

Public Comment
Alexander Lopez-Majano

Because I endorse the letter written by Ms. Spotila and Ms. Dimmock to NIH Director Francis Collins I would like to ensure that it is part of the public record.

Dear Dr. Collins:

We are writing to request that you cancel the Office of Disease Prevention's Pathways to Prevention Workshop on ME/CFS ("P2P Workshop"). Your immediate action is required to ensure that ME/CFS research and policy is based on the best scientific evidence and processes.

In your April 16, 2014 letter to Representative Zoe Lofgren and colleagues, you said that the P2P Workshop would produce recommendations to move the field forward.

We believe that this is not the case, and we offer the following documentation to support our conclusion:

- The Workshop is unnecessary and redundant given the recommendations of disease experts and other NIH efforts to advance ME/CFS research and clinical care. See Attachment 1.
- The Workshop has been structured to address the problem of medically unexplained fatigue, and not the disease(s) known as ME/CFS. See Attachment 2.
- NIH has paid lip service to collecting input from stakeholders, but in reality has not involved them in a meaningful way. See Attachment 3.
- The P2P Workshop process is inappropriate for this disease, particularly because the decision makers will be non-ME/CFS experts. See Attachment 4.
- The goal of this Workshop is unclear as a result of numerous contradictory and confusing public statements by HHS about the purpose of the Workshop. See Attachment 5.

Dr. Collins, we are not objecting to the P2P Workshop simply to make a political point or for the sake of criticizing federal efforts to address the challenges of this disease. We are appealing for your help because we know you recognize that ME/CFS is a serious public health issue that needs the best of what science can offer. We sincerely believe that the evidence included with this letter raises genuine concerns that the P2P Workshop does not represent the best of what science can offer, and may very well take us in the opposite direction.

For all of these reasons, we request that you cancel the P2P Workshop. Further, we request that NIH reexamine how to best collaborate with the ME/CFS research and clinical community to achieve the goals of a research definition and strategy. Those who are researching and treating this disease are in the best position to define how to move forward.

We thank you for your consideration of this issue, and we look forward to your reply.

Sincerely,
Jennifer M. Spotila, JD

Mary E. Dimmock

As of 9 June 2014, no response received from Dr. Collins