



The CFIDS Association of America

Leveraging patient-centered
research to cure ME/CFS

Dear Cindy,

As the IOM clinical case definition discussion continues, the CFIDS Association takes every response and each call to action extremely seriously. We do not make any of these decisions as a person or a staff, but as an Association that seeks to advocate for the ME/CFS community and draw on the expertise of many. We have been contacted by members of congress for information on how they should respond to their constituents. Yesterday we were contacted by a journalist reporting for the pharmaceutical industry for our reaction to the letter to the Secretary calling for the IOM contract to be abandoned.

On Monday, after weighing all input, putting this in the context of the FDA meeting and the need for definition and regulatory guidance to industry, we released a statement in support of the IOM contract specifying how we thought it would be most effective. [Read it HERE.](#)

Later that same day we received word that the contract had been awarded, work would proceed with IOM and that all of the concerns advocates had raised were addressed in the terms. [Read the announcement HERE.](#)

Within an hour of that announcement, the letter opposing the contract came out with your signatures.

I spoke to Cindy Bateman to try to understand the letter and the controversy. Cindy explained that the letter writing effort started a few weeks ago when there was little information and early skepticism about the IOM contract. However, Cindy now believes that the IOM effort as described more comprehensively in the Monday announcement is a positive course of action. She suggested contacting those of you who signed the letter and see how you feel now as well.

It is important that the Association make every attempt to bring clarity to this issue with a strong voice, defining the best course of action, framed in the most reasonable tone that is influenced by leaders in the field such as you. That is why I am reaching out to you today.

The CFIDS Association wants to weigh all of your input and help bridge communication between our community, the agencies and the media. Given this additional information we have regarding the IOM contract, can you tell us - either on or off the record - where you stand by the terms in the letter? Do you still want the IOM contract to be abandoned and the CCC to be adopted as the official definition? If you have any misgivings about

the timing or content the letter, or feel the IOM contract should proceed as now outlined, we need to hear from you. We will completely respect anyone that wants to remain off the record, but we must give the patients - all patients - the guidance and proper information they so desperately need.

Please consider sharing your response with Leigh Reynolds, our engagement manager, who is working on the next wave of our communication on this important issue. She can be reached at XXX-XXX-XXXX or by email at LAREynolds@CFIDS.org. If you are willing to go on record, that would be fantastic. If you would rather remain anonymous in your response, we will absolutely respect that and would never betray that trust. Either way, we look forward to hearing from you with all feedback at your earliest convenience - if at all possible, by noon tomorrow (Friday, September 27th.)

Suzanne D. Vernon, PhD
Scientific Director
The CFIDS Association of America
Working to make ME/CFS widely understood, diagnosable, curable & preventable

"I alone cannot change the world, but I can cast a stone across the waters to create many ripples." - Mother Teresa



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The CFIDS Association of America | PO Box 220398 | Charlotte | NC | 28222-0398