

## **Testimony**

**Pat Sonnett**

Dear Dr. Jones,

I hereby submit my public testimony for the May 10-11, 2011, CFSAC meeting and request that printed copies of my testimony be included in the record and distributed to the Committee members.

### **Public Comments for May 10-11, 2011:**

Thank each of you for the time and dedication you continue to devote to discovering treatments and finding a cure for ME/CFS. Those of us with this illness appreciate your efforts to help us survive and live somewhat productive lives. Many more ME/CFS patients would likely be completely bedridden (or worse) without your continued help in fighting this battle we find ourselves in.

Thank you Dr. Jones for providing the current CFSAC Recommendations progress report, and the live videocasting of the CFSAC meetings.

### **There are five specific areas I would like to address for this meeting:**

1. The HHS and CDC should declare ME/CFS a national health crisis and respond accordingly.
2. We have been requesting Centers of Excellence since 2004 and, pursuant to the recommendation from this Committee at the 10/10 meeting, now specifically request that there be developed "a national research and clinical network for ME/CFS using regional hubs to link multidisciplinary resources in expert patient care, disability assessment, educational initiatives, research and clinical trials."

This request is urgent! We need these regional hubs desperately and we need them now. Some of us have had ME/CFS for almost 30 years and we may not have another five or ten years left. There are over one million people in this country suffering from this disease. It borders on criminal neglect that this many people have so few places to go for help. Many have been shuffled from specialist to specialist and had hundreds of tests run repeatedly which have completely drained their financial resources. After all these years, there is no logical explanation as to

why there aren't regional hubs where people can go for diagnosis and treatment in one facility and physicians can be trained to treat these patients.

3. Initiate and fund studies to identify subsets of ME/CFS so patients can receive proper treatment. This is not a one-size-fits-all illness in triggering factors in developing the illness nor in what treatments are appropriate for the subsets.

4. Initiate and fund longitudinal studies now while those of us who have had this illness for decades are still living and our records and history are still available.

5. Post the agendas for the meetings in a more timely fashion so we have that information before the deadline for submitting testimony. The testimony is due today but the agenda for the meeting has not yet been posted to the site.

Thank you for your continued hard work on behalf of the ME/CFS community. I realize your job isn't easy and I appreciate your dedication and professionalism. While there is much excitement about the work that is being done and the information supplied at the recent NIH State of Knowledge Conference provided much-needed encouragement, there is also a greater sense of urgency among the patients than we have seen before. We need help and we need it now. We need you to share that same sense of urgency.

Sincerely,

Pat Sonnett  
Miami CFIDS Support & Advocacy Group