

CFSAC Testimony

April 23, 2010

Submitted by Shelley Lauer

I have been ill with this disease since 1991, unable to work and be a contributing member of society. My son never knew a healthy Mom. I am college educated, worked for a major corporation, and was involved in my community.

There is NO excuse for the marginalization, abuse, disbelief and lack of adequate medical care I and so many hundreds of thousands of others have endured.

PLEASE, CFSAC - you are our voice to the powers that be. PLEASE take the bull by the horns, change the paradigm and dynamic, and get us the attention and help we are so overdue for. We aren't well enough to fight as hard as we want to. Most of us are old enough that we don't have parents fighting for us as the autism sufferers do. You must fight for us and demand more budget, more resources, and don't take NO for an answer. If nothing else, the XMRV and blood safety issue should have ignited serious action. Prostate cancer has all ready gotten money based on that, but not us. This must change and change NOW!

I strongly support the renewal of the Chronic Fatigue Syndrome Advisory Committee Charter. I suggest the following additions and/or revisions to the Charter.

Thank you for the opportunity to submit my testimony.

Functions

An additional advisory function should be added to the Functions section of the Charter: to evaluate the likely etiology(s) and develop an accurate and effective definition of Myalgic/Encephalitis/Chronic Fatigue Syndrome.

Comments:

Until the Committee addresses the important issue of the definition, it will be difficult to adequately advise the Secretary about the other three topic groups that are currently in its Charter. Once an adequate definition has been established, this issue can be removed from the Charter. I comment further about this at the end of my testimony.

If a single etiologic agent is found for ME/CFS, this issue can also be removed from the Charter. However, until that occurs it is extremely important for the Committee to continue to encourage the search for etiology(s) and to evaluate the accumulated evidence and the impact the current evidence has on prevention, diagnosis, treatment, accommodation and services.

By ignoring the important issue of etiology in its Charter, the Committee is tacitly implying that there is no etiology for this illness, which, in turn, endorses the "all in your head" hypothesis. This was never an acceptable hypothesis, but, in 2010, we have an abundance of evidence of physiologic abnormalities in ME/CFS, some of which point to one or more potential etiologies. It is time to acknowledge this in the Committee's charter.

Establishing a consistent definition and/or the etiology(s) of the illness will lead to a better name.

Structure

Two new ex officio members should be added to the Committee: a representative from the Agency for Healthcare Research and Quality, and a representative of the Surgeon General.

Individual ex officio members should have a term not longer than ten years.

Comments:

The AHRQ representative will help to identify best practices in the treatment of ME/CFS and to disseminate that information to health care providers and patients. The Surgeon General's representative can help to facilitate the production of a Surgeon General's letter about ME/CFS, and to promote awareness of the illness by health care professionals, federal agencies and the general public.

Although continuity of representation of federal agencies is valuable, ex officio members can also become mired in preconceptions and controversies from the past. It is valuable to introduce new perspectives, both for the Committee and for the federal agencies.

Meetings

Preface:

There is a need for adequate time for the committee to address its responsibilities. It is of grave concern that the current meeting (May 10, 2010) is one day instead of the usual two, and that the time for public comment has been limited to a point where it is practically impossible for anybody to say anything.

In the past the Committee has met four times a year. This schedule should be resumed. Each of the three topic areas discussed in the current charter (knowledge and research about epidemiology and risk factors, current and proposed methods for diagnosis and treatment, and development and implementation of information programs) should be the topic of one of three of the quarterly meetings and the fourth meeting should address etiologies and definitions, an issue that is not currently being addressed in the charter, as discussed above. If and when etiology is established, it will be possible to drop back to three meetings per year. At the end of each 2 day meeting 2 hours should be devoted to integration, which should consist of two parts: first, a current action plan (of items Committee members or ex officio members need to research or act on) and current recommendations (to the Secretary), and, second, an assessment of the results of past action plans and recommendations. This assessment should also be forwarded to the Secretary.

All meetings should be videocast via the internet in real time and should be archived and available on the Committee's website.

Comments:

According to the Federal Advisory Committees Database, "it is anticipated that the CFSAC will continue to serve as a conduit for information from the Department to the patient population and vice versa." It is impossible for patients or non-Committee care providers to communicate usefully with the Committee in three minute sound bites. The amount of time for public testimony should be increased, not decreased. Patients, researchers and caregivers have a great deal of useful information about this illness to communicate.

It is noted in the Federal Advisory Committees Database that only 18% of the Committee's recommendations have been acted upon. This essentially means that 82% of the Committee's time is being wasted. This is expensive. During the assessment section of the meeting the following questions should be addressed by the Committee members with the active participation of the ex officio members: why are the recommendations not being implemented? Are they unreasonable or are Federal agencies unresponsive? This assessment should also be forwarded to the Secretary.

Videocasts are a necessary accommodation for the disabilities and financial realities of people with ME/CFS.

Annual Cost Estimate

If the number of meetings is increased the cost of Committee functions will also increase and will have to be calculated.

Comments:

If the number of people suffering with ME/CFS in the United States is conservatively estimated at 800,000, the current cost of the Committee to U.S. taxpayers is currently approximately 20 cents per patient. Given the economic impact of the disease, a doubling of this cost does not seem unreasonable.

Report

A report of the status of all recommendations made by the Committee should be produced at the end of each meeting and posted on the website. The report should categorize the recommendations according to which federal agency is responsible for implementation, where applicable.

Comments:

This would enable all interested parties, including Committee members, ex officio members, the Secretary, members of Congress, as well as the patient, research and provider communities, to

keep track of progress toward reaching the goals of preventing, rapidly diagnosing and treating &/or palliating this difficult illness.

Further comments related to the function of the committee at this time:

I am among the many people who appreciate the effort the CDC appears to have made to change the leadership of its CFS division. Hopefully, this will be the first of many steps forward. However, it will be impossible to move forward until there is a reasonable and consistent definition of ME/CFS that is used by all clinicians and researchers. There is nothing more important to the advancement of the science of ME/CFS than an accurate and consistent definition. Without a definition, it is impossible to advance research, evaluate potential etiologies, diagnose and treat patients, and fairly deliver services.

Thankfully, we have an accurate and consistent definition of ME/CFS: the Canadian Consensus Definition. I ask this committee to endorse this definition and to insist that it be used to identify patients in all studies funded by our taxpayer dollars. In my testimony in October, 2009, I pointed out that the Fukuda definition is flawed but has been used in a significant body of research. Dr. Leonard Jason has recently produced a video, sponsored by the CFIDS Association of America, that discusses the flaws in Fukuda and the consequences of those flaws. I urge this committee to watch this video or to ask Dr. Jason to present this information directly to them at its next (hopefully quarterly) meeting. It is especially important for the ex officio members of this committee, who represent our important health-related federal agencies, to understand the issues he raises. Failure to understand the importance of an accurate definition of ME/CFS has the potential to cause tremendous harm, not only to people with ME/CFS now, but to the general population who may be at risk of acquiring it. We do not know if this is an infectious disease or not. If we do not correctly address the issue of the definition we may never know the answer to this question. We are in danger of wasting precious resources on research that will tell us little, if anything. Please endorse the Canadian Consensus Definition. In addition, we need increased funding for ME/CFS research, for a collaborative trials network, and for centers of excellence where patients can be studied and treated and professionals can be trained.