



# Research1st

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Research1st News from the CFIDS Association of America  
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## NEW @ RESEARCH1st

We're delighted to introduce **Leigh Reynolds**, a new addition to our team! Leigh joins us as our first engagement manager, bringing many years of experience working with nonprofit communities large and small. Meet Leigh and respond to a survey that will help her spread the word about how CFS impacts your life: <http://bit.ly/welcome-leigh>.

**Peter Rowe, M.D.**, and colleagues describe how they have connected post-exertional relapse, exercise intolerance and other common features of CFS to problems with nerve mechanics and function they observe in their clinic patients. This article includes information to share with your health care team about an approach to manual therapy that may help improve mobility and some symptoms: <http://bit.ly/manual-tx-pt-1>.



Rick Violand conducting a straight leg raise test

Within two weeks the U.S. Food and Drug Administration (FDA) is expected to render a decision on **Hemispherx Biopharma's** application to market its experimental drug, **Ampligen**, for CFS. Data submitted by the company was reviewed at a public FDA advisory committee meeting held on Dec. 20. Although the committee felt there was adequate information to demonstrate that the drug was safe (by a vote of 8-5), the final recommendation went against approval (5-8). FDA is not bound by the advisory committee's guidance and a

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broad range of factors will determine the final decision, expected by Feb. 2, 2013. Read more at <http://bit.ly/FDA-panel-outcome>.

## OTHER NEWS & EVENTS

### Policy Matters

The federal **CFS Advisory Committee** (CFSAC) is soliciting nominations for the addition of three ME/CFS organizations to join the committee as non-voting liaison representatives. Organizations selected from the nominees will contribute to discussion of research, diagnostics, treatments, public and professional education, and strategies to improve the quality of life of people living with ME/CFS. Nominations are due on Feb. 22, 2013. For more information, please see the Federal Register notice: <http://1.usa.gov/10WqbLL>.

Next spring, **FDA** will sponsor a stakeholder meeting about drug development and clinical outcome measures in ME and CFS. We'll share additional details as they become available. The FDA has archived information about drug development in ME/CFS here: <http://1.usa.gov/N1zk2S>.

The **IACFS/ME Primer for Clinical Practitioners** has been posted to the National Guideline Clearinghouse hosted by the U.S. Agency for Healthcare Research and Quality: <http://guideline.gov/content.aspx?id=38316>.



### You Matter

Toni Bernhard, J.D., a writer living with CFS, reports the American Psychiatric Association's decision to maintain the new classification of "**Somatic Symptom Disorder**" in the upcoming new edition of its DSM-V manual. From Toni's "Turning Straw Into Gold" blog at *Psychology Today*: <http://bit.ly/10invq7>.

*FasterCures'* executive director Margaret Anderson looks ahead at **important trends in medical research** for 2013. From the Huffington Post: <http://huff.to/XDwmyf>.

Our CEO, Kim McCleary, shares her perspective on **patient-centered research** as part of *FasterCures*' "Time = Lives" campaign to speed treatments to those who need them. Here's the video:

<http://bit.ly/10U1T4B>.



Marathon runner **Jennifer Williams** is featured this month on the Twin Cities in Motion website for placing seventh overall among all fundraisers for last October's Twin Cities Marathon. Jennifer honored her husband, Mark, and all people with CFS by using the marathon event to raise more than \$4,300 for the CFIDS Association's research program. Go Jen go! Here's her story: <http://bit.ly/XGWulo>.

Sleep problems core to CFS are often addressed with a combination of medications and behavioral approaches. For some, that may include taking medicines like zolpidem (Ambien) to initiate sleep. The FDA has just recommended lower doses of Ambien be used in women; they metabolize the drug more slowly. Here's a report from the *New York Times*:

<http://nyti.ms/W5ccli>.



Michael Breus, Ph.D., "The Sleep Doctor," writes about **sleep issues** in CFS for his *Psychology Today* blog, "Sleep Newzzz": <http://bit.ly/X1AaXP>.



Leigh Reynolds, Engagement Manager

**Share your story** with our newest staff member, engagement manager Leigh Reynolds, and help shape our communications outreach by responding to this 26-item survey about ways in which CFS impacts your life: <https://www.surveymonkey.com/s/N8B2QB7>.

We'll be back in February with a regular edition of Research**1st** News featuring journal highlights and other updates.

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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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