

To: P2P Workshop Panel  
From: Michelle Strausbaugh  
Re: P2P Workshop Executive Draft Summary

Firstly, I would like to thank the panel for volunteering their time and energy in attending the P2P conference and rather quickly writing up a lengthy report on such a complex, multi-systemic disease. As a housebound (mostly bedbound) patient of 16 years, I truly appreciate your efforts in addressing how the science has, of yet, failed to produce a treatment for me and one million other Americans (let alone prevented our getting this disease in the first place), as well as how the science might yet move forward to produce a treatment that will allow me to join those living life outside the four walls of my bedroom.

As I am too ill to offer more specific comments at this time (save for the few below), I wish to endorse the comments of the CFSAC and patient Jennifer Spotila. Moreover I would suggest the following:

the F-word: Many have expressed concern about the term “fatigue” and how post-exertional malaise is a better term. I might also suggest “pathologically-long recovery from exertional” though it is, admittedly, more unwieldy.

Line 32: “ME/CFS exists.” Doesn’t saying it exists underscore a sense that it might not? As in the old “methinks thou protesteth too much?” Another way of putting it might be the old writer’s cliché: show, don’t tell. May I suggest that the committee consider striking this phrase and letting the report make that clear itself?

Line 79-80: “Educational efforts are needed to help patients...” I have noticed that some patients have felt that this phrase is demeaning to the fact that patients are frequently MORE educated than their clinicians about this disease and are often among the most well-educated about their disease than any other patient population (they have expressed similar concerns about the term “self-management”). However I read this to mean that NEW(or newly diagnosed) patients need to be educated about the seriousness of their disease and especially about the harm that accompanies over-exertion. I wish very much my own clinician would have known and communicated to me this concern (indeed, I wish my clinician would have understood *anything* about ME/CFS) as I may well have conserved far more functional capacity than I currently have. I might suggest that the committee consider changing the wording of this sentence.

Line 328 “5. Finding new funding resources...” As you may have heard repeatedly at the conference and read in the comments to the draft report, funding is the central issue, grievance and impediment to moving the science forward. I do not argue that HHS should simply throw money at the problem without clearly defined goals and adequate accountability. **But the single biggest reason that I have spent the last 16 years sick without any treatment for the underlying disease mechanism — that, indeed, the underlying disease mechanism isn’t even**

**known — is due primarily to the woeful lack of funding at the federal level for the last 30 years.** Moreover, there appears to be a “catch-22” in which NIH officials argue they cannot increase funding because there are not enough researchers in the field to fund, while the researchers in the field state that their grant applications are routinely denied (1).

I would implore the committee to instruct DHHS to consider:

- Moving ME/CFS out of the purview of the Office of Research on Women’s Health and into one of the NIH Institutes (it was at one time under the purview of NIAID). Not only is ME/CFS not a disease specific to women, but the move to ORWH has been commensurate with a decline in ME/CFS research funding (which most likely says something about how the importance we place on women’s health as a whole in this country but I digress...).
- Think outside the bureaucratic box. Just because something isn’t or hasn’t been done by NIH or CDC before, doesn’t mean they shouldn’t. I think this is especially important given the multi-systemic nature of ME/CFS as well as the abysmal level of funding over the last 30 years (i.e. the need to make up for lost time). While I am happy to see the panel encourage federal agencies utilize the bureaucratic tools at their disposal, ME/CFS may require them to go above and beyond those well-used tools and get creative about truly jump-starting what I think we can all agree is an appalling situation that requires remedy with all due haste.

I again state that, if I could, I would make all of the same points that CFSAC and patient Jennifer Spotila have made and hope you will carefully considered their suggestions. Thank you again for the long hours you have and are putting into this workshop and its accompanying report. I am truly grateful.

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1. Just a few examples of this discussion can be seen at:

"Chronic Fatigue Syndrome: CDC and NIH Research Activities Are Diverse, but Agency Coordination is Limited" GAO report to Senator Harry Reid June 2000

Craig Maupin "Scientific Review, CFS, and the NIH -- The CFS Special Emphasis Panel" at The CFS Report  
[http://www.cfidsreport.com/Articles/NIH/NIH\\_CFS\\_3.htm](http://www.cfidsreport.com/Articles/NIH/NIH_CFS_3.htm)

Cort Johnson "Unfulfilled Commitments/Broken Promises: The NIH and Chronic Fatigue Syndrome After Twenty-Five Years" at Health Rising  
<http://www.cortjohnson.org/blog/2013/12/22/unfulfilled-commitments-broken-promises-nih-chronic-fatigue-syndrome-twenty-five-years/>

Mindy Kitei "Candid Conversation with Dr. Ian Lipkin" at CFS Central

<http://www.cfscentral.com/2014/05/candid-conversation-with-dr-ian-lipkin.html>

Lipkin, a renowned pathologist, is quoted as saying:

*"I have been in competition now twice to get funded, and the people there who reviewed me gave me abysmal scores. And the critiques of my work were unfair, and one of the people who critiqued my work said, in fact, that this is a psychosomatic illness. I was floored. I protested, and for reasons that are obscure to me this same individual wound up back on the study section, and I got a similar unfundable score. Am I upset about this? Absolutely."*