



The CFIDS Association of America

Research 1st News

PARTICIPATORY RESEARCH | PREDICTIVE MEASURES | PERSONALIZED TREATMENTS



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March 2014

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Dear Kim,

A persistent shortage of volunteers for clinical trials slows scientific progress. Patients pay the ultimate price for under-enrollment in clinical research, facing few new treatment options.

[The science needs you!](#) Overall:

- 30% of all clinical trials fail to recruit a single person
- 85% of clinical trials face delays due to limited participation
- Fewer than 10% of patients ever take part in trials, despite overwhelming interest in working with scientists to help speed treatment breakthroughs

In 2014 we're taking steps to expand our SolveCFS BioBank to also serve as a Patient Registry. When you sign up for our BioBank & Patient Registry, think of yourself as the research national guard, ready to be called into duty when needed.

Not a part of our SolveCFS BioBank & Patient Registry yet?

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

Quick Links

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)

ME/CFS Meetings

[CFS Advisory Committee](#) (CFSAC)

March 11, 12 - 5:00 pm (ET)

Anyone can attend this web conference. More information and webinar instructions can be found on the [CFSAC Website](#).

[IACFSME Biennial Conference](#)

Transforming Science Into Clinical Care

March 20-24, 2014

SolveCFS BioBank & Patient Registry - Breaking Down Barriers, Speeding Progress

In a recent 4 part blog series, we laid out some of the work being done through the SolveCFS BioBank. In case you missed all or part of the series, here it is:

[Part 1 - An Important Tool for Accelerating Discovery](#)

[Part 2 - Breaking Down Barriers to ME/CFS Research](#)

[Part 3 - Breaking Down Barriers Through Biomarker Discovery](#)

[Part 4 - Calling YOU to Participate in Gathering a Breadth and Depth of Data](#)

Identifying safe and effective treatments for ME/CFS is going to require a number of key ingredients, and patient participation in the process is a critical piece of the puzzle.

Our primary goal is to **accelerate the path for safe and effective treatments**. Our Research Institute Without Walls (RIWW) is building a more collaborative and productive approach to the science of solving ME/CFS. The SolveCFS BioBank & Patient Registry is the cornerstone of the RIWW, building a collaboration of research projects among leading experts working in diverse disciplines while building a ready army of patients ready to engage in research.



If you have not yet enrolled in the BioBank and want to be a part of that progress, take the first step to enrollment today by contacting the Solve BioBank Coordinator:

Gloria E. Smith
(704) 362-2343
biobank@cfids.org

San Francisco, CA

Learn More & Register by
[visiting their website HERE.](#)

New Interactive Feature Launched on Facebook

You are an important part of the puzzle in Solving ME/CFS and now we've created an easy way to tell your friends on Facebook just that...

If you are a fan of ours on Facebook, check it out today. If not, today's a great day to like our page to receive news and updates and connect with others whose lives have been touched by ME/CFS!

<https://www.facebook.com/CFIDSAssn>



Research Digest

[Identifying Defining Aspects of CFS](#)

There are several case definitions of ME/CFS, each composed of many of the symptoms that are prevalent in ME/CFS patients. The difference in the case definitions lies in what each one *requires* as a symptom in order for someone to be defined as a person with ME/CFS (a "case").

Computer science students Samuel Watson and Amy Ruskin worked with investigators at DePaul University, including Dr. Lenny Jason, to use computer analysis to determine which case definition - Fukuda, the Canadian and the ME-ICC - was better or worse at defining a case of ME/CFS. They also analyzed which symptoms were more prominent and important to classify or define a person with ME/CFS.

The results showed that these three case definitions identified ME/CFS cases with similar levels of sensitivity (detecting all possible patients) and specificity (detecting only the most "true" positive patients). They also identified 15 symptoms that were most predictive of ME/CFS shown in the following table and ranked in order of predictive power:

Rank	Symptom
1	Fatigue/extreme tiredness
2	Next day soreness or fatigue after nonstrenuous, everyday activities
3	Minimum exercise makes you physically tired
4	Physically drained or sick after mild activity
5	Dead, heavy feeling after starting to exercise
6	Feeling unrefreshed after waking up in the morning
7	Problems remembering things
8	Muscle weakness
9	Difficulty finding the right word to say or expressing thoughts
10	Only able to focus on one thing at a time
11	Pain or aching in your muscles
12	Difficulty paying attention for a long period of time
13	Mentally tired after the slightest effort
14	Absentmindedness or forgetfulness
15	Sensitivity to noise

[Read the full paper HERE](#)

[Five Things You Should Know About Benefit-Risk, Kim McCleary, Faster Cures](#)

Assessing benefits and risks is core to medical product development, regulation, and healthcare decision-making. The trade-offs between desired benefits and tolerable risks may look quite different whether you're a patient, a physician, a regulator, or a drug/device developer.

... "There is growing acceptance of the value of eliciting, understanding, and incorporating patient preferences for benefits and tolerances for risks at every stage from early clinical development to marketing medical products"

[Read the full article...](#)

[Medicine to Treat Neurogenic Orthostatic Hypotension Gets FDA Approval for Parkinsons -](#)

Testing in CFS Halted due to Enrollment Issues

Neurally mediated hypotension (low blood pressure upon standing that occurs in people with an underlying neurologic disease) has been associated with patients suffering from Chronic Fatigue Syndrome. The drug that was the subject of this trial - Nothera - has been approved in Japan for the treatment of neurogenic orthostatic hypotension and it is hypothesized that regulating the autonomic nervous system in patients with Chronic Fatigue Syndrome may prove to be clinically beneficial. Dr. Charles W. Lapp, M.D., Hunter-Hopkins Center was the primary investigator for the CFS Nothera trial, but unfortunately [the trial was terminated due to enrollment issues](#).

[ME/CFS Profile on WomensHealth.gov](#)

Last fall we were contacted by the Office of Women's Health to suggest women with ME/CFS for them to profile on their website. We were thrilled to learn they selected **Lindsey McGrath** for the January 2014 "Spotlight on Women's Health."

[Read her profile HERE](#)

[Association President, Carol Head, Addresses the IOM Committee](#)



On Monday, January 27th, 2014, Carol Head, Association President and CEO was in Washington D.C. along with several other organization leaders, advocates and patients to take part in the first public meeting of the IOM Committee for Diagnostic Criteria for ME/CFS. She presented some breaking research being conducted through or Research Institute Without Walls. In addition, she shared the results of our *Patient Diagnosis Journey* survey, proudly representing so many patients who could not tell their own story themselves.

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

Access the [full report created from the "Road to Diagnosis" survey we conducted HERE](#)

Stay up to date on the activities of the committee and see the full broadcast [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 & Patient Registry. The Association is fully committed to driving progress and maximizing your investment. 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.

There are many ways to be involved:

- Stay engaged - follow us on [Facebook](#) , by liking our page today!
- Sign up for the **SolveCFS BioBank** to engage in research. Contact Gloria Smith at 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.



[Click here to donate now!](#)