



# The CFIDS Association of America

## Research 1st News

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The CFIDS Association of America

September 2013

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If you have questions or comments, please write to us at [Research1stNews@CFIDS.org](mailto:Research1stNews@CFIDS.org)



### ME/CFS Clinical Case Definition

If you are plugged in to the ME/CFS social media world, you may be aware of a proposed contract between [Health and Human Services \[HHS\]](#) and the [Institute of Medicine \(IOM\)](#) to recommend clinical diagnostic criteria for ME/CFS. Some oppose this move.

### Quick Links

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

[Research1st](http://Research1st)

On Monday, September 23, the CFIDS Association weighed in on the debate. [READ the Post HERE...](#)

Later that same evening, we received confirmation via the CFSAC listserv that "the Institute of Medicine (IOM) will begin

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## About Us

### Our Vision

We strive for a world free of ME/CFS

### Our Mission:

We will 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)

conducting a study on Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome..."

The full details of the [announcement can be read HERE...](#)

## The Voice of the Patient FDA Report

On April 25, 2013, FDA held a public meeting to hear perspectives from patients with chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME) about their disease, its impact on their daily life, and currently available therapies. The CFIDS Association was there.

On May 17th we reported on the meeting in [THIS SUMMARY post to Research1st.](#)

On May 29th, we reported on [our survey findings](#)- A survey we presented in summary to FDA at the meeting and then again, in full, prior to the final deadline for public comment on August 2nd.

Recently, [FDA released their report](#) on this meeting. The report acknowledges that the input FDA received through the meeting and the public docket underscore the chronic and serious nature of ME/CFS. The full range of cognitive and physical symptoms discussed by participants are described on page 6-10, while participants' discussion on the range of treatments, their effectiveness and their downsides is described in more detail on page 11-13. The report then goes on to summarize all of the public comments, including those submitted by the Association. (Made possible due to the tremendous response we received to our online survey.)

The report concludes by stating "*FDA recognizes that patients have a very unique ability to contribute to our understanding of this broader context of the disease, which is important to our role, and that of others, in the drug development process. We share the patient community's commitment to facilitate the development of safe and effective drug therapies for this disease.*"

The CFIDS Association will continue to do all it can to ensure the patient voice - ***your voice*** - is appropriately heard.

You can [access the full report HERE...](#)



## Putting **YOU** at the CENTER of Research

### Catalyst Cafes Making the Rounds!

The CFIDS Association has been hosting events across the country so that ME/CFS community members coast to coast can learn more about our innovative approach to research. At each *Catalyst Cafe* event, Association leaders share exciting news about the progress taking place through our [Research Institute Without Walls](#), shifting the paradigm for the way nonprofits participate in and support medical research.

#### Upcoming Events:

- Denver, CO - October 6
- Columbus, OH - October 12
- Portland, OR - October 19

D.J. Gilbert recently attended a Catalyst Café in Los Angeles and shared his experience in the Summer issue of *SolveCFS: The Chronicle of the CFIDS Association of America*. [Read how he now has hope and is empowered to make a difference!](#)

If you are interested in hosting a Catalyst Cafe in your town, let us know! Email us at [CFIDS@CFIDS.org](mailto:CFIDS@CFIDS.org)

### Investing In Progress



The reality is, progress takes investment. Who is more motivated to fuel this progress than those most impacted by ME/CFS? **We need your involvement and your support.** The staff and board are fully committed to doing all they can to ensure progress and maximize your investment. Any level of investment fuels the path forward. Please donate today.

Where YOU Fit In:

- Learn more by following us on [Facebook](#), [Twitter](#) and [YouTube](#) and be an active, positive advocate on all social media outlets.
- Sign up for the [SolveCFS BioBank](#), making your de-identified clinical information and blood samples available for research studies, lowering the threshold for involvement by researchers to conduct studies. Contact Gloria Smith at [GESmith@CFIDS.org](mailto:GESmith@CFIDS.org) to learn more.
- [Lend financial Support](#); any level of investment fuels the path forward.