



# Research1st

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Research1st News from the CFIDS Association of America  
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## In This Issue

CATALYZING INFORMED ACTION:  
YOUR SPRING WEBINAR SERIES &  
PATIENT-CENTERED SURVEY

ALSO NEW @ RESEARCH1st

JOURNAL HIGHLIGHTS

POLICY MATTERS

OTHER NEWS & EVENTS

## Quick Links

[Catalyzing Informed Action:  
Webinar Series & Patient Survey](#)

[FDA Workshop Agenda & Details  
Announced](#)

[Upcoming Webinar: Overview of  
the Drug Development Landscape](#)

[New \\$2 Million CFS Grant  
Awarded to Dr. Dikoma Shungu &  
Team](#)

[Introducing New Additions to Our  
2013 Board of Directors](#)

[Research1st Blog](#)

[E-newsletter Archive](#)

[The Catalyst Fund](#)

## CATALYZING INFORMED ACTION: YOUR SPRING WEBINAR SERIES & PATIENT-CENTERED SURVEY

The April 25-26 FDA workshop (described below in Policy Matters) provides a **historic opportunity** for the ME/CFS community to establish ME/CFS as an important priority for drug development. We can also set the standard for patient engagement for other conditions that will follow in an FDA series of 20 disease-specific, patient-focused meetings. **Let's lead the way!**



To inform, educate and engage with the community so that our individual contributions have amplified impact, we are pleased to announce a **spring webinar series and a special patient-focused survey**.

We invite you to complete a **new survey** for people living with ME/CFS and those closest to them. It poses open-ended questions to allow respondents to describe the symptoms, daily impacts that matter most, as well as share personal perspectives on treatment. **Your participation** will help us develop a robust profile of what it's really like to live with ME/CFS!

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The spring series of **six weekly webinars** is designed to build awareness and deepen understanding of topics that will be discussed at the April FDA workshop and the May meeting of the federal CFS Advisory Committee. Even if neither of those two meetings are of interest to you, we believe the issues we'll cover in this weekly series will be!

Learn more about how you can participate in the webinar series and survey: <http://bit.ly/spring-series>.

## ALSO NEW @ RESEARCH1st

### New \$2 Million CFS Grant Awarded to Dr. Dikoma Shungu & Team:

**Dr. Dikoma Shungu & Team:** Weill Cornell Medical College has been awarded more than \$1.9 million by the National Institutes of Health to lead an innovative research study using advanced neuroimaging and clinical evaluations of patients with ME/CFS. The new four-year clinical study aims to expand the scientific understanding of CFS, improve diagnostics for the condition and discover novel biomarkers, all of which may lead to the identification of new and more effective treatment targets. Pilot data that led to the successful NIH application was collected with support from the CFIDS Association, thanks to the generosity of our donors. Read more about this exciting NIH award: <http://bit.ly/new-NIH-grant>.

NIH Awards \$2 Million to Dr. Dikoma Shungu & Team for CFS Biomarker & Treatment Study



Weill Cornell Medical College



Icahn School of Medicine at Mount Sinai



Beth Israel Medical Center



The CFIDS Association of America  
Leveraging patient-centered research to cure ME/CFS

### Introducing New Additions to Our Board of Directors:

An active, engaged Board of Directors is at the heart of any organization's success. Board service requires active leadership: defining mission, setting policy and stewarding human and financial resources. The varied talents and contacts of a board from diverse backgrounds can help an

organization grow. In 2013, the Association welcomes five new members to its Board of Directors. Meet Maryam, Michael, Pam, Lynn and Terry: <http://bit.ly/new-2013-directors>.



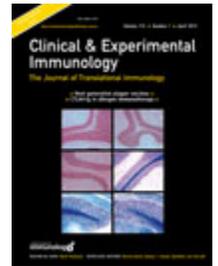
2013 Board of Directors



The CFIDS Association of America  
Leveraging patient-centered research to cure ME/CFS

## JOURNAL HIGHLIGHTS

**Altered B Cell Subsets:** Researchers at St. Helier University (U.K.) studied 33 people meeting Fukuda and Canadian definitions for CFS & ME/CFS with 33 matched healthy controls. They did a detailed analysis of B cell subsets and founded changes that suggest "a subtle tendency to autoimmunity." They were prompted to conduct the study based on the promising 2011 report of R rituximab therapy leading to improved symptoms in 10 of 15 CFS patients. ([Clinical & Experimental Immunology](#), Apr. 2013)



**CFS & ME Compared:** Using 3 independent data sets (including the SolveCFS BioBank), Dr. Leonard Jason and colleagues found that fewer subjects met criteria for ME than CFS and symptoms were more severe and impairments were greater for subjects who met ME criteria. ([Fatigue: Biomedicine, Health & Behavior](#), Mar. 20, 2013)

**Heart Rate Variability During Sleep:** The 52 female patients with CFS studied by Drs. Benjamin Natelson and Fumharu Togo showed evidence for sleep disruption in the form of significantly reduced total sleep time, reduced sleep efficiency, and changes in whole night heart rate variability when compared to matched healthy controls. "Our study showed that cardiovascular regulation of CFS patients differed from that of healthy controls even when we eliminated effects of sleep macro-architecture. This could be a reason why CFS patients report their sleep to be unrefreshing." ([Autonomic Neuroscience](#), Mar. 18, 2013)

**Abnormal Pain Processing:** 19 patients with CFS/FM, 16 patients with rheumatoid arthritis (RA) and 18 sedentary controls participated in a double-blind crossover trial of a single dose (1 g) of acetaminophen with tests of pressure pain threshold before and after treatment. The group of Belgian researchers led by Dr. Mira Meeus report, "CFS/FM patients present more central pain processing abnormalities than RA patients; acetaminophen may have a limited positive effect on central pain inhibition, but other contributors have to be identified and evaluated." ([Pain Physician](#), Mar. 13, 2013)

**Air Hunger Common:** Researchers at Georgetown University, including Dr. James Baraniuk, report on a two-cohort CFS study of dyspnea, an inability to fully inflate or deflate the chest. 363 CFS subjects (94 Fukuda) and 546 healthy controls were studied using two different criteria for dyspnea. Rates of dyspnea in CFS were 54% and 67% compared to 3% and 23% in the control group. Pulmonary function was normal in CFS. ([Global Journal of Health Science](#), Dec. 12, 2012)

Keep up with journal highlights on our Research1st website at <http://bit.ly/journal-hilites>.

[Back to top](#)

**APRIL FDA WORKSHOP:** The **U.S. Food and Drug Administration** (FDA) will host a workshop, "*Development of Safe and Effective Drug Therapies for CFS and ME*," on April 25-26, 2013. This FDA workshop will also serve as the first of 20 disease-specific meetings where the FDA will gather patients' perspectives as part of a mandated "Patient-Focused Drug Development Initiative." The workshop is open to the public and will be webcast live; advance registration is required for both means of participating. We've collected all the details here: <http://bit.ly/fda-mtg-agenda>.

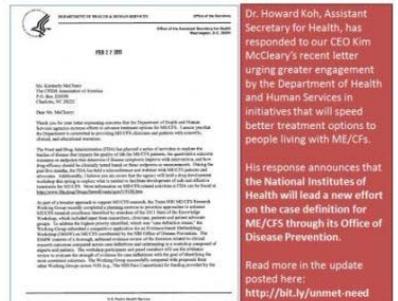


The banner features the U.S. Department of Health & Human Services logo at the top left. Below it is the FDA logo and the text "U.S. Food and Drug Administration Protecting and Promoting Your Health". The main title of the workshop is "Development of Safe and Effective Drug Therapies for CFS and ME". The dates and location are "APRIL 25-26, 2013 Bethesda, Maryland".

The Workshop will include patient panels and time for public testimony. It will be webcast live.

**ADVANCE REGISTRATION IS REQUIRED TO ATTEND IN PERSON OR BY WEBCAST.**

**MAY CFS ADVISORY COMMITTEE MEETING:** Dates of the spring 2013 meeting of the federal CFS Advisory Committee have been announced: May 22-23 in Washington, D.C. Meetings are usually webcast live and allocate time to public testimony. Watch for more details at the committee's website: <http://www.hhs.gov/advcomcfs/>. We'll keep you posted, too!



The image shows a scanned letter on official government stationery. The letter is dated 05/17/2013 and is addressed to Kim McCleary, CEO of the National Institutes of Health. The letter is from Dr. Howard Koh, Assistant Secretary for Health. The text of the letter discusses the case definition for ME/CFS and the need for collaborative action. To the right of the letter, there is a red text box with white text that summarizes the letter's content and provides a link to the full text.

**ASSISTANT SECRETARY FOR HEALTH ANNOUNCES NEW CASE DEFINITION EFFORT:** Last month our CEO Kim McCleary wrote to Assistant Secretary for Health **Dr. Howard Koh**; his written response came by mail last week. In it he announces a new NIH initiative to address case definition issues. We've updated the Research**1st** post, "Serious Unmet Demands Collaborative Action," with a link to Dr. Koh's letter & other details: <http://bit.ly/unmet-need>.

[Back to top](#)

**OTHER NEWS & EVENTS**

**Our new look:** We're in the process of developing a new "look" for the Association, bringing all our publication titles and websites into a more cohesive design so you'll recognize all our great resources and programs more easily. We're also incorporating the term ME/CFS. We will use the term ME/CFS to refer to conditions also known as chronic fatigue syndrome, CFS, myalgic encephalomyelitis, myalgic encephalopathy, ME and by other names. Next month's issue of "Research1st News" will get an update too--we welcome and look forward to your feedback about these changes!

Please join us for **our first webinar**, "Overview of the Drug Development Landscape," at **1 p.m. (Eastern) on March 28** featuring Kristin Schneeman from *FasterCures* and our CEO Kim McCleary. This is an important program for anyone interested in how basic science discoveries lead to treatments and cures. More details:

<http://bit.ly/2013-webinar-1>.



If you're planning to attend the April 25-26 FDA workshop on CFS and ME in person OR by webcast, you must **register in advance**:  
<http://mecfsmeeting.eventbrite.com/#>.

The March 17, 2013, *NY Times Sunday Review* features an opinion piece by Laurie Edwards titled, "The Gender Gap in Pain."

Ms. Edwards includes CFS, MS, rheumatoid arthritis, FM and other conditions among those that affect more women than men. She cites

the **Campaign to End Pain in Women and Institute of Medicine reports** about the inadequate care women with pain often receive. From the *New York Times*: <http://nyti.ms/YkYHlv>. The CFIDS Association is one of the partners leading the Campaign to End Pain in Women:  
<http://www.endwomenspain.org/>.

**BioWorld**, a daily news source for the pharmaceutical industry, has published several articles by Randy Osborne about the recent FDA decision to decline approval for Ampligen. Now Randy is keeping tabs for the industry on the upcoming FDA workshop. Here's his latest story, from March 14: <http://bit.ly/16ya6eG>.

The April FDA workshop on CFS and ME also attracted attention from the **Pink Sheet Daily**, a leading pharma publication. "CFS and ME will be the focus of the first meeting convened under FDA's Patient-Focused Drug Development initiative, and the inaugural session may serve as a model for future workshops under the program... The decision to make CFS/ME the focus of one of the highly coveted 'disease of the quarter' meetings under the reauthorized Prescription Drug User Fee Act cements these conditions as a test case for incorporating patient input into the drug development process for conditions with a high unmet need." The March 11 article is behind an \$85 paywall at: <http://bit.ly/WWW5FI>.

Ekua Brenu and colleagues at Griffith University and Bond University (Australia) have authored a chapter about **parallels between CFS/ME and autoimmune disorders** in a textbook titled, *Genes and Autoimmunity - Intracellular Signaling and Microbiome Contribution*. Read it here:  
<http://bit.ly/WW9iPa>.

This month's **DISCOVER** magazine features an article titled, "Chasing the Shadow Virus." It's writer

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about our  
**patient-centered**  
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The CFIDS Association of America

Hillary Johnson's account of how XMRV was linked to, then uncoupled from, CFS:  
<http://bit.ly/XMGKVc>.

CFS gets a close look from freelance writer Karen Shan. She interviewed the Association's CEO, Kim McCleary, and two local doctors for the *Poughkeepsie Journal*: <http://pojone.com/15sKQoK>.

**FOX17** in Western Michigan portrays two women with CFS, Jessie DeDecker and Lori Chapo-Kroger, their struggles to get diagnosed and treated, and the need for greater awareness about CFS: <http://bit.ly/Z4nH7U>.

CFS and Lori Chapo-Kroger of P.A.N.D.O.R.A. are featured in an **ABC News** story about the new DSM-V diagnosis, "Somatic Symptom Disorder" that may lead some healthcare professionals to miss underlying medical illness based on what they deem to be an unhealthy preoccupation with symptoms and diminished function. Here's the story:  
<http://abcn.ws/YGd5y7>.



**Invest in ME**, a U.K. charity, will host IIME8, "Infection, Immunity and ME," in Westminster, London on May 31, 2013. More information: <http://bit.ly/YGhQnN>.

Your votes can help the **National ME/FM Action Network of Canada** win a cash prize! Click on the "N" in the charities list at <http://www.sharethebounty.ca/charities.php>. You can vote daily until March 29 from anywhere in the world.

For **daily updates** about research, policy and media, join us on [Facebook](#) and follow us on Twitter [@plzsolvecfs](#).

[Back to top](#)

## 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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