

Editorial Note: The CFSAC had made a recommendation at the previous meeting of Oct. 13-14, 2010 to adopt the term of "ME/CFS" at Dept. of Health and Human Services programs. Therefore, this article reflects the change made by the CFSAC.

The Chronic Fatigue Syndrome Advisory Committee (CFSAC) meeting of May 10 -11, 2011 concluded with a committee discussion of the numerous topics presented over the two-day meeting. Most of the panel felt this was one of the best meetings they could remember as well as the most-heavily attended.

Dr. Nancy Klimas reported on a proposition, described as interesting and exciting, coming from the Center for Medicare and Medicaid Services (CMS). The CMS is looking for a consortium or a group of people who are dealing with certain illnesses whose treatment protocols could serve as a model to Medicare. There is the intent to develop treatment models for specific illnesses such as ME/CFS for better and more cost-effective care under Medicare. Dr. Klimas suggested that this is a project in which members from the CFSAC research subcommittee should be involved.

To do it, they would need to form a working group and create the framework for a protocol plus use a good mechanism that would drive the data for this model. "Reverse translational research" was brought up as a very efficient mechanism for a project like this. Reverse translational research refers to capturing/feeding information from the bedside to the bench (i.e., the opposite of the flow of information in translational research). As poignant as the patients' personal stories and experiences were, another researcher pointed out that collecting and tabulating meaningful data from patients like these would carry much more weight (i.e., have more practical use) than personal testimonies.

Tools and systems that can collect data already exist, reported Dr. Klimas. One such system is called REDCap (Research Electronic Data Capture). Its advantages include that it: is free, offers a turnkey approach (i.e., meaning that is ready to use), provides quick and ready access to clinical and research networks, and has as its only expense the cost of linking. Dr. Klimas suggested they (i.e., the working group they intend to form) just get started with REDCap, work towards selecting 4 or 5 key assessment tools to measure the domains of the illness (as described in Dr. Klimas' own words), and put together a small working group to demonstrate this at the upcoming IACFS meeting in Ottawa. Briefly, REDCap is a web-based system designed for the capture of data used in research studies which also provides an interface by which to enter the data, and includes import/export features, audit trails and reporting capabilities.

Editorial Note about what is behind the CMS request: The proposition brought up by Dr. Klimas for a "model of care" is not a casual request, but instead is part of the new programs and initiatives pursued by the Medicare and Medicaid Innovation Center, in compliance with the provisions of the Affordable Care Act of 2010. The mission stated at the CMS Innovation Center

is to transform Medicare, Medicaid and Children's Health Insurance Programs by exploring new ways of providing good quality health care while reducing costs. Part of this process will include testing "care" and "payment" models. This ties into some of the programs recommended by Dr. Koh earlier on Day 2. What we've heard or seen so far is actually the beginning of a long series of changes that the CMS, as one federal agency, is required to plan and put into practice over the next 5 to 8 years. The health care reform of programs that are administered by federal agencies (like the CMS) is already underway.

A patient advocate on the committee, Eileen Holderman, spoke about the many public service announcements (PSA) that are out there, for a wide range of causes, and many of these are supported by various government agencies. While listening to a radio station that broadcasts via the internet, she heard five different PSA's along these lines. For example, one of these was the recently launched PSA campaign for lupus erythematosus that was sponsored by the Office of Women's Health. Therefore, she believes that the timing is right for ME/CFS to be recognized in the same way and suggested that a PSA be seriously considered as way to get our message out.

The committee was mutually interested in seeing that the evaluation process of the most severely ill applicants for Social Security disability benefits be faster. Initially, many committee members thought the best way to accomplish this would be to recommend that Social Security Administration add ME/CFS in the Blue Book list of impairments. This way the most profoundly ill patients could meet the criteria at the third step of the evaluation process and receive their benefits sooner. However, this approach might pose a higher hurdle, cautioned Dr. Wanda Jones, and an addition to the Blue Book would also require going through a formal process complete with the rationale for such an addition. Instead, a motion was made to request that the DHHS sponsor a workshop that would review disability measures for ME/CFS, invite experts, and work towards creation of chart or cut points which could help to identify disability. The committee agreed that a virtual, half-day seminar would be an acceptable way to handle this.

Furthermore, mutual interest was shown by the committee to advance the quality of life issues for pediatric cases. They would like to pull together an expert group who could present at a national conference on education.

Dr. Wanda Jones announced that she will be replaced by Dr. Nancy Lee, as the Designated Federal Official for the CFSAC. Dr. Lee was appointed as the Deputy Assistant Secretary of Health-Women's Health, and the Director of the Office on Women's Health (OWH) in the Office of the Secretary, U.S. Department of Health and Human Services (DHHS). Prior to this recent appointment, Dr. Lee had worked for a while as a private consultant in public health and before

that, spent 22 years at the Centers for Disease Control and Prevention (CDC).

Resources

The U.S. Department of Health and Human Services (DHHS) recently posted the official minutes for the CFSAC Meeting for May 10, 2011 - [click here to view CFSAC Day 1 Minutes.](#)

The Center for Medicare and Medicaid Innovation has created a website detailing plans and programs, in the works, for the revision of Medicare services and payment models - [read more at the CMS Innovation Center](#)