



Research1st

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

CEO Kim McCleary shares a "thank you" video made during the first investigators meeting for the Research Institute Without Walls, and the story behind its making. [Read more and watch the short video...](#)



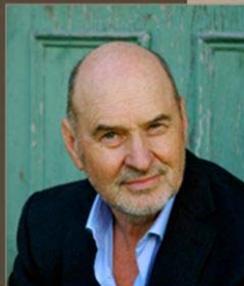
WEBINAR SERIES CONTINUES TODAY

A conversation with **{TODAY}**
Roger King and Wilhelmina Jenkins
May 9 at 2:00 PM (Eastern time)

LOVE AND FATIGUE

IN AMERICA

ROGER KING



health relationships work illness chronic fatigue syndrome
career love parenting rest play doctors travel sudden loss
grief redefinition relapse loneliness companionship fear
attraction comfort mastery redemption healthcare
foreignness familiarity friendship personal history memory
composure balance unpredictability hope wholeness

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CFIDSLink is now Research1st News

News, commentary & more



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Join us all month at Research1st.com

Our webinar series continues today, May 9, with guests novelist **Roger King and Wilhelmina Jenkins**, a former Board member and visible advocate for CFS. Roger's acclaimed autobiographical novel, *Love and Fatigue in America*, will serve as a backdrop for a discussion about the experiences Wilhelmina and Roger share as people living with CFS for two decades. Even if you haven't heard about or read Roger's novel, we think you'll enjoy this program and we hope you'll join us!

Date: Wednesday, May 9, 2012 (today)

Time: 2:00 PM (Eastern Daylight Time)

Free registration: <http://bit.ly/May9-webinar>

The recording, slides and more than a dozen other resources from our April 11 webinar on **cognition** are available on-demand on our Research1st site at <http://bit.ly/cognition-resources>.

RESEARCH INSTITUTE WITHOUT WALLS

Five new research grants

announced in February 2012 are described in the latest issue of our print publication, *SolveCFS*. Copies were mailed to 4,269 donors on May 1. If you would like to receive a copy, please send an email

to Research1stNews@cfi

ds.org with your full name and mailing address and "SolveCFS issue" in the subject line. You can read an [overview](#) of the Research Institute Without Walls and find more technical descriptions in our article titled, ["Breaking Ground."](#)



NEW @ RESEARCH1st

Making connections between studies that are published at different times, by different investigators, using different technologies is always a challenge. **Dr. Dane Cook** responds to two questions about results of biomarker studies led by Dr. Kathleen Light and Dr. Steven Schutzer published in 2011 in a post titled, "[From Discovery to Application.](#)"



Post-exertional malaise (PEM) is considered a hallmark of CFS by many patients, physicians and researchers. **Dr. Leonard Jason** and colleague **Meredyth Evans** examine PEM and its importance in defining the condition in "[To PEM or Not to PEM? That is the question for case definition.](#)"



Our scientific director, Dr. Suzanne Vernon, was one of 250 "disruptives" participating in the third annual **Sage Bionetworks Commons Congress** held Apr. 19-20, 2012 in San Francisco. Two posts to Research1st describe the purpose of this unconventional meeting and provide additional resources, including links to recorded meeting sessions. Check out "[SageCon Rocks #OpenScience Agenda](#)" and "[SageCon & Open Access Resources.](#)"

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OTHER RESEARCH NEWS

Researchers at the Centers for Disease Control & Prevention studied 18 people with CFS and 41 healthy controls using **functional MRI**. They found differences in activity in the basal ganglia region of the brain, although the study couldn't tell whether these differences were a cause or effect of the illness. The study was reported at the Experimental Biology conference held last month in San Diego and results haven't yet been published. More from *US News & World Report*: <http://bit.ly/IOaVW8>

Dr. Leonard Jason and colleagues **assessed fatigue** in 90 CFS patients every 30 minutes over the course of one day to define symptom patterns. Individuals clustered into three groups. One group evidenced high fatigue intensity, low variability and fatigue intensity stayed the same over time. A second group had moderate fatigue intensity, high variability and fatigue intensity decreased over time. A third group had moderate fatigue intensity with high variability but intensity increased over time. The three clusters of patients differed on measures of actigraphy, pain and immune functioning. The study was e-published ahead of print on May 1, 2012 in the *Journal of Mental Health*. Abstract: <http://bit.ly/KLrI8H>



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POLICY MATTERS

The next meeting of the federal **CFS Advisory Committee** (CFSAC) will be held on June 13 and 14 in Washington, D.C. The meeting will also be webcast live. The announcement regarding opportunities to testify has not yet been made. More info: <http://1.usa.gov/l87eX9>



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. The group organizes its activities around the CFSAC meeting (see above) and will make Capitol Hill visits on June 14. Contact Denise at SpeakUpAboutME@gmail.com for details.



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CATALYSTS IN ACTION

Two years ago, **Catalyst** [Jennifer E. Wright](#) had the world by the tail. A new marriage, a new job, pursuing a graduate degree and celebrating her 24th birthday were highlights of 2009. Then CFS hit and her whole world changed. "One month I was training for marathons and the next month I couldn't walk."

For every person with CFS, there is a story like Jennifer's. **Lives forever changed** by an illness that still carries too many unknowns. Jennifer urges everyone to become a Catalyst for hope and change through support of the Association's Research Institute Without Walls (RIWW). "Every branch of the RIWW is working collaboratively for the common goals of CFS research. Your gift will keep hope alive for all of us affected by CFS," she says.



[Your gift](#) to the Association's spring campaign will propel research and speed better diagnostics and treatments for CFS. Our [secure donation page](#) is ready 24/7 and all gifts, small and large, will be directed to programs that help people like Jennifer reclaim their lives. **Thank you for your generosity.**

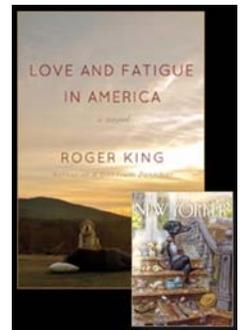
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MORE NEWS & EVENTS

Love and Fatigue in America traces novelist Roger King's journey across the U.S. following his diagnosis with CFS. It's beautifully written and poignant. The book received a starred review by Publisher's Weekly and was highlighted in the April 30, 2012 issue of *The New Yorker*. For more information about the novel, the author and links to several reviews, please visit <http://bit.ly/May9-webinar>.



This year marks the 20th anniversary of the observance of **May 12th** as international CFS/CFIDS/ME/NIDS awareness day. The date was selected by activist Thomas Hennessy, Jr., to honor Florence Nightingale who suffered a CFS-like illness in the later years of her life. Learn more about Florence Nightingale's life and illness in this two-part post by Romeo Vitelli that starts at <http://bit.ly/J7zzmH>. Many groups around the country are organizing events this week and throughout May to mark the occasion. Our May 12 Awareness packet is available at



<http://www.cfids.org/advocacy/awareness-day.asp> and we're posting additional materials to share on our [Facebook page](#) throughout the month of May.

Unbroken, the acclaimed book chronicling the life of Louis Zamperini, recently marked its 75th consecutive week on the *New York Times* Bestseller list; 13 of those weeks were spent at #1. The book has now sold more than 2.5 million copies. Congratulations to author Laura Hillenbrand, one of our exemplary Catalyst donors, for these tremendous achievements!



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

PANDORA and NeedyMeds hosted a webinar on May 2 to inform people about ways to obtain brand-name prescription medications at reduced cost or for free. You can **watch a recording** of the 30-minute program at <http://bit.ly/JQUrrU>. Additional resources are available at <http://bit.ly/IMoz6k>.

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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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