Written Testimony for CFSAC, Spring 2010- from Sarah Goodwin

My health has regrettably declined to the point I am unable to submit to you the type of well thought out testimony I have in the past. Instead, I must provide you with a brief introduction and a series of points. I would like to remind you that the written, telephone, and in person testimony you receive is representative of the needs and demands of thousands of patients who are too ill to manage even this.

I am astonished that at such a critical juncture in the history of this disease the time allotted for this committee and for public testimony has decreased. I am astonished that the very existence of this committee is uncertain. The problems that led to the creation of this committee are far from resolved. We, out here- as patients- cannot see much in the way of progress.

- We still live with the preposterous name "chronic fatigue syndrome" as a label for our complex disease. We cannot tell people what disease it is that we have and expect them to understand what it means without a lengthy explanation, if at all.
- It is still nearly impossible for us to find knowledgeable doctors and effective treatments that are covered by insurance.
- Our disability claims are still being unjustly denied.
- Medical schools are still not adequately training doctors to treat us, or even to understand what this disease actually is. Medical schools do not even have staff capable of accomplishing this.
- We have no government- sponsored centers of excellence to look to when we need treatment.
- William Reeves may be gone from the CDC, but the flawed research definition and the faulty research done with that flawed cohort remain.
- Our doctors are still receiving this inaccurate research with the seal of approval of the CDC, and as a result, we are still suffering the consequences of the CDC's past research.
- A definition of this disease that insists upon post exertional malaise as a hallmark symptom has yet to be adopted by the CDC.
- A permanent director of the CDC CFS program has yet to be appointed, and we have no word on what will replace the irresponsibly crafted five year research plan, or the direction that the CDC program will take. Will the Emory University psychiatry department still be taking part in research into this physical condition?
- We remain shocked and dismayed that the NIH budget is still directing exponentially more resources to health issues such as erectile dysfunction than it is to this chronic disabling disease, especially when we see what the funding levels of diseases with similar disability levels and prevalence rates are.
- We deserve better than what we are getting, and we have deserved better for an inexcusably long time.

So, the time to act is now. This committee is more essential now than it ever has been, we are not out of the woods yet and we will not be for some time- the charter absolutely must be renewed. Due to our disability and marginalization from society and the medical system, we are unable to consistently advocate for ourselves. Due to the laughable nature of the name "chronic fatigue syndrome" we are still politically

untouchable and invisible. When it comes to representation of our interests in Congress and to government agencies, we remain as disenfranchised as ever. As you work through the process of renewing your charter, please do what you can to increase the committee's relevance and effectiveness, and work towards mechanisms that will yield results. Here are some suggestions of things to include in the renewed charter:

- The committee must go back to 2 day sessions, and allow the previous levels of public comment.
- The committee must revert to meeting 4 times a year, given the increased interest and pace of research, in order to ensure that the committees recommendations are acted upon, and that subcommittees have adequate time to formulate them.
- Videocasting of the event needs to be guaranteed in the charter to allow access to the proceedings for the majority of affected parties who are too ill to attend. Accommodations for people with disabilities on site must be guaranteed as well.
- Right now, this committee is the only way for affected parties to hold relevant government agencies accountable for their actions regarding this disease, this accountability needs to be maximized in every possible way. Look to the charters of other advisory committees, especially those with higher implementation rates, and find mechanisms to increase the implementation of committee recommendations.
- The status of all recommendations, past and present, should be kept updated on the CFSAC website, and all responses from government agencies concerning these recommendations must be made public as well.
- The committee should appoint ex officio members from any relevant agencies who are not already involved in this committee.
- Above all else, remember that this is not the time to simply maintain the status quo, this is the time to push for as much relevance, authority, and accountability as is feasibly possible. We are counting on you.