



# Research1st

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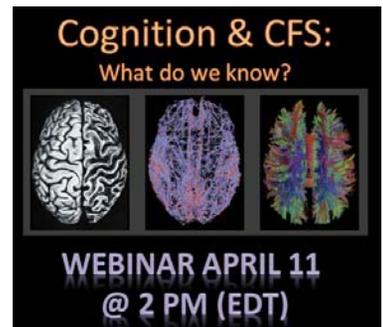
## FROM THE CHAIRMAN'S DESK

**Chairman Amy Squires** shares the Board's perspective on the Association's work and the Research Institute Without Walls, an innovative approach to expediting effective treatment for CFS. [Read more...](#)



## WEBINAR SERIES RESUMES

**Impaired cognition in CFS** is one of the most disabling and frustrating symptoms patients experience. Deficits in short-term memory, information processing and processing speed have been documented by several research groups. How closely does the medical literature reflect patients' experiences and how can cognitive testing help support self-reported measures? Please join us on April 11 for a web program provided free-of-charge to all.



**Date:** Wednesday, April 11, 2012

**Time:** 2:00 PM (Eastern Daylight Time)

**Free registration & resources on cognition:**

<http://bit.ly/cognition-intro>

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## RESEARCH INSTITUTE WITHOUT WALLS

The Association's scientific director **Dr. Suzanne Vernon** and CEO **Kim McCleary** described the Association's new comprehensive research initiative, the [Research Institute Without Walls](#), during a 90-minute webinar presented on Mar. 7. The recording is now available for on-demand viewing on our YouTube channel at <http://bit.ly/RIWW-webinar>.

Webinar recording  
now available



RESEARCH INSTITUTE WITHOUT WALLS  
<http://bit.ly/webinar-RIWW>

On Mar. 11-12, the researchers who form the **inaugural Research Institute Without Walls** were led by scientific director Suzanne Vernon, PhD and CEO Kim McCleary in detailed discussions about each of the research projects and integration of efforts through a data-sharing platform. [Read more...](#)



## NEW @ RESEARCH1st

The **Patient-Centered Outcomes Research Institute (PCORI)** was created to conduct research to provide information about the best available evidence to help patients and their health care providers make more informed decisions. Board member Christine Williams, M.Ed., recently testified about CFS as a model condition for PCORI's focus. [Read Chris' testimony...](#)



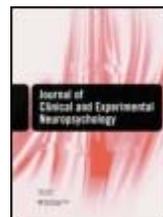
Between 1998 and 2004, 234 individuals with severe CFS at 12 clinical sites took part in a study of the **experimental therapy rintatolimod**, also known as Ampligen. The study met its primary and secondary endpoints for success; however, responders to the drug seem to be buried in the larger group based on the normed results. Study data were published on Mar. 14, 2012, in *PLoS ONE*. [Read Dr. Suzanne Vernon's summary...](#)

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## OTHER RESEARCH NEWS

**Biobanks** play an increasingly important role in medical research of all kinds. With the SolveCFS BioBank as the "hub" of our [Research Institute Without Walls](#), the CFIDS Association of America is very involved in a wide range of issues related to ethical biobanking. In fact, our scientific director, Dr. Suzanne Vernon, is considered one of the top experts in participant-driven biobanks like the SolveCFS BioBank. She will be on the faculty of the international biobanking conference later this spring and would like your views on biobanking issues. Please complete our **short ANONYMOUS survey** at <http://svy.mk/survey-bb>. Results will help shape her presentation. Thank you for sharing your views!

A new study of **cognitive effort** using the Validity Indicator Profile was published by Drs. Cockshell and Mathias of University of Adelaide. Results showed that people with CFS gave high levels of effort and an intention to do well. Other studies of cognitive impairment have hypothesized that people with CFS intend to perform poorly. Study abstract: <http://bit.ly/GLfpKL>.



Dr. Henry Heng of Wayne State University will investigate whether overall **genome instability** may cause CFIDS. Dr. Heng will use a technique called spectral karyotyping, or SKY analysis, to examine patients' blood samples. [Read more in this CBS-Detroit news story...](#)

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## POLICY MATTERS

The first meeting of the federal **Interagency Pain Research Coordinating Committee** was held Mar. 27, 2012 at the National Institutes of Health. Two members of the Chronic Pain Research Alliance (CPRA), Terrie Cowley and Christin Veasley, have been appointed to this committee. The CFIDS Association is a founding member of CPRA. The meeting was webcast live; more info and a link to the recording are available at <http://iprcc.nih.gov/iprcc-inaugural.htm>.

**Speak Up About ME** is a grassroots effort to YANK (not tug!) at the nation's heartstrings with organized visits to Capitol Hill and participation in the spring meeting of the federal CFS Advisory Committee. Dates are not yet set; contact Denise at [SpeakUpAboutME@gmail.com](mailto:SpeakUpAboutME@gmail.com) to be included on the email list as details are set.



Speak Up About ME and Phoenix Rising have joined effort to collect information about **Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)** applications and experience from people with ME/CFS and related conditions who live in the U.S. They will use this information in testimony at the next meeting of the federal CFS Advisory Committee (the date for which has not yet been announced). Respond to their SSDI/SSI survey at <http://bit.ly/GSPmTp>.

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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:

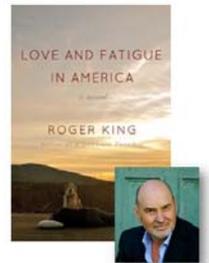


- **Joyce Tynes** has been ill since 1987, but she says she's never going to give up hope. "If I can't get better, then maybe someone else won't get it, or if they do get it, they will get better faster. That's why I support the new research." [Meet Joyce...](#)
- **Robert Radovich** is an 84-year-old retired postal worker who was diagnosed with CFS after he experienced trouble sleeping, then couldn't shake a stubborn cold after seven months. He supports research, "[not] out of the goodness of my own heart. I want to find something that will get me well, and if not help myself, help others with CFS." [Meet Robert...](#)
- After having to leave a promising career as an attorney 17 years ago, **Jennie Spotila** has found numerous ways to contribute to the cause that changed her life. Although homebound, she served as chairman of the Association's board for two years, leading the Association through a crucial period of strategic thinking and planning. Her Board service has ended but she continues supporting the Association's research program and blogs regularly about issues that matter to her. [Meet Jennie...](#)

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## OTHER NEWS & EVENTS

Novelist **Roger King** has written a new autobiographical novel, *Love and Fatigue in America*, about his journey following diagnosis with CFS. It's beautifully written and poignant. Freelance writer Jean Zimmer's review includes several short excerpts that illustrate King's gift for describing life with CFS. [Read Jean's review...](#)



On March 30, *The Guardian*, a UK daily newspaper, published an article about severe cases of ME that have resulted in death. The author, Scott Jordan Harris, recently reviewed the ME documentary "Voices From the Shadows" for the *Chicago Sun-Times*. [Read the Guardian article...](#)

A new **continuing medical education program** about CFS has been launched on Medscape as a collaboration between Medscape Education and the Centers for Disease Control & Prevention. The video program, "CFS: The Challenges in Primary Care," features expert physicians Dr. Anthony Komaroff, Dr. Lucinda Bateman and Dr. Charles Lapp. Credits are available to health care professionals for one year, through 3/23/13. Free registration required to access at <http://www.medscape.org/viewarticle/759095>.

The **Massachusetts CFIDS Association** will host Dr. Benjamin Natelson at its 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...](#)

We've been building a vibrant community on **Facebook** since February 27, 2009. Today, we are delighted to host an ongoing dialogue among more than 6,803 people who interact daily. We share news, photos and links to resources dozens of times every week. We recently converted to Facebook's new "timeline" format with this striking photo from our "[What Would You Do?](#)" video, a self-portrait taken by Catalyst donor Lauren Kenney. [Come visit](#) and join the conversation!



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## 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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