

To Whom It May Concern,

Thank you for allowing me to opportunity to respond to the committee and to provide additional comments.

I have reviewed the upcoming charter. There are some areas that appear restrictive in thought and meaning. I will comment in reference to the particulars.

The purpose of the Advisory Committee is noted as being established to provide “science-based advice and recommendations”. It’s admirable to see that the research and medical community’s efforts will be taken under advisement. I am bothered by the wording and interpretations from the words. If the committee members have no affiliations or connections with an agency, unit, or medical facility that may make progress, does it mean that these advancements are overlooked? It is evident based on current wording that where there is no definitive test or test results that the committee members would perceive as important or mentionable, the treatments and /or results would be either ignored or not considered based on previous bias.

The intent of the committee’s purpose should be to provide information from a **broad** spectrum of all types of physicians, researchers, and scientists that deal with CFIDS on a daily basis. I truly appreciate all of the research being done on CFIDS. However, devoted physicians with an honest devotion to their professions and patients concede they are muddling through an illness that they have no experience in treating. These individuals who treat patients have a better insight to the disease’s ramifications.

I am puzzled regarding the compilation of the committee members. Clearly the bulk of the member roster is biomedical research scientists whose sole focus on CFIDS is a cause and cure of the sickness. Is it necessary to have seven members when maybe four or five could offer the same extent of information? The four members united to “health care delivery, private health care services or insurers or voluntary organizations: all approach membership each with individual agendas based on their perspective agencies. I am perplexed that there is not one CFIDS sufferer on the committee. The only conclusion that can be deduced is that the government, researchers, and private agencies are willing to gather to discuss CFIDS-related topics omitting any and all feedback and/or data from actual CFIDS patients. Doesn’t it make logical sense to share information directly with sufferers instead of filtering through extraneous agencies?

I firmly believe there should be at least three CFIDS patients as members present on the committee even if their only function is information gathering and dissemination to other CFIDS sufferers. How can CFIDS concerns be discussed without direct experiences as part of the equation?

Committee membership service limits should be performance based not time restrictive. If a committee member is pledged to his or her position and creates a solid contribution, he or she deserves to continue founded on said merit.

I can see where there is opportunity for the committee to become cloistered based on the committee's ability to refresh itself with its own preferences. How about comprising a list of prospective invitees based on varying CFIDS interest parameters to be automatically considered for future committee vacancies without being nominated by other committee members?

Our economy is in dire straits. It is understandable to pay the members for their time to work on the committee. I feel the per diem rate should be eliminated if the member is paid for services. Travel expenses should be half the committee member's cost and half the government's responsibility. If the member is pledged to his or her position, there should be no objection to the pay adjustments. If there is an issue, one can't help but wonder what is the actual intent of being a committee member in his or her mind? Does the person have a self-serving agenda?

I have suffered with CFIDS for over two decades. It has been an exasperating yet enlightening experience. In the many years I have endured this sickness, I am amazed that little overall progress has been made. Understandably, the government and the medical community do not perceive CFIDS as a disease high on the priority list. Other countries ME research excels the United States. We need to put more efforts into discovering the entire gamut of CFIDS and what it encompasses.

I have seen over twenty-six doctors and specialists over the span of my sickness. Four doctors (counting those who diagnosed my daughter and me) offered direction, support, and empathy for my ordeal. Every other physician treated me symptomatically, ignored me, or quickly elected to be rid of the "problem patient" as soon as possible.

I was asked by the medical program which covers me to find a primary care physician. The doctor I went to was demeaning and insulting. He said the entire disease was all in my head.

At the end of the visit, he said he would only be my doctor on paper and not in practice because I refused to follow his drug protocol to treat me for mental illness. I was very angry and frustrated. Prejudice towards and about CFIDS is still rampant.

Almost a year later, I recently approached another doctor to be my PCP. I tried to be hopeful. She graduated from medical school a few years ago so I figured she would be current on CFIDS. I was wrong. She was condescending that I knew more than she did about the sickness. She made a lot of empty promises in getting to the crux of what is **really** wrong with me. She claimed she didn't think I have CFIDS yet admitted she doesn't know much about the illness. I was told I would hear from her office for further blood work to diagnose what is **really** wrong with me. I called her office three times since and left messages. It has been almost a month and I have never received a call.

These are examples of the results of having a limited and restricted traditional medical background. Doctors opt not to deal with a disease that does not fit into known parameters, have a test for instantaneous diagnosis, or a pill that offers a cure. Why aren't physicians trained to admit when they do not know? Is it an ego or "I know better than the patient" attitude? What happened to the practice of the Hippocratic Oath?

The four doctors who have helped all perceived CFIDS as a challenge to overcome. They researched on their own time, connected with colleagues, and never gave up. They gained my respect through actions not words.

Sixteen years ago, I was totally disillusioned and frustrated with traditional medicine. All it managed to do was make me much sicker. I was sick of jumping hoops and constantly defending the fact that I was ill. Alternative medicine was a last recourse. I decided to give it a try figuring at this point I had nothing to lose. It was the best decision I ever made. Acupuncture, regular dietary monitoring, plus dietary supplements contribute to my survival with CFIDS. I am blessed to have a wonderful reputable naturopath and acupuncturist named Julie Taylor (she would make a great addition to your committee) who genuinely cares about me as a patient and person who is suffering. Traditional doctors could learn a lot about compassion and empathy from her. Yet, Dr. Taylor is not licensed to take blood, give me intravenous or injections because she is a doctor who does not practice traditional medicine. Why is that? Why can't traditional medicine embrace Eastern medicinal practices as an equitable partner? Eastern medicine has been around for centuries because it works.

Many CFIDS sufferers, including myself, have benefited from it. We realize it cannot cure the disease but can help to cope with CFIDS.

I am not a scientist or doctor but there are some perceptible connections concerning CFIDS. A viral infestation on the cellular level is somehow at the source of the sickness which makes the body more susceptible to other infections. Over the years, I have been vulnerable to all kinds of other viruses (especially any type of viral flues) thanks to having a CFIDS weakened immune system. Body systems weaken or do not function properly. Does the virus or viruses that create CFIDS “attract” other viruses to the debilitated body?

There is a definite genetic link. It is very clear in my family that I inherited a predisposition for CFIDS from my maternal grandmother (an Italian immigrant) who died at the age of thirty-nine years. My ten year old daughter had CFIDS first after a bout with chicken pox. After caring for her, working two jobs to pay her medical bills, plus having surgery, I was next to exhibit CFIDS. Consequently, there are three female cousins and one male maternal cousin who now have CFIDS. All show some sign of the disease but none have it to the severity that I do.

My daughter’s CFIDS reappeared at age thirty. In our family, the age of thirty years is indicative of a CFIDS connection. Could it be the original onset of peri-menopause that somehow plays a role in CFIDS? If so, then hormones are another obvious piece of the puzzle. My weight was always consistent my entire life. Within a few months of having CFIDS, I gained sixty pounds of what I refer to as “CFIDS bloat”. I had not gained that much weight since I was full term pregnant. Once I reached menopause at forty-eight, the weight came off immediately.

Digestion issues from flues=dehydration=skyrocketing blood pressure. Many CFIDS sufferers complain of the same pattern. The viable treatment is saline IV replenishment. Once the body is re-hydrated, the stomach settles. Serious consideration should be given to make saline IV treatments a requirement in treating CFIDS patients.

Hypersensitivity to foods, light, sound, environment, etc. indicates the body’s over-extension to compensate. It merits some further investigating.

Thank you for your consideration of my input. I hope that it offers insight into my view of the charter and CFIDS.

Yours truly,  
Anna Harriman