

Public Comment
CFSAC | December 2014
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Thank you for the opportunity to present to you today.

If you haven't read it, I recommend the book *Merchants of Doubt*, on the techniques used by vested interests to impede progress on issues like acid rain, tobacco and global warming. Deny, refute, and above all else drown out the science with doubt.

The political issues with ME are clear. Muddled definitions have confounded research. Bad clinical guidelines have misled doctors and harmed patients. Patients stigmatized. And an economic impact of \$18-23 billion dollars a year.

And yet NIH only spends \$5M – less than 0.03% of the yearly economic impact. Even that money is hard to get with researchers told the disease is psychosomatic or the field is not ready for their science. NIH rejected CFSAC's latest RFA request stating and I quote – “there remains a lack of definitive evidence regarding the etiology, diagnosis and treatment for ME/CFS.”

But wait. What about the evidence for neurological problems like the studies on neuroinflammation and brain abnormalities? What about studies on immune disruption or studies proving energy production dysfunction? What about the treatment studies using Rituxan and antivirals and all those biomarker studies?

Oh, yea, right. Those studies don't count. At least that's what the AHRQ Evidence Review said when it excluded all of them. The P2P Workshow agenda is positioned to do the same thing. Just ignore the science behind doors 1, 2 and 3.

And don't get me started on those muddled, non-specific definitions that HHS refuses to let go of. This disease is *not* “Extreme fatigue not made better by rest” as HHS keeps asserting. And does HHS really believe that it is appropriate to lump eight disparate definitions together based solely on the ill-defined symptom of fatigue plus the current state of medical knowledge? Please. This is where that little boy comes in and shouts that the emperor is not wearing any clothes.

The list goes on and on. HHS' unilateral action and lack of transparency. The call by disease experts to adopt the Canadian Consensus Criteria ignored. CDC's rejection of CFSAC input on medical education. Allegations of intimidation of CFSAC members. FOIA violations and the latest FACA violations. CFSAC recommendations routinely ignored. HHS staff refusing to answer legitimate questions from the public.

So what is really going on here? What's driving this? Ignorance? Arrogance? Scientific sloppiness? Outdated and erroneous misperceptions? An orphan disease trapped in the cracks of bureaucratic disinterest? Or hidden agendas, reminiscent of Merchants of Doubt?

Regardless of the cause, it's clear that every single facet of HHS' public health response to ME for the last thirty years has had nothing to do with the science of ME. And ultimately, HHS'

public health response has not produced a single tangible outcome that has made a difference in patients' lives. Worse, HHS' befuddled response has degraded patient reality even further, thwarting all forward progress and abandoning patients to rot under shrouds of disbelief.

So you tell me. Why does HHS persist along such a misguided path when their key stakeholders – the patients and experts - are shouting out how wrong-headed it is. The path taken certainly has nothing to do with science.