

# 2013 Current Fiscal Year Report: Chronic Fatigue Syndrome Advisory Committee

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<b>1. Department or Agency</b>	<b>2. Fiscal Year</b>
Department of Health and Human Services	2013

<b>3. Committee or Subcommittee</b>	<b>3b. GSA Committee No.</b>
Chronic Fatigue Syndrome Advisory Committee	5136

<b>4. Is this New During Fiscal Year?</b>	<b>5. Current Charter</b>	<b>6. Expected Renewal Date</b>	<b>7. Expected Term Date</b>
No	09/05/2012	09/05/2014	

<b>8a. Was Terminated During Fiscal Year?</b>	<b>8b. Specific Termination Authority</b>	<b>8c. Actual Term Date</b>
No		

<b>9. Agency Recommendation for Next Fiscal Year</b>	<b>10a. Legislation Req to Terminate?</b>	<b>10b. Legislation Pending?</b>
Continue	No	Not Applicable

<b>11. Establishment Authority</b>	Agency Authority		
<b>12. Specific Establishment Authority</b>	<b>13. Effective Date</b>	<b>14. Committee Type</b>	<b>14c. Presidential?</b>
42 USC 217a	10/17/1962	Continuing	No

**15. Description of Committee** Scientific Technical Program Advisory Board

**16a. Total Number of Reports** No Reports for this Fiscal Year

**17a. Open** 2 **17b. Closed** 0 **17c. Partially Closed** 0 **Other Activities** 0 **17d. Total** 2

## Meetings and Dates

Purpose	Start	End
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Topics discussed included: Biomarkers: An Overview and Future Look; FDA and Drug Development; Social Security Administration; ME/CFS Case Definitions -- A Path Forward; and Agency Updates by the CFSAC Ex Officio Members. The meeting agenda also included a panel discussion on ME/CFS Organizations and a Committee discussion to finalize recommendations

10/03/2012 - 10/04/2012

Topics discussed included: Approval of Prioritized List; Approval of Proposed List of ME/CFS Organizations Websites; Medicare Coverage; How To Get More Clinicians Involved in ME/CFS; and Agency Updates from CFSAC Ex Officio Members

05/22/2013 - 05/23/2013

**Number of Committee Meetings Listed: 2**

	<b>Current FY</b>	<b>Next FY</b>
<b>18a(1). Personnel Pmts to Non-Federal Members</b>	\$12,298.00	\$12,667.00
<b>18a(2). Personnel Pmts to Federal Members</b>	\$0.00	\$0.00
<b>18a(3). Personnel Pmts to Federal Staff</b>	\$134,085.00	\$145,418.00
<b>18a(4). Personnel Pmts to Non-Member Consultants</b>	\$0.00	\$0.00
<b>18b(1). Travel and Per Diem to Non-Federal Members</b>	\$29,850.00	\$30,746.00
<b>18b(2). Travel and Per Diem to Federal Members</b>	\$0.00	\$0.00
<b>18b(3). Travel and Per Diem to Federal Staff</b>	\$0.00	\$2,500.00
<b>18b(4). Travel and Per Diem to Non-member Consultants</b>	\$0.00	\$0.00
<b>18c. Administrative Costs (FRNs, contractor support, In-person/hybrid/virtual meetings)</b>	\$0.00	\$0.00

<b>18d. Other (all other funds not captured by any other cost category)</b>	\$50,000.00	\$51,500.00
<b>18e. Total Costs</b>	\$226,233.00	\$242,831.00
<b>19. Federal Staff Support Years (FTE)</b>	2.50	2.50

**20a. How does the Committee accomplish its purpose?**

The Committee advises, consults with, and makes recommendations to the Secretary, through the Assistant Secretary for Health, on a broad range of topics including (1) the current state of knowledge and research about the epidemiology and risk factors relating to chronic fatigue syndrome, and identifying potential opportunities in these areas; (2) current and proposed diagnosis and treatment methods for chronic fatigue syndrome; and (3) development and implementation of programs to inform the public, health care professionals, and the biomedical, academic and research community about chronic fatigue syndrome advances.

**20b. How does the Committee balance its membership?**

The Committee consists of 11 members, including the Chair, who are appointed by the Secretary or the Secretary's designee. The Committee composition includes 7 individuals selected from the category of biomedical research scientists with demonstrated expertise in biomedical research applicable to chronic fatigue syndrome and 4 individuals with expertise in health care delivery, private health care services or insurers, or voluntary organizations concerned with the problems of individuals with CFS. The voting members are appointed to serve overlapping

terms of up to four years. It recently was authorized for the Committee composition to be expanded to include three non-voting liaison representative positions. These positions will be occupied by representatives from organizations that are concerned with CFS. The representative organizations will be selected by the DFO or designee and will serve two-year terms. The Committee structure also includes ex-officio representation from the Social Security Administration (SSA) and the following 6 HHS operating divisions: Agency for Healthcare Research and Quality (AHRQ); Centers for Disease Control and Prevention (CDC); Centers for Medicare and Medicaid Services (CMS); Food and Drug Administration (FDA); Health Resources and Services Administration (HRSA); and National Institutes of Health (NIH). The Committee structure can be expanded to include additional representation from other Federal agencies by the Secretary or the Secretary's designee, as it is deemed necessary and/or beneficial to accomplish the mission of CFSAC.

**20c. How frequent and relevant are the Committee Meetings?**

The Committee is authorized to meet no less than two times a year.

**20d. Why can't the advice or information this committee provides be obtained elsewhere?**

The formation of this Committee was in the public interest in connection with the performance of duties imposed on the Department by law, and such duties can best be performed through the advice and counsel of such a group. It is not feasible for the Department or any of its existing committees to perform these duties.

**20e. Why is it necessary to close and/or partially closed committee meetings?**

CFSAC meetings are open to the public.

**21. Remarks**

The Chronic Fatigue Syndrome Advisory Committee (CFSAC) serves to provide science-based advice and recommendations to the Secretary on a broad range of issues and topics pertaining to chronic fatigue syndrome (CFS) and other related health conditions. The Committee brings together leading scientists, advocacy groups, patients diagnosed with CFS, and representatives from Federal agencies to discuss advances in the diagnosis, treatment and prevention of CFS. The Committee is comprised of 11 members with expertise in biomedical research in the area of CFS, health care delivery services, insurers and voluntary organizations concerned with the problems of individuals with CFS. The Committee structure also includes seven non-voting, ex-officio members who represent the following six HHS agencies: Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control and Prevention (CDC), Centers for Medicare and Medicaid Services (CMS), Food and Drug Administration (FDA), National Institutes of Health (NIH) and Health Resources and Services Administration (HRSA), and the Social Security Administration (SSA). The non-voting ex-officio members provide critical information regarding their respective agency activities related to CFS at each Committee meeting. Composition of the Committee also includes three non-voting liaison representative positions occupied by individuals who are selected by their organizations to serve as representatives of organizations that are concerned with myalgic encephalomyelitis/chronic

fatigue syndrome (ME/CFS). The following organizations were designated to occupy these representative positions for a two-year term: (1) International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis; (2) CFIDS Association of America; and, (3) New Jersey Chronic Fatigue Syndrome Association, Inc. During the FY 2013 reporting period, two subcommittees focused on topics of concern to the CFS community. Both subcommittees, Patient Care Quality of Life (PCQL) and Research held conference calls to discuss ME/CFS-related issues and reported back to the parent Committee at the biannual Committee meetings. The Committee held two meetings, one in October 2012 and May 2013. At each meeting, Committee members developed recommendations that were forwarded to the Secretary for review, through the Assistant Secretary for Health (ASH). Also at each meeting, recommendations that had been forwarded to the Secretary from the Committee's previous meeting were reviewed and discussed. The following recommendations were developed during the October 2012 meeting: 1) CFSAC recommends that the Secretary will promptly convene (by 12/31/12 or as soon as possible thereafter) at least one stakeholders' (ME/CFS experts, patients, advocates) workshop in consultation with CFSAC members to reach consensus for a case definition useful for research, diagnosis and treatment of ME/CFS beginning with the 2003 Canadian Consensus Document case definition and its utility for diagnosis and treatment of ME/CFS. 2) CFSAC recommends a dedicated standing committee for ME/CFS at NIH. 3) CFSAC recommends that the Secretary directs NIH to issue an RFA for biomarker discovery and validation in ME/CFS patients that is in the \$7–\$10 million range. 4) The

Secretary would instruct the NIH to issue an RFA to establish outcomes measures which would include but not be limited to biomarker discovery and validation in patients with ME/CFS. 5) CFSAC recommends that the Secretary endorse the Coalition for ME/CFS Option 1 proposal for the ICD-10-CM that was recommended at the September 19, 2012 NCHS public meeting. 6) CFSAC recommends that the Secretary allocate specific funds to study CFS cluster outbreaks. 7) CFSAC recommends that the Secretary allocate funds to study the epidemiology of severe ME/CFS patients. The October 2012 agenda included key areas of interest to the Committee and presentation were: Biomarkers: An Overview and Future Look (highlights centered on biomarkers as being the common language that will allow clinicians to communicate in the same language and be able to move forward for a specific treatment that is specific for ME/CFS); Food and Drug Administration's Drug Development (FDA recognized that there are currently no approved therapies indicated to treat CFS and ME. The lack of approved therapies indicated for the treatment of CFS and ME represents a public health concern and FDA is committed to finding avenues to collaborate with interested parties to foster drug development for viable treatment options for serious diseases such as CFS and ME. Chronic Fatigue Syndrome applications are supported in the Division of Pulmonary, Allergy, and Rheumatology products to provide one-stop shopping for sponsors coming in with chronic fatigue syndrome applications); Social Security Administration (SSA's five-step sequential evaluation process for the assessment of disability claims of evidence and materials submitted to the disability examiner and medical consultant team in assessing the case and role of

adjudicators to determine if a CFS application applies for disability); ME/CFS Organizations (ME/CFS organizations were invited to provide an opportunity for dialog with the Committee members and expand communication and outreach to the broader ME/CFS community); ME/CFS Case Definition – A Path Forward (discussions regarding the complex issues involved in the case definition of ME/CFS and the IACFS/ME body of medicine and science involved in CFS as well as the 2003 Canadian definition. Additional information regarding the meeting of the CFSAC on October 3 – 4, 2012 is located at <http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac10032012.pdf> and <http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac10042012.pdf>

During the May 2013 meeting the CFSAC members welcomed a new voting member, Rebecca Collier, with more than 25 years of nursing experience and 10 years of case management experience in disability management. The Committee also unanimously approved the new priority recommendations list that will be added as they are approved in chronological order. Recommendations can be removed by a majority of CFSAC voting members in a regularly scheduled meeting. The three liaison organizations were also recognized as the CFSAC charter had been amended in September 2012 to include them. The Chair noted that as non-voting members, they bring a voice and a visible presence at the meetings with IACFS/ME, the New Jersey CFS Association, and the CFIDS Association of America and provide the opportunity to improve collaboration and communication across the organizations, the department, and through the Committee to help bolster the work that it does. CFSAC members unanimously approved the various ME/CFS

Organizations web links and documents to be posted on the website. The Committee Chair introduced and described the following working group concept to support the Committee's preparation of future recommendations: (a) It should be a core group of voting members, ex officio, and liaison organizations. (b) The minimum number should be three; the recommended number is somewhere less than seven. (c) Outside input can be invited as needed on an ad hoc basis. (d) We can add to or take from the working group based upon specific need. (e) The goal will be to develop a core plan along with timelines for implementation, timelines for progress toward developing implementation, and provision of interim progress reports that can be discussed. (f) The end goal is to prepare the background as well as the specific recommendation for CFSAC to approve and then have forwarded to the Secretary. The May 2013 agenda included key areas of interest to the Committee and presentation were: CMS Medicare Coverage (CFSAC members and other CFS stakeholders are working with CMS to determine if necessary tests and treatments for CFS are covered by Medicare and if not, what evidence would be needed to support a request for coverage determination); Health Insurance (overview on the Health Insurance Marketplace as one example of the opportunity to ensure that individuals with ME/CFS who might be uninsured, underinsured, or at risk for losing their health insurance know about options to help increase the chances that they have health insurance and that they can access healthcare to better manage their symptoms and their condition); How to get more clinicians involved in ME/CFS? (Two Committee clinicians, who care for ME/CFS patients with regularity, discussed their professional

experiences and opportunities to use this information as a basis of a CFSAC work group to figure out how to reach other medical practitioners with proper information and education. The Committee established two working groups: Working Group 1 will investigate strategies to increase the number of capable investigators that are successfully funded for ME/CFS research, and Working Group 2 will develop recommendations for increasing the number of interested and capable healthcare providers to give the highest caliber of expert clinical care for ME/CFS patients. Additional information regarding the meeting of the CFSAC on May 22 – 23, 2013 is located at [http://www.hhs.gov/advcomcfs/meetings/minutes/cfsacmay22\\_final\\_508.pdf](http://www.hhs.gov/advcomcfs/meetings/minutes/cfsacmay22_final_508.pdf) and [http://www.hhs.gov/advcomcfs/meetings/minutes/cfsacmay23\\_final\\_508.pdf](http://www.hhs.gov/advcomcfs/meetings/minutes/cfsacmay23_final_508.pdf) from the CFSAC website. In addition to the frequent updates to the CFSAC website, the CFSAC listserv has 300 registered persons and was initiated in July 2012 in an effort to increase communication to the ME/CFS community. Members of the public were able to view all meetings via live video cast and archived video tapes are accessible via the CFSAC website <http://www.hhs.gov/advcomcfs/>. The public can access current information related to the Committee's work on the CFSAC website. Information posted on the website includes Federal Register notices that are published to announce meetings, charter renewals, recommendations developed and approved by the Committee to be forwarded to the Secretary and other Committee-related business; meeting agendas and minutes developed during each meeting. Copies of written public comment provided to the Committee will be made available upon request at [cfsac@hhs.gov](mailto:cfsac@hhs.gov). The only annual reporting requirement CFSAC must satisfy is

updating and maintaining information held in the FACA database for the annual comprehensive review. There is no additional requirement to provide an annual written report on the Committee's activities/accomplishments.

### Designated Federal Officer

Nancy C. Lee Deputy Assistant Secretary for Health - Women's Health

Committee Members	Start	End	Occupation	Member Designation
Casillas, Adrian	06/13/2012	06/13/2016	Program Director, Allergy and Immunology Section,	Special Government Employee (SGE) Member
Collier, Rebecca	04/01/2013	06/13/2016	Registered Nurse	Special Government Employee (SGE) Member
Cook, Dane	05/10/2010	05/10/2014	Assistant Professor, Kinesiology	Special Government Employee (SGE) Member
Corbin, Lisa	06/13/2012	06/13/2016	Associate Professor, Dept. of General Internal Medicine;	Special Government Employee (SGE) Member
Dimatrakoff, Jordan	05/10/2011	05/10/2015	Clinical Fellow	Special Government Employee (SGE) Member
Eileen, Holderman	05/10/2010	05/10/2014	Patient advocate	Special Government Employee (SGE) Member
Fletcher, MaryAnn	06/13/2012	06/13/2016	Director, E.N. Papper Laboratory of Clinical Immunology	Special Government Employee (SGE) Member
Friedberg, Fred	05/22/2013	05/22/2015	President	Representative Member
Krafchick, Steven	07/01/2010	07/01/2014	Private practice attorney; disability law	Special Government Employee (SGE) Member
Levine, Susan	05/10/2010	05/10/2014	CFS practitioner	Special Government Employee (SGE) Member

Marshall, Gailen	05/10/2010	05/10/2014	Professor, Medicine and Pediatrics; Bomedical research	Special Government Employee (SGE) Member
Moore, Billie	05/22/2013	05/22/2015	Liaison Organization Delagate	Representative Member
Reynolds, Leigh	05/22/2013	05/22/2015	Engagement Manager	Representative Member
Vincent, Ann	05/10/2011	03/25/2013	Medical Director of the Fibromyalgia and Chronic Fatigue Clinic	Special Government Employee (SGE) Member

**Number of Committee Members Listed: 14**

**Narrative Description**

CFSAC supports the Department's efforts to advance the health and well-being of Americans and the Department's strategic goal of enhancing the capacity and productivity of the Nation's health science research enterprise. CFSAC provides expert advice and recommendations to the Secretary and the Assistant Secretary for Health on topics, including the epidemiology and risk factors relating to chronic fatigue syndrome (CFS) and diagnosis and treatment methods for the condition. The Committee also advises on the development and implementation of programs to inform the public, health care professionals, and the biomedical, academic, and research communities about advances related to CFS.

**What are the most significant program outcomes associated with this committee?**

Checked if  
Applies

- Improvements to health or safety
- Trust in government
- Major policy changes
- Advance in scientific research
- Effective grant making
- Improved service delivery
- Increased customer satisfaction

- Implementation of laws or regulatory requirements
- Other

**Outcome Comments**

Since the inception of the Committee, the CFSAC website has been significantly updated with links to other federal partners regarding the chronic fatigue syndrome and tools for caregivers and patients. The website has received almost four times the number of visitors/inquiries since modifications have been made. Also, public testimonies have been posted to the website. The public has responded favorably to the CFSAC listserv established in June 2012 by the Department to provide additional means of communicating/disseminating information pertaining to CFSAC. In addition, webcasting was provided in the October 2012 and May 2013 meeting to the public. Webcasts are archived so that the meeting proceedings can be viewed on the CFSAC webpage, [www.hhs.gov/adv.comcfs/](http://www.hhs.gov/adv.comcfs/) by those who wish to do so.

**What are the cost savings associated with this committee?**

Checked if Applies

- None
- Unable to Determine
- Under \$100,000
- \$100,000 - \$500,000
- \$500,001 - \$1,000,000
- \$1,000,001 - \$5,000,000
- \$5,000,001 - \$10,000,000
- Over \$10,000,000
- Cost Savings Other

**Cost Savings Comments**

NA

**What is the approximate Number of recommendations produced by this committee for the life of the committee?**

76

**Number of Recommendations Comments**

Some recommendations overlap.

**What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?**

45%

**% of Recommendations Fully Implemented Comments**

N/A

**What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?**

0%

**% of Recommendations Partially Implemented Comments**

NA

**Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?**

Yes  No  Not Applicable

### **Agency Feedback Comments**

The DFO communicates with the Committee Chair through scheduled leadership conference calls. This information is shared with the other members, as well as the public, at full Committee meetings. Additional information pertaining to the Committee and other CFS-related matters can be found on the Committee website. The Ex-officio members and the DFO report on the status of Departmental efforts at each public meeting. The website is <http://www.hhs.gov/advcomcfs/>

**What other actions has the agency taken as a result of the committee's advice or recommendation?**

Checked if Applies

Reorganized Priorities	<input checked="" type="checkbox"/>
Reallocated resources	<input type="checkbox"/>
Issued new regulation	<input type="checkbox"/>
Proposed legislation	<input type="checkbox"/>
Approved grants or other payments	<input type="checkbox"/>
Other	<input type="checkbox"/>

### **Action Comments**

During each Committee meeting, the ex-officio members provide updated information regarding efforts and/or actions being undertaken by their respective agency to respond to

the Committee's recommendations.

**Is the Committee engaged in the review of applications for grants?**

No

**Grant Review Comments**

NA

**How is access provided to the information for the Committee's documentation?**

Checked if Applies

- |                           |                                     |
|---------------------------|-------------------------------------|
| Contact DFO               | <input checked="" type="checkbox"/> |
| Online Agency Web Site    | <input checked="" type="checkbox"/> |
| Online Committee Web Site | <input checked="" type="checkbox"/> |
| Online GSA FACA Web Site  | <input checked="" type="checkbox"/> |
| Publications              | <input type="checkbox"/>            |
| Other                     | <input type="checkbox"/>            |

**Access Comments**

N/A