

Article Index

[Overview of topics covered on Day 2](#)

[Statement by Dr. Howard Koh, Assistant Secretary of Health](#)

[5-Step disability evaluation process used by SSA](#)

[ERISA: the basics and where to get more information](#)

[Links to recommended sources of information](#)

Spring 2011 CFSAC Meeting - Day 2 (May 11) highlights federal programs available to patients

The Chronic Fatigue Syndrome Advisory Committee (CFSAC), which is an official advisory committee within the federal Department of Health and Human Services, held its spring two-day conference on May 10 -11, 2011. Dr. Christopher Snell served as Chair and Dr. Wanda Jones as Designated Federal Officer. Day 2 covered a lot of material including a review of the 5-step process used by the Social Security Administration to determine a claimant's eligibility for disability; a report on ERISA provisions by a member of the U.S. Department of Labor; and then a wrap-up by the CFSAC in its review and recommendations.

Due to sheer volume of material, this article will concentrate on the federal programs that were reviewed and list sources for useful information on the same. We will soon post a final article in this series on the meeting which will review the CFSAC committee discussions and recommendations.

[Back to top](#)

Statement by Assistant Secretary of Health puts focus on patient suffering and poor quality of life

Members of the CFSAC committee were introduced to Dr. Howard Koh, the Assistant Secretary for Health for the U.S. Department of Health and Human Services, who was appointed to this

position by President Obama in 2009. Dr. Koh oversees numerous public health offices and serves as senior health advisor to the Secretary of Health, Kathleen Sebelius. Dr. Koh welcomed the committee and issued a statement that summed up his understanding of the major CFS/ME issues and challenges and the means by which they can be confronted.

In his presentation, Dr. Koh:

- Stated that while he serves in this position, as Assistant Secretary for Health, he will remain committed to working with the CFSAC committee
- Commended the work of the CFSAC: its recommendations and accomplishments over recent years
- Stated that he will strive to bring a unified approach to ME/CFS, its etiology, treatment and quality of life for patients with ME/CFS
- Indicated that he had recently met with the Secretary of Health and reviewed the status of CFSAC recommendations over recent years
- Indicated that Secretary of Health Sebelius appeared to be very interested and supportive .
- Remarked that he is grateful to Dr. Francis Collins (at the NIH). Dr. Koh's expectations of Dr. Collin's involvement in CFS/ME are very positive, particularly in view of his scientific background and commitment.
- Acknowledged how many doctors have never heard of ME/CFS
- Acknowledged the level of disability caused by this illness and how it impacts quality of life
- Advised patients to be sure to check out the Affordable Care Act and Pre-existing Condition Insurance Plan (PCIP) which are part of the new health law. Links to these laws and programs are included at the end of this article.
- Recognized the importance of provider education and the need to update the current provider information (i.e., like the information provided by CDC)
- Expressed concern and sincere interest to put an end to the type of patient hardships (i.e., patients not able to find knowledgeable doctors) that were heard during public testimonies
- Made a pledge that he wants to be at all future CFSAC meetings, while he is the Assistant Secretary of Health, and work closely with this committee

Dr. Koh concluded that the best strategy would be to go after the best science and best scientific leads available at this time. He recommended waiting for the results of the two studies currently funded by the NIH (due to come in around the end of the year). Meanwhile, he felt there were several things that could be addressed in the near future (as mentioned above) which could help to alleviate the suffering and hardships endured by patients.

[Back to top](#)

5-Step SEP used to determine one's eligibility for Social Security disability

The next item on the agenda, Social Security Administration (SSA): Presentation on Disability, was provided by John Federline, the (Alternate) Deputy Director for the Office of Medical Listings Improvement with the SSA. Since seeking disability status is a very involved, complicated process, as well as one which has not changed all that much, this article provides only a cursory explanation of this process. The eligibility of an applicant (also known as a claimant) for Social Security disability is determined by whether he or she meets certain criteria during a stringent evaluation process called the Sequential Evaluation Process (SEP). "The 5 steps of SEP" was the title of a flowchart used by Mr. Federline during his presentation.

Briefly, the evaluation of an applicant follows a set order of 5 steps; each step comes with its own criteria; each step requires a decision; and the claim for an applicant will move to the next step only if the criteria at each preceding step can be satisfied. The first three steps are: (1) a determination whether the applicant is engaged in substantial, gainful activity (which is checked against SSA guidelines for maximum income limits); (2) an examination of the severity of the applicant's impairments or combination of impairments (to determine if these indeed are severe enough to affect his or her ability to work); (3) a determination whether these impairments meet or equal the SSA listing of impairments. The last two steps evaluate the applicant's ability to do his or her prior work and determine if he or she can do any other kind of work. The SEP is carried out by disability examiners who adhere to multiple guidelines, listings, rulings, and manuals published by the Social Security Administration.

In response to a question asked by one of the panelists, Mr. Federline assured the committee that all SSA adjudicators are trained in a consistent manner across the country and are able to process ME/CFS claims with the same degree of accuracy and consistency. Besides their training, he pointed out consistency is also achieved and maintained by use of the same Social Security Rulings (i.e., SSR 99-2p issued in April 1999 explicitly for the evaluation of CFS impairments and SSR 96, specific parts of which help to identify other relevant impairments, and the role of various medical opinions) as well as use of the Program Operations Manual System (POMS). POMS was defined as "SSA's official vehicle for issuing program instructions" on another one of Mr. Federline's slides. In conclusion, he believes the SSA determination of disability process is thorough, fair and impartial.

Another question was raised about whether ME/CFS could be listed as an impairment in the Blue Book (the listing of impairments described above in step 3), with the idea that the disability

evaluation process could be satisfied by the third step during the SEP. Federline explained that although the SSA rewrites and updates the Blue Book about every 5 years and periodically adds new impairments, the requests for additional impairments are numerous and SSA can consider only a limited number.

Furthermore, he felt that just having an impairment listed in the Blue Book, on that alone, may not improve nor shorten the evaluation process. Mr. Federline explained, "If some of their impairment contributes to it [the disability] with CFS, such as the mental impairment, the whole person has to be considered. It would still be there even if it is in the Blue Book."

When applicants file for disability benefits due to CFS, the primary impairments will usually be post-exertional malaise and fatigue, cognitive dysfunction and/or other primary manifestations of the illness. It is possible that an applicant could have a mood disorder or reactive depression (as a result of the illness), and these impairments might be listed as secondary ones. But there are also times when patients have seen physicians who don't understand the illness and report their patients' illness/ impairments as being mental disorders. Dr. Nancy Klimas felt this continues to be a huge problem for considerable number of patients.

Another situation brought up by Dr. Klimas was how veterans often have their impairments "added up" - a percentage for multiple physical impairments, plus a percentage for mental problems and so on. It is not unusual to end up with a veteran who is considered as being 180% disabled. It does not work this way with the SSA - disability is determined to be "all or nothing".

[Back to top](#)

ERISA, highlights from CFSAC meeting, and where to find more information

Lisa Alexander spoke about ERISA as a representative from the U.S. Department of Labor. More precisely, Ms. Alexander's serves as Chief of the Division of Coverage, Reporting and Disclosure, which is one of the divisions that make up the Office of Regulations and Interpretations. The latter, along with multiple other offices, form the Employee Benefits Security Administration (EBSA), a federal agency within the U.S. Department of Labor. It is important for consumers to know at least this much regarding the breakdown of this complex organizational structure. First, consumers will get a better understanding of which division is responsible for

the management of programs they might be using. Second, it is always good to know where to find help and accurate information about programs before there is a problem. Much of what Ms. Alexander discussed is overseen by EBSA. This agency is involved with ERISA provisions, COBRA and other health insurance plans and has a huge amount of information available at its website. The link to the main EBSA website is provided at the end of this article and it could be tremendously helpful, not only for ERISA matters, but also numerous insurance and health laws-an area which is rapidly changing.

Now to address the acronym of ERISA, which has been mentioned several times already. It refers to the Employee Retirement Income Security Act of 1974. ERISA is a federal law that sets minimum standards for most voluntarily established pension and health plans in private industry which provide protection for individuals in these plans. Some important points to highlight from Ms. Alexander's presentation is that changes can be made to a plan or to conditions covered by a plan which, in turn, could change or terminate coverage in some cases. Insured individuals should receive a notice informing them about any modifications or exclusions to their plan, within a certain time frame. If or when individuals have problems with coverage for plans overseen by EBSA, have questions, or could use assistance from one of the benefits advisors, Ms. Alexander urged that people call the EBSA's toll-free number: 1 (866) 444-EBSA (3272).

[Back to top](#)

Links to recommended sources of information

The Affordable Care Act is actually part of the Patient Protection and Affordable Care Act-a law signed by President Obama in early 2010 and one that will provide many health-related provisions over a four-year period. For an easy to understand introduction about this new health law, [click here](#) .

The Pre-existing Condition Insurance Plan (PCIP) is a new program that will provide a health coverage option for individuals who have been uninsured for at least six months; have a pre-existing condition; and have been denied coverage (or have been offered insurance but without coverage of pre-existing condition) by a private insurance company. To learn more about the Pre-Existing Condition Insurance Plan (PCIP), [click here](#) .

Employee Benefits Security Administration's (EBSA) home page is a source of information that really needs to be bookmarked. Most people will not readily recognize this federal agency, nor realize which programs it oversees. The EBSA site provides a wealth of information such as consumer information, compliance assistance, publications, the latest news, workshops and webcasts on many topics, including ERISA, COBRA, and the Affordable Care Act (all of which

are meshed together under EBSA). To access the EBSA homepage, [click here](#) .

A few patient-friendly articles about ERISA are available from the Massachusetts CFIDS/ME & FM Association library of articles as follows:

- [Disability Discussion - Barbara Comerford, ESQ](#)
- [Disability Insurance Claims: General - an article by Atty. George Thompson, specialist in Long-Term Disability](#)

To watch the video of the meeting, which we highly recommend, go to the [CFSAC archived videos webpage](#) and click on video for Day 2, May 11, 2011. A screen will open up and the lecture will start promptly. Below this screen is a display of the items scheduled for Day 2 discussion. Scroll down and click on the title for desired topic and the video will reposition itself (after a brief buffering).

The Massachusetts CFIDS/ME & FM Association has already posted an article highlighting key topics discussed on Day 1. Taking into consideration the amount of material presented over this two-day period and wanting to give adequate attention and coverage to major issues, we have decided to also create a third, separate article. The last installment article for the Spring 2011 CFSAC meeting will report on the committee's discussion and recommendations. Stay tuned for the release of the final article in the near future.

[Back to top](#)