

Justin Reilly, esq.
[redacted]

January 22, 2014

By Email

Dr. Mundaca-Shah
ME/CFS Definitional Study Panel
Institute of Medicine
500 Fifth St., NW
Washington, DC 20001
mecfs@nas.edu

Re: Statement of Work Requirement that Panel Consist of "Thought Leaders and Stakeholders"

Dear Dr. Mundaca-Shah:

In the Statement of Work¹ for the Institute of Medicine ("IoM") Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome ("M.E.") Redefinition, IoM agreed that it would convene a panel of "thought leaders and stakeholders." Please see below the top three Google results produced for the search term "thought leader definition."

It is clear that the phrase "thought leaders" in this context (especially considering the pairing with the term "stakeholder") means M.E. experts. Please form a panel entirely of M.E. experts and patients as you agreed to do in the Statement of Work.

Millions of patients' wellbeing hangs in the balance. We can absolutely not afford to have a panel including non-experts redefine this disease! Patients and experts are completely committed to stopping this definition from now, throughout the process and afterwards, if necessary, until this definitional process or resultant definition is abandoned.

IoM can only lose by continuing down this path ignoring the reasonable and necessary demands of the vast majority of M.E. experts and patients. There are too many of us, we are too sick and we have been abused by HHS for far too long and we are *absolutely not* going to stand for it any longer! Please, do what is right, right now!

If you wish, please feel more than free to contact me at [redacted]. Thank you for your attention to this matter.

¹ HHS, *National Academies Umbrella Contract, Statement of Work/Request for Proposal, Project Title: Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome* at p.2;
https://dl.dropboxusercontent.com/u/57025850/MECFS_IOM_SOW.pdf

- Thought Leader Definition:
- Google Dictionary (and Oxford US English Dictionary):
"One whose views on a subject are taken to be authoritative and influential."
 - Wikipedia.com:
"A thought leader can refer to an individual or firm that is recognized as an authority in a specialized field and whose expertise is sought and often rewarded."

Sincerely,

/s/

Justin Reilly, esq.