

I am writing to express my support of the CFSAC Committee and the need for the renewal of the committee's charter.

I am a CFS patient and have been ill for 15 years. Although CFS has been associated with multiple body system malfunctions there is still no laboratory test that is definitive for CFS. Because there is no known "cause" of the illness, it has been virtually ignored by medical schools and physicians. Even with the WPI's research into the association of CFS and XMRV, physicians continue to believe that the CFS patient is a "somatizer" with "unwellness beliefs." They are interested only in "de-medicalizing" the CFS patient", preferably out of their offices.

For those of us who suffer with this illness, this attitude isolates us from the medical community. Many of us have come to believe it is better to suffer in silence rather than be dismissed by our doctors, often rerouted to a psychiatrist. Many times I have been handed a prescription with the name of a psychiatrist and told, "there is nothing more I can do for you." I really believe that if that doctor could walk in my shoes he would be horrified at the weakness, pain, exhaustion and confusion I experience everyday. There are millions of people just like me. Without any understanding of this illness you can be assured that there will be millions more in the future. Because we lack the physical ability to demonstrate our government has been able to simply ignore us. We do not march on Washington because we are simply unable to do it. We suffer and die in silence, out of sight and mind.

The CFSAC Committee is a lifeline to patients like me. Many of it's members are the only known CFS physicians and, as patients, we trust that they are representing our interests as they advise the Secretary of Health and Human Services on our behalf. Only recently has Dr. Wanda Jones web cast the meetings of the CFSAC Committee. Hundreds of us have logged in to these meetings to watch and, by telephone and DVD, give testimony to the devastation of CFS and the gratitude of the CFS patient to the committee and all CFS treating doctors. Dr. Jones herself has been a lifeline to the CFS patient.

I am writing today to request that the CFSAC Charter be renewed and Dr. Jones continue in her role as the Designated Federal Officer for CFSAC. I would like for the CFSAC meetings to be held, and web cast, four times a year. Until CFS is no longer ignored, and often scorned, by the medical community the CFSAS Committee is the only source of information on new discoveries and treatments for the CFS patient. When web cast, these meetings give the CFS patient hope that somewhere CFS research is making gains and CFS patients are receiving treatment. This gives very ill patients with no resources a reason to hope that someday they will find a doctor who might be able to help them improve their health.

This past year CFS research has been a real challenge for the CFS patient. The research results are changing rapidly and the variety of special interests with conflicting opinions make it virtually impossible for the typical CFS patient to keep up or understand any of it. We need our committee to break it down for us and tell us which treatments show promise and which ones are downright dangerous. Which viruses are causative and which ones are "passengers". Since most of us have doctors who still think we are "crazy and lazy", these meetings are the only medical consultation most of us get.

I am appalled at the lack of research funds for this disease by my government. I do not believe there is any disease that receives fewer funds than CFS or many diseases that affect more people. I am disgusted by the failure of my government to educate our physicians. Although I can't understand why it is so, I believe that the psychiatric wing of the medical profession has wrongly claimed CFS and my government has been an accomplice.

I have listened to my government proclaim, for many years, that they are "in the process" of educating physicians and still CFS is not being taught at medical schools. I know that millions of research dollars were spent NOT educating our future doctors.

I was pleased to see that after causing many years of patient suffering Dr. Reeves was finally removed from his position. I am still concerned that he may not have been kicked upstairs but perhaps given even more power over the CFS patient in his new position.

As you can see from the above, I no longer believe that my government is looking out for the CFS patient. What little faith I have is invested in the CFSAC Committee. I implore you to renew the charter.

Susan Magowitz