts at **Banbury Center**, Sept. 13-16. The productive session, **"From Infection to Neurometabolism: A Nexus for CFS Research,"** ended with an ambitious action list and great promise for reshaping the CFS research field through enhanced collaborations.
- The Association launched a channel on **YouTube** to house short videos and connect through this popular social media site. The first video posted featured CFS patient and former Association Board member Wilhelmina Jenkins discussing the cognitive problems that are the most daunting challenge of life with CFS.
- Suzanne completed a **Public Health Genomics continuing education course** at Sarah Lawrence University on Sept. 23-26, finishing the requirements to earn her certificate in public health genomics.
- The Association became a member of **Genetic Alliance**, a coalition of more than 600 disease advocacy organizations. In addition to being experts in the world of genetics, Genetic Alliance provides access to disease-specific information, as well as translating research into services. It originally focused on rare genetic diseases, but has expanded its scope to serve any disease organization that needs information and infrastructure to effectively participate in research. By joining Genetic Alliance, the CFIDS Association has access to all of its resources including: disease-specific search information, wikiadvocacy, family history toolkits, a resource repository and networking with other disease organizations. Genetic Alliance has also developed a state-of-the-art Biobank, a repository for clinical information and biologic samples. This infrastructure was developed for individual disease organizations to customize and manage. The Biobank accepts clinical information (disease-specific and standardized medical information) and biologic samples (blood, tissue) in a standardized and secure manner, complying with HIPAA and other regulations.
- In response to a notice in the Federal Register, the Association submitted **nomination packages for seven highly qualified individuals** to the federal **CFS Advisory Committee**.
- The Association nominated Suzanne to serve on the **Council of Public Representatives (COPR)**, an advisory board to the director of the NIH.
- For the week beginning September 21, "The Faces of CFS" exhibit was on display at CoolSprings Galleria near **Nashville, Tenn.** Media coverage generated by regional outreach generated stories about local CFS patients and provided information from local experts.
- **Ashley Comstock** joined the Association's staff as major gifts officer. Her development experience has been with the Alzheimer's Association and the American Diabetes Association.
- The Association joined **Twitter** nation at <http://twitter.com/PlzSolveCFS>.



October 2009

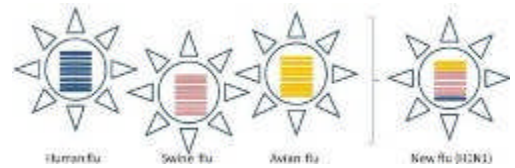
- Based on the 1,784 responses to the August profile survey, Kim and daughter Lauren collaborated to make the short movie, **"What Would You Do?"** using Lauren's original photography and some additional shots taken by other volunteers to depict answers to the question, What would you do if you were completely well tomorrow? The video was posted on the Association's YouTube channel on Oct. 5 at www.youtube.com/solvecfs.
- As part of the **annual fund campaign** to raise support for the Association's research and public policy program and its operating costs, a companion website was launched at www.SolveCFS.org on Oct. 5.
- The Lights' study on blood biomarkers being funded by the Association was published (in print) and a figure from the article was featured on the **cover of the October issue of the Journal of Pain**.
- With the Oct. 8 publication of a study in the prestigious journal *Science* that detected a human retrovirus, XMRV, in CFS patients the Association issued its congratulations to researchers at the **Whittemore Peterson Institute (WPI)**, shared the news through its various electronic lists (*CFIDSLink*, Grassroots Action Center, Facebook, Twitter) and gave media interviews, recognizing the study as "landmark" and "game-changing." Resources and links to other expert opinions on the importance of the study and implications for CFS patients and the public were quickly developed.
- On Oct. 9, **continuing medical education (CME)** credits for the Association-sponsored Medscape CME unit titled, "CFS: From Diagnosis to Management" reached the one-year expiration date. In that time, 31,948 medical professionals took the course for credit and nearly 180,000 used the materials for reference. Nurses accounted for about half of those obtaining credit for the course and physicians represented one-fourth. Pharmacists, medical students, physician assistants and other medical professionals made up the other fourth.
- Suzanne wrote an analysis of the *Science* article titled, **"Xplained,"** that was widely distributed and posted among the Association's growing list of XMRV resources, updated regularly.
- The **BIRN steering committee** accepted the Association's application for an expanded CFS research network to be housed in its technology framework.
- The Association sought **guidance from the National Cancer Institute (NCI)** about transmission of XMRV and precautions that should be taken while research proceeds. NCI's interim guidelines were posted on Oct. 23 at www.cfids.org/xmrv/nci-guidelines.asp.
- With B&D Consulting staff, on Oct. 28 Kim **met with several congressional staff** about opportunities presented by the XMRV study for expanded CFS research.
- Kim attended and gave testimony at the Oct. 29-30 **meeting of the CFS Advisory Committee**. A detailed report on this meeting that focused on the XMRV discovery and the CDC's deeply disappointing five-year research plan is available on the Association's web site at www.cfids.org/cfidslink/2009/110401.asp and www.cfids.org/advocacy/testimony-kkm-oct09.pdf.



November 2009

- "The Faces of CFS" closed out its national tour at Westfield North County Fair near **San Diego, Calif.**, from Oct. 26-Nov. 1. Initially scheduled for just 12 venues, the exhibit traveled to 36 public venues and nine medical provider conferences, generating coverage in all the top 25 media markets and scores of print articles, radio interviews, television stories and online features and listings.

- Concern about **H1N1 flu** had been building since April, but by the pandemic's peak in November, questions about risks to CFS patients posed by the illness and the vaccine matched interest in XMRV.
- Suzanne was invited to participate as a member of the **XMRV Scientific Working Group**. She also continued linking lab researchers with clinical experts to facilitate testing of CFS cases similar to those studied by WPI.
- The Association rapidly shared a **Q&A from the National Cancer Institute** about XMRV (www.cancer.gov/newscenter/pressreleases/XMRV_QandA) and summarized information about two commercial XMRV tests and guidance from experts about testing at www.cfids.org/xmrvtesting.asp



December 2009

- At the request of producers for **"The Dr. Oz Show,"** the Association prepped and screened a dozen clinical experts and patients to discuss CFS and XMRV. Producers selected Dr. Donnica Moore, a women's health expert and CFS mom, to appear on the Dec. 3 program along with Gina, a young woman who tested XMRV-positive in the WPI study.
- Kim accepted an invitation to serve on the **AABB** (formerly the American Association of Blood Banking) **Interorganizational Task Force on XMRV** that will oversee the XMRV Scientific Research Working Group.
- Kim issued an **open letter** to the CFS community on Dec. 11, calling for greater unity in the quest for rigorous science that provides "absolute validation, definitive answers and unbridled hope."
- Just as fall came to an end, the fall issue of the Association's print publication, **SolveCFS: The Chronicle of the CFIDS Association of America**, was mailed to supporters. The issue focused on XMRV and research updates from the Association's funded investigators.
- The Association will serve as the **community-based organization** on a NIH grant for Building Sustainable Community-Linked Infrastructure to Enable Health Science Research. The grant was submitted with principal investigators Dr. Leonard Jason of DePaul University and Dr. Julian Stewart of New York Medical College.
- The Association's Board of Directors prepared for transition as **Jennie Spotila, JD** stepped down as chairman on Dec. 31 and **Adam Lesser** took the post on Jan. 1, 2010. Two other directors, Lynn Royster, PhD, JD and Susan Jacobs, Esq. reached their maximum years of consecutive service (six) and three new directors joined the Board: Diane Bean, Vicki Boies, PsyD, and Bob Raidt.
- With year-end giving in full swing, progress toward the Association's ambitious **\$1 million annual fund goal** was bolstered by late-December gifts from individuals as modest as \$1 and as magnanimous as \$100,000. Financial results for 2009 are provided on the following page.



2010 Board of Directors

Adam Lesser
Chairman

Amy Divine
Vice Chairman

Bruce Allshouse
Treasurer

Jennie Spotila
Secretary

Christoph Bausch, PhD

Diane Bean

Katrina Berne, PhD

Vikki Boies

Stuart Drescher, PhD

Kim McCleary

Dimitris Papanicolaou, MD

Bob Raidt

Brian Smith

Amy Squires

Patrick Venetucci

THE CFIDS ASSOCIATION OF AMERICA, INC.

Statement of Activities
 Year Ended December 31, 2009
 (With Comparative Totals for Year Ended December 31, 2008)

	Year Ended December 31, 2009			Totals	Year Ended December 31, 2008
	Unrestricted	Temporarily Restricted	Permanently Restricted		
Support and revenues					
Public support:					
Contributions and grants	\$ 723,179	\$ 136,680	\$ -	\$ 859,859	\$ 1,445,613
Federal funds:					
Government grants	228,380	-	-	228,380	336,119
Revenues:					
Membership dues	62,172	-	-	62,172	118,672
Educational material sales	5,246	-	-	5,246	7,338
Interest and other	3,901	2,033	-	5,934	10,360
	<u>71,319</u>	<u>2,033</u>	<u>-</u>	<u>73,352</u>	<u>136,370</u>
Assets released from restrictions	721,502	(721,502)	-	-	-
Total support and revenues	<u>1,744,380</u>	<u>(582,789)</u>	<u>-</u>	<u>1,161,591</u>	<u>1,918,102</u>
Expenses					
Program services:					
Research	727,778	-	-	727,778	350,186
Public Policy	197,781	-	-	197,781	235,845
Education	447,470	-	-	447,470	890,608
Supporting services:					
Management and general	108,827	-	-	108,827	136,675
Fund raising and development	119,029	-	-	119,029	213,084
Total expenses	<u>1,600,885</u>	<u>-</u>	<u>-</u>	<u>1,600,885</u>	<u>1,826,398</u>
Change in net assets	143,495	(582,789)	-	(439,294)	91,704
Adjustments					
Cumulative affect of accounting changes (see Note 7)	(4,118)	4,118	-	-	-
Change in net assets after adjustments	139,377	(578,671)	-	(439,294)	91,704
Net assets					
Beginning of year	684,661	977,546	5,400	1,667,607	1,575,903
End of year	<u>\$ 824,038</u>	<u>\$ 398,875</u>	<u>\$ 5,400</u>	<u>\$ 1,228,313</u>	<u>\$ 1,667,607</u>