



# Research1st

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Research1st News from the CFIDS Association of America  
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## FEDERAL CFS ADVISORY COMMITTEE MEETS THIS MONTH

The Department of Health and Human Services **CFS Advisory Committee** (CFSAC) meets next on June 13-14 in Washington, D.C. The meeting will be webcast live. An audio-only feed will also be available.

Additional details:

[http://www.ofr.gov/OFRUpload/OFRData/2012-13097\\_PI.pdf](http://www.ofr.gov/OFRUpload/OFRData/2012-13097_PI.pdf)



Requests to provide oral testimony must be received by June 6:

<http://www.blsm meetings.net/CFSACPublicComment>

Those planning to attend the meeting in person must register in advance by June 8:

<http://www.blsm meetings.net/CFSACJune2012>

Still to come from DHHS are the meeting agenda and an announcement about the appointments of new members to fill vacancies created by terms of four members that ended in April. Watch the [CFSAC website](#) for further details. You can also sign up to join the CFSAC's email listserv:

[http://www.hhs.gov/advcomcfs/cfsac\\_email\\_list.html](http://www.hhs.gov/advcomcfs/cfsac_email_list.html)

## NEW @ RESEARCH1st

Three new studies published last month prompted an update on the status of the once-promising research that linked CFS to **XMRV**. Check in on the latest with "[XMRV Today: Where does](#)

[Research1st Blog](#)

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Researchers at the National Cancer Institute reported in the journal *Cancer* an association between CFS and later diagnosis of **non-Hodgkin lymphoma**. The study looked for connections between a large cancer registry and

Medicare records. Our scientific director, Dr. Suzanne Vernon, provides a summary and analysis in "[Risky Business](#)"...

### Post-exertional

**malaise/relapse (PEM)** is one of the most vexing CFS symptoms for patients and researchers alike. It is considered by many to be the hallmark of CFS. We pooled resources about PEM, including Jennifer M. Spotila's excellent four-part series, in [this post...](#)

Advocates of **open access**, including the CFIDS Association, believe that wider access to research data and results will spur new discoveries and accelerate progress. In particular, access to results of federally funded research should be made available without additional cost to taxpayers. A White House petition has attracted the 25,000 signatures required for an official response from the administration, but you can still register your support to send an even stronger message. Learn more: "[How You Can Change Research In America](#)"...

May 24 marked the first anniversary of our Research1st website/blog. The first year's top 10 stories are [recapped here...](#)

### Post-Exertional Malaise

A Four-Part Series by Jennifer M. Spotila, J.D.



Part 4:  
Power to the People

Jennifer M.  
Spotila, J.D.



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## OTHER RESEARCH NEWS

Researchers at Osaka University in Japan published results of a study using **infrared spectroscopy** to distinguish CFS cases (defined by 1994-Fukuda criteria) from healthy controls. They successfully selected 80.6 percent of the controls and 77.2 percent of CFS subjects on the basis of this noninvasive test. The abstract for the paper, "Visible and near-infrared spectra collected from the thumbs of patients with CFS for diagnosis," is [available here...](#)

A new collaboration that teams investigators at Bond University in Australia and Dr. Daniel Peterson produced two publications last month on **immune dysfunction in CFS** patients. The first, "[Cytotoxic lymphocyte microRNAs as prospective biomarkers in CFS/ME](#)," reported results of 28 CFS/ME patients (1994-Fukuda criteria) and 28 non-fatigued controls. They found changes in subjects' microRNAs in certain immune cells that reflect decreased ability for the cells to fight infection and perform other immune surveillance. They are conducting additional validation studies in hopes of translating these observations to clinical applications. The second study, "[Longitudinal investigation of natural killer cells and cytokines in CFS/ME](#)," followed immune function in 65 CFS/ME patients for 12 months and compared results to 21 non-fatigued controls. Similar to reports by other groups over the past 20 years, they found that the function of natural killer (NK) cells was decreased in patients compared to controls and that some cytokines had elevated activity in patients. They suggest that decreased NK cell function might be an appropriate biomarker for CFS/ME given its stability in the patients studied over 12 months.



**Invest in ME** held its [London conference](#) on June 1. The U.K. organization also announced formation of a [clinical autoimmunity](#) working group that met May 30-31. Tweets sent by conference attendees using #MELondon can be [read here...](#)

The **IACFS/ME** announced on June 2 that it has entered into an agreement with an academic publisher to form a new peer-reviewed journal, *Fatigue: Biomedicine, Health & Behavior*. The journal, scheduled for release in Jan. 2013, will "welcome all fatigue-related research and clinical approaches to the treatment of this often debilitating symptom." Read IACFS/ME president Fred Friedberg's [announcement...](#)

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## CATALYSTS IN ACTION

World War II hero and Olympian Louis Zamperini was profiled on "CBS Sunday Morning" 69 years after his bomber was shot down over the Pacific Ocean. The writer who told his story in her bestselling book, *Unbroken*, **Laura Hillenbrand**, was also interviewed. Louis called Laura "his inspiration" for her courageous battle with CFS. Watch [the segment...](#)



**Denise Lopez-Majano** and her sons **Matthew** and **Alexander** have organized Speak Up About ME to YANK (not tug!) at the nation's heartstrings with organized visits to Capitol Hill. 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](mailto:SpeakUpAboutME@gmail.com) for details.

On May 9, our webinar series hosted a "conversation" between novelist Roger King and **Wilhelmina Jenkins**, a Catalyst, former Board member and visible advocate for CFS. With Roger's autobiographical novel, *Love and Fatigue in America*, as a backdrop, they talked about the experiences they share as people who live with CFS. [Links to the recording](#) and other information about the book and the speakers...



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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. He was profiled in the May 11 edition of the *Amherst Bulletin* with a [front-page story](#). Roger's next public reading is at the [Powerhouse Arena](#) in Brooklyn on June 14.



The third annual mountain biking endurance event, **24 Hours in the Enchanted Forest: A Race to SolveCFS**, will be held on June 16 in the mountains near Gallup, New Mexico. The organizers have generously pledged 25 percent of net proceeds to support the CFIDS Association of America. Learn more about [the event...](#)

We've launched a series of regional events called "**Catalyst Cafés**" to provide supporters with updates about the Association's research program and how the innovative [Research Institute Without Walls](#) advances the field. The next event will be June 21 in downtown San Francisco. Space is limited and we're almost at capacity, but if you're in the area and would like more info, please send an email to [catalystsinaction@cfids.org](mailto:catalystsinaction@cfids.org) with "SFO" in the subject line.

Over the Association's 25 years of service to the community, we've used a variety of print and electronic communications to keep people informed about the latest research, policy and education efforts. Here are [seven ways](#) you can **stay "CFS savvy"** with timely and reliable information from the Association.

The **IACFS/ME** has released a 42-page primer about ME/CFS for clinical professionals with the stated goal, "to provide the information necessary to understand, diagnose and manage the symptoms of chronic fatigue syndrome - also known as myalgic encephalomyelitis (ME/CFS)." Download [the primer...](#)



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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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