

**Public Comment**  
**Pat Sonnett**

Dear Dr. Lee:

I submit this as my written testimony to the CFSAC for the June 13<sup>th</sup> and 14<sup>th</sup>, 2012, meeting. I am not requesting time for oral testimony, but do request that my written testimony be distributed to the committee members and made a part of the public record.

First, I would like to thank you for once again providing the live-stream video of this meeting which will make it much easier for those of us with ME/CFS to be able to follow the proceedings.

**There are three issues I would like to address for this meeting, all three having been requested at previous meetings.**

1. Post the Agenda for the Meeting in a Timely Manner: I once again request that the meeting agenda be posted to the CFSAC website in advance of the deadline for submitting public testimony. Public testimony is due today and there is still no agenda posted. Public testimony could be better directed to specific issues, and more beneficial, if we knew what topics were going to be covered at the meeting.
2. Tissue and Organ Biobank: I again request that a repository for ME/CFS tissue and organ samples be established. There are a number of biobanks that have collected samples of ME/CFS patients' blood, but there doesn't currently seem to be any location where patients can donate tissue samples for ME/CFS research. There are many of us who have had this illness for decades and, as part of the general aging process, are making arrangements for burial or cremation upon our demise. I'm sure there are many who would be willing to donate organs or organ tissue to be used for ME/CFS research. I would think that much valuable information could be gained from such research and it would be a shame to pass up the opportunity to collect such valuable data. Since I first made this request in 2011, our Support Group has lost two people who both had ME/CFS for well over a decade. Both individuals would have wanted to be able to make their final contributions to ME/CFS research had it been possible.
3. Initiate and Fund Longitudinal Studies: I again request that longitudinal studies be initiated and funded while this first generation of ME/CFS patients is still able to provide the information.

Some early ME/CFS patients have already reached an age where they no longer qualify to be able to participate in current research studies. We need to know how this illness progresses over a long period of time and one sure way to determine that is to follow the progression of documented cases, many of whom have records going back to the mid-eighties. Not initiating and funding these studies at this time will be another missed opportunity to collect data.

Thank you to all of the committee members for your time, dedication, and service to the ME/CFS patient community. We remain truly grateful.

Sincerely,

Pat Sonnett