



# The CFIDS Association of America

## Research 1st News

PARTICIPATORY RESEARCH | PREDICTIVE MEASURES | PERSONALIZED TREATMENTS



The CFIDS Association of America

December 2013

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Happy Holidays to all in our ME/CFS Family! Our wish is that you are able to celebrate the holidays surrounded by the people you love. Our hope is that some day soon we will all celebrate a world free of ME/CFS.

### What Would YOU Do... If Tomorrow You Were Well?



### Quick Links

[SolveCFS.org](http://SolveCFS.org)

Donate Securely

## 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](https://www.facebook.com/CFIDSAssn)

[Twitter.com/PlzSolveCFS](https://twitter.com/PlzSolveCFS)

[YouTube.com/SolveCFS](https://www.youtube.com/SolveCFS)



## IOM & the Clinical Case Definition Committee

On Tuesday, December 3, the Institute of Medicine (IOM) announced the provisional Clinical Case Definition Committee slate. The Association has reviewed the full slate of committee members and is optimistic that this committee has the potential to be effective in fulfilling its important mandate.

[Read more...](#)

## CFIDS Association Update to CFSAC

On Wednesday, December 11, Carol Head, President and CEO, delivered an update to the CFSAC.

[Read the transcript of her comments HERE](#)

## Guest Blog - Anna Zapp

*Rocky Mountain Highs:* For many who suffer with ME/CFS, "coming out" to family and friends can be a tremendous challenge, especially at the holidays. But this conversation is an important piece of the puzzle.

Anna Zapp openly and courageously shared her personal story with us in November. [Read it HERE.](#)

You can also see her story in the most recent issue of the SolveCFS chronicle - headed your way and [available online.](#)

## Research Digest

In 2008 the CFIDS Association funded a study that used an exercise challenge to determine the affect on the gut microbiome and gene expression. Meyer, Light and Shukla et al., have

[published the gene expression findings in the current issue of \*Fatigue: Biomedicine, Health & Behavior\*](#). They report a novel finding of increased expression of the glucocorticoid receptor gene and increased confusion in ME/CFS patients up to 72 hours post-exercise. The glucocorticoid receptor gene is regulated by cortisol in order to ensure proper immune and metabolic function in the body. This study provides evidence for neuroimmune and endocrine disruption in ME/CFS patients and provides important clues to the biological pathways involved in post-exertion malaise.

[Access the summary report HERE](#)

The **prevalence of chronic fatigue syndrome in children** and the significant impairment it causes to their physical functioning, school attendance and performance, and extracurricular activities, are at the root of a new Chicago-based study led by DePaul University psychologist Leonard A. Jason. The five-year study aims to determine the prevalence of pediatric chronic fatigue syndrome in a community based sample of more than 20,000 Chicago area youth ages 5 to 17.

Both Jason and his co-researcher, physician Ben Z. Katz are Association funded researchers and Jason is currently utilizing BioBank data in his research efforts.

[Read more HERE](#)

Considerable controversy has transpired regarding the core features of myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). Current case definitions differ in the number and types of symptoms required. This ambiguity impedes the search for biological markers and effective treatments. This study sought to empirically **operationalize symptom criteria and identify which symptoms best characterize the illness**.

This important study examining case definition criteria for chronic fatigue syndrome and myalgic encephalomyelitis is authored by Leonard A. Jason, Madison Sunnquist, Abigail Brown, Meredyth Evans, Jacob D. Furst, Valerie Simonis **and our own Suzanne D Vernon**

[Read more HERE](#)

CDC recently used evidenced-based literature, focus group data, patient case studies, and health behavior theories to develop **new CFS educational curricula aimed at medical students**.

Dissemination of the educational curriculum is occurring using MedEd Portal, and CDC is submitting materials to MedEd Portal for peer-review publication.

We have not yet been able to review the materials and provide assessment, but the investment in these new materials is, in our view, a positive sign.

[Read the press release about the project HERE.](#)

## Tips for Surviving the Holidays



In this busy end-of-year bustle of events, family gatherings, celebrations and holidays, we are happy to offer some resources for holiday survival.

Take a moment to refresh your mind with these strategies for surviving the holidays. [Read the full post HERE](#)

## Hope on the Hill - ME/CFS in Washington

The CFIDS Association is focused on efforts to fund and conduct research leading to improved methods of diagnosis and treatment of ME/CFS. We recognize the importance of the federal government in this process. We can disagree at times with how governmental power it is wielded, but we cannot ignore it.

In a recent blog post, the Association offered its perspective on the federal government and why we continue our work... [Read more](#) of our review of their roles of the different offices and a summary of some recent encouraging work...

[Access the full post HERE](#)

## Investing In Progress

The CFIDS Association of America



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. The Association is fully committed to driving progress and maximizing your investment. Please give a gift that is significant to you.

There are many ways to be involved:

- Stay engaged - follow us on [Facebook](#), [Twitter](#) and [YouTube](#)
- Sign up for the **SolveCFS BioBank** to engage in research. Contact Gloria Smith at [GESmith@CFIDS.org](mailto:GESmith@CFIDS.org) to learn more.
- **[Provide financial Support](#)**; any level of investment fuels the path forward. Please consider a gift that is personally significant to you and take advantage of a generous matching grant. *Now through December 31st, the McGrath Family Foundation has pledged to double your donation!*



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