



Solve ME/CFS Initiative

Leveraging patient-centered
research to cure ME/CFS

FORMERLY KNOWN AS THE CFIDS ASSOCIATION OF AMERICA

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June 12, 2014

I am writing concerning the Pathway to Prevention workshop for ME/CFS. Our organization, the Solve ME/CFS Initiative, applauds the fact that a P2P is focusing on ME/CFS. And at the same time, we have concerns about the evidenced-based literature review in the most recent protocol posted by AHRQ evidence-based assessment center on May 1, 2014.

We have identified what we believe to be serious flaws with the sample search strategy described in the appendix. This search and corresponding criteria will bias the evidence base to CBT and GET trials – treatment approaches that are not specific to ME/CFS (as noted by AHRQ) – and will fail to assess any of the important biomarker research that has been conducted and funded (primarily) by NIH over the past 25 years. This would be a grave and substantial error. **The search criteria must include terms that reflect important advances made in biomarker research for ME/CFS.** We believe it is not too late to correct this and that the P2P working group and other appropriate stakeholders would be willing to participate to help make the P2P as effective as possible.

It is imperative that this P2P workshop effectively address gaps in research. We are hopeful that NIH will use the P2P evidence-based report to inform a new ME/CFS funding opportunity, given that the current program announcement expires October 25, 2014. Assuming so, it is critically important that the P2P go forward with an evidence-based review that will result in a compelling funding opportunity that will attract investigators to ME/CFS research.

As you know, Dr. Suzanne Vernon, the Solve ME/CFS Initiative's Scientific Director, continues to serve on the working group to help make this ME/CFS P2P workshop the best it can be. We are bringing these flaws to your attention in the hopes that the P2P will make the changes needed. Dr. Vernon will be contacting you directly to discuss this and ways she can be involved in a process to improve the protocol and the evidence-based review process.

We also understand that there will be opportunity to comment and offer feedback on the evidence-based report. We trust that you will share information on how and when to participate as soon as it is available. We look forward to working together to do what we can to ensure the resulting P2P recommendations will improve the status of ME/CFS research. Great research is desperately needed.

Sincerely,

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