

2018 Current Fiscal Year Report: Chronic Fatigue Syndrome Advisory Committee

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1. Department or Agency

Department of Health and Human
Services

2. Fiscal Year

2018

3. Committee or Subcommittee

Chronic Fatigue Syndrome Advisory
Committee

3b. GSA

Committee No.

5136

4. Is this New During Fiscal Year?

5. Current Charter

6. Expected Renewal Date

7. Expected Term Date

No

09/05/2016

8a. Was Terminated During Fiscal Year?

Yes

8b. Specific Termination Authority

8c. Actual Term Date

09/05/2018

9. Agency Recommendation for Next Fiscal Year

Continue

10a. Legislation Req to Terminate?

No

10b. Legislation Pending?

Not Applicable

11. Establishment Authority

Authorized by Law

12. Specific Establishment Authority

42 USC 217a, Section
222

13. Effective Date

09/05/2002

14. Committee Type

Continuing

14c. Presidential?

No

15. Description of Committee

Scientific Technical Program
Advisory Board

16a. Total Number of Reports

No Reports for
this Fiscal Year

17a. Open Meetings and Dates

2 17b. Closed0 17c. Partially Closed0 Other Activities0 17d. Total2

Purpose

Start

End

The first of two required annual meeting to discuss progress on a number of issues and work groups updates and recommendations to the entire Committee. 12/13/2017 - 12/14/2017

The second of two required annual meeting to discuss progress on a number of issues and work groups updates and recommendations to the entire Committee. 06/20/2018 - 06/21/2018

Number of Committee Meetings Listed: 2

	Current FY	Next FY
18a(1). Personnel Pmts to Non-Federal Members	\$13,000.00	\$0.00
18a(2). Personnel Pmts to Federal Members	\$0.00	\$0.00
18a(3). Personnel Pmts to Federal Staff	\$123,272.00	\$0.00
18a(4). Personnel Pmts to Non-Member Consultants	\$0.00	\$0.00
18b(1). Travel and Per Diem to Non-Federal Members	\$28,000.00	\$0.00
18b(2). Travel and Per Diem to Federal Members	\$0.00	\$0.00
18b(3). Travel and Per Diem to Federal Staff	\$0.00	\$0.00
18b(4). Travel and Per Diem to Non-member Consultants	\$0.00	\$0.00
18c. Other(rents,user charges, graphics, printing, mail, etc.)	\$25,547.00	\$0.00
18d. Total	\$189,819.00	\$0.00
19. Federal Staff Support Years (FTE)	1.50	0.00

20a. How does the Committee accomplish its purpose?

The Committee advises and makes recommendations to the Secretary, through the Assistant Secretary for Health, on a range of topics including: (1) opportunities to improve knowledge and research about the epidemiology,

etiologies, biomarkers and risk factors for ME/CFS; (2) research on the diagnosis, treatment, and management of ME/CFS and potential impact of treatment options; (3) strategies to inform the public, health care professionals, and the biomedical academic and research communities about ME/CFS advances; (4) partnerships to improve the quality of life of ME/CFS patients; and (5) strategies to insure that input from ME/CFS patients and caregivers is incorporated into HHS policy and research.

20b. How does the Committee balance its membership?

The Chronic Fatigue Syndrome Advisory Committee (CFSAC) serves to provide science-based advice and recommendations to the Secretary, through the Assistant Secretary for Health, on a broad range of issues and topics pertaining to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and other related health conditions. The Committee brings together leading scientists, advocacy groups, patients diagnosed with ME/CFS, caretakers, and representatives from federal agencies to discuss advances in the diagnosis, treatment and prevention of ME/CFS. The Committee is comprised of 13 voting members with expertise in biomedical research in the area of ME/CFS, health care delivery services, insurers, voluntary organizations concerned with the problems of individuals with ME/CFS and patients and care givers. The voting members are appointed to serve overlapping terms of up to four years. The voting members are appointed by the Secretary. The Committee structure also includes eight non-voting, ex-officio members who represent the following five HHS agencies: Agency for Healthcare Research and Quality, Centers for

Disease Control and Prevention, the Food and Drug Administration, the National Institutes of Health and the Health Resources and Services Administration plus three other federal agencies: the Social Security Administration, the Department of Veterans Affairs, and the Department of Defense. The non-voting ex-officio members provide critical information regarding their respective agency's activities related to ME/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 the interests of their respective organization. These organizations have interest in the work being done to properly address ME/CFS. The representative organizations are selected by the Designated Federal Officer (DFO) or designee and serve a term of two years. The following organizations currently occupy the non-voting representative positions on the Committee: (1) ME Action; (2) Massachusetts CFIDS/ME & FM Association; (3) Simmaron Research Inc.

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

The Committee is authorized to meet not less than two times a year. The Committee meets to receive, as well as share information about work that is being done to properly address this important public health concern.

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

The establishment of this Committee was in the public interest. Chronic fatigue syndrome is a very debilitating health condition. Utilizing individuals who have knowledge and expertise in biomedical research, health care delivery services, and the

problems of individuals living with ME/CFS will assist in developing departmental efforts to properly address this important public health concern.

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

CFSAC meetings are open to the public.

21. Remarks

At the first CFSAC meeting of FY18 held in December 2017, the Committee made a total of ten recommendations to HHS. 1. CFSAC asked HHS to disseminate the treatment recommendations in the 2014 IACFS/ME Adult Primer and in the 2017 ME/CFS Pediatric Primer; 2. CFSAC asked the CDC to continue to move forward with the June 2017 CFSAC recommendation to create a plan for developing clinical practice guidelines for ME/CFS; 3. CFSAC recommended that all educational materials disseminated by the HHS, VA and DoD for healthcare providers and for the general public be informed by the findings of the IOM, the IACFS/ME 2014 Adult Primer and 2017 ME/CFS Pediatric Primer; 4. CFSAC recommended that all outdated federal websites or outdated material provided by federal agencies be removed or updated as quickly as possible and by no later than the end of 2018; 5. CFSAC recommended that the materials provided by HHS, the VA and the DoD are to be regularly reviewed and updated as warranted by the research and consensus expert opinion; 6. a. CFSAC recommended that the agencies within the HHS provide sufficient funding for ME/CFS Project ECHO (Extension for Community Health Outcomes) programs, b. Provide funding for CME/CE training conferences/programs on ME/CFS led by experts

for MD, DO, NP, PA, Nurses, Social Workers, Psychologists, Psychiatrists, c. Continue school health and pediatric ME/CFS educational initiatives as recommended in January 12-13, 2017 in person CFSAC meeting, d. Continue outreach to professional medical societies, internet medical provider information websites (e.g. UpToDate), and internet “public” medical websites (e.g. Mayo Clinic, Healthwise) to inform them of new information on the CDC and other federal agency websites; 7. Recommended that all materials published or distributed by HHS take special care to address negative provider attitudes and disease stigma; 8. a. Recommends that AHRQ works to get the 2016 Addendum of the 2014 ME/CFS AHRQ Evidence Review published in the Annals of Internal Medicine; 9. Endorsed the IAFCS/ME’s proposal for changes to the ICD-10-CM coding for ME/CFS and 10.

Recommended that CMS be added as an ex officio when the charter is renewed in 2018. At the second CFSAC meeting of FY18 held in June 2018, the Committee made a total of four recommendations to HHS. 1. CFSAC recommended that the National Center for Health Statistics work with ME/CFS experts and advocates to resolve concerns regarding the IACFS/ME proposal of how to reclassify CFS in the ICD-10-CM and ensure that the IACFS/ME proposal is placed on the agenda for the September 2018 meeting; 2. CFSAC recommended that CDC add a “diagnostic coding” section to its ME/CFS website for medical providers to explain that the code for “chronic fatigue, unspecified” (R53.82) should not be used for ME/CFS, and direct providers to use the existing code for myalgic encephalomyelitis or post viral fatigue (G93.3) when coding the diagnosis of ME/CFS; 3. CFSAC recommended

that all federal agencies providing ME/CFS information and outreach to medical providers should include this diagnostic coding clarification related to a diagnosis of ME/CFS; and 4. CFSAC endorsed the establishment of an ME/CFS Project ECHO (Extension for Community Healthcare Outcomes) or equivalent tele-mentoring program, to be conducted by ME/CFS disease experts and established through an existing academic center Project ECHO. Thus, CFSAC recommends that the relevant HHS agencies, including but not limited to CDC, HRSA, and AHRQ, plus the VA and DOD, evaluate the feasibility of supporting and promoting an ME/CFS Project ECHO and identifying potential grants, contracts, or other funding mechanisms that could be used to support the development of ME/CFS ECHO from the relevant agencies. Committee members Alisa Koch, Jose Montoya, Donna Pearson and Faith Newton were extended up to 180 days. The members' term ended on 9.5.18 when the charter expired and the Committee was terminated.

Designated Federal Officer

Gustavo Ceinos Senior Public Health Analyst,
Office on Women's Health

Committee Members	Start	End	Occupation	Member Designation
Bateman, Lucinda	12/13/2017	09/05/2018	Physician	Special Government Employee (SGE) Member
Belay, Ermias	01/01/2016	09/05/2018	Associate Director for Epidemiologic Science, CDC	Ex Officio Member
Cook, Dane	05/10/2010	11/10/2017	Assistant Professor, Kinesiology	Special Government Employee (SGE) Member
HsuBorger, Ben	06/19/2017	09/05/2018	Community Organizer	Representative Member
Kaplan, Gary	11/01/2013	11/10/2017	Physician	Special Government Employee (SGE) Member

Koch, Alisa	06/16/2014	09/05/2018	Eli Lilly	Special Government Employee (SGE) Member
Lange, Gudrun	12/13/2017	09/05/2018	Researcher	Special Government Employee (SGE) Member
Levine, Susan	05/10/2010	11/10/2017	CFS practitioner	Special Government Employee (SGE) Member
Maynard, Janet	01/01/2016	09/05/2018	Clinical Team Leader, Division of Pulmonary, Allergy, and Rheumatology Products, FDA	Ex Officio Member
Miller, Courtney	06/19/2017	09/05/2018	Simmaron Research Board President	Representative Member
Montoya, Jose	06/16/2014	09/05/2018	Professor of Medicine, Stanford University School of Medicine	Special Government Employee (SGE) Member
Newton, Faith	07/01/2014	09/05/2018	Associate Professor Education, Delaware State University	Special Government Employee (SGE) Member
Pearson, Donna	06/16/2014	09/05/2018	Patient Advocate	Special Government Employee (SGE) Member
Sanchez, Carmen	02/08/2018	09/05/2018	Education Program Specialist	Ex Officio Member
Shahzad, Amrit	12/13/2017	09/05/2018	Researcher	Special Government Employee (SGE) Member
Tracy, Christopher	02/01/2018	09/05/2018	Chief, Rheumatology Services (DoD)	Ex Officio Member
Whittemore, Vicky	01/01/2016	09/05/2018	Program Director, National Institute of Neurological Disorders and Stroke, NIH	Ex Officio Member
Williams, Cheryl	01/01/2016	09/05/2018	Director, Office of Medical Policy, SSA	Ex Officio Member
Williams, Leah	06/19/2017	09/05/2018	MassCFIDS Treasurer	Representative Member

Number of Committee Members Listed: 19

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 myalgic encephalomyelitis and chronic fatigue syndrome (ME/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	<input checked="" type="checkbox"/>
Trust in government	<input checked="" type="checkbox"/>
Major policy changes	<input checked="" type="checkbox"/>
Advance in scientific research	<input checked="" type="checkbox"/>
Effective grant making	<input type="checkbox"/>
Improved service delivery	<input checked="" type="checkbox"/>
Increased customer satisfaction	<input checked="" type="checkbox"/>
Implementation of laws or regulatory requirements	<input type="checkbox"/>
Other	<input type="checkbox"/>

Outcome Comments

Since the inception of the Committee, the CFSAC website has been updated with links to other federal partners regarding ME/CFS and tools for caregivers and patients. Public testimonies have been posted to the website. The public has responded favorably to the CFSAC listserv established in June 2012 to provide additional means of communicating/disseminating information pertaining to CFSAC. A listening only telephone line is provided during all CFSAC meetings so the public could listen to the meetings.

What are the cost savings associated with this committee?

Checked if Applies

None	<input checked="" type="checkbox"/>
Unable to Determine	<input type="checkbox"/>
Under \$100,000	<input type="checkbox"/>
\$100,000 - \$500,000	<input type="checkbox"/>
\$500,001 - \$1,000,000	<input type="checkbox"/>
\$1,000,001 - \$5,000,000	<input type="checkbox"/>
\$5,000,001 - \$10,000,000	<input type="checkbox"/>
Over \$10,000,000	<input type="checkbox"/>
Cost Savings Other	<input type="checkbox"/>

Cost Savings Comments

NA

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

112

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?

32%

% 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?

6%

% 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 regular conference calls and emails. Additional information pertaining to the Committee and other ME/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