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Subj: Comments on the Pathways to Prevention Draft Report on Myalgic  
Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Note: These comments use the 403-line version of the draft report.

Thank you for your efforts. The panel has done a splendid job given the steep learning curve and tight deadline.

On lines 401-402 the panel recommends, "that the ODP convene another ME/CFS Expert Panel in the future to monitor progress." To my thinking, this is the report's single most important recommendation. For many years, the National Institutes of Health (NIH) and the Department of Health and Human Services (DHHS) have talked about the need to help us, but repeatedly declined to do so. They have consistently denied requests very similar to the recommendations in the panel report. Here are three examples:

1. Funding a Research-Sharing Network

On lines 204-205, as well as 340-349, the draft report endorses a research-sharing network. In response to a June 2014 DHHS Chronic Fatigue Syndrome Advisory Committee (CFSAC) recommendation, the NIH explicitly denied funding a data-sharing platform, calling it "cost-prohibitive". They also rejected a new Request for Applications (RFA), saying it would "not be an effective strategy". What's more, at least three times, the CFSAC has requested the establishment of Centers of Excellence, to no avail. Will they reconsider now?

2. Microbiome research

On lines 89, and 237 through 241, the panelists recommend research into the gut microbiome, the billions of microbes lining the human digestive system. However, the NIH was unable to find a mere one million dollars for such a study only last year, when Dr. Ian Lipkin of Columbia (colleague of Dr. Mady Hornig who presented on the microbiome at P2P) applied for funding. Will the NIH reverse their decision now? Will you tell them to?

3. Single Definition

On lines 379-381, the panel recommends retiring the Oxford definition. Thank you, this is long overdue. Furthermore the panel suggests, "that the ME/CFS community agree on a single case definition (even if it is not perfect)." The few existing ME/CFS researchers already did this on

September 23, 2013. They wrote an open letter to then-DHHS Secretary Sebelius proposing the Canadian Consensus Criteria of 2003 as a diagnostic standard. Instead, the government chose to go ahead with the P2P meeting. Now the panel has recommended what ME/CFS investigators have already done. The money spent on this effort and the complementary (or competing) Institute of Medicine study could have funded Dr. Lipkin's work above.

What is the impact of government under-funding of ME/CFS work? While rheumatology has adopted our sister illness fibromyalgia, exactly no one has adopted ME/CFS. We have no home in a medical discipline, and are therefore a de facto ward of the state. We cannot conduct the type and scope of research the panel recommends using the proceeds of gluten-free bake sales. We need governmental support.

Please urge the government to show us the money. Thank you.