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Research1st News from the CFIDS Association of America
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FROM THE CEO'S DESK

On Feb. 23, 2012, we announced a set of eight carefully selected and tightly integrated research projects to be supported and coordinated under our "research institute without walls." Now, we're bringing the news straight to you. Please join us on Wed., Mar. 7 at 2 p.m. (EST) for a **free webinar** so you can hear more about the next generation in CFS research from our scientific director, Dr. Suzanne Vernon. [More info...](#)

On Wed., March 7
WE COME TO YOU VIA WEBINAR



Learn about the next generation of CFS research without leaving your home/office

Join us on Wed., March 7 at 2 PM EST for a free webinar

Register at <http://bit.ly/webinar-mar7>

RESEARCH INSTITUTE WITHOUT WALLS

Your participation and generous donations have inspired a transformative shift in how the Association supports research -- the **research institute without walls (RIWW)**. Catch up on the ground-breaking news through the [press release](#) issued on Feb. 23, a [description of the RIWW](#), [media coverage](#) of the announcements and a [tribute to our donors and supporters](#) who made it possible.

LEARN MORE

Research1st.com is your home base for info about our new research initiative



RESEARCH INSTITUTE WITHOUT WALLS

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fuels research into better
diagnostics and treatments.



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CFIDSLink is now Research1st News

News, commentary & more



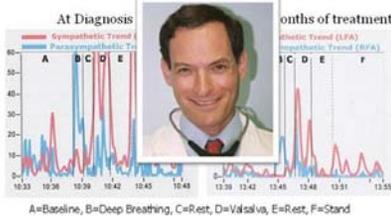
Join us all month at Research1st.com

Our funded investigators will meet for the first time in Baltimore, Mar. 11 and 12. We have a packed agenda to synchronize and optimize the individual projects and their collective ability to advance treatment for CFS.

NEW @ RESEARCH1st

DÉJÀ VU ALL OVER AGAIN: Just a year after publication of the controversial PACE study, *The Lancet* published another report of treatment success following behavioral therapy, this time in teens using an internet-based approach. Headlines were more tempered this time, but the results paint a rosier picture than may be warranted. We took a close look at the study. [Read more...](#)

CFS Sympathetic and Parasympathetic Activity Before and After Treatment



DYSFUNCTION JUNCTION: Dr. Alan Pocinki describes the body-wide impact of abnormal autonomic function that may be to blame for many of the symptoms that people with CFS experience. [Read more...](#)



You can [subscribe to email updates](#) each time a new blog post is added to Research1st.

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OTHER RESEARCH NEWS

The University of Pacific recently featured the work of the **Pacific Fatigue Lab** (PFL) to understand post-exertional relapse in CFS and help people with CFS document the disability that arises from it using a test-retest exercise challenge. The CFIDS Association funded the PFL's research in 2004-2006. [Read more...](#) You can learn more about their testing methods in [this Research1st post](#).



The **National Cancer Institute** recently reported in *PLoS ONE* that samples collected from CFS patients who participated in the Lombardi et al., study of XMRV showed evidence of multiple sources of contamination that may have been responsible for falsely positive results. [Read more...](#)

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POLICY MATTERS

On Feb. 14, the **U.S. Senate Health Education, Labor and Pensions Committee** held the first-ever hearing on chronic pain. The Association is a founding member of the Chronic Pain Research Alliance that was instrumental in getting the Senate's attention on this important issue that affects 116 million Americans. CPRA leader Christin Veasley delivered powerful testimony and skillfully participated in the discussion that followed prepared statements from five witnesses. The Association submitted testimony for the record prepared by Jennifer M. Spotila, J.D., former chairman of the Board. News about the hearing was carried by several news agencies, including ABC News. [Read more...](#)

Full Committee Hearing - Pain in America: Exploring Challenges to Relief

Date:
Tuesday, February 14 2012, 2:30 PM

Place:
430 Dirksen Senate Office Building



On Feb. 21, Association scientific director Suzanne Vernon, Ph.D., delivered a presentation about CFS to the **Food & Drug Administration** Center for Drug Evaluation and Research's Division of Pulmonary, Allergy, and Rheumatology Scientific and Regulatory Rounds. This is the FDA division that in 2011 was assigned sole responsibility for the review of CFS-related drug applications.

Open access advocates, including the CFIDS Association, cheered on Feb. 27 when the two congressional sponsors of the **Research Works Act** abandoned the effort. The bill would have banned the National Institutes of Health from requiring that researchers supported by federal funds submit their peer-reviewed manuscripts to a publically accessible archive. [Read more...](#)

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CATALYSTS IN ACTION

We have been honored to share stories about our Catalysts, supporters of [The Catalyst Fund](#). In science, catalysts are substances that change the rate of chemical reactions. "Positive" catalysts speed a particular reaction. For the CFIDS Association, Catalysts speed transformation through their support of our research program. Meet three more of our Catalysts:



Marian Sonnenfeld



Laura Hillenbrand

- **Laura Hillenbrand's** name is as recognizable as any author could hope their name to be. More than the fame or awards her writing has earned, she wants to be well and she wants others who share her diagnosis to be well too. Laura's exemplary \$250,000 donation to the Catalyst Fund has given hope to many. [Meet Laura...](#)
- **Marian Sonnenfeld** was felled by a flu 21 years ago. She had to give up her career as a physician and is sicker now than she was when she talked about CFS on the MacNeil/Lehrer NewsHour in 1992. Like many other Catalysts, research is her hope. [Meet Marian...](#)
- **James York** became ill with pneumonia that slid into "the ensuing nightmarish galaxy of ME/CFS symptoms" in 2004, abruptly ending his rewarding career as an underwater cameraman and marine coordinator. James was the first person to consent and enroll in the SolveCFS BioBank and he's been an inspiration in other ways, too. [Meet James...](#)



James York

OTHER NEWS & EVENTS

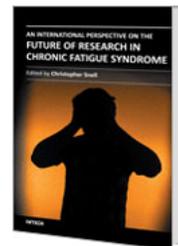
CEO Kim McCleary and scientific director Suzanne Vernon, PhD, were guests on Mar. 1 on the "**Charlotte Talks**" radio program, heard on NPR stations in the local area and now archived on WFAE's website. [Listen now or later](#) to the one-hour discussion about CFS and CFS research.



The **Massachusetts CFIDS Association** will host Dr. Benjamin Natelson at their spring conference on April 28, 2012. [More info...](#)

The 7th annual **Invest In M.E.** conference will be held in London on June 1, 2012. [More info...](#)

Christopher Snell has edited a five-chapter open access book, ***The Future of CFS Research***. From his intro: "A common theme in [this book] is CFS as a multisystem disease with the possibility of more than one cause and influenced by a variety of interacting features." [Free download from InTech...](#)



The CFIDS Association of America

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.

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