



# The CFIDS Association of America

Research 1st News

PARTICIPATORY RESEARCH | PREDICTIVE MEASURES | PERSONALIZED TREATMENTS



The CFIDS Association of America

April 2014

## In This Issue

About Us

IACFSME & New Primer

Research Digest

ME/CFS Mortality Study

IOM Questionnaire

Ask an Expert

NIH P2P

FDA Draft Guidance

Seeking a Congressional RFA

Investing In Progress

Dear Kim,

We are in a race to solve ME/CFS and you, your family and friends are central to the effort. It's a race to gather the "BIG DATA" that will enable ME/CFS to be diagnosed with objective tests (rather than by exclusion) and result in matching the right person with the right treatment. The SolveCFS BioBank & Registry gives you an opportunity to be a part of the solution.

Our SolveCFS BioBank & Registry has grown to over 800 participants; we are aiming for 1,200 by the end of 2014. Right now 650 ME/CFS patients and 150 "healthy controls" have enrolled. Control participants are essential because they serve as the comparison group. For example, when we conduct a genetics study we may want to compare to family members; when we study environmental exposures we would compare you to a neighbor.

Later this year we will be providing you with the tools you need to encourage family and friends to join this effort as healthy controls. In the meantime, if you are not yet signed up yourself,



don't be on the sidelines - join the team and together we will Solve ME/CFS!

[Learn more and sign up today!](#)

Enjoy this free & informative email and [share it with someone you know](#) that might benefit from this information about ME/CFS.

## Quick Links

[SolveCFS.org](#)

[Donate Securely](#)

[Email forwarded to you? Sign up to receive it directly!](#)

## About Us

### Our Vision

We strive for a world free of ME/CFS

### Our Mission:

Make ME/CFS understood, diagnosable and treatable

### Contact Us...

CFIDS@CFIDS.org  
704-365-2343

### Follow Us!

[Facebook.com/CFIDSAssn](#)

[Twitter.com/PlzSolveCFS](#)

[YouTube.com/SolveCFS](#)

## The IACFSME and a New Primer for Clinical Practitioners

On March 20-23, 2014, in San Francisco, CA the IACFSME held its 11th Biennial Conference. The CFIDS Association was able to put together this video of Dr. Komaroff's conference summary presentation and is happy to be able to [share it with you HERE](#)



At this year's event the [IACFSME](#) unveiled its newly updated primer for clinical practitioners. This is a wonderful resource to take to your doctors to help them understand this illness. We have made it available in our [resources section on www.SolveCFS.org](#)

[You can also access it HERE](#) through the IACFSME.

## Research Digest

There is no one "target organ" affected in ME/CFS patients that we can sample so blood has been used as our window into understanding ME/CFS - a molecular biopsy if you will. In the past, there has been some concern expressed among the scientific community that blood may not be the right biological sample.

Ten years ago, Dr Suzanne Vernon, CFIDS Association Scientific Director, [published a paper](#) that explored how blood gene expression could be used to understand brain and endocrine processes. [Read it HERE](#).

In [an article published online this month](#), Dr. Richard S. Lee's group from Johns Hopkins University School of Medicine reported on their studies in mice that show that epigenetic changes in the blood do have a correlation with disease-specific changes in the brain. Examining the blood will help us understand what is happening in the brain.

This is great news for CFIDS Association funded investigator, Dr. Patrick McGowan, who is [studying how epigenetics changes in the immune system affect brain function in ME/CFS using blood samples from our SolveCFS BioBank](#). McGowan and Lee did their post-doctoral work together; ongoing research will continue to benefit from the work they both do. This is an example of how the CFIDS Association's leadership and programs drive progress, create an open research environment and foster learning from the best and the brightest in a number of research areas that are relevant to helping us solve ME/CFS.

---

### SolveCFS BioBank Investigator Honored

Fighting disease is one of the longest, toughest battles in the world. But the rewards of scientific breakthroughs are great - often revolutionary - leading to diagnosis, treatment and cure. The Canada Gairdner Awards celebrate and reward the scientists who make these discoveries. [Steve Elledge, currently working with the CFIDS Association and our SolveCFS BioBank was recognized with one of these majors award last year](#). We are honored to have him in the fight to Solve ME/CFS

Learn more about the award [HERE](#) and [HERE](#)

Learn more about Steve Elledge and his work on ME/CFS with the Associations Solve CFS BioBank [HERE](#) and [HERE](#)

---

A recent study shows that [PET scans could potentially be used to diagnose Chronic Fatigue Syndrome](#). Researchers have found that inflammation of the nervous system is higher in patients with Chronic Fatigue Syndrome (CFS) than in healthy people. The results of this study could have potential impact on the naming of ME/CFS; something [under consideration through the IOM Committee on Diagnostic Criteria for ME/CFS](#)

Read more [HERE](#) and [HERE](#)

## ME/CFS Mortality Study

Dr. Lily Chu has addressed the ME/CFS mortality issue at a variety of venues and in multiple presentations. *"I have personally known two young people that have passed away within the last year ; I have heard/ read of many others. Yet outside of the patient community and a few ME/CFS researchers and clinicians, the fact that people do die from ME/CFS is hardly acknowledged anywhere and rarely investigated."*

Chu has urged the CFSAC to take action on these issues, saying *"I hope to never hear about another preventable death nor to attend another funeral due to ME/CFS."* And when the IACFSME released its new primer, Chu pressed for more clarity around the mortality issue in the document, stating, *"Documenting mortality influences issues like research funding and access to health services."*

Knowing that this issue of ME/CFS mortality is an important concern, **we'd like to encourage you to take part in an online study on the issue.**

DePaul University's Center for Community Research is currently [recruiting respondents for a study on myalgic encephalomyelitis \(ME\) and chronic fatigue syndrome \(CFS\) mortality](#). They are looking to recruit surviving family members, friends, and/or caregivers of individuals who had been diagnosed with ME or CFS and are now deceased.

The intention is to document the experience of these deceased individuals, and the experience of their family and friends, to improve knowledge of ME and CFS and to help those individuals who are currently suffering

from the illness. Participants will be asked to complete a confidential online survey and will be given the opportunity to volunteer for an additional in-person or phone interview.

Please read the [FULL FLYER HERE](#) and consider inviting anyone you know to participate in this important study.

### Third Meeting of the IOM Committee on Diagnostic Criteria for ME/CFS

The [third meeting of the Institute of Medicine committee on Diagnostic Criteria for ME/CFS](#) will be held May 5-6, 2014 in Washington, D.C. On the afternoon of May 5, the committee will hold an information-gathering session that will be open to the public.

Read more about the meeting [HERE](#)

In this open session the committee will gather information and assemble evidence that it will examine and discuss in the course of making its findings, conclusions, and recommendations. The objectives for the committee during this open session are to learn more about the cognitive, sleep, and diagnostic issues related to ME/CFS; and to seek input from patients and caregivers regarding their interaction with health care professionals. They are asking for input from patients on two specific questions.

In order to gather as much response from the patient community as possible, the CFIDS Association has created a simple online survey to address the IOM Committees's specific questions. We will compile your answers into a report and submit them in full prior to the April 23rd deadline.

[Access the online questionnaire HERE](#) - DEADLINE, April 22nd at noon, Central  
<https://www.surveymonkey.com/s/IOMQuestions>

### Ask an Expert

Do you have a health issue you'd like to pose to ten of the most experienced ME/CFS doctors on the planet? Cort Johnson of Health Rising is coordinating just such an effort. [Read more about it HERE](#)

Vote on the first question [HERE](#) But don't wait... Voting closes on Friday April 18th.

### NIH Pathways to Prevention for ME/CFS

There is a lot of activity on a federal level related to ME/CFS -including the Pathway to Prevention (P2P) initiative through the National Institutes of Health. In a recent post we broke down the P2P program and where ME/CFS is in the approval process so far.

[Read it HERE](#)

### FDA Releases Draft Guidance for Industry for ME/CFS

On March 11, 2014, FDA released a draft guidance for industry entitled "*Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: Developing Drug Products for Treatment*." The purpose of this guidance is to assist sponsors in the development of drug products for the treatment of CFS/ME.

On Wednesday, April 23, 2014 from 1pm-2pm, [FDA will host a webinar](#) regarding the Draft Guidance for Industry Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: Developing Drug Products for Treatment.

[Read more](#) about the draft guidance, your opportunity to provide feedback and get the details of the webinar [HERE](#)

## Effort Underway to Secure Congressional Support for an RFA

There is an effort underway by some very determined advocates in California to secure Congressional support for a \$7-10 million Request For Application (RFA) for ME/CFS funding at NIH. An RFA identifies a more narrowly defined area for which one or more NIH institutes have set aside funds for awarding grants - it is almost like designated funding. Over several years, members of Dr Lily Chu's support group and others have spoken to Congressional members about ME/CFS, the disability levels, the prejudices patients face, the poor amount of funding, and the overall importance of the issue.

As a result of this effort, two important letters have been composed by Dr. Ben Gutman, who works for Rep. Zoe Lofgren and supported by Rep. Eshoo (both of California). Representatives Lofgren and Eshoo both personally know people affected by ME/CFS, so they are very motivated to help.

These letters call for a very specific action - money for an RFA - so it is something specific that members of Congress can do to sign and support it. This RFA is backed by CFSAC's recommendation in 2011 and 2012. **We were pleased to work with Dr. Gutman on the language of the letter, at his request.**

Read Jennie Spotilla's Occupy CFS blog post about this work, see the letters, and [learn how you can support this effort HERE](#)

## Investing In Progress

The CFIDS Association of America



Are you looking for a new way to support the work of the CFIDS Association? [Consider becoming a monthly partner](#) in the CFIDS Associations' efforts to speed a cure for ME/CFS! By providing steadfast income throughout the year, you help fund high-impact research as efficiently as possible while maintaining our momentum and progress on all fronts.

Want to get creative in your support? ...Several for-profit organizations generously donate a portion of sales to the CFIDS Association of America.

Whether you are shopping for birthdays, anniversaries or baby showers, your purchase means increased ME/CFS research progress. [Learn more about our partners in this effort HERE](#) and shop your way to research support today!

Research progress takes investment. **We need your involvement and support to continue our important work through the Research Institute Without Walls and its SolveCFS BioBank & Patient Registry.** Please give a gift that is significant to you.

We are immensely grateful for the ongoing support of so many that makes our work possible.



Click here to donate now!



Try it FREE today.

This email was sent to [research1stnews@cfids.org](mailto:research1stnews@cfids.org) by [research1stnews@cfids.org](mailto:research1stnews@cfids.org) |  
Instant removal with [SafeUnsubscribe™](#) | [Privacy Policy](#).  
The CFIDS Association of America | PO Box 220398 | Charlotte | NC | 28222-0398