

Nancy C. Lee, MD
Designated Federal Officer
Chronic Fatigue Syndrome Advisory Committee

Dear Dr. Lee,

On behalf of the International Association for Chronic Fatigue Syndrome/ME, I request that the US DHHS restore live video streaming for the upcoming Chronic Fatigue Syndrome Advisory Committee (CFSAC) meeting on November 8–9, 2011. Since May 2009, CFSAC meetings have been video streamed in real time. Dr. Wanda Jones, the former Designated Federal Officer of the CFSAC, has reported that as many as 800 patients, researchers and healthcare professionals have attended the Advisory Committee meetings remotely at one time.

Prior to live video streaming, very few stakeholders were able to participate in these meetings. Perhaps most importantly, a live video stream of the CFSAC meetings is a reasonable accommodation for the large number of ME/CFS patients who are too ill to attend.

An audio stream only is problematic for the following reasons:

- (1) Speakers will not be easily identifiable.
- (2) Remote listeners will not have access to the slides and data that are integral to many presentations.
- (3) In previous CFSAC meetings, DHHS has wisely required sub-titles for video streams to accommodate hearing impaired viewers. For instance, CFS patients who have cognitive processing difficulties turn down the audio of the video stream and rely on the sub-titles. These measures are in accordance with Section 508 of the Rehabilitation Act.
- (4) Access to an archival version of the meeting's proceedings after the meeting would not be possible with audio streaming. Patients who attend remotely actively text, tweet, and email questions and comments in reaction to what is presented in the meetings. Many of these questions and comments are then incorporated into the meeting record. Thus, access to an archived version of the CFSAC meeting is important.

In sum, we respectfully request that live video streaming be continued for the November 8 & 9, and all future meetings of the CFSAC so that access to the meeting is widely available to patients, professionals and other stakeholders.

Thank you for your attention.

Sincerely,

Fred Friedberg

Fred Friedberg, PhD
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