

CFS Advisory Committee Public Comment, June 2014
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I am rarely at a loss for words, but I had trouble writing this comment and the newly reduced time limit makes it even more difficult. I've chosen to spend my limited time on two issues at NIH.

First, I've asked Dr. Collins to cancel the P2P Workshop, and reexamine the best way to collaborate with the research community. I am part of this effort because I have legitimate scientific and policy concerns about the Workshop, including:

1. The Workshop is duplicative of other efforts already underway.
2. The Workshop has been structured to focus on medically unexplained fatigue.
3. NIH has not involved stakeholders in a meaningful or substantive way.
4. The Workshop decision makers are non-ME/CFS experts; and
5. The goal of the Workshop has become unclear.

I do not like calling for meetings to be cancelled, and I generally take a moderate approach to advocacy. My concerns are based on careful review of documents, both public and obtained through FOIA, as well as previous P2P efforts. I do not see how the Workshop can succeed given all of these issues. The full letter and supporting documentation are in your meeting materials, and I respectfully urge you to review them carefully.

Second, I urge you to renew your recommendation that NIH immediately issue an RFA of \$7 to 10 million for ME/CFS research. This advisory committee has made similar recommendations six times in the last ten years. Yet now, you seem poised to abandon that recommendation, by waiting until after the P2P and IOM reports are published. I believe this would be a mistake.

On March 19th, eleven Congressmen wrote to Dr. Collins urging him to take decisive action on your RFA recommendation. On April 18th, the IACFS/ME joined them, urging Dr. Collins to issue an RFA at a funding level of \$7 to 10 million per year for five years. ME/CFS advocates have been emailing Secretary Burwell with a similar request.

Now is not the time to abandon your recommendation! Members of Congress, the IACFS/ME, and advocates have all taken up the call, and momentum is building. We have a new HHS Secretary who needs to receive your best and most important recommendation, with accompanying justification. It would be a monumental strategic error for you to discard this critical recommendation just as we are making progress towards achieving it.

Whatever other recommendations you make at this meeting, I urge you to renew your call for NIH to immediately issue a \$7 to 10 million RFA for ME/CFS research. I sincerely believe that this is the step that will truly move us forward.