

Gina Bettor

Dear Secretary Burwell,

The purpose was for record and telephone, so I made sure it was in by 4pm. I didn't know we had until 11:59 or it wouldn't have been so short. I received an email stating be prepared to speak at 1:33 today. I just wanted to make sure I was on record as protesting the P2P for ME/CFS.

That would be pretty tricky getting an insurance company to pay for a disease that doesn't exist. ME has a WHO code or had. Fatigue is in many illnesses. I have been debilitated from a full life since 6/16/93. I have ME according to the MEICC, however they don't reference their work in the P2P, only PACE was considered of good research value.

I had such high hopes when you became the secretary of health, Kathleen Sebelius was asked by President Obama to make headway with the ridiculously named chronic fatigue syndrome, after speaking with Robert Miller's wife Courtney.

My Congresswoman Debbie Wasserman Schultz from So FL, when I lived in Cooper City had breast cancer and thank God she is able to live life to the fullest. My ability to live life to the fullest stopped when I was a 33 at 3pm on June 16, 1993

My story is too long, but oh so common. The suffering, intense. I wouldn't have believed a flu could come one day and you would never ever get well again, if it didn't happen to me. Sadly it did and to 17 million people worldwide, that look to the US government for leadership. The Japanese have a more effective brain PET scans than we do. Ours is all about blood flow. I doubt you are going to read the article I am referencing, so I will stop here and lastly state for the record it is quite obvious the ME ICC primer didn't even get discussed The P2P is junk, if you refer to the PACE trial one time, when you consider a good source of research, it isn't comprehensible. So Jerrold Spinhire's letter needs to be discussed in entirety, not 15 minutes.

Hoping I was right to have high hopes about you, and you are willing to help us now. If this P2P goes forward, we are destined to be discarded and stigmatized for another 30 years, unimaginable, but our past treatment is the best predictor of future treatment by the medical profession. If you are lucky enough to even have a knowledgeable and compassionate physician, willing to treat you in the first place. We were lucky enough to have experts that have treated us and defined us. Why in the world would you waste 2 million dollars on 2 contracts, when the experts and patients have been against this?

Why were the contracts signed without public discussion. Please insert the CFSAC charter here, and read the responsibilities of the DFO. **MUST COMMUNICATE BETWEEN COMMITTEE MEMBERS AND THE ASSISTANT SECRETARY OF HEALTH. NOT, REMOVE COMMITTEE MEMBERS FOR VOICING AN OPPOSING OPINION.** Please don't go down in history as another Strauss or Bill Reeves.

Protect our health and cancel the P2P. Distribute the MEICC primer far and wide. Any other decision, is proof this process was, is and will continue to be a well orchestrated charade.