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Research1st News from the CFIDS Association of America
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NEW @ RESEARCH1st

XMRV Ruled Out: Using their own tests, three participating labs looked for XMRV and related pMLV viruses in samples freshly collected from 147 well-defined CFS cases and 146 matched controls. [The results](#), published on Sept.

18, 2012 in *mBio*, conclusively determined that these viruses have no role in CFS. Speaking at a [press conference](#) that day, study coordinator and renowned virus hunter Dr. Ian Lipkin stated, "[The labs involved] found no evidence of XMRV or related viruses in either the subjects with CFS/ME or the controls. Everyone here at this podium, scientists around the world, are committed to solving this problem." Dr. Judy Mikovits, senior author on the 2009 *Science* paper that heralded the breakthrough said, "We have rigorously excluded our original work. We looked carefully and it is simply not there." For more information about this study, please see these two posts on our Research1st blog: [The De-Discovery of XMRV](#) and [Multicenter Study Reports No XMRV](#). The [NIH has announced](#) that aliquots of blood samples collected for this study are available to others for research. Proposals must be submitted and approved through the regular NIH process; there are no set aside funds for such studies. XMRV has also been ruled out in prostate cancer. More about



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that related research in [Case Closed](#).

Mark Stone Joins Association Staff: This week we welcome Mark as our [new director of development](#) following a nationwide search. Learn more about Mark's record of achievement with the PKD Foundation and other organizations and his new role with the CFIDS Association.



Mark A. Stone
Director of Development

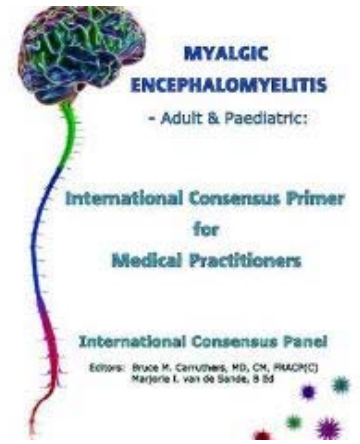
Board Chairman Testifies: Association Chairman of the Board Amy Squires challenged the U.S. federal health agencies to "move forward, aggressively and strategically" during her [Oct. 3 testimony](#) to the CFS Advisory Committee.

Seeking Your Input: We invite your insights into two patient-centered areas of research: health-related app use and biobanking. These [two surveys](#) represent joint efforts with two sets of partners and data is being collected across multiple groups of people engaged in improving health. This information will help shape plans and future strategies for better ways to serve our community and advance research. Thank you in advance for your time and interest!



Novelist's Afterword: "My previous novels induced only handfuls of letters...It's clear that something quite different is going on with *Love and Fatigue in America*. [Messages from readers] do affect me, and my idea of who I am and my relationship in the world..." writes Roger King in a [message he penned](#) after reading a letter from a reader who has had ME for 25 years. The novel is his fourth; it's based on the first eight years following his own diagnosis and it received acclaim from critics and fellow patients alike. He's at work now on his fifth novel.

ME Primer for Healthcare Professionals: Led by Bruce Carruthers, MD, authors of the [International Consensus Criteria for ME](#) (July 2011) have self-published a consensus primer for ME. The 36-page document reviews epidemiology and pathophysiology and addresses assessment, diagnosis, treatment and management. These guidelines are intended for clinical settings and may also be useful to people with CFS to guide self-care techniques. Full text at <http://bit.ly/R61fss>.



Bottom-Up Educational Approach: A research group at the University of Manchester (U.K.) has developed a DVD and other educational materials based on structured interviews with CFS/ME patients, caregivers and physicians. Their paper describes the process of developing these materials and includes quotes from participants about their experiences seeking/providing care for CFS/ME. (*BMC Family Practice*, Sept. 21, 2012; full text)

Review of Pain in CFS: The Chronic Pain and Chronic Fatigue Research Group in Belgium reviewed the literature on pain in CFS through Dec. 2011 and suggested where more research is needed and ways to make the treatment of pain in CFS more effective. (*Pain Physician*, Sept./Oct. 2012; full text)

Review all the journal highlights at Research1st: <http://bit.ly/journal-hilites>

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POLICY MATTERS

The federal **CFS Advisory Committee** met Oct. 3-4, 2012 in Washington, D.C. In addition to hearing agency updates and public testimony, the committee discussed biomarkers and case definition. Recordings of the meeting webcast have been posted to YouTube. The first session can be [viewed here](#); view subsequent sessions by choosing from the list of videos to the right of the viewer. Minutes and presentations will be posted in coming weeks on the [CFSAC website](#).



The **Food and Drug Administration (FDA)** has recently created a [new web page](#) to house information related to drug development for ME and CFS. The agency will host a one-hour webinar titled, "Excellence in Advocacy" on Nov. 15, 2012 at 2:00 p.m. They have also committed to sponsoring a stakeholder meeting about clinical outcome measures in ME and CFS in the spring of 2013. We'll share additional details as they become available.

Under provisions of the recently passed **Prescription Drug User Fee Act (PDUFA)**, the FDA will conduct a series of 20 disease-focused meetings. CFS has been included on the list of possible disease focus areas. A meeting will be held Oct. 25 at FDA to obtain public input on the preliminary list and the process for obtaining stakeholder input. Comments can also be submitted in writing by Nov. 1. For more information, please read the [Federal Register notice](#).



CATALYSTS IN ACTION

Koerner Gray Buchta is walking across Michigan to raise awareness and funds for CFS research. He started his trek on Aug. 18 and is walking short segments -- 1.5-2 miles at a time -- from Detroit to Holland. He rests for a day or more between walking days and took an extended break to complete his college applications. This past weekend he reached the halfway point in Lansing. He has raised \$2,328 toward his goal of \$10,000 for research. Check out the [Walk Across Michigan website](#) for poignant posts from Koerner and his support team about his travels, the people he has met and things he's seen along the way. He also writes about how the walk is affecting his symptoms; although he has recovered significantly from the worst point in the illness, he is careful not to push too hard and to listen when his body tells him to rest. Thank you to Koerner and his entire support team!



Our sixth Catalyst Café donor event of the year will be held in **Washington, D.C. on Nov. 4**. These events provide an opportunity to connect with Association leaders and other guests, share insights and ask questions. We're mobilizing support for patient-centered research conducted through our [Research Institute Without Walls](#) and reporting to you on the return on your investment. For more details, please send a message to Gloria Smith at gesmith@cfids.org.

Jennifer Williams ran her [first marathon](#) on Oct. 7 and finished as the 7th most successful fundraiser for the Twin Cities Marathon! She used this "bucket list" event as an opportunity to raise awareness and funds for the Association's research program on behalf of her husband, Mark, and others like him who have been kept on the sidelines by CFS. By race day Jen and Mark had met their \$4,000 goal; their generous network of friends and family continues adding to that total, now at \$4,329. Way to go Jen and Mark!



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 advance 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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UPCOMING EVENTS

Oct. 18: Association grantee [Biovista](#) will host a lunch and panel discussion on strategic drug repurposing in Washington, D.C. Kim McCleary is one of the panelists. [Click here](#) for event details.

Oct. 21: The **New Jersey CFS Association** will host its annual fall conference in Eatontown, N.J. Our scientific director, Dr. Suzanne Vernon, will be among the participants. [Conference details here](#).

Oct. 25: The **Food & Drug Administration** will host a public meeting to discuss plans for complying with new regulations to host 20 disease-specific meetings. [More information here.](#)

Oct. 29: The Association will participate in [two of the four finalist](#) presentations for the **Sanofi US Collaborate | Activate Challenge** at an event to be hosted at the Newseum in Washington, D.C. Finalists compete for total prize money of \$400,000 and access to non-monetary resources provided by one of the world's largest pharmaceutical companies. CEO Kim McCleary will lead the presentation for the Partnering to End Pain team. You're [invited to participate](#) in person or by webcast.



Nov. 4: Three members of our Board of Directors will host a **Catalyst Café** event in Washington, D.C. Scientific director Dr. Suzanne Vernon will provide an update on the Association's [Research Institute Without Walls](#). Kim McCleary and new director of development Mark Stone will be on hand as well. For more details, please send an email to Gloria Smith at gesmith@cfids.org.

Nov. 15: The FDA will host a webinar, "**Excellence in Advocacy**," to engage stakeholders in best practices for fostering treatment research. [More details here.](#)



Nov. 28-29: The Association will present its **partnership with Biovista** to repurpose existing drugs for CFS at the Partnering for Cures conference hosted by *FasterCures*. Thirty organizations were selected by *FasterCures* for these sought-after ["Innovator" presentations](#) to feature collaborations that cut the time to identify medical solutions for people who need them.

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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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