



Research1st News from the CFIDS Association of America
July 11, 2012 | Vol. 1, No. 13

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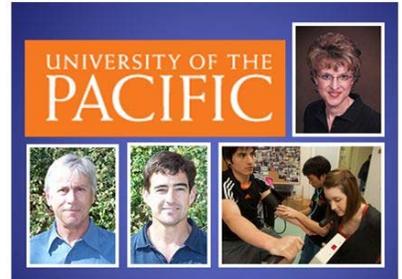
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WEBINAR SERIES CONTINUES

Post-exertion relapse (also known as post-exertional malaise or PEM) is one of the hallmarks of CFS. It's also a vexing feature for patients, physicians and researchers to grapple with day-to-day, in the clinic and in research studies on CFS.

This topic is one of most-often requested and the nearly 500 registrations for this program so far reflect intense interest.



Join us on July 19 when three researchers from the Pacific Fatigue Lab will share their insights into the characteristics of PEM. They will address the 10 most-asked questions about it, based on questions registrants have submitted. The PFL team was first to document the serious abnormal response to exercise testing through the test-retest protocol conducted over two days. Their research has been supported by the CFIDS Association of America.

DATE: July 19, 2012
TIME: 2:00 PM (Eastern Daylight Time)
FREE REGISTRATION: <http://bit.ly/PEM-webinar-reg>

RESEARCH INSTITUTE WITHOUT WALLS

FasterCures is a disease research "action tank" founded by the Milken Institute to save lives by saving time in the research, discovery and development of new treatments for deadly and debilitating diseases. *FasterCures* has featured the CFIDS Association's Research

Institute Without Walls in its July "[Innovator Spotlight](#)" This gets the word about our innovative research model out to *FasterCures'* diverse and influential network of medical research foundations, biotech and pharmaceutical companies, academic researchers, policymakers and venture philanthropists. Read the [FasterCures Q&A](#) with our CEO, Kim McCleary.



Learn more about the Research Institute Without Walls that is generating so much buzz. A ["Close-Up"](#) on our Research1st site describes the model and provides links to reader-friendly descriptions of each of the sponsored research projects we're funding.

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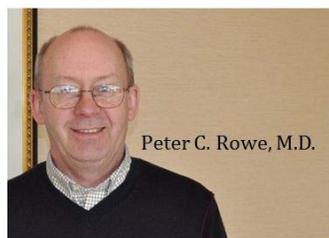
News, commentary & more



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NEW @ RESEARCH1st

Dr. Peter C. Rowe of Johns Hopkins University addressed the June 2012 meeting of the federal CFS Advisory Committee. He shared the slides and text of his presentation, "[Pediatric CFS: Gains and Gaps,](#)" on our Research1st site.



Over the first half of 2012 CFS has had steady **media attention**. Catch up on the people and topics that have attracted news coverage so far this year with our ["Newsworthy Highlights"](#) recap.

Last month's federal CFS Advisory Committee drew attention to the different roles each of the **federal health agencies** plays in the research-education landscape. "[Federal Agency 411](#)" provides a quick primer on seven agencies that are required to report regularly on CFS-related activities.



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OTHER RESEARCH NEWS

Researchers at **University of Melbourne** reported results of a study analyzing blood samples from 11 CFS patients and 10 non-fatigued controls to identify metabolites as biomarkers for CFS using H NMR spectroscopy. They found significantly decreased levels of glutamine and ornithine in CFS blood samples. ([Clinica Chimica Acta](#), June 15, 2012)

A group at the **University of Hong Kong** reported results of a four-month qigong program for participants who had CFS or chronic fatigue. Qigong improved physical fatigue symptoms, but did not have much effect on mental fatigue or physical functioning. They suggest qigong as an alternative therapy or rehabilitation program for CFS. This is the third study of qigong in CFS to show therapeutic benefits. ([Annals of Behavioral Medicine](#), June 27, 2012)



A follow-up study of 25 adolescents diagnosed with CFS by **Dr. David Bell** between 1984 and 1987 demonstrates the chronicity of CFS. Twenty of the 25 participants reported no longer carrying a diagnosis of CFS while 5 reported that they still have CFS. The 20 individuals who fell into the "remit" category scored 32.55 on symptom severity scales, compared to 6.1 for healthy adults who were 10 years older. The five "persist" patients scored 58.2 on the same scale. ([Journal of Clinical Psychology](#), June 29, 2012)

Understanding Long-Term Outcomes of Chronic Fatigue Syndrome

Molly M. Brown,^{1*} David S. Bell,² Leonard A. Jason,¹ Constance Christos,¹ and David E. Bell²

¹ De Paul University

² State University of New York at Buffalo



Author	Year	Journal	Volume	Issue	Page
Molly M. Brown	2012	Journal of Clinical Psychology	78	6	582-591
David S. Bell	2012	Journal of Clinical Psychology	78	6	582-591
Leonard A. Jason	2012	Journal of Clinical Psychology	78	6	582-591
Constance Christos	2012	Journal of Clinical Psychology	78	6	582-591
David E. Bell	2012	Journal of Clinical Psychology	78	6	582-591

Drs. Norman Booth, Sarah Myhill and John McLaren-Howard reported results of two groups of ME/CFS patients tested for cellular energy defects. They found all 138 had measurable mitochondrial dysfunction that correlated with illness severity. The test may not be specific to CFS and has not been compared to results from patients with other conditions associated with mitochondrial dysfunction, including Parkinson's and autism. ([International Journal of Clinical and Experimental Medicine](#), June 30, 2012)

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CATALYSTS IN ACTION

We are grateful to all who have contributed to the Association's [Catalyst Fund](#) so far this year. Our spring fundraising campaign closed out with a successful first-time donor challenge - 150 new donors secured a [\\$10,000 challenge pledge](#) from the Lesser family. In all, donations to the Association this spring topped \$400,000, helping fuel research into better diagnostics and treatment.

Author **Roger King** is busy signing copies of *Love and Fatigue in America* for 20 lucky individuals and couples whose names were drawn at random from [516 eligible entries](#) based on gifts

of \$50 or more. We've notified the winners and will feature their stories next month. Roger was a guest on New Hampshire Public Radio's ["Word of Mouth"](#) program on June 21, talking about his life with CFS and his latest novel, *Love and Fatigue in America*.

A big thanks to the girls softball team at Deerfield High School in Deerfield, Ill., for the \$2,145 raised in support of the Catalyst Fund at their **"Strike Out CFIDS"** game. The girls pulled together in support of a team member's aunt who lost her battle to CFS earlier this year. Thanks Warriors!

Donors to the [Catalyst Fund](#) receive **monthly updates** from Association leaders and news about the people who fuel the Association's research-focused mission. They also receive invitations to special events around the country and on the web. Make [a gift today](#) in support of research and stay in the know!

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OTHER NEWS

Dr. Alison Bested will lead the Complex Chronic Disease Clinic to be located at BC Women's Hospital & Health Centre in Vancouver. The clinic, announced in 2011 by the British Columbia Ministry of Health, will focus on Lyme disease, ME/CFS and fibromyalgia syndrome. Media advisory from the hospital: <http://bit.ly/NhONGS>



Lyrica, the first drug approved by FDA for the treatment of fibromyalgia, will soon be available in generic form at a lower cost than Pfizer's brand name drug. From MedPage Today: <http://bit.ly/NfyQhS> (free registration may be required to access)

This month on [Facebook](#) we're featuring covers from the past 25 years of print publications sent to Association supporters since our founding in 1987. Join us and 7,314 friends for the retrospective and daily news covering a wide variety of topics. This week alone our posts have reach 50,761 people!

Our [YouTube channel](#) has attracted 64,798 views of past webinar recordings, our popular "What Would You Do?" video and others. Check out the [top 10](#) or [peruse them all](#).



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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:

Integrity, Respect, Transparency, Accountability, Collaboration

Empowerment, Innovation, Inclusivity, Diversity, Sustainability

Leadership, Excellence, Teamwork, Communication, Flexibility

Adaptability, Resilience, Openness, Honesty, Responsibility

Accountability, Integrity, Respect, Transparency, Accountability

Collaboration, Empowerment, Innovation, Inclusivity, Diversity

Sustainability, Leadership, Excellence, Teamwork, Communication

Flexibility, Adaptability, Resilience, Openness, Honesty

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