

P2P Comments from Jim Ellsworth

Public Comment on the ME/CFS "P2P" Draft Report

I have been suffering with this illness for over ten years. I have spent thousands of hours trying to understand the illness and why there has been so little progress in the past thirty years.

My conclusion is that the NIH and CDC do not want to help us, and will not fund the research needed to find real answers. Therefore I completely reject the P2P draft report and the contrived process used to create it.

We do not need more government reports, conferences, or "stakeholder meetings". We need cash for research. That's all that's needed. Everything else is just re-arranging deck chairs on the Titanic. This illness is a solvable puzzle. We have highly intelligent and well experienced researchers that know how to solve this puzzle, and would like to do so, but they have to eat, too. And buy stuff for their labs.

This situation goes well beyond simple benign neglect. Federal agencies that were created to improve public health are actively working against us, even to the point of openly violating well-established federal laws and agency policies. I urge the authors of the draft report to carefully consider the history of agency actions regarding this illness before signing off on a report that will, at worst, be used against patients, or, at best, be ignored and put on a shelf.

Perhaps the report's authors are familiar with the federal law known as "Freedom of Information Act", or FOIA. On October 30, 2013, patient and advocate Jeannette Burmeister submitted a FOIA request to HHS regarding the IOM contract to redefine ME/CFS. After being rebuffed and ignored for months, Ms. Burmeister was forced to file a suit in federal court on January 9, 2014. Please note that the law normally requires the documents to be provided within twenty days.

In the words of the judge who found in Ms Burmeister's favor (eight months later), "the government has 'improperly withheld agency records' in violation of FOIA." The judge also noted, "the government's conduct throughout its dispute with Ms. Burmeister was unreasonable." In fact, the government's behavior went well beyond unreasonable. They have fought tooth-and-claw to avoid compliance, to raise the cost of litigation as high as possible, and to damage Ms Burmeister's already fragile health.

In the end, the federal court awarded \$139,000 in attorneys fees to Ms Burmeister, money that could have been spent on helping patients instead of stonewalling them.

I have seen the emails released as a result of Ms Burmeister's efforts on behalf of all patients. They reveal, in black and white, the government's disdain for the patient community, as well as general incompetence throughout the NIH bureaucracy. But

now the shoe is on the other foot, and we are fighting back. After all, we have nothing to lose, since it's either fight for help or be sick until death.

In the now-infamous words of Susan Maier,
"Fasten your seatbelts [sic] and return your tray tables to the upright position because its' going to be a bumpy ride :-)"

At the current pace of research, I will be dead and buried long before the answers are found. The most likely causes of death for me will be cardiac arrest, cancer, or by my own hand. Even so, privately funded research is moving ahead in spite of NIH intransigence. Our researchers and clinicians are making real progress, progress that was excluded from the AHRQ Evidence Review, and therefore the draft report. I have every reason to believe that answers will be found, even if I don't live to see them.

I can not stop the P2P report. I can not stop the authors from signing the report. But with this letter, the authors can not claim that they are completely ignorant of NIH actions and policies that harm patients, or their own role in promoting those harmful polices.

The NIH tells us everyday, in every way, that we are a bunch of lazy whiners. The patients I know do not ask, "Why me?". But they do want to know, "Why won't the NIH help us?"

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