Anonymous #1

Here are my comments in regards to the P2P report that. Feel is important for CFSAc members to know.

1) Words matter. At least twice in the report there is mention of frustrated patients. There is no need to make mention of that. Patients are represented as whiny children, which we are not. we have been left behind for decades.

2) The P2P committee agrees that Oxford definition needs to be retired. Then they should not use PACE trial in their analysis nor should they recommend CBT or GET. PACE trial is grossly flawed. Moreover, even if they are saying that ME exists, they are still alluding that patients need CBT and GET and 'multi-modal therapies'. No more psychiatric, behavioral research is needed nor desired by patients. Patients need biomedical research starting by basic science. I will remind the committee that Dr Friedberg's research had a 48% drop-out rate.

3) Recommendations of complimentary medicine research will further stigmatize our patient community. What is needed here is mainstream, biomedical research. moreover, assigning the disease to a medical specialty would be extremely helpful for the field.

4) Dr Carmen Green mentioned at the workshop and it is mentioned in the report that there is only 1billion in economical cost to society. this value is not correct. dr Jason estimated the cost to society to 29 billions back in 2008. This needs to be corrected. Underestimating costs to society means patients are short-changed.

i am asking the CFSAC members to speak on our behalf. Enough is enough. we are asking to please do no more harm.