



The CFIDS Association of America

Research 1st News

PARTICIPATORY RESEARCH | PREDICTIVE MEASURES | PERSONALIZED TREATMENTS



Research 1st News | May 2014

Research1st News is your monthly e-newsletter from the CFIDS Association of America. Forward it to someone you know that may benefit from the information here.

We are driven by a vision of a world free of ME/CFS, working tirelessly to leverage experience, relationships and collective knowledge to propel the ME/CFS research field to the next level so that scientific advances can translate into better care for patients. It is because of your support that we are able to fund high-quality ME/CFS studies, foster increased collaboration among ME/CFS researchers and push the federal government to make ME/CFS a greater priority.



It will take all of us - patients, researchers, funders, government agencies, other ME/CFS organizations – working together to bring safe and effective, approved therapies to market and ultimately eradicate this dreadful and debilitating disease. Thank you for being a part of all we do.

Carol E Head
President and CEO

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Research Digest

Post-exertional malaise (PEM) is characteristic of ME/CFS – considered a hallmark of the disease. Despite this hallmark status, research has not defined what PEM is or how to measure it. Patients describe PEM as a crash that occurs following physical or mental exertion. In this issue we also share how Dr. Larry Baldwin refers to it as Post-Exertional Debility, finding that a more suitable name for what he experiences.

Reading how patients described crash in the [FDA “The Voice of the Patient” report](#) sounds similar to a phenomenon known as “hitting the wall” – where all energy stores are depleted and functional capacity is lost.

Because PEM is a hallmark of ME/CFS, studying it can provide clues to what is going awry and what could be causing it. To do this PEM has to be induced using physical or mental challenges. [This month we highlight three recent publications that use exercise and cognitive challenge to study PEM in ME/CFS. READ MORE](#)

Post-Exertional Debility

Dr. Larry Baldwin,

FDA Draft Guidance Review

On May 12, 2014, the CFIDS Association submitted a thorough review of the FDA Draft Guidance for Industry concerning ME/CFS.

licensed physician and ME/CFS patient, worked with our Scientific Director, Suzanne D. Vernon, PhD to provide comment on post-exertional debility to the Institute of Medicine Committee on Diagnostic Criteria for ME/CFS.

We have made his compelling and intelligent insights available as a guest blog post... [Read it HERE](#)



Read our feedback on the document and learn more... [Read it HERE](#)

Changes in Social Security Ruling

The Social Security Administration rescinded their standing ruling on ME/CFS (SSR 99 2-p) and replaced it with SSR 14-1p bringing clarity to the evidence needed to determine eligibility. It is important that you know what is expected should you be applying for social security disability. [Read more...](#)

IOM Holds Another Public Meeting

On May 5, 2014, the IOM Committee held another public meeting concerning their work on diagnostic criteria for ME/CFS. Some very compelling testimonies were given. Access the video testimonies and our written report on the patient comments submitted through our online survey [HERE](#)

Pathway to Prevention Moves Forward

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. [Read more about the P2P Process HERE](#)

Since that post was published, we have learned that **the P2P for ME/CFS was approved**. The [study protocol for the systematic review of ME/CFS](#) has been posted by the Agency for Healthcare and Research Quality.

We are reviewing the available information and assessing where there might be an appropriate opportunity for input. When there is an opportunity for public comment, we will report that and share the means by which you can effectively participate.

May 12th Kicked Off Awareness Month

On Monday, May 12th, patients and their loved ones from across the globe came together to help spread awareness of and compassion for ME/CFS on International ME/CFS and Fibromyalgia Awareness Day. The awareness efforts continue all month long and we've created some tips, tools and resources to help you participate... [Check the out HERE](#)

SolveCFS.org»

Several organizations—like Amazon, iGive and eBay—offer you the opportunity to donate a portion of your purchases to the CFIDS Association. Whether you are shopping for birthdays, anniversaries, baby showers, or just picking up a few things for yourself, your purchase can help fuel our mission to make ME/CFS understood, diagnosable, and treatable.

Learn more at www.SolveCFS.org/Get-Involved/Shop-Give

We are immensely grateful for the ongoing support of so many that makes our work possible. Please consider a gift that is meaningful to you.

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