

As We Went To Press...

Publication of several **XMRV studies of CFS patients** is anticipated, with papers pending from groups at the U.S. Centers for Disease Control & Prevention, Koch Institute in Germany (presented at Centennial Retrovirus Meeting in Prague), Tufts University (presented at Invest in ME conference in London), Institut de recherches cliniques de Montréal (presented at the Cold Spring Harbor Laboratory's Conference on Retroviruses) and other institutions. This summer, the Department of Health and Human Services Blood XMRV Scientific Research Working Group, of which Association scientific director Suzanne D. Vernon, PhD is a member, will analyze results of analytical samples of XMRV processed by six laboratories (including the Whittemore Peterson Institute) to standardize assay results.

The *Wall Street Journal* has published a series of articles about dozens of infectious agents (including XMRV) that pose potential threats to the **blood supply**. Added donor education and screening measures are filling gaps while scientists improve methods of testing for and preventing spread of these agents. The Interorganizational XMRV Task Force convened by the American Association of Blood Banking continues its discussion of donor and recipient safety issues for CFS patients. Association CEO Kim McCleary serves on this committee. (See page 3 for more on blood safety.)

Dr. Martin Lerner, a clinician-researcher who treats and studies CFS patients, has published results of **antiviral treatment** of two patient groups in the journal, *Virus Adaptation and Treatment*. He found that CFS patients who had one or more herpesvirus infections (i.e., Epstein-Barr virus, HHV-6, cytomegalovirus) but did not have co-infections with other agents (e.g., *Borrelia burgdorferi*, *Anaplasma phagocytophila*, *Babesia microti*, and anti-streptolysin O) responded well to long-term treatment with valacyclovir (Valtrex) and/or valganciclovir (Valcyte). Beginning treatment earlier in the course of illness appeared to be a factor that distinguished "responders" from "non-responders" among the group that did not also have co-infections with other agents.

For all the latest updates, please visit www.cfids.org/SolveCFS/SS10.asp. ■

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Our main website with thousands of pages of resources, references and archives.

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Our website aimed at engaging others in the cause of making CFS widely understood, diagnosable, curable and preventable. Also home to information about the SolveCFS BioBank.

www.facebook.com/CFIDSAAssn

Participate with a community of more than 4,000 "fans" on our main social networking site with daily updates and exchanges on a wide variety of topics of interest.

www.twitter.com/PlzSolveCFS

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SOLVE CFS

The Chronicle of the CFIDS Association of America

Spring/Summer 2010

So Much News to Share!

Our fall 2009 issue of *SolveCFS* informed readers about an important study linking CFS to a newly discovered human retrovirus called XMRV. News about this discovery and other topics has been evolving so rapidly that it's been a challenge to get another issue of *SolveCFS* off to print! We anticipate that there will be many new developments between the time this issue is published and when you read it; if there was ever an ideal time to connect to us online, it's now! In addition to our monthly e-newsletter, *CFIDSLink*, you can find us on Facebook, Twitter and YouTube, as well as our main website at www.cfids.org. Call our Resource Line at 704-362-2343 if you need help getting "linked up" to our online resources.

The stories in this issue will help bring you up to date (or refresh your memory) about the busy events of the past few months. Here are a few brief updates about topics that we don't report more fully elsewhere in this issue. You can find links to these and other resources on the web page devoted exclusively to this issue of *SolveCFS* at www.cfids.org/SolveCFS/SS10.asp.

- Several very different infectious agents have been shown to result in persistent CFS-like illness in a subset of those who become acutely ill. In two articles "Precipitating Pathogens" and "We Are Not Alone," our scientific director, Suzanne D. Vernon, PhD, reviews recent literature.
- Post-exertional malaise is a cardinal feature of CFS that distinguishes it from many other

conditions. Dr. Vernon describes how exercise challenges that provoke post-exertional malaise are being used by research groups to further our understanding of CFS in her article, "The Hallmark of CFS." A new series of articles on this topic began in our June *Link*.

- Dr. Julia Newton's group at University of Newcastle published results of a study showing muscle proton abnormalities following exercise in CFS patients. Dr. Vernon describes this study and how it brings together other pieces of the CFS puzzle in the "Litmus Test."
- U.S. Centers for Disease Control & Prevention announced that its CFS Research Program would have new leadership and Elizabeth Unger, PhD, MD, took over as acting chief of the Chronic Viral Diseases Branch on Feb. 14, 2010.
- This year the Association will be working to establish CFS as a topic eligible for funding by the Department of Defense's Peer Reviewed Medical Research Program. We have asked to hear from veterans and active duty military about their experiences with CFS and CFS-like illnesses.
- One of the U.K.'s national daily newspapers, the *Guardian*, published an exceptional article about CFS/ME on May 13, "The Trouble with M.E." There has been a great deal of affirming media coverage about CFS so far this year. ■

XMRV Accelerates Scientific Interest in CFS

In the October 8, 2009 issue of *Science*, researchers at the Whittemore Peterson Institute, the Cleveland Clinic and the National Cancer Institute reported that 67 percent of 101 CFS patients tested positive for infection with xenotropic murine leukemia virus-related virus (XMRV), a gammaretrovirus associated with a subset of prostate cancer. Only 3.7 percent of 218 healthy subjects tested were positive for the virus.

A January 6, 2010 report, by researchers at the Imperial College in London, found no evidence of XMRV by polymerase chain reaction (PCR) testing of 186 CFS patients' banked samples. A third study reported finding no evidence of XMRV infection in 186 CFS patients in the United Kingdom. The fourth

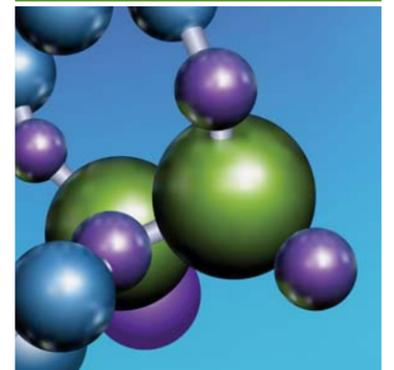
study, by researchers in the Netherlands, did not find XMRV in the 32 patients' samples they tested. Laboratory methods and patient selection criteria differed between the four studies in substantial ways, leading to accusations and speculation from both sides of the Atlantic in follow-up media

reports, online forums and direct correspondence made public. As our scientific director, Dr. Suzanne D. Vernon, has stated, "None of the follow-up studies published so far represents a true replication study and more work needs to be done to fully understand the finding published in *Science*."

The May 14, 2010 issue of *Science* published commentary about the initial study from three groups of researchers, as well as a response from Judy Mikovits, PhD, and Francis Ruscetti, PhD, two of the 13 authors of the initial study. The response offered amplification of certain details but contradicted information presented elsewhere over the past eight months. Bottom line — more study is needed to resolve the important questions raised by all these reports.

Fortunately, further research is under way at several institutions in the U.S. and other countries and more reports are forthcoming. There is currently no FDA-approved test available for XMRV and clinical studies of treatments must be conducted to test their efficacy against XMRV infection and their safety in XMRV-positive patients.

For more on the evolving studies of XMRV and related blood safety issues, read our more in-depth article on page 3. Visit www.cfids.org/SolveCFS/SS10.asp for other resources and links. ■



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Validate. Innovate. Eliminate.

Embarking on the SolveCFS BioBank

When scientific director Suzanne D. Vernon, PhD, joined our staff in late 2007, one of her goals was to fill scientific “infrastructure” gaps she believed were barriers to attracting new investigators and validating some of the known biological markers published by research groups in the U.S. and other countries. Linking bench researchers to well-defined clinical populations was one of the foremost challenges.

In September 2009, Suzanne completed her certificate in public health genomics at Sarah Lawrence College and met leaders from Genetic Alliance (GA), a network of more than 1,000 disease-specific advocacy organizations committed to transforming health through genetics. She learned how GA had created a centralized registry and repository to enable translational research for a host of underfunded and rare conditions, addressing the cohort access issue. GA president Sharon Terry recounts her goal in establishing the GA BioBank with other leaders in disease research advocacy: “The Genetic Alliance BioBank was built with organizations like the CFIDS Association in mind — to provide them with the infrastructure to pursue sophisticated, novel research collaborations with academia and industry to develop new diagnostics and therapeutics to better understand and treat disease.”

Suzanne conducted her own careful research, comparing the Genetic Alliance model to several others, weighing the costs and benefits to the organization, the patient community and researchers in academia and industry. Summarizing her findings, she told our board of directors last fall, “The Genetic Alliance uses a cooperative, cost-sharing model that translates into a tightly controlled, comprehensive infrastructure for biobanking. Their standards for ethics, security and privacy are top-notch. Organizations that start from scratch often spend millions of dollars just to put the systems and documentation in place before a single sample is collected.”

The Association’s board of directors approved plans to join the Genetic Alliance BioBank and approval from GA’s Institutional Review Board was granted in March 2010.

On March 29, 2010, the CFIDS Association announced creation of the **SolveCFS BioBank**. The **SolveCFS BioBank** will collect and store a bank of biological samples (such as blood,

tissue, cells and DNA) and clinical information at the GA BioBank laboratory facility from individuals with CFS and healthy individuals (controls). It ensures

that individual privacy and confidentiality are protected and that samples are available to researchers whose research projects have been reviewed and approved by the Association’s Medical Research Advisory Committee.

Through the **SolveCFS BioBank**, individuals can enroll once and will then contribute information to multiple projects, advancing our understanding of CFS on multiple fronts. Because the **SolveCFS BioBank**’s purpose is dedicated to research and in order to preserve the privacy and security of all participants’ information, participants do not receive personal results about any tests performed using their samples.

The Association will provide regular updates about how **SolveCFS BioBank** samples are being used, as well as the results of research conducted. Researchers will be required to publish their results in peer-reviewed medical journals.

The Association has established its first study collaboration and is working with several clinical and academic collaborators and major industry partners. As such, enrollment criteria for the inaugural study are rather strict. As Suzanne indicates, “The **SolveCFS BioBank** is an innovative research resource that will be used for validation of promising biomarkers, genetic studies, family studies and genomics research. It will be a resource for discovery, diagnostics

and targeted treatments. We hope to have adequate funding soon to expand recruitment beyond the inaugural study requirements. This will truly empower more people affected by CFS to participate in this exciting research, and will ultimately lead to the answers we all seek.”

We look forward to sharing additional updates, news about expanded recruitment and, best of all, results from research that utilizes the **SolveCFS BioBank**. We are grateful to Association supporters for making this new initiative possible. It is just one of many reasons that 2010 promises to be a year of important advances in making CFS widely understood, diagnosable, curable and preventable. ■

General Enrollment Requirements for SolveCFS BioBank

(as of June 8, 2010)

Individuals with CFS are eligible for General Enrollment in the **SolveCFS BioBank** if they have been diagnosed with CFS by a licensed physician using either the Fukuda (1994) research criteria or the Canadian (2003) clinical criteria and meet the general inclusion and exclusion criteria listed below.

Under General Enrollment, participants provide written informed consent and complete detailed clinical questionnaires to become part of future **SolveCFS BioBank** studies. Blood and tissue samples will be requested from enrollees who meet more specific criteria for approved studies. This new enrollment status facilitates greater participation by members of the community, expands the clinical population available to interested investigators, and enables the Association to defer the expense of sample collection until those samples are needed for an approved study.

If you are interested in learning more, contact our BioBank Coordinator, Gloria E. Smith, at (704) 362-2343, or by e-mail at biobank@cfids.org.

General Inclusion Criteria for CFS Subjects

You must fulfill all these criteria in order to be eligible:

1. Fatigue persists for at least six months.
2. Post-exertional malaise defined as an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, and/or fatigue and/or pain and a tendency for other associated symptoms within the patient’s cluster of symptoms to worsen after even minimal physical or mental exertion. Pathologically slow recovery period usually lasting 24 hours or longer.
3. Significant cognitive impairment in short-term memory and concentration.
4. Minimum age of 10 at the time of signing the informed consent; there is no upper age limit.
5. A female subject is eligible to participate if she is not pregnant, not within three months postpartum, and not currently lactating per self-report.
6. Capable of giving written informed consent to the CFIDS Association of America, which includes compliance with the requirements and restrictions listed in the consent form.

General Exclusion Criteria for CFS Subjects

A subject will not be eligible for inclusion in current studies if they do not meet the Fukuda criteria or the Canadian criteria (see references below) or if the following general exclusion criteria apply:

1. Alcohol or substance abuse within two years before onset of chronic fatiguing illness defined as an average weekly intake of more than 14 drinks for males or more than 7 drinks for females. One drink is equivalent to 12 g of alcohol: 12 ounces (360 ml) of beer, 5 ounces (150 ml) of wine or 1.5 ounces (45 ml) of 80 proof distilled spirits.
2. Where participation in the study would result in donation of blood or blood products in excess of 500 mL within a 56-day period.
3. Major surgery within six months after operation or minor surgery within three months after operation.
4. Major infections such as sepsis or pneumonia within three months post-resolution.
5. Myocardial infarction or heart failure within five years after event.
6. Morbid obesity defined as body mass index (BMI) greater than 40.
7. Psychiatric conditions including lifetime diagnosis of bipolar affective disorders, schizophrenia of any subtype, delusional disorder of any subtype, organic brain disorders, or major depressive disorder with psychotic or melancholic features, anorexia nervosa, or bulimia within 5 years before the onset of chronically fatiguing illness.
8. Unwillingness or inability to provide written informed consent.
9. Mental or legal incapacitation.

For the latest updates and criteria for healthy control subjects, please visit
www.cfids.org/SolveCFS/SS10.asp

**SOLVECFS
BIOBANK**

Comparison of Published XMRV Studies in Patients with CFS

Publication Date	Oct. 8, 2009	Jan. 5, 2010	Feb. 15, 2010	Feb. 25, 2010
Article Title	Detection of an infectious retrovirus, XMRV, in blood cells of patients with CFS ¹	Failure to detect the novel retrovirus XMRV in CFS ²	Absence of XMRV in UK patients with CFS ³	Prevalence of XMRV in patients with CFS in the Netherlands: retrospective analysis of samples from an established cohort ⁴
Journal (ISI Impact Factor, a journal rating system)	<i>Science</i> (29.78)	<i>Public Library of Science One (PLoS ONE, not rated)</i>	<i>Retrovirology</i> (4.6)	<i>British Medical Journal</i> (12.827)
Lead Author	V. Lombardi	O. Erlwein	H.C.T. Groom	F.J. Van Kuppeveld
Institution(s), Country	Whittemore Peterson Institute, National Cancer Institute, Cleveland Clinic, USA	Imperial College, United Kingdom	Medical Research Council, United Kingdom	Radboud University, Nijmegen Medical Center, the Netherlands
Author(s) with prior XMRV publications	R.H. Silverman		J.P. Stoye	
Author(s) with prior CFS publications	V.C. Lombardi and D.L. Peterson	S. Wessley and A. Cleare	J.R. Kerr and J.W. Gow	
Number of CFS subjects	101	186	142 (PCR, antibody)	32
Number of control subjects	218	none	157 (PCR, neutralizing)	43
Number (%) CFS subjects positive for XMRV	68 (67%)	0	0/142 PCR 0/142 antibody 1/28 neutralizing activity	0
Number (%) controls positive	8 (3.7%)	0	0/157 PCR 22/157 neutralizing activity	0
Positive test demonstrated by	PCR, culture	PCR	PCR, antibody	PCR
CFS criteria used	Fukuda, Canadian	Fukuda	Fukuda	Oxford
Other CFS characteristics	Some had cognitive deficits, immunological abnormalities and exercise testing abnormalities ^{5,6}			May have excluded patients who did not recover from viral illnesses
Source of CFS samples	Collected from 25 patients identified during outbreak in Incline Village and 76 patients with sporadic cases from around U.S. ⁶	Clinic attendees who had participated in studies of CBT and neuroendocrine measures	St. George's Univ., London and Glasgow Caledonian Univ.	Dutch clinic conducting CFS research (1991–1992)
Source of controls	People visiting a doctor's office for routine tests and purchased from paternity clinic ⁶	n/a	Healthy blood donors, prenatal clinic; patients with blood disorders; liver patients and kidney clinic.	Matched neighborhood controls
Patient demographics	Age range 19–75 with a mean age of 55. 67% female ⁶	Unwell for a median of 4 years with high levels of fatigue and disability	Not described	Avg. age: 40 yrs (25–67 yrs); Avg. symptom duration: 7 yrs (2–45 yrs)
CFIDS Association study analysis (see www.cfids.org/SolveCFS/SS10.asp)	"Xplained"	"XMRV Negative Results Emphasize Need for Robust Replication Study"	"Second XMRV Negative Study: Still In Search of a Proper and Robust Replication Study"	"Playing A Weak Hand Well"

¹ Lombardi VC, Ruscetti FW, Das Gupta J, Pfof MA, Hagen KS, Peterson DL, Ruscetti SK, Bagni RK, Petrow-Sadowski C, Gold B, Dean M, Silverman RH, Mikovits JA (2009). Detection of an Infectious Retrovirus, XMRV, in Blood Cells of Patients with CFS. *Science*. Vol. 326, 585.

² Erlwein O, Kaye S, McClure MO, Weber J, Wills G, Collier D, Wessely S, Cleare A (2010). Failure to detect the novel retrovirus XMRV in CFS. *PLoS ONE*, 5 (1).

³ Groom HCT, Boucherit VC, Makinson K, Randal E, Baptista S, Hagan S, Gow JW, Mattes FM, Breuer J, Kerr JR, Stoye JP, Bishop KN (2010). Absence of XMRV in UK patients with CFS. *Retrovirology*: 10.1186/1742-4690-7-10

⁴ Van Kuppeveld FJM, de Jong AS, Lanke KH, Verhaegh GW, Melchers WJG, Swanink CMA, et al. Prevalence of XMRV in patients with CFS in the Netherlands: retrospective analysis of samples from an established cohort. *BMJ* 2010;340:c1018.

⁵ Lombardi VC, Ruscetti FW, Gupta JD, Pfof MA, Hagen KS, Peterson DL, Ruscetti SK, Bagni RK, Petrow-Sadowski C, Gold B, Dean M, Silverman RH, Mikovits JA (2009). Supporting online material for Detection of an infectious retrovirus, XMRV, in blood cells of patients with CFS. *Science*. Vol. 326,

⁶ Mikovits, JA and Ruscetti FW (2010). Response to Comments on Detection of an Infectious Retrovirus, XMRV, in Blood Cells of Patients with CFS. *Science*. Vol. 328, 825.

Blood Safety Issues Explored

The CFIDS Association of America has long advised against CFS patients donating blood or making organ transplants. On May 18, 2010, the Association's Board of Directors affirmed this guidance to the CFS community:

"The CFIDS Association of America reiterates its long-standing recommendation urging that individuals with CFS voluntarily not donate blood or organs. This recommendation is based on issues of blood donor safety and blood recipient safety. Research has demonstrated that orthostatic intolerance, low blood volume and infections are common in CFS. Until more is known about the role of various infectious agents in CFS, it is prudent for individuals with a past or present diagnosis of CFS to refrain from giving blood and donating organs to protect the safety of the blood and transplant organ supply for all recipients."

Guidelines in the United Kingdom and other countries have restricted CFS patients from donating blood. Canadian Blood Services revised its guidelines for persons with a history of CFS on Apr. 7, 2010. Persons with a history or current symptoms of CFS will now be "indefinitely deferred" by Canadian Blood Services. The Australian Red Cross announced on Apr. 28, 2010 that it would indefinitely defer CFS patients from donating blood and that it will re-evaluate its policy in two years. New Zealand will follow Canada's new guidelines. So far none of these new policies require any additional testing.

The United States' blood supply is regulated by the Food and Drug Administration (FDA), but it is dependent on donations of blood from healthy volunteers collected at community blood centers, hospitals, by the Red Cross and, in some areas, for-profit entities. While there is no formal policy in the U.S. at this time, eligibility criteria state that blood donors must be "healthy," over age 16 and at least 110 pounds. "Healthy" is defined by the Red Cross as: "feeling well and able to perform normal activities. If you have a chronic condition such as diabetes

or high blood pressure, 'healthy' also means that you are being treated and the condition is under control." Taking various medications can also be a barrier to blood donation. The FDA maintains a list of prohibited medications. The AABB Interorganizational XMRV Task Force is reviewing available data on the potential risk of transmission of XMRV through blood transfusions on an ongoing basis and is considering appropriate recommendations regarding messages for donors, recipients and the public.

These guidelines are intended to help you make decisions about whether to donate blood and/or organs while more research is conducted that may lead to new restrictions. Staff or volunteers at local blood drives or collection centers are unlikely to be as informed as you are about the general health risks associated with CFS or XMRV, and you may have to decline participation more than once.

The U.S. government is coordinating a study to ascertain whether XMRV poses a risk to the safety of the blood supply. Visit www.cfids.org/SolveCFS/SS10.asp for other resources and links. ■

CFS Advisory Committee Makes Five Policy Recommendations

The federal CFS Advisory Committee met on May 10, 2010, for its 17th semi-annual meeting since being chartered in 2003. The meeting was videocast live and the recording has been archived for reference. **Dr. Wanda Jones**, explained that the one day format was necessary due to constraints of time and budget, to ensure that the practice of meeting every sixth months continued.

All voting members of the committee were present, including five new members welcomed by the new committee chairman, **Dr. Christopher Snell** of University of Pacific. New members were sworn in prior to the meeting by Assistant Secretary of Health **Dr. Howard Koh**, who attended the first segment of the meeting, offered opening comments and took questions from members of the committee.

A presentation by **Elizabeth Unger, M.D.**, acting chief of the Centers for Disease Control and Prevention's Chronic Viral Diseases Branch



Members of the CFS Advisory Committee with Dr. Howard Koh (second from right)

where the CFS research program is housed, was the only formal update provided by federal ex-officio members of the committee. This was the first meeting since the leadership transition of the CFS program following Dr. William Reeves' reassignment on February 14, 2010.

Dr. Jerry Holmberg of the DHHS Office of Public Health and Science and senior advisor for blood safety, gave a much-anticipated update on blood safety issues. Dr. Holmberg had addressed the committee on Oct. 30, 2009, to announce the Department's efforts to understand the impact of the report of XMRV in CFS patients and healthy controls as it related to the nation's blood supply. At the May 10 meeting, he described progress of laboratory efforts to standardize tests for XMRV that could be used for large-scale screening and of a second group looking at the blood donor education and communications that had been convened by the AABB and includes several federal agency representatives. The second group's activities were recently informed by three

countries' decisions to indefinitely defer individuals who volunteer information about present or past CFS diagnosis.

Nine individuals, including Association CEO **Kim McCleary**, were invited to address the committee for three minutes each and most of the testimony focused on the topic of the committee's charter as had been requested. Seventy members of the public submitted written testimony of up to five pages each for the record.

The bulk of the committee's time was spent discussing the committee's charter, scheduled to expire on Sept. 5, 2010. Dr. Jones and Dr. Koh both emphasized the Department's unequivocal intention to renew the charter, so the committee's dialogue was intended to recommend changes that would strengthen the committee itself and formalize certain practices (like videocasting and reserving time for public comment).

These are the five formal recommendations sent to the Secretary:

- Given concerns for patient health, that government and non-government organizations responsible for the U.S. blood supply indefinitely defer individuals with a current or past history of CFS from donating blood;
- That the Secretary recognize the special challenges of ensuring CFS is part of any efforts to train and educate health care professionals under health care reform;
- That health agencies AHRQ, HRSA and CMS be directed to develop private and/or public demonstration grants for health service paradigms that result in more effective, efficient care and better health outcomes for individuals with CFS;
- That any attempt to classify CFS as a psychiatric disorder in revisions of the International Classification of Diseases be vehemently opposed; and,
- That the addition of third CFSAC meeting by webinar or webcast be fully explored for 2011.

A more comprehensive meeting summary is available at www.cfids.org/SolveCFS/SS10.asp. ■

Capitol Hill Visits Emphasize Opportunities to Expand Research



CEO Kim McCleary and scientific director Suzanne Vernon, PhD at the Capitol Building

Who? Members of the Association's board of directors (**Diane Bean** and **Amy Squires**), Association staff (**Kim McCleary** and **Suzanne Vernon, PhD**), a long-time volunteer (**Loretta Spotila, PhD**) and staff from B&D Consulting (**Dave Zook, JD** and **Jennifer Carey**)

When? March 3 & 4, 2010

Why? The annual appropriations process of directing the use of federal funds through legislation begins with subcommittee meetings in the Senate and House that generally take place in April or May. Deadlines for Congress members' requests hit much earlier, and individual offices set even earlier deadlines to gather input from constituents and interest groups.

Our meetings emphasized the research and education opportunities presented by the surge of interest in CFS generated by the published report of a link between XMRV and CFS. This information was explained to staff representing members of the Senate and House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies (L/HHS).

We also met with staff members of Congressmen/women who serve on the Appropriations Subcommittee for Defense, to build support for the inclusion of CFS as an eligible topic under the Congressional Directed Medical Research Program funded by the Department of Defense. We tied our request, which must demonstrate military relevance, to the Feb. 25, 2010 announcement by the Veterans Administration to re-examine the services provided to up to 697,000 service men and women who served in Operations Desert Shield and Desert Storm (the Gulf War) and returned from service with multi-

symptom illnesses. There is considerable research associating some of these illnesses with CFS.

What Was Distributed? Depending on which committee the member of Congress served, we provided one or both of our funding request justifications and recent related media articles about CFS. You can access our written justifications at www.cfids.org/SolveCFS/SS10.asp.

How? We worked in two teams to cover 20 meetings over two days. After a short preparation session on the morning of the first day, we headed for the Hill with our information packets and fanned out to the three House of Representatives buildings and three Senate buildings, often walking back and forth across the Capitol to accommodate busy staff schedules.

What's Next? The annual appropriations cycle was interrupted by passage of health care reform legislation, but we continuously monitor the extended process, now expected to conclude after the November elections.

How Can I Help? Our 6th Annual Virtual Lobby Day enables advocates to echo these requests using pre-addressed message templates. As of the end of May, more than 6,136 messages had been sent. There's still time to add your requests to those of fellow advocates! Visit our **Grassroots Action Center** at www.capwiz.com/cfids/home. ■

Webinars Bring World-Class Learning Directly Into Your Home

Imagine that you're offered the opportunity to hear a world-class scientist or clinician talk about a topic near and dear to your heart: CFS.

Think about all the details involved: travel, time, expense...and most important, precious energy.

Now imagine that you can hear that world-class scientist or clinician talk about CFS from the comfort of your own home — no travel, minimal expense and you can stay in bed during the presentation if you'd like!

Welcome to the Association's 2010 Webinar Series! A "webinar" is a seminar that is broadcast over the Web. It's another way we're using technology to deliver the information you want and need from top experts in the field in a cost-effective, convenient way. In the first half of the year, we've served more than 5,000 people with programming that's hard to find anywhere, let alone in your own living room or office!

What's a webinar?

Think about a webinar as a way to attend a conference without leaving home. Using a computer and telephone, you can hear a presentation (like a conference call) and also see the presenter's slides (watching over an Internet connection). You won't be able to see the presenter or the moderator, or others attending the program — and they won't be able to see you. (A plus if you want to attend in your pajamas!)

The Association will send email reminders to subscribers of our monthly electronic newsletter, **CFIDSLink**, and you can check the schedule printed below and posted on our website for details on upcoming programs. Register online

to reserve your space and you will receive an email confirmation with sign-on instructions, as well as reminder notices a day before the program and two hours before it begins.

Preregistration also gives you the opportunity to submit questions that are shared with the speaker in advance. The login URL changes for each program, so you'll need to register for each program you wish to attend.

If your Internet connection isn't very fast (for instance, if you use a dial-up connection), you can still listen (like a conference call) to the audio presentation by calling the phone number included in the confirmation email. In most cases, you'll be charged regular rates for the time you're on the phone. If you have a cell phone with an ample (or unlimited) usage plan, consider using it so that you don't incur expense for the call.

What if I miss one or more programs I want to hear?

Not to worry! The Association has archived webinar recordings for later viewing. You can find the recordings and slides for past presentations on our website. There is no charge to access the webinar recordings.

Learn more about the technology of webinars, what to expect during a webinar and how to access past program recordings at www.cfids.org/SolveCFS/SS10.asp.

The Association is grateful for a donation from a family that wishes to remain anonymous given in support of our 2010 Webinar Series. ■

Past Programs In Our Archive

XMRV: Implications for CFS

(Jan. 15, 2010)

Speaker: Lucinda Bateman, MD, Fatigue Consultation Clinic

Association Research Program Update: Part 1 of 3 and Part 2 of 3

(Feb. 18, 2010 and May 4, 2010)

Speaker: Suzanne D. Vernon, PhD, Scientific Director

Going With the Flow — Blood Flow, That Is

(Mar. 25, 2010)

Speaker: Marvin Medow, PhD, New York Medical College

Defining CFS: Diagnostic Criteria and Case Definitions

(Apr. 14, 2010)

Speaker: Leonard Jason, PhD, DePaul University

Chronic Pain Conditions & the Overlapping Conditions Alliance

(May 5, 2010)

Speakers: Mary Lou Ballweg, Terrie Cowley, Kim McCleary and Christin Veasley

Treating CFS & FM: The Stepwise Approach

(May 20, 2010)

Speaker: Charles W. Lapp, M.D., Hunter-Hopkins Centers

SolveCFS BioBank

(June 8, 2010)

Speakers: Suzanne D. Vernon, PhD, Scientific Director and Liz Horn, PhD, MBI, Genetic Alliance BioBank

CLIP THIS SCHEDULE

Day/Date/Time (all times are Eastern)	Topic	Speaker(s)
Thurs., June 17, 1:00 p.m.	CFIDS Association Research Program Update: Part 3 of 3	Dr. Suzanne Vernon, scientific director, The CFIDS Association
Thurs., July 15, 12:00 p.m.	XMRV Update	Dr. Lucinda Bateman, The Fatigue Consultation Clinic, Salt Lake City, UT and Dr. Vincent Racaniello, Columbia University
Thurs., Aug. 12, 2:00 p.m.	XMRV & Blood Safety	Dr. Louis M. Katz, Mississippi Valley Regional Blood Center
Thurs., Aug. 19, 1:00 p.m.	Navigating Social Security Disability	Charles Sasser, JD, Sasser Law Firm, Charlotte, NC
Tues., Sept. 7, 12:30 p.m.	Orthostatic Intolerance: Management	Dr. Peter Rowe, Johns Hopkins Children's Hospital, Baltimore, MD
Thurs., Sept. 16	CFS & The Viral Connection	Dr. Steve Gluckman, University of Pennsylvania Medical Center, Philadelphia, PA
Tues., Oct. 5	Expanding Research: Building on Your Investment	Dr. Suzanne Vernon, scientific director, The CFIDS Association
Thurs., Nov. 11	Doc Talk: Communicating with Your Health Care Professional	Dr. Lucinda Bateman, The Fatigue Consultation Clinic, Salt Lake City, UT
Thurs., Nov. 18	Minimizing Relapses: Pacing Yourself Through the Holidays	Dr. Bruce Campbell, CFIDS and Fibromyalgia Self-Help Program and Dr. Dane Cook, University of Wisconsin – Madison
Thurs. Dec. 2	Spirituality and Health	Dr. Gail Ironson, University of Miami

First National CFS Awareness Campaign Comes to a Close

Chronic fatigue syndrome (CFS) is a debilitating illness estimated to affect at least one million people in the U.S. and millions more worldwide. Although CFS strikes every age, racial, ethnic and social group, it is about four times as common in women compared to men. Despite its prevalence, studies have shown that fewer than 20 percent of U.S. CFS patients are properly diagnosed and attitudinal research of members of the healthcare provider community reflect a rather skeptical view of the illness. Surveys and focus groups showed that the depth of understanding among the general public was limited.

To make a start at combating these prevailing views, in 2006 the Centers for Disease Control and Prevention (CDC), in collaboration with the CFIDS Association of America, initiated the first national awareness campaign to impact consumer and healthcare professionals' knowledge, attitudes, and beliefs concerning CFS. The primary target audiences included women between 34–60 years-of-age and healthcare professionals working in primary care settings. Key messages urged the public to become aware of the symptoms and to seek diagnosis and care, if appropriate.

Campaign components included a series of integrated communication strategies involving formative research and message development, TV and radio public service announcements (PSAs), collateral materials (a patient brochure and toolkit and resource guide for healthcare providers), Web site, a launch event at the National Press Club in Washington, D.C. on Nov.

6, 2006, that also included a video news release and satellite media tour, a traveling photo exhibit (the "Faces of CFS"), ongoing media outreach, paid advertising and partnership development.

Results from the campaign reveal several indicators of success. First, the "Faces of CFS" photo exhibit was displayed at 36 public venues and media markets across the country, along with nine national healthcare professional conferences, with foot traffic estimates in 2007–09 indicating 6,813,191 people were directly exposed to campaign messages. News stories in print, broadcast and online media about the "Faces" exhibit numbered in the thousands and clippings for the articles generated fill seven four-inch notebooks. Following the fall 2006 launch, tracking in mainstream and trade publications found the campaign generated excellent message coverage and reinforced the serious and disabling nature of CFS.

Through December 2009, the 30-second TV PSA ("Missing My Life") played 18,035 times on 368 stations in 207 markets, with over 132 million total viewer impressions at an estimated value of approximately \$1 million in airtime. From early 2007 through the first half of 2008, the PSAs consistently ranked in either the top quarter or top two-thirds of the approximately 500 campaigns tracked by Nielson. Through December 2009, the radio PSAs aired 44,621 times for an audience impression total of over 278 million and estimated free airtime worth about \$2.5 million.

In 2006-07 the full-page print ad ran 14 times in national magazines for a combined reach of 328+



Television PSA and print ad from the campaign

million reader impressions. The online banner ads on those magazines' websites delivered 15.6 million impressions. Additionally, approximately 300,000 print and downloaded copies of the collateral materials were disseminated.

Although not sensitive enough to determine campaign effects, surveys conducted for CDC by Porter Novelli revealed relatively high levels of awareness of CFS among public and healthcare professional subgroups, as well as positive attitudes toward diagnosis and disease management. Preferred sources of CFS information differed between consumers and healthcare professionals.

The campaign has come to an end and the Association has fulfilled all of its obligations under the contract with the CDC's National Center for Health Marketing that funded and oversaw the work of the campaign. Several articles about the campaign published over the past four years are linked at www.cfids.org/SolveCFS/SS10.asp. ■

New Pain Campaign Gets Off the Ground

Chronic pain — defined as pain persisting more than six months — is all too common. It is estimated to affect 25 percent of Americans and account for more than 20 percent of all physician office visits. Chronic fatigue syndrome (CFS), endometriosis, fibromyalgia, interstitial cystitis (IC), irritable bowel syndrome (IBS), temporomandibular (TMJ) disorders and vulvodynia are just some of the conditions that have sidelined as many as 50 million lives and cost up to \$80 billion each year. These six illustrative conditions either solely affect women, or target women at least four times more often than men.

The **Campaign to End Chronic Pain in Women** aims to improve the quality of life for all those

living in chronic pain by raising awareness of chronic pain conditions that disproportionately impact women, as well as the neglect, dismissal and discrimination faced by women suffering from chronic pain. Men suffering the double stigma of chronic pain and conditions commonly considered to be women's conditions are addressed as well.

The Campaign launched with a Capitol Hill event on May 19, 2010 that attracted standing-room-only participation from congressional staff from 35 offices, leaders of women's organizations and health organizations and reporters. The event was held in cooperation with the Congressional Caucus on Women's Issues at the Capitol Visitor Center. At the event, the Campaign released a groundbreaking report, "Chronic Pain in Women: Neglect, Dismissal and Discrimination," which offers policy recommendations that could save the government billions of dollars in wasted healthcare costs each year. The hour-long launch event also featured the premiere of a short film, "Through the Maze: Women & Pain," and the unveiling of the Campaign website. CFIDS Association CEO Kim McCleary served as emcee for the event. Pfizer helped offset the cost of campaign materials.

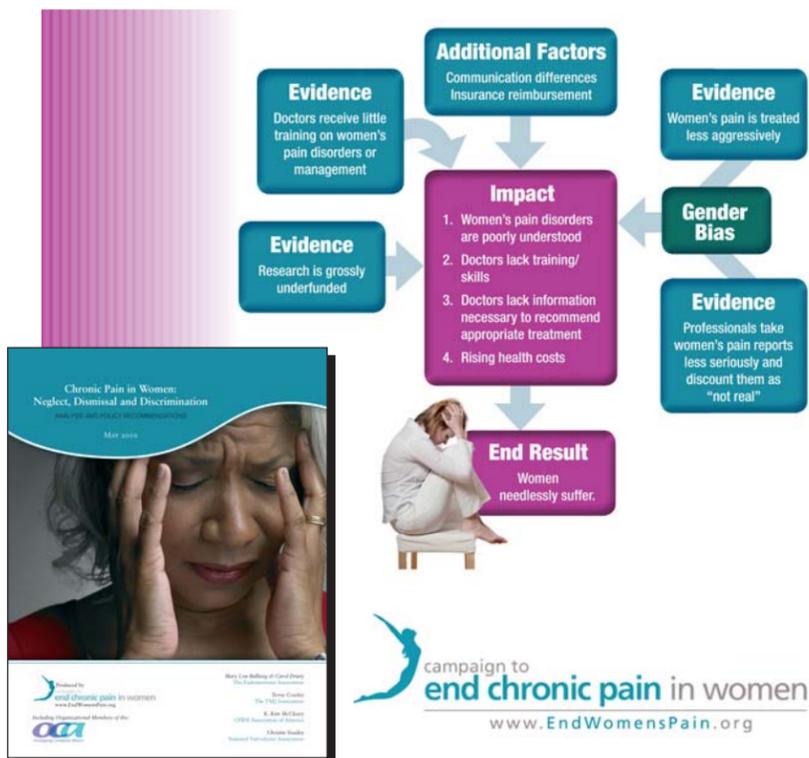
After the event, leaders of the CFIDS Association of America, the Endometriosis Association, the TMJ Association and the National



The May 19 launch event and meetings on the Hill were a big success.

Vulvodynia Association met with staff in the offices of the Senate Majority Leader (Sen. Harry Reid), the Speaker of the House (Rep. Nancy Pelosi), chairman of the Senate Health, Education, Labor and Pensions and Appropriations Committees (Sen. Tom Harkin), chairman of the Senate Aging Committee (Sen. Herb Kohl), chairman of the House Energy and Commerce Committee (Rep. Henry Waxman) and other House authorizers and appropriators. They discussed the policy recommendations in the report and ways in which they align with new programs being implemented under the Patient Protection and Affordable Health Care Act.

Learn more about this important Campaign, read the detailed report and watch the compelling film at www.cfids.org/SolveCFS/SS10.asp. ■



Conferences Spotlight CFS

The Association has taken advantage of several opportunities to highlight CFS at meetings around the country and around the world. Here is a list of meetings and conferences at which CFS has commanded and will gain attention:

Recent Past

Scientific director Suzanne Vernon, PhD, gave grand rounds at the **National Institute for Public Health and the Environment** in the Netherlands on May 11. The Netherlands is experiencing a widespread occurrence of CFS-like illness following Q fever, an infectious illness caused by the bacterium *Coxiella burnetii*.

Dr. Vernon represented the Association at the **International Society for Biological and Environmental Repositories (ISBER) 2010 Annual Meeting**, "Diversity in Biobanking: Embracing Differences, Harnessing Commonalities," May 11–15, in Rotterdam.

Upcoming

Dr. Vernon will give a presentation about the current status of CFS research at the **6th Conference of Fatigue Science** in Osaka, Japan. The conference will be held June 24–26, 2010.

CEO Kim McCleary will be a speaker at the **2010 Genetic Alliance Annual Conference**, "Advancing Novel Partnerships," July 15–18, 2010 in Bethesda, Maryland.

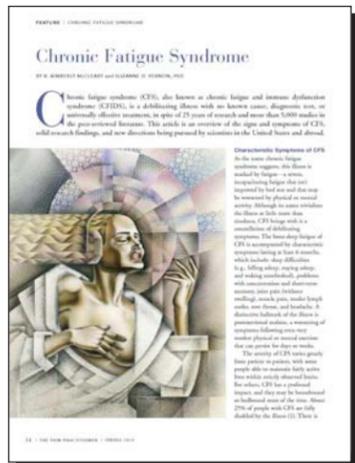
Dr. Vernon has been invited to serve on the scientific committee for the **First International XMRV Workshop** being co-sponsored by the National Institutes of Health (NIH) and Virology Education. The workshop will be held Sept. 7–8, 2010 on the NIH campus in Bethesda, Maryland.

The Association will sponsor its invitation-only annual meeting of CFS investigators funded by the Association, the National Institutes of Health and other institutions at the Banbury Center of Cold Spring Harbor Laboratories Oct. 24–27, 2010. The meeting, titled, "**From Infection to Neurometabolism: A Comprehensive Research Network for CFS,**" will bring together clinicians and scientists from diverse disciplines in an intimate setting that fosters data-sharing and collaboration that continue well beyond the meeting. ■

Other News from the CFIDS Association of America:

Many important events and milestones were marked in 2009 and so far in 2010. We've published a **month-by-month recap** of some of the CFIDS Association's key contributions. We have also assembled a list of **Frequently Asked Questions** about the Association and its priorities.

Please take part in our **online risk factors survey**. This 50-item questionnaire will collect information about factors that might have contributed to the onset of your illness. Questions are structured to make it quick and easy to complete, so don't be intimidated by the number of items. All responses are anonymous and results will be reported in the aggregate only. This survey will close on July 16, 2010. You can link to it directly at <https://www.surveymonkey.com/s/RiskFactors>.



The spring 2010 issue of *The Pain Practitioner*, published by the American Academy of Pain Management, features an article about CFS by Association CEO Kim McCleary and scientific director Suzanne D. Vernon, PhD. This journal reaches 6,000 professionals who manage pain patients; you can print a copy of the article for your health care professional by visiting our site at www.cfids.org/SolveCFS/SS10.asp.

The **Diagnostic and Statistical Manual for Mental Disorders** is being revised by the American Psychiatric Association (APA) for release in 2013. Creation of a new category of mental disorder called

"Complex Somatic Symptom Disorder" (CSSD) generated concern by CFS advocates and organizations. On Apr. 1, 2010, the CFIDS Association submitted detailed written comments and an urgent recommendation to abandon creation of the CSSD classification. The APA reported that it received a total of 6,400 comments about proposed changes

As of April 16, the Association satisfied all of the **Better Business Bureau's 20 standards for charity accountability**, making it the only CFS-related organization to be accredited under the BBB's Wise Giving program.

A generous donor family made a donation of \$10,000 in April and added a challenge to their gift: if the Association could raise \$10,000 by May 12, they would donate another \$10,000! We are delighted to announce that this mini-campaign, conducted largely through our **Facebook page**, was successful and raised \$14,039 to secure the match, for a combined total of \$34,039.

24 Hours in the Enchanted Forest: A Race to SolveCFS, is a mountain bike endurance event that will be held on June 19–20, 2010, near Gallup, New Mexico. It is being planned by volunteers who support the CFIDS Association of America and hope to attract mountain bikers and other sports enthusiasts to the cause. ■



The Legacy Fund YOUR PLANNED GIFT

Many of us wonder if our lives were to end today, what difference would we have made to others? What legacy would we leave behind? The fact is, by including the CFIDS Association of America in your estate plans, the impact of your life will be felt and remembered for generations. Many people believe they lack sufficient assets to include a charitable gift in their wills. They assume that the joy of philanthropy is a privilege of the wealthy. Today, however, people of all ages and financial means are discovering that they, too, can leave a legacy.

Planned gifts are the ultimate expression of confidence in the CFIDS Association of America. A planned gift is one that is made as part of your overall financial and estate plan. We have created The Legacy Fund to honor patients, families and friends who have established a planned gift. The Legacy Fund helps you help the Association carry on until its mission is fulfilled.

Because all planned gifts represent an expression of lifetime commitment to the CFIDS Association, The Legacy Fund has no minimum gift level. Joining The Legacy Fund accommodates creative and flexible strategies for your estate and charitable planning. Some planned gifts provide you with income. Many of them can reduce your taxes. The greatest benefit, however, lies in knowing that you support the mission of the CFIDS Association.

You can start today. Make sure you have a current will (or living trust) that reflects your charitable objectives. Without these documents, you surrender control of your property and assets to the courts. Contact your financial advisor to express your interest in establishing a charitable gift. He or she can help you think beyond cash. You can gift stocks, real estate, insurance policies, IRAs and personal property to the Association. It's easy to make a change to existing plans to reflect your interest in The Legacy Fund.

"I have done a lot of planning for my daughter, who has CFS, so that she has financial and personal support to take care of her after my wife and I are gone. Part of that planning includes keeping the CFIDS Association of America financially strong and active in the CFS community because of all the work they do to provide help and hope for patients."

Bruce, Legacy Fund Member

To date, more than 50 people have joined The Legacy Fund and the Association has received a cumulative total of more than \$1 million in estate gifts over the years. This source of support is vital to sustaining progress. Think about your legacy and help us achieve our mission to make CFS widely understood, diagnosable, curable and preventable. For more information, contact Ashley Comstock, major gifts officer, at aacomstock@cfids.org or 704-365-2343. ■