

SOLVE CFS

The Chronicle of the CFIDS Association of America

Spring/Summer 2009

Welcome!

For 22 years, the CFIDS Association of America has been at the leading edge of CFS research, policy and education. Through “thick and thin,” this organization has responsibly represented the needs of CFS patients and their loved ones. Inspired by the courage and passion of volunteers and fueled by gifts small and large from supporters committed to a vision of a world without CFS, the Association has adapted to new challenges and opportunities while remaining true to its roots.

The Association’s Board of Directors has recently adopted new statements of the Association’s mission, strategy and core values to represent what this organization stands for and how it will work to achieve its ultimate goal.

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

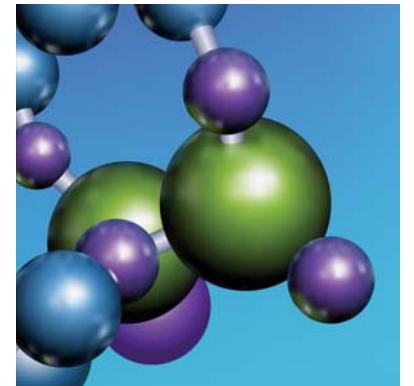
To lead with integrity, innovation and purpose.

These statements now guide all of our plans and programs and will be reinforced in the communications we send to supporters, researchers, legislators, public health officials, health care professionals, media professionals and members of the public. We are energized by the clarity they bring to our collective effort.

We are also excited to introduce a new format for our print publication, and to update its name, while preserving the tradition of the beloved *CFIDS Chronicle*. *SolveCFS: The Chronicle of the CFIDS Association of America* will be distributed three times a year to all Association supporters. It will highlight how the Association is advancing progress in CFS research and policy and it will share global news of interest to those who are committed to our cause.

SolveCFS will supplement our monthly electronic newsletter, *CFIDSLink*. We recognize that even in this internet age, many people still do not have regular access to online publications, and that others find screen-based text difficult to read, retain and/or share with others. *SolveCFS* is created with this audience in mind, and will also extend our tradition of having a print publication to serve as a tangible touchpoint for our supporters.

We hope you enjoy the debut issue of the latest addition to our publication family! We look forward to hearing your feedback about its content, design and layout so that we can best serve your needs and those of other readers. ■



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Dr. Suzanne Vernon Honored by IACFS/ME

The Association’s Scientific Director, **Suzanne D. Vernon, PhD**, received an award on March 14, 2009 at the 9th international research conference held in Reno, Nevada. Dr. Vernon was humbled by the IACFS/ME award for research excellence, sponsored by Utah’s O.F.F.E.R., but urged her colleagues to strive for higher levels of achievement. “CFS is a public health crisis but it will not get the respect and research dollars the CFS community deserves until we — the research community — learn to put egos aside and work together to generate the kind of evidence-based research that is required in order to have policy makers understand the magnitude of the problem at hand.” The full text of Suzanne’s acceptance speech is posted at www.cfids.org/solveCFS/SS09.asp. ■



Dr. Suzanne Vernon (left) is congratulated by CFIDS Association president and CEO Kim McCleary at the March awards banquet.

Advancing Policy: A New Partnership for Progress

The Association’s mission to make CFS widely understood, diagnosable, curable and preventable relies upon effectively harnessing the government’s ability to conduct and support CFS research. We are very pleased to announce a new strategic partner to help us do this — the B&D Consulting health and life sciences team. Led by **Dave Zook, J.D.** and **Debra Lappin, J.D.**, B&D Consulting has established a nationally recognized practice that works with voluntary health organizations, medical technology innovators and research institutions to advance legislative, reimbursement and regulatory policy solutions across the federal government.

Zook has worked in the national and federal policy arena for nearly 25 years. Prior to joining B&D, Zook served as counsel to two members of the U.S. House of Representatives and the House Committee on Appropriations and was senior vice president of the Arthritis Foundation. Lappin has led a

number of major public policy campaigns including the effort to promote “open access” with the NIH. She worked on the Genetic Information Nondiscrimination Act passed in 2008 and has served on several top advisory committees to agency leaders, including directors of the CDC and NIH. B&D Consulting is part of the international law firm of Baker & Daniels, LLP.

Working closely with president and CEO Kim McCleary and scientific director Dr. Suzanne Vernon, B&D will define activities designed to expand public investment in research, validate the burden of illness imposed by CFS and shape public policy that is responsive to the needs of CFS patients.

“Our team is pleased to have the opportunity to serve the CFS community,” observed Zook. “We specialize in building

(continued on page 8)

Validate. Innovate. Eliminate.

Reno Wrap-Up: A Report on the 2009 IACFS/ME Conference

From March 12–15, 2009, researchers, clinicians, patients, caregivers and advocates from around the world gathered in Reno, Nevada, to share information, critique the latest research and network in the hallways and over meals. The 9th research and clinical conference sponsored by the International Association for CFS/ME (IACFS/ME) drew about 220 participants for the four-day event held at the Peppermill Resort & Casino.

Marking the 25th year since CFS was first brought to national attention, pioneering clinician and researcher **Dr. Daniel Peterson** had the honor of being the local host as well as opening and closing the conference sessions. Dr. Peterson is well-known for having been among the first, with his then-partner **Dr. Paul Cheney**, to recognize CFS among a cluster of ill patients in his internal medicine practice in Incline Village, Nevada, just over Mount Rose from Reno. Dr. Peterson has stuck with CFS and by his patients with CFS, so it seemed a fitting tribute to hold the meeting in his “backyard.” Philanthropists **Annette and Harvey Whittemore**, whose adult daughter Andrea has CFS, have founded a center for research and clinical care, the Whittemore Peterson Institute, that will open mid-2010 on the campus of University of Nevada Reno. Several conference attendees drove past the construction site at McCarran and Virginia streets while they were in Reno.

Conference organizers established the first day as a patient-oriented conference designed to provide an overview of current research and management, with longer presentations on general topics delivered by current and past members of the IACFS/ME board of Directors. Researchers who arrived early chose from four workshops on topics that reflected current research challenges in the field of CFS.

The sessions on Friday, Saturday and Sunday were dedicated to short (11-minute) data presentations by researchers on specific study results that bridged somewhat overlapping topics of treatment, epidemiology, immunology, assessment, pediatric CFS, genomics, genetics, brain functioning and the integrative approach being utilized by the Japanese

to study CFS. **Dr. Anthony Komaroff** of Harvard Medical School closed Sunday’s session with a brilliant overview of the 115 presentations delivered from the podium and via two poster sessions displayed in the exhibit hall. A video of Dr. Komaroff’s conference summary is available for free online at www.instatapes.com/IACFS.

President and CEO **Kim McCleary** and scientific director **Dr. Suzanne Vernon** represented the Association at the conference. Vernon led an opening day workshop attended by about 50 investigators. They both participated in the formal sessions and held informal meetings before, during and after the daily programs. McCleary posted daily updates and photos from the conference to the Association’s Facebook page (see article on page 5). Vernon was honored at the conference banquet on Saturday night for excellence in research (see page 1) and was elected to the IACFS/ME’s Board of Directors at the membership meeting held earlier that day.

Here are a few of the most intriguing study results presented at the conference. You can find all the Association’s conference reports and links to other conference resources at www.cfids.org/solveCFS/SS09.asp.

The brain: Two studies used different techniques to document brain abnormalities in CFS patients. **Dr. Frank Duffy**, a Harvard neurologist, studied a large group of patients using spectral coherence EEG and was able to discriminate, with nearly 90% accuracy, patients with rigorously defined CFS from healthy control subjects and from subjects with major depression. He stopped short of calling this pattern diagnostic, but stated that it did define CFS as an organic brain-based condition. The study was large, with a total of 632 subjects; however, the CFS patients referred by community-based physicians did not demonstrate the same frequency of EEG patterns, suggesting that the label of CFS may be misapplied in some settings. **Leighton Barnden, PhD**, of the University of Adelaide in Australia, analyzed brain magnetic resonance (MR) images from 25 CFS patients and 25 healthy control subjects. Comparing

volume differences in specific areas of the brain, Barden reported that changes in CFS subjects were consistent with the symptoms and symptom severity they reported. For example, changes in the medulla and insula are consistent with the autonomic dysfunction reported in CFS. He was unable to determine, based on this study alone, whether the changes represent the cause of the symptoms or the effect of CFS.

Triggering agents/factors for CFS: While early studies of CFS sought to identify a single agent that caused the illness, most researchers now appear to agree that CFS can be “triggered” by a number of different insults including microorganisms (bacteria, viruses, etc.), environmental exposures and severe injuries (such as closed head trauma). At this conference, researchers reported data on a number of agents that set off a CFS-like illness.

Subgrouping by biologic abnormalities: Another sign of the maturing of the CFS research field is the broad agreement that the definition for CFS results in a rather heterogeneous patient group and that studies should seek to define subgroups of patients using one or more biologic measures. Several research groups reported evidence of immune system and neuroendocrine abnormalities, building on some of the earliest CFS reports in the biomedical literature. One of the most impressive presentations was delivered by **Alan Light, PhD** of University of Utah. His group reported differences between CFS patients, healthy controls and a smaller group of MS patients on adrenergic and sensory receptor peripheral blood cell gene expression after a modest exercise challenge. The CFIDS Association of America is providing support to expand the study that was begun with a grant from the National Institutes of Health.

The CFS group at the University of Miami (UM) and collaborators presented several immune system abnormalities in Gulf War Illness/CFS patients following a graded exercise test, including elevated levels of neuropeptide Y (NPY) (**Mary Ann Fletcher, PhD**, UM) and a plasma cytokine shift from Th1 (antiviral defense) to Th2-type (proinflammatory activation) immune response (**Nancy Klimas, MD**, UM). These observations were confirmed by **Gordon Broderick, PhD**, at University of Alberta who found distinct patterns of coordinated change in NPY, cytokine and cortisol concentrations at rest and under challenge using data collected from the UM subjects. Dr. Broderick is also one of the Association’s current grantees.

Metabolic/mitochondrial dysfunction: Several studies advanced the idea that CFS stems from a problem producing energy at the cellular level. The most interesting of these was presented by **Dr. Norman Booth** of University of Oxford. He reported results obtained from 71 CFS patients using an ATP profile test combined with the Bell Ability Scale as a measure of functional capacity. Booth’s collaborating physicians found a correlation between the degree of mitochondrial dysfunction and the severity of illness, suggesting that the fatigue in CFS is due to cellular respiration dysfunction.

Treatment: There was a disappointing lack of new information about CFS treatment, and most of the studies presented focused on behavioral techniques such as CBT and graded exercise. Studies of three pharmacological agents were presented: Ampligen, isopinosine and sodium oxybate. **David Strayer, MD**, of manufacturer Hemisphere, reported that Ampligen improved the physical function of CFS patients as measured by exercise treatment duration. He indicated that the drug, now under review by the Food and Drug Administration (FDA) for marketing approval, was well-tolerated and that its use allowed patients to reduce their dependence on other drugs.





Top: The Honorable Dr. John Kitzhaber, former Oregon governor, with Dr. Suzanne Vernon following his keynote address. **Bottom:** Dr. Judy Mikovits of the Whittemore-Peterson Institute leads a panel Q&A session.

A decision is expected from FDA in late May. Isoprinosine is sold in Ireland and Costa Rica under the trade name Immunovir. **Maria Araceli Vera, MD**, of UM, presented a chart review of 61 patients who took isoprinosine for six months. Using data from their charts to assess both clinical status and immune status, Dr. Vera concluded that there was highly significant improvement in both clinical and immunological status, stating that a large, randomized clinical trial would be appropriate based on this review. **Natalie Hone, MD**, of UM, also presented results of a chart review of 27 CFS patients with documented alpha-wave intrusion in slow-wave sleep who had taken sodium oxybate (Xyrem) to treat this condition. 20 of these patients reported improvement in their sleep after treatment. Like her colleague, Hone concluded that further studies are indicated.

In summary, at this truly international meeting, representatives from 17 countries where CFS is being studied expressed much enthusiasm for the varied approaches being taken and the new technologies being employed to investigate CFS. There was some disappointment with the small and preliminary nature of many of the studies, but this was largely seen as a function of the meager funding streams available in the U.S. and most other countries. Hopefully when IACFS/ME convenes its next conference in two years, some of these investigations will have matured and there will be more standardization of studies through enhanced communication, established networks (like the one being formed by the CFIDS Association's funded investigators) and expanded funding opportunities.

Visit www.cfids.org/solveCFS/SS09.asp for links to daily conference reports posted by the Association to its Facebook page and links to other conference resources. ■

From Scientific Director Suzanne D. Vernon, PhD A Run for the Money

The American Recovery and Reinvestment Act (ARRA) is intended to stimulate our economy by creating new jobs, preserving existing jobs and addressing long-neglected challenges. The National Institutes of Health (NIH) received an unprecedented \$29 billion through ARRA, most of which is directed to buildings and infrastructure; \$500 million will support medical research grants and training.

At least \$200 million was designated for the NIH Challenge Grants in Health and Science Research; this is sufficient to fund about 200 scientifically meritorious applications at \$500,000 per year for two years. Another new program called Research and Research Infrastructure "Grand Opportunities" or "GO." This fund contains \$200 million to support large projects of \$500,000 or more each year for two years.

The CFIDS Association partnered with Drs. Sanjay Shukla and Steve Yale of the Marshfield Clinic Research Foundation on a Challenge proposal titled, "Interaction of Genetic Susceptibility Markers and Intestinal Microbiome in Interstitial Cystitis/Painful Bladder Syndrome and Overlapping Clinical Syndromes." The crux of the proposal is 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. We propose to 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. Challenge Grant applications will be reviewed in June and July with the earliest start dates for successful grants in September 2009.

In response to the GO announcement, the CFIDS Association has recruited several top-notch co-investigators in an attempt to both expand the Association's CFS Research Network (see below) 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 will be joining the CFIDS Association on this application. With this team of investigators we propose to measure autoantibodies that are present in serum against several thousand proteins to generate autoantibody repertoires. We hypothesize that these autoantibody repertoires will identify CFS subtypes and may also indicate how CFS was caused (for example, by infection, vaccination, etc). The GO Grants will also be reviewed in June and July with the earliest start dates for successful applications beginning in September.

The CFIDS Association also submitted an application to the Congressionally Directed Medical Research Program (CDMRP). 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. Our application is 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 are the Weizmann Institute of Science, University of Alberta, University of Utah Health Sciences Center and Walter Reed Army Medical Center. The funding amount for this award would be \$750,000 for three years. Funding decisions will be made by October.

The Association is working diligently to expand public support of CFS research by developing innovative multidisciplinary research teams capable of meeting these funding agencies' rigorous standards. We hope to share news of positive reviews as the process continues. ■

A Coordinated Response

When I was young I thought of coordination as balance and agility when in motion. Now, as a professional, I appreciate this definition: "Coordination is the act of making different people or things work together for a goal or effect." Under its expanded research program, the Association is coordinating scientists to work together through a research network for early detection, diagnosis and treatment of CFS. Working to establish this first-ever funded CFS research network has been exciting and gives me confidence that the pace of CFS research will indeed accelerate as we had promised last year during the research fundraising campaign.

This type of coordination is critical to advance the state of CFS knowledge but it is not without its challenges. Science is generally considered solitary thoughtful pursuit of knowledge, and by its nature it nurtures and rewards individual discoveries and advances. Teamwork doesn't come naturally to many who choose a career in science. After all, Nobel prizes are not awarded to teams.

But a shift toward "team science" is happening. Two unprecedented studies recently published in the prestigious journal *Nature Genetics*, reported on two independent team-based efforts. More than 90 researchers at more than 40 centers in Europe and North America identified a set of previously unconsidered genes that increase the risk of diabetes. Another large international team reported a number of unsuspected genes associated with high blood pressure. Teams may be forming in recognition that medical challenges are far too complex for any one discipline or any one individual to solve alone. Collaborative scientific pursuit is an effective and efficient approach to accelerate the rate of important discoveries that will impact the health challenges of today, including CFS.

Scientists love a good challenge. CFS certainly provides ample challenge and intrigue once we get scientists interested. (I speak from that experience myself!) That's why I spent a great deal of time last year encouraging applications to our call our proposals. Now the six research projects funded by the Association link all the investigators through a research network, as mentioned above, and these researchers are expected to work together. Even though most of their individual projects are still in the early stages, the CFS research network has taken off. We exchange information, expertise, publications and ideas. The network itself has sparked lively discussion and new concepts, challenging all of us to regularly think beyond our individual areas of expertise. The Association has applied for funding to expand the network to include additional investigators and reflect new research approaches. In collaboration with Cold Spring Harbor Laboratory and NIH, in September we will host a think-tank type meeting titled "From Infection to Neurometabolism: A Nexus for CFS." It will serve as an interim meeting of our funded investigators and will create another opportunity to expand the CFS research network.

Another quote I think of often these days is, "If you build it, they will come," from the baseball movie "Field of Dreams." I am thankful to every person who believed we could build this research network. This is your team and I'm constantly coaching to be sure we hit home runs for you. ■

More Hope for People with Fibromyalgia Pain

Chronic fatigue syndrome (CFS) and fibromyalgia (FM) share many symptoms. Studies of both patient groups estimate that in referral clinics, up to 70% of FM patients meet the criteria for CFS, and 35–70% of CFS patients meet the definition for FM. Although some research studies have found differences between carefully selected FM and CFS patient groups, in the real world there is great similarity in the experience of having CFS and having FM.

Pain, disrupted sleep and difficulty thinking and concentrating are some of the symptoms that plague both CFS and FM sufferers. For both conditions, symptom management is still the state of the medical art; neither one has a primary therapy or cure.

Three drugs, **Lyrica**, **Cymbalta** and **Savella**, have been approved for the management of FM, while CFS still awaits its first FDA-approved treatment. (See info about Ampligen at far right.) CFS patients give mixed reviews of these three drugs in online forums and at meetings and conferences, but for those seeking better control over symptoms, more awareness of Lyrica, Cymbalta and Savella might be helpful before your next appointment with a health care professional.

Keep in mind that most drugs have side effects and potentially dangerous interactions with other prescription, over-the-counter and natural therapies. Most CFS patients find that they are unusually sensitive to medications and that they cannot tolerate even the standard minimum dosages. As with any new medicine, start low and increase slowly. Monitor benefits and side effects and discuss any changes (good or bad) with your prescribing professional or pharmacist. Antidepressant medications Cymbalta and Savella are required to carry safety information about the increased risk of suicidality reported in studies of these types of medicines.



Big-budget national advertising campaigns to expand awareness of FM and demand for Lyrica and Cymbalta have drawn criticism from journalists and people inside the medical community. Some patients feel misled and deeply disappointed when the drugs don't work for them. Pharmaceutical company spokespersons and FM patient advocates respond that the backlash is likely a consequence of increased awareness of a condition that has been misunderstood for too long, and for which more research is needed.

Whether you or a loved one have been diagnosed with FM or you'd like to explore "off-label" use of one of these drugs, take time to become more informed. The drug sites listed below include more information about which symptoms each one is most effective in treating, common and rare side effects, and helpful tips for talking to your doctor about these medications.

FOR MORE INFORMATION

Lyrica: www.lyrica.com

Cymbalta: www.cymbalta.com

Savella: www.savella.com

Drug Prices: www.PharmacyChecker.com

Help Paying for Prescription Medications:

The Partnership for Prescription Assistance is a service sponsored by the pharmaceutical industry. It offers a single point of access to more than 475 patient assistance programs. www.PPARx.org. ■

Treatments Further Explored

At the Reno conference (see p. 2), researchers presented studies on several possible CFS treatments. Here is some additional information about some of those that appeared promising.

Ampligen

Ampligen is an experimental therapy that has been studied in CFS and other conditions for more than 20 years. It is now being considered by the Food and Drug Administration (FDA) for marketing approval for CFS; if approved, it will be the first primary treatment for CFS. An immunomodulatory drug administered by IV, Ampligen has been reported to be of greatest potential benefit to those patients with an acute flu-like onset. For the past 10 years, it has been available through a controversial cost-recovery program at selected sites in the U.S. A decision about the future availability of Ampligen is expected from FDA in late May. Its manufacturer is also seeking approval in other countries and for other conditions, which will hopefully bring down its high cost if approved.

Eye Movement Desensitization and Reprocessing (EMDR)

Dr. Elke van Hoof of Vrije Universiteit Brussels presented a study on EMDR that showed some decrease in the "hypervigilance" (or dominance of the sympathetic nervous system) seen among CFS patients. EMDR is a form of psychotherapy that uses an eight-phase approach to address traumatic memories or experiences that trigger a wide range of conditions. EMDR seems to have a direct effect on the way the brain processes information. Through therapy, normal information processing is resumed and following a successful EMDR session, a person no longer relives the images, sounds and feelings when the traumatizing event is brought to mind. Dr. van Hoof is collecting more data on the effectiveness of EMDR compared to controls, EMDR plus biofeedback and biofeedback alone. She will report whether EMDR had any effect on the abnormal heart rate variability seen in many CFS patients.

Probiotics

Dr. Nancy Klimas of University of Miami included probiotics in her treatment presentation at the patient session on the first day of the conference. "There's never any harm in loading up on probiotics," she urged patients, noting the overlap of gastrointestinal symptoms of CFS with those common in irritable bowel syndrome. Probiotics are defined as "live microorganisms administered in adequate amounts which confer a beneficial health effect on the host." Most probiotic products contain bacteria that can influence a healthy balance of microorganisms in the lining of the intestines and colon. Both *lactobacilli* and *bifidobacteria* are normal inhabitants of the healthy intestine; when introduced through over-the-counter probiotic products (like yogurts and supplements), they can help promote healthy immune responses. The role of specific probiotics that might be beneficial in CFS (or subsets of CFS) requires more investigation.

Xyrem

Sodium oxbate is a controlled, schedule III prescription medication marketed as Xyrem for the treatment of narcolepsy. It can be helpful to those with alpha intrusion during slow-wave sleep and has been studied in fibromyalgia and CFS. It has shown some benefit, but FDA has not given marketing approval for either condition. Xyrem is a form of the street drug known as GHB, or the "date rape drug." Because of the potential for abuse, research has proceeded somewhat cautiously among very well-defined patient populations. It is taken at night in two doses; the first is taken at bedtime and the second is taken 2.5 to 4 hours later. (Yes, you have to wake up to take it.) The dosing regimen is quite strict, as are the limitations on what other medications you can take while using Xyrem. Generally, doctors will not prescribe it for people living in households with young children or for patients who have a history of sleep apnea or depressive episodes. ■



Name: Lyrica™ (pregabalin)

Manufacturer: Pfizer

FDA Approval: June 2007

Type of Drug: antiepileptic

Recommended Dosage: 150–450 mg daily

Average Retail Cost: \$2.17–\$2.99 per 150 mg

Other FDA-Approved Indications: Nerve pain associated with diabetes, nerve pain associated with shingles, add-on treatment of partial seizures

Proposed Mechanism of Action: "Although the exact mechanism of action is unknown, results from animal studies suggest that Lyrica reduces the number of electrical signals that the brain cells send to each other. This could reduce the amount of pain you feel from fibromyalgia." (Pfizer)



Name: Cymbalta™ (duloxetine hydrochloride)

Manufacturer: Eli Lilly & Co.

FDA Approval: June 2008

Type of Drug: serotonin-norepinephrine reuptake inhibitor (SNRI)

Recommended Dosage: 60 mg

Average Retail Cost: \$2.21–\$4.38 per 60 mg

Other FDA-Approved Indications: Depression, generalized anxiety disorder (GAD), diabetic nerve pain (DNP)

Proposed Mechanism of Action: "While the mechanism of action for Cymbalta is not fully known, its effects on depression, GAD, DNP and fibromyalgia may be due to increasing the activity of two naturally occurring substances in the central nervous system, serotonin and norepinephrine." (Lilly)



Name: Savella™ (milnacipran HCl)

Manufacturer: Forest Laboratories and Cypress Bioscience, Inc.

FDA Approval: January 2009

Type of Drug: selective serotonin and norepinephrine dual reuptake inhibitor (SNRI)

Dosages Tested in Clinical Trials: 100 mg/day and 200 mg/day

Average Retail Cost: (now in pharmacies; pricing not available)

Other FDA-Approved Indications: No other approved indications

Proposed Mechanism of Action: "Although the exact mechanism by which Savella improves the symptoms of fibromyalgia is unknown, some researchers believe that abnormalities in certain brain neurotransmitters may be central to fibromyalgia. Savella blocks the reuptake of both norepinephrine and serotonin, with greater selectivity for the inhibition of norepinephrine reuptake in vitro. This may be the mechanism by which Savella acts to improve the symptoms of fibromyalgia." (Forest Laboratories, Inc.)

Association Debuts On Facebook

In response to requests from supporters, CFIDSLink subscribers and others, the Association launched a profile on Facebook on February 28. A special notice was sent to announce the page to Link subscribers on Monday, March 2, and the response has been terrific so far. The page has 1,088 fans as of May 26 and a related “cause” page, “SolveCFS,” has 552 members.

The welcome we’ve received is warm, indeed. Here are just a few quotations from messages people have posted to our “Wall”:

“I want to tell you all how good it feels to connect with people who also suffer from CFS (& FMS, too). You — along with your loved ones who understand our illness — are like family to me, even though I probably don’t know a single one of you personally. That doesn’t matter, because what’s most important is that you understand!” (JK)

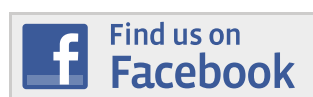
“Thank you CFIDS Association...you have connected me with others who deal with the same thing I do on a daily basis. It’s nice to come here to read information and chat with others about this mystery syndrome!” (DHF)

“Bravo to CFIDS AA for joining the Facebook era!! You guys are so important and vital to ME/CFS patients and this cause. I’m proud to be a member and proud to annually donate money for all the wonderful things you guys do, and the research you’ve been supporting. THANK YOU!” (EHM)

After we announced our Facebook presence, a few individuals sent us e-mail messages, unhappy or uncertain about the Facebook foray. Privacy concerns

are an issue for patients still working or trying to maintain a sense of “normalcy” in their relationships. We agree and think Facebook is great for making connections, but because identities are “transparent,” it’s not always ideal to reveal your illness status or share information about medications or test results. Still, some individuals choose to do so. It’s good to keep in mind that social networking sites are open to anyone — including employers and insurers.

Lack of time and energy were also expressed by a few “Linkers” who weren’t likely to join Facebook. As one person wrote, “Some of us are too busy trying to survive to spend time on Internet games.” We know it’s not for everyone, but we have also heard from many people who use sites like Facebook to maintain family and social relationships that would otherwise suffer because of the unpredictability of CFS. Finally, money is an issue. Although Facebook is free, computer access often isn’t, and the sites don’t work well if you’re using a dial-up connection. We’ve added Facebook as another means of connecting with the community, but we’ll continue providing CFIDSLink and keep looking for other novel ways to serve your information needs.



If you’re online and haven’t tried Facebook yet, open a free account and

find us at www.facebook.com/home.php?#/pages/The-CFIDS-Association-of-America/47921632107. After you read the posts on the “Wall,” take a minute to browse the “Notes” and “Photo Albums” to find other information of high interest. We hope to hear from you there! ■

Association Offers Free Educational Materials

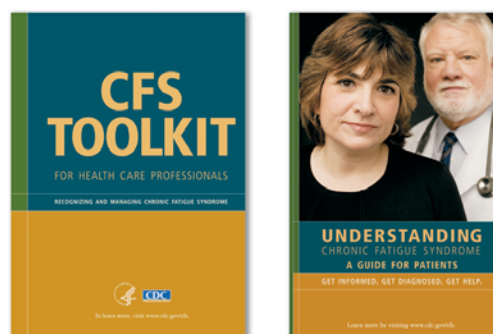
Through the Spark! awareness campaign (see p. 7), we can provide you and/or your organization with basic materials about CFS intended to educate the public, patients and health care providers for conferences, meetings, health fairs and presentations.

Understanding CFS is a single sheet pamphlet with basic information about diagnosis of and help for CFS. It is intended for the public and patients.

CFS Toolkit for Health Care Professionals is a printed folder with six insert sheets providing an overview of CFS and information about diagnosis, supportive care, managing symptoms, managing activity and cognitive behavioral therapy. The folder also contains a copy of the Understanding CFS pamphlet and a brochure-format “resource guide.”

Materials are branded with the CDC logo and refer readers to the CDC’s CFS web site. (The Spark!

campaign is funded by CDC through a contract to the CFIDS Association.) Please call the Association’s Resource Line (704-365-2343) or send an email to cfids@cfids.org with the name/date of the educational event and the quantity of each material that you’d like to receive. Quantities are limited to those already in print, and we are required to track and report how materials are used. ■



Alliance Formed to Represent Overlapping Conditions

To help millions of Americans suffering from multiple chronic medical conditions, six independent nonprofits have come together to form the Overlapping Conditions Alliance (OCA). OCA will promote research into the underlying connection(s) between coexisting conditions. As part of this effort, the Alliance has launched an informational web site at www.OverlappingConditions.org.

Millions of Americans suffer from one or more of these chronic disorders: CFS, endometriosis, interstitial cystitis (painful bladder syndrome), irritable bowel syndrome (IBS), temporomandibular joint and muscle disorders (TMJ) and vulvodynia. Health care providers receive limited training on these conditions, leading to frequent misdiagnosis and inappropriate treatment for millions of patients.

Studies indicate these conditions often “overlap.” Much more research is needed to understand the connection(s) and develop more effective treatments.

All of these conditions cause enormous physical and emotional distress for sufferers and their families. In addition, they cost the U.S. billions of dollars each year in medical costs and lost productivity.

The mission of the OCA is to change this situation by advancing the scientific, medical and policy needs of individuals afflicted with multiple chronic conditions. The Alliance is composed of the CFIDS Association of America, the Endometriosis Association, the Interstitial Cystitis Association, the International Foundation for Functional Gastrointestinal Disorders,

Survey Series Reveals Reader Interests

Through the months of February, March and April, the Association asked readers of its monthly e-newsletter, CFIDSLink, to complete a series of online reader surveys. About 70% of the responders also read the *Chronicle*, so this information is helpful to us in shaping the content of both print and electronic publications. Here’s a short recap of what we learned from these surveys:

- The five topics of greatest interest to those who responded are (in order of preference):
 1. Articles about CFS treatment
 2. Research stories about topics being studied in CFS
 3. Research summaries from the published literature
 4. Media reports on CFS
 5. Personal stories from CFS patients and caregivers
- Treatment stories about well-studied therapies of any kind (93%) ranked highest; only 32% indicated having high interest in faith-based strategies. The other categories (pharmaceutical, behavioral, alternative, self-care and coping therapies) fell in between.
- Readers want most to hear treatment news from expert CFS physicians (69%), with individual patients’ accounts ranking second and health care professionals from any discipline ranking third.
- Research studies about treatment were the most popular (94%); studies of the cause of CFS came in second (82%).
- Patient stories offering tips for recovery (84%) and tips for coping (79%) were most popular. Stories about patients with severe bedbound illness received low interest marks; memorials and stories about patients who have died received the lowest marks of all.
- The coping/self-care topics of greatest interest (in order of preference) are:
 1. Strategies for energy conservation
 2. Reviews of other information sources
 3. Healthcare advocacy
 4. Obtaining emotional support
 5. Low-energy entertainment options
 6. Assistive devices

An overwhelming 98% said “yes” to a question asking if they would be willing to participate in surveys that provide information to researchers studying CFS. We are now conducting our first online research survey and you can participate through the link found at www.cfids.org/solveCFS/SS09.asp. ■

the National Vulvodynia Association and the TMJ Association.



Many other disorders share similar symptoms or features and might be appropriate for inclusion in the Overlapping Conditions Alliance. These six organizations joined in a collaborative spirit and represent the founding groups. They will work cooperatively with other organizations and institutions to bring greater attention and research funding to this broad family of disorders. ■

“The label that doctors use to make a diagnosis for these conditions often has less to do with patient’s particular symptoms than it does their familiarity with one or more of these conditions. We can help by pointing out where the similarities and differences lie.”

Kim McCleary, president and CEO of the CFIDS Association of America



CDC Solicits Input and Gets Plenty

by Kim McCleary, President and CEO

The CFS research program at the U.S. Centers for Disease Control & Prevention (CDC) is almost 25 years old. Its home in the Coordinating Center for Infectious Diseases,

under a unit called the Chronic Viral Diseases Branch (CVDB) suggests that CDC defines CFS as a condition resulting from a chronic viral infection and that its research program is designed to understand it as such. Yet the most recent studies from CDC investigators link CFS to traumatic events in early life and repeat others' findings of poor sleep in CFS. A quarter of a decade after the first investigation of CFS by CDC in Incline Village, Nevada, the CVDB's lack of understanding of "true" CFS could not be more obvious. Here is a report of a recent CDC meeting, as well as information about how the Association has been pushing for reform for nearly two years.

A public meeting held at CDC on Monday, April 27, 2009, invited "stakeholder" input on a five-year strategic research plan being developed to guide the CFS program. The heightened alert caused by rising numbers of swine flu (H1N1 virus) in the U.S. put CDC on the front lines of that outbreak and its Global Communications Center was swamped by reporters, video crews and photographers at noon on April 27. A press briefing being held in auditorium B-1 garnered most of the traffic, but a few of us walked farther down the hall to B-2 where the CFS meeting was held. There were about thirty people in the room, nearly half of whom were CDC employees. The advocates were mostly local patients, with just a few of us having traveled from out of state to attend the half-day meeting. CFS patient **Alyson Butcher** and her husband **Kenny** flew in from Houston that morning and **Dr. Nancy Klimas** was there from Miami. I had driven from Charlotte the night before.

Acting CDC director Dr. Richard Besser had planned to make opening comments, but on arrival we were told that he, of course, had to change his schedule to accommodate media interviews about the swine flu outbreak. **Dr. Lonnie King** filled in, recounting worn CDC messages and offering the story of "one of their own" agency employees who came forward as a CFS patient after the November 3, 2006 press conference led by then-CDC director Dr. Julie Gerberding. **Dr. Steve Monroe** provided an overview of the planning process and gave an update on the agency's full-force efforts to respond to the "public health emergency" caused by swine flu, of which there were then 20 U.S. cases. **Dr. William Reeves**, chief of CVDB and CDC's lead CFS researcher, gave a short and overly general synopsis of current activities. The moderator then provided ground rules to the public for making comments, both in person and by telephone, which those of us in the auditorium could hear broadcast over the P.A. system.

The lack of detail about CDC's research plan released before the session left many to use their time to plead broadly for help with better diagnostics and treatment, or access to physicians who would recognize the severity of their symptoms and offer some relief. Others expressed strong emotions about the lack of progress over 25 years and deep concern about CDC's propagation of a broader "empiric" classification method for identifying CFS patients enrolled in its studies. Tempers often flared about the lack of respect shown by Reeves and others for patients' concerns and the lack of productivity and direction that defined CDC's CFS research in recent years. Several people demanded new program leadership and others stated outright that Reeves should be replaced.

By 5 p.m., about 35 people had offered their input and 3 of the four CDC leadership representatives (**Sarah Wiley**, **Dr. Monroe** and **Dr. Michael Miller**) were still attentive, making notations in their green lab notebooks and ignoring their Blackberries and cell phones, in spite of swine flu updates likely being issued to CDC staff. But Reeves, seated on the first row with his head bowed, glasses off and eyes closed, remained still through the lengthy comment period.

Was he even listening? He vanished as soon as closing remarks were delivered by Monroe.

Three Association representatives delivered comments during the testimony period: board chairman **Jennie Spotila**, board member **Dr. Katrina Berne** and me. We had written our comments independently but they all echoed messages the Association had been delivering for the past 20 months to CDC leadership. The program was broken, or as I chose to say from the podium that afternoon, it had "lost its mojo."

Our most recent concerns were first directly expressed in 2007 through the decision not to pursue a sole source contract offered by CDC to continue a multi-year provider education project. While the need for provider education is urgent, CDC's methods were inefficient and the contract terms unfavorable. In a letter sent to contract officer Jeff Miller on August 16, 2007, I stated, "the many potential risks and vulnerabilities in the terms of this contract, as well as growing concerns about the direction of the CFS program and the manner in which the contracting process has been handled, have led to the decision not to continue the proposal process."

Conversations with coordinating center leadership went nowhere and a Blue Ribbon Panel's set of recommendations didn't go much farther in changing current practices that fall. So, we asked for a Congressional inquiry into program direction and funding accountability through a letter sent to Senate Majority Leader Harry Reid and other influential members of the Senate and House in March 2008:

"Senator Reid...we know that you are committed to assisting us in fulfilling the promise of better diagnostics and therapeutic approaches to reduce the significant burden of illness posed by CFS. Your immediate assistance in helping us determine the state of the CFS program at CDC and restore its promise would be incredibly important and hopefully will lead to improved transparency, accountability and performance."

Reid forwarded our letter to then-CDC director Gerberding, who responded with a promise to look into the matter. A meeting held in Reid's office on June 7, 2008 with Miller, Monroe, Wiley and two D.C.-based CDC staffers gave us the opportunity to directly state our concerns and to ask questions about a written update circulated by CDC at the May 2008 CFS Advisory Committee (CFSAC) meeting. They promised regular updates and a complete accounting of the CDC's expenditures between 2005-2008.

A series of conference calls throughout the summer and fall of 2008 continued the dialogue and provided additional opportunities to continuously reinforce our message about the need for reforming the program. We closely examined the expenditures CDC reported and were given descriptions of the activities supported, although CDC staff didn't seem concerned by the lack of outcomes for the millions of dollars that had been spent and obligated to the program. At the October 2008 CFSAC meeting, I went "public" with these concerns and advisory committee members recorded theirs as well.

As scheduled, two weeks later CDC convened a long-overdue external peer review of its program. The participants were selected from lists of candidates submitted by the Association, the CFSAC and others earlier that spring; however, only five reviewers were chosen and one was unable to attend. Based solely on the report issued after the review, material presented to them must have focused on past work over a 10-year period since the prior peer review in 1999, rather than more recent past or planned studies. This surprisingly positive endorsement of CDC's program was used by CDC to inoculate other criticism, and at that point, the focus shifted to developing a five-year plan, as the reviewers recommended.

The November 2008 election brought opportunities to engage new leaders in the dialogue, but delays in

confirming a new Secretary of Health meant that a new CDC director might not be appointed for months after the election. The Association sent a letter to Monroe on February 10 citing President Barack Obama's directive to enhance data sharing and transparency:

"The data amassed by the CDC CFS Research program is a valuable resource that must be released and shared in accordance with the CDC/ATSDR Policy on Releasing and Sharing Data and the President's memorandum dated January 21, 2009 that directs all executive agencies to 'take appropriate action, consistent with law and policy, to disclose information rapidly in forms that the public can readily find and use.'"

While waiting for the dust to settle after Senator Tom Daschle withdrew from consideration as Secretary of Health, on March 11 the Association sent a heavily footnoted seven-page memo to acting CDC director Besser, describing the history of CDC's engagement in CFS research and our recommendations for corrective measures.

"...progress toward understanding CFS as a chronic condition with multiple triggering and perpetuating factors has stalled and the lack of program staff's experience in dealing with chronic conditions, particularly in establishing and maintaining the type and variety of partnerships and collaborations recognized as being critical to the study of chronic conditions, is undoubtedly one of the essential elements currently missing from the agency's approach to CFS."

We also provided this information to Congressional appropriators and shared concerns that CDC was developing its five-year plan without including a process for obtaining stakeholder input. (Besser responded on April 22, conveying his assurances that CDC is "committed to supporting a rigorous research program on CFS and to address the requests and concerns of your organization and others.")

A month after receiving our memo to Besser, CDC announced the April 27 meeting. The lack of a planning document to examine left us feeling that the meeting was likely to erupt into a full-blown "gripe" session, especially with the immediate frustration expressed by advocates for the late notice of the date, lack of accessibility, and absence of an agenda and a report draft. We asked CDC leaders to broaden access and we helped circulate notices to encourage participation, hoping that CDC would hear from a broad segment of its constituency. The meeting date was also the deadline for one of the NIH mechanisms to apply for funds available under the Recovery Act, so we knew this would limit participation from the scientific community, but hoped they might respond if the deadline was extended. CDC accepted input until May 1.

All our predictions about the public meeting turned out to be accurate, as others' published accounts of the meeting document. In my 18 years with the Association, I can't recall another occasion on which the patient community was so consistent in its call for change.

CDC has agreed to release its draft plan on May 27 at the CFSAC meeting and on its web site. It will accept public comment on the draft plan through June 30. We continue to encourage anyone interested in the future of CDC's research on CFS to express views and offer input into the plan. As taxpayers and advocates, it is our responsibility to see that these funds are put to the best possible use to discover ways of objectively diagnosing and effectively treating CFS.

For updates on the CDC's plans and links to others' meeting reports, visit www.cfids.org/solveCFS/SS09.asp ■

Public Awareness By The Numbers

by Sara Collins, Public Relations & Events Manager

What do you get when you add 54.9 million + 108.4 million + 923 + 116 + 450?

You get at least 164 million people who saw, heard or read about CFS in 2008.



Now in its third and final year, the CDC-funded, \$6 million CFS public awareness campaign continues to generate media

coverage, educate Americans and cultivate compassion for those suffering from the illness.

Here are the campaign's 2008 results by the numbers:

Public Service Announcements

- The television public service announcement (PSA) aired 4,173 times, reaching an estimated 54.9 million viewers. This free commercial airtime is valued at \$195,087.
- Two versions of the radio PSA aired 32,865 times to deliver an estimated 180.4 million listeners, worth nearly \$3.4 million.

"The Faces of CFS" Traveling Photo Exhibit

- "Faces" was displayed in 10 more cities and as many as 923,116 consumers were directly exposed to the photo exhibit at these venues.
- Media outreach using the exhibit as a news hook resulted in 172 print, broadcast and online stories.
- "Faces" was also displayed at the American Academy of Physician Assistants Annual Meeting, where 450 attendees visited the booth.

Campaign Materials

- 24,154 copies of *Understanding CFS: A Guide for Patients*, were distributed. (See p. 5)
- 56,650 copies of the *CFS Toolkit for Health Care Professionals* and its fact sheets were distributed. (See p. 5)

- 12,243 copies of the brochure for medical professionals, *Recognition and Management of CFS*, were distributed.

Partnerships with Health Care Organizations

- The Association contacted hundreds of HMOs, hospitals and health organizations in cities and regions where the photo exhibit was exhibited, resulting in the dissemination of campaign messages through print and online publications.
- The Association also partnered with numerous other medical, general health and women's organizations to distribute campaign materials in print and online, with articles published in *Journal of the American Academy of Physician Assistants*, *Drug Topics*, *Clinical Advisor*, *Cortlandt Forum*, *U.S. Medicine*; and on the websites of the U.S. Health Resources and Services Administration and *Our Bodies, Our Selves*, to name a few.
- In August, more than 700 clinicians participated in a Kaiser Permanente Medical Group-sponsored videoconference on CFS in northern California.

Earned Media

- The campaign has been highly successful in extending media coverage far beyond the November 2006 press conference launch event. General media outreach and outreach related to the photo exhibit resulted in more than 400 print, broadcast and online stories nationally about CFS.
- These media stories generated tens of millions of audience impressions and exposed consumers to multiple educational CFS messages.

Although the public awareness campaign is winding down, the need to educate people about CFS remains. The Association is exploring ways to build on the campaign's momentum and keep CFS in the media spotlight. Links to the Faces exhibit schedule, media stories, etc., can be found at www.cfids.org/solveCFS/SS09.asp. ■

Medscape Course Makes An Impact

In October 2008, Medscape, the world's leading source of health information for consumers and health care professionals, launched a clinical update on CFS in partnership with the CFIDS Association of America. The course was marketed to physicians, physician assistants, nurses, pharmacists and other clinical staff in 19 general and specialty medical professions. Through May 2009, the course has educated more than 47,000 health care professionals and 28,000 continuing education hours have been issued. Total page views exceed 243,000. By comparison, the CDC's online CFS continuing education unit issued just 1,533 certificates in four years.

Ninety-five percent of the professionals who completed the course indicated they would recommend it to a colleague and 85% indicate that what they learned will impact their practice.

Make sure your health care provider knows about the availability of this course. Simply tell him/her to search for "chronic fatigue syndrome" on Medscape's CME site or cite this URL to take the course: cme.medscape.com/viewprogram/17442. The course is available for continuing education credit through October 2009.

The Association acknowledges the financial support received from a family that wishes to remain anonymous, as well as the assistance provided by Drs. Lucinda Bateman and Charles Lapp to make these popular and effective resources available to medical professionals worldwide. ■

The Media Isn't Tired of CFS

Part of the power of the public awareness campaign is to draw media attention to CFS and those who suffer from it. Driven in large part by "The Faces of CFS" portrait exhibit (see left), interest in CFS from local and regional media outlets continues to be robust.

In March, Reno-area media outlets ran stories and segments about the "Faces" display at Meadowood Mall during the IACFS/ME conference (see p. 2). Eight stories appeared in local newspapers; four radio stations aired interviews with CFS experts and local patients; one television talk show host mentioned it; and the online event calendars of 11 local newspapers and radio and TV stations provided details.

CFS had an explosion of coverage, particularly in broadcast outlets, in the St. Louis area before, during and after the April display of "Faces" at St. Louis Mills. Eight newspapers included information about the exhibit; seven websites posted stories and calendar listings; and three television stations included segments about CFS and "Faces" on news and talk shows.

St. Louis provided tremendous radio coverage too, with nearly six weeks of programs sandwiching the exhibit's display. Several stations ran simple announcements about "Faces," while 13 others hosted Association staff, CFS patients and a health care professional as guests on talk shows.

Even at the peak of swine flu news coverage, Milwaukee-area media outlets made sure folks knew about CFS and the photo exhibit's display in May: one print publication and nine websites included details in event calendars, while 15 radio stations aired announcements or entire CFS segments.

Outreach efforts around the photo exhibit have also yielded other regional and national (international, if you include the Web) coverage this year, including appearances by Association staff and guests on radio shows in California and Oregon; two Internet broadcasts of popular call-in radio show "Ask Dr. DeSilva;" and talk show "SpeakUp!" on Internet channel WomensRadio.com. For links to more coverage visit www.cfids.org/solveCFS/SS09.asp. ■

Have You Seen the Face of CFS?

Of course, you may see it every day in the mirror or when you glance across the room at a loved one, but you can see 10 other faces of CFS when you visit "The Faces of CFS" traveling photo exhibit.



Renowned photographer George Lange captured the strength and courage of eight CFS patients and two health care professionals who are experts on the illness. Their portraits were printed on 10 banners, each more than seven feet tall, that have been seen in 40 venues across the country since 2006.

The next stop for "Faces" is in Meriden, Conn., at Westfield Meriden mall (near Hartford) from June 15–21. It will also be displayed at the annual students and residents conference of the American Academy of Family Physicians from July 30–August 1. We're scouting venues in other cities across the country for more displays through October. Check www.cfids.org/solvecfs/SS09.asp for details. ■

Virtual Lobby Day: Five Years Strong

For each of the past five years, the Association has hosted an online "Virtual Lobby Day" to enlist advocates in contacting elected officials, top health policymakers and the media through our Grassroots Action Center. In past years, this activity was coordinated with our "live" Lobby Day event in Washington, D.C. This year, for numerous reasons, we decided not to host a live Lobby Day, so we relied even more heavily on our virtual event to get the word out on international CFS/ME awareness day, May 12.

We created three easy-to-complete actions with pre-written template letters to local media (Action 1), newly appointed Secretary of Health Kathleen Sebelius (Action 2), and elected officials President Barack Obama, Vice President Joe Biden and the individual's U.S. House and Senate representatives

(Action 3). On May 11, we sent notices to Grassroots Action Center alert subscribers, CFIDSLink subscribers and Facebook fans, asking them to complete the actions and spread the word.

Within the first three weeks, 2,835 letters had been sent through the Grassroots Action Center in response to Virtual Lobby Day. We'll continue the campaign through the end of June; you can find links to the three actions at www.cfids.org/solvecfs/SS09.asp. Complete them today and ask family and friends to do the same! ■



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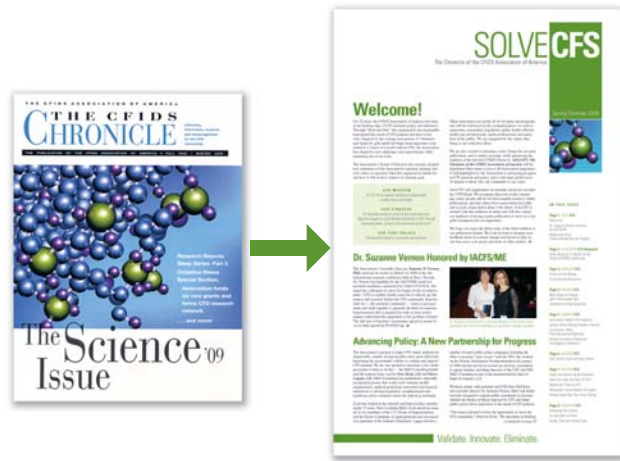
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Extending the Lifeline: A New Look!

In the winter 2009 issue of the *CFIDS Chronicle* we announced that we were evaluating our publications strategy to serve loyal readers at a lower cost, while acknowledging that many people now prefer to receive information electronically. Here is our new print publication, *SolveCFS: The Chronicle of the CFIDS Association of America*. (See also our Welcome! letter on page 1.) *SolveCFS* serves as a supplement to our free monthly e-newsletter, *CFIDSLink*, and stands on its own.

Another change we've made will consolidate our dues structure. In the past, people who received the *Chronicle* fit into one or more of these groups: members paying \$35 annual dues, monthly pledges, or donors making gifts of \$250 or more. This was often confusing to the individual, and sometimes it wasn't clear to us what the supporter's intentions were — whether they meant to join or simply donate.

Beginning June 1, anyone who makes an annual gift of \$35 or more will receive this print publication three times a year. Donations, unlike dues, are fully tax-deductible — that's one immediate advantage of this new structure!

We hope that these changes will help meet the information needs of our supporters, expand the number of people served by our publications and make it easier for you to express your financial support of the Association's vital research and policy initiatives. Please share your thoughts and ideas and/or sign up to receive *CFIDSLink* by sending a message to cfids@cfids.org or the mailing address at the bottom of this page's left column or by calling our Resource Line at 704-365-2343. ■

As We Went To Press...

The challenge of any print publication, no matter its frequency, is that it's outdated before readers receive it. A few current events were pending as this issue went to press. We've recapped here and will link to updates on our website at www.cfids.org/solveCFS/SS09.asp.

CFS Advisory Committee Meeting: The federal committee met May 27–28, 2009 in Washington, D.C. to receive agency reports, review a draft of the Centers for Disease Control & Prevention's five-year strategic plan draft, and hear testimony from the public. For the first time, the meeting was videocast and will be archived at www.hhs.gov/advcomcfs/.

Food and Drug Administration (FDA) Decision on Ampligen: The FDA was set to announce its decision on the new drug application for Ampligen. (See p. 4.) If approved, it would be the first treatment allowed to be marketed for CFS.

Outcome of Association's First NIH Grant Application: The Association partnered with Cold Spring Harbor Laboratories in submitting a grant application to host a think-tank type meeting titled, "From Infection to Neurometabolism: A Nexus for CFS." (See p. 3.) The application was favorably reviewed but the final decision was expected by May 29. ■

Address Area

Continued from page 1

Advancing Policy: A New Partnership for Progress

effective public-private partnerships to address the burden of disease. Debra and I believe that this collaborative strategy can significantly accelerate progress toward new therapies."



Dave Zook

McCleary shared her respect for the firm's past accomplishments. "B&D has represented the interests of disease communities facing similar challenges and has contributed to increased attention to and funding for arthritis, Alzheimer's and ALS, to name just a few conditions. We look forward to applying their experience and strategic approach to advance our cause."



Debra Lappin

Prior to engaging B&D Consulting in May, the Association benefited greatly from a longstanding relationship with the Sheridan Group and its founder Tom Sheridan. With the rapidly changing political and economic landscapes and a more intense organizational focus linking research and public policy that culminated at year-end, the Association canvassed several firms to help set a course for the new administration.

Four firms submitted detailed proposals to address our policy-oriented objectives. B&D's innovative approaches, deep experience and excellent reputation earned the highest marks from reviewers. After consulting with several of the firm's current clients and other Washington, D.C. contacts, B&D emerged as the best fit to help us leverage past successes and overcome current challenges.

We are excited about this transition and the promise it holds for advancing CFS research and public policy, and we look forward to sharing more news of progress with our supporters! ■