

**CFSAC Recommendations Since September 2004**

**Sorted by Focus Area, Agency, and Progress**

**Last Updated: July 26, 2011**

Key: May 2011 Recommendations

**AGENCY RELEVANCE**

<b>TEXT/DATE</b>	<b>HHS</b>	<b>CMS</b>	<b>CDC</b>	<b>FDA</b>	<b>HRSA</b>	<b>NIH</b>	<b>SSA</b>	<b>AHRQ</b>	<b>PROGRESS</b>	<b>NOTES</b>	<b>COMPLETED</b>
<b>RESEARCH</b>											
Develop a national research and clinical network for ME/CFS (myalgic encephalomyelitis/CFS) using regional hubs to link multidisciplinary resources in expert patient care, disability assessment, educational initiatives, research and clinical trials. The network would be a resource for experts for health care policy related to ME/CFS. (10/10)	X	X	X	X	X	X	X	X	No	-	-
Direct the NIH to establish five Centers of Excellence within the United States that would effectively utilize state of the art knowledge concerning the diagnosis, clinical management, treatment, and clinical research of persons with CFS with funding in the range of \$1.5 million per year for five years. (9/04;8/05)	X	-	-	-	-	X	-	-	No	-	-
HHS establish 5 regional clinical care, research, and education centers, centers which will provide care to this critically underserved population, educate providers, outreach to the community, and provide effective basic science, translational, and clinical research on CFS. (5/07)	X	-	-	-	-	-	-	-	No	-	-
Establish Regional Centers funded by DHHS for clinical care, research, and education on CFS to provide care to this critically underserved population, educate providers, outreach to the community, and provide effective basic science, translational, and clinical research on CFS. (5/09)	X	-	-	-	-	-	-	-	No	-	-
Establish Regional Centers funded by DHHS for clinical care, research, and education on CFS. (10/09)	X	-	-	-	-	-	-	-	No	-	-

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Based on the positive response to the NIH's Request for Applications issued in July 2005 (funded in 2006), the Committee recommends equivalent funding for a second RFA. (11/06)		-	-	-	-	X	-	-	Yes	NIH issued 2 Funding Opportunity Announcements in 2008 (PA-08-246 & PA-08-247).	✓
DHHS should provide funds to develop an international Network of Collaborators that would allow for multidisciplinary CFS-related research using standardized criteria accepted by the international CFS research community. (9/04)	X	-	-	-	-	-	-	-	No	-	-
DHHS should provide support and funding for an intramural staffed laboratory committed to CFS research. (9/04; 8/05)	X	-	-	-	-	-	-	-	Yes	CFS research is co-housed with other research at CDC and NIH. Intramural NIH investigators (NIAID, NCI and NHLBI) are working on CFS-related projects.	-
Promote, encourage, and fund research directed toward the diagnosis, epidemiology, and treatment of CFS in children and adolescents. (9/04; 8/05)	X	-	-	-	-	-	-	-	Yes	NIH program announcements PA-08-246 & PA-08-247 specifically invite CFS research proposals on these patients.	✓
Through the CDC and NIH, continue to sponsor, even accelerate, focused workshops in specific areas of CFS and invite investigators not currently working on CFS who have been identified as having an interest in the illness. (9/04; 8/05)	X		X	-		X			Yes	NIH sponsored the Sept 2010 conference on XMRV, and is involved in hosting a State-of-the-Knowledge Workshop on CFS in Spring 2011. Such conferences attract interdisciplinary investigators.	✓
Recommend the FY 08 and 09 budgets of the CDC for research be restored to or increased beyond the FY 05 level in order to sustain the CDC's remarkable momentum including the ability to finish the Georgia Study (especially the longitudinal portions). (11/06)	X		X	-	-	-	-	-	No	CDC funding has declined since 2005 as evidenced by the 2005-2009 allocation.	✓
CFS be included in the Roadmap Initiative of the NIH. (11/06)	-	-	-	-		X		-	Yes	CFS researchers have applied to standard roadmap and infrastructure initiatives.	✓
<b>Restructure CDC effort on CFS to reflect broader expertise on the multifaceted capabilities required to execute a comprehensive program that incorporates the following:</b>	-	-	X	-	-	-	-	-	Yes	CDC's 5-year plan addresses structure [note: each point below was presented as a separate recommendation]	✓
An extramural effort directed by the Office of the Director	-	-	X	-	-	-	-	-	No	-	-
Sufficient funds for a program for which the authority and accountability is housed at the level of a coordinating center director	-	-	X	-	-	-	-	-	No	The Center Director is accountable for CFS program activities but delegates program responsibility to the Division Director.	-

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A lab-based component that maintains the current search for biomarkers and pathophysiology	-	-	X	-	-	-	-	-	Yes	CDC's 5-year plan addresses laboratory components	✓
The recommendations of the external CDC Blue Ribbon Panel, including developing, analyzing, and evaluating new interventions and continuing support for longitudinal studies	-	-	X	-	-	-	-	-	Yes	The Blue Ribbon Panel's recommendations were prioritized in CDC's 5-year plan	✓
An expanded patient, healthcare provider, and family caregiver effort that is managed by staff with appropriate expertise in clinical and public education strategies (11/07)	-	-	X	-	-	-	-	-	Yes	CDC's 5-year plan includes an expanded educational outreach effort that was endorsed by the Blue Ribbon Panel.	-
CDC consider the following specific individuals for its external peer review process of the CDC CFS research program: Drs Lucinda Bateman, David Bell, Birgitta Evengard, Kenneth Friedman, Elke van Hoof, Anthony Komaroff, James Oleske, and Christopher Snell (5/08)	-	-	X	-	-	-	-	-	Yes	Dr. Oleske was invited to serve on the Panel, but could not attend the meeting. Dr. Komaroff chaired the panel.	✓
CDC's external review process [should] evaluate CDC's use of third party contracts for provision of logistical support for research projects. (10/08)	-	-	X	-	-	-	-	-	Yes	The Review panel report supported professionalism and efficacy of the third party contracts obtained by the competitive process. Evaluation of some sole source contracts was not performed.	✓
CDC's external peer review process [should] focus on the CFS program's progress on provider education, the search for specific diagnostic biomarkers and the identification of CFS' etiology; evaluate CDC's use of expertise outside the agency; and evaluate CDC's establishment of research priorities. (5/08)	-	-	X	-	-	-	-	-	Yes	Many of these areas were covered by the Panel. The panel noted that CDC's effort regarding CFS leads the world in basic and public health research. As recommended by the panel needed elements such as a formal strategic plan and substantive engagement with public health organizations have been developed and initiated, respectively.	✓
<b>Provide adequate funding to CDC to effectively carry out a detailed 5-year plan. This should include, but not be limited to, immediate progress in these priority areas:</b>	X		X	-	-	-	-	-	Yes	See notes concerning the same recommendations made again in October 2009 (10.09).	✓
identification of biomarkers and etiology of CFS	X		X	-	-	-	-	-	-	-	✓

TEXT/DATE	HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ	PROGRESS	NOTES	COMPLETED
creation of guidelines for adult and pediatric CFS management in full partnership with organizations representing CFS scientific and clinical expertise	X		X	-	-	-	-	-	-	-	✓
provision of web-based guidelines for CFS management given our current state of knowledge and expert opinion, again in full partnership with organizations representing CFS clinical and scientific expertise	X		X	-	-	-	-	-	-	-	✓
provision of comprehensive information about CFS in partnership with CFS experts to the scientific community, medical and mental health providers, educational institutions and the public for both adult and pediatric CFS through DHHS resources. (5/09)	X		X	-	-	-	-	-	-	-	✓
<b>Provide adequate funding to CDC to effectively carry out a detailed 5-year plan. This should include, but not be limited to, immediate progress in these priority areas (Resubmitted from May 2009 with minor modification to [a]):</b>	-	-	X	-	-	-	-	-	Yes	The 5-year plan currently has adequate funds to implement priority items. The CDC in its 5-year strategic plan has outlined its continued research into the biomarkers and etiology of CFS. CDC optimizes use of the CFS budget allocation to meet program goals.	✓
Identification of biomarkers, with increasing efforts in viral etiology of CFS:	-	-	-	-	-	-	-	-	Yes	CFS program partnered with Division of HIV/AIDS Prevention-Surveillance & Epidemiology Laboratory Branch to examine the role of XMRV and with NIH to study HHV-6.	✓
Creation of updated guidelines for adult and pediatric CFS management in full partnership with organizations representing CFS scientific and clinical expertise;	-	-	-	-	-	-	-	-	Yes	CDC will continue to rely on science-based, peer-reviewed published studies to continue updating guidelines for adult and pediatric CFS.	✓
Provision of updated web-based guidelines for CFS management given our current state of knowledge and expert opinion, again in full partnership with organizations representing CFS clinical and scientific expertise; and	-	-	-	-	-	-	-	-	Yes	CDC provides guidelines and comprehensive information concerning CFS on its website. The website is in top 30 of all CDC websites and published research regarding the site has been lauded in the public health field.	✓

TEXT/DATE	HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ	PROGRESS	NOTES	COMPLETED
Provision of comprehensive information about CFS in partnership with CFS experts to the scientific community, medical and mental health providers, educational institutions and the public for both adult and pediatric CFS through DHHS resources. (10/09)	-	-	X	-	-	-	-	-	Yes	CDC will continue to provide comprehensive information based on science-based, peer-reviewed published studies for its public communications.	✓
Establish progressive leadership at the CDC that can achieve efficient meaningful progress in CFS research, clinical care and education (5/09; 10/09)	X		X	-	-	-	-	-	Yes	CDC continues its long tradition of leadership as evidenced in the CFS Research Program's 5 year plan.	✓
Endorses the planned State of the Knowledge Conference to be developed by NIH (10/08)	-	-	-	-	-	X	-	-	Yes	NIH is currently working with CFSAC, AHRQ, NIH Institutes, and other organizations on a State of the Knowledge Workshop in Spring 2011.	✓
ME/CFS is an illness with enormous economic and human costs. The April 2011 NIH State of Knowledge Workshop identified a number of gaps in what is known about the illness. To address these gaps warrants an interagency effort comprising, but not limited to, NIH, CDC, and AHRQ. Further, the focus should be on interdisciplinary discovery and translational research involving interacting networks of clinical and basic science researchers. Areas to be examined would include the following: identification of patient subsets for detailed phenotyping and targeted therapeutic interventions, biomarker discovery, systems biology approaches and disability assessment. (5/11)	X	-	X	-	-	X	-	X	No	-	-
AHRQ is expected to complete a review of CFS for the NIH State of the Knowledge Workshop. After this process, we recommend that the findings be communicated immediately to key medical education, accreditation, licensing, specialty, and certification boards and organizations. In addition, we recommend a Surgeon General's letter be disseminated to inform clinicians and other health professionals throughout the US and its territories on the impact of CFS on the health of US adults and children. (10/09)	-	-		-	-	X	-		Yes	NIH is in discussions with AHRQ regarding the preparation and delivery of this review.	-

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<b>EDUCATION AND TRAINING</b>											
Pursue making CFS a topic of training for health care providers, wherever appropriate at regional and national conferences sponsored by the Department. (9/04; 8/05)	X	-	-	-	-	-	-	-	No	-	-
Request that the Surgeon General send a letter to state health departments, health professional education programs, national organizations for physicians, PAs, nurses, and other allied health professional groups informing them about the CDC and NIH CFS resources, including the CDC toolkit, CME course, and other resources. (5/07)	X	-	-	-	-	-	-	-	No	-	-
Direct the Administrator of HRSA to communicate with each Area Health Education Center regarding the critical need for provider education of CFS. HRSA has the potential to disseminate information on CFS to a wide range of providers, communities and educational institutions. HRSA should inform these groups that persons with CFS represent an underserved population and that there is a dramatic need for healthcare practitioners who can provide medical services to CFS patients. HRSA should further inform these groups that the CDC offers a web based CME program on CFS, and encourage AHEC providers to participate in this CME program. Additionally, HRSA should alert AHECs of the availability of a CDC CFS provider toolkit. (5/08)	X	-	-	-	X	-	-	-	Yes	HRSA communicated to its networks in the summer of 2008.	✓
Encourage continuing education for Social Security reviewers and adjudicators. The Secretary of DUIS [sic] should recommend that adjudicators follow the Social Security Policy ruling 99-2P which specifically clarifies policies regarding CFS. (9/04; 8/05)  Note: 8/05 recommendation uses "DHHS" in place of "DUIIS"; that abbreviation is not a recognized entity.	X	-	-	-	-	-	X	-	Expected	SSA training for its adjudicators is ongoing.	-

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CFSAC asks that HHS organize a workshop to engage experts in disability assessment, the outcome being a document useful to patients and adjudicators which could contribute to more efficient and fair disability process. (5/11)	X	-	-	-	-	-	X	-	No	-	-
Increase public education on CFS through a public awareness campaign. Discrimination in health care, education, and the workplace should be actively confronted. (9/04; 8/05)	X	-	-	-	-	-	-	-	Yes	CDC developed and ran a public awareness campaign.	✓
The FY 08 and 09 budgets of the CDC for CFS public awareness education [should] be restored to or increased beyond the FY 06 level based on the positive initial response to the November 2006 campaign launch. (11/06)	X	-	X	-	-	-	-	-	Yes	CDC funding for the public awareness campaign extended through FY08, with a no-cost extension of activities through March 2010. Through its photo exhibit outreach (36 public venues, nine medical conferences, 850 targeted media outlets) the estimated total foot traffic exposure is 6,813,191. Overall print advertising included online banner advertising of 15.6 million impressions, and 328 million reader impressions for the paid print ads.	✓
Request HHS operating divisions to produce a concept paper on CFS to be considered by the Office of the Surgeon General for development of a future Surgeon General's Workshop. (5/08)	X	-	-	-	-	-	-	-	No	-	-

TEXT/DATE	HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ	PROGRESS	NOTES	COMPLETED
Develop, or contract with a third party vendor to develop, a CFS Tool Kit for Patients and caregivers of patients (something similar to the CFS Toolkit for Providers) containing: information pertinent to diagnosis, treatment, and a detailed list of tools for CFS patients to help alleviate their symptoms and with diagrams of exercises that are beneficial, sleep health tips. And pain relieving tools that include physical therapy, medication, and other tools. The Patient Tool Kit should provide the patient and caregivers with resources to help patients manage their illness and find evidence-based treatment options. (10/08)	X	-	-	-	-	-	-	-	No	-	-
The Secretary should recognize the special challenges of ensuring that CFS is part of any efforts to train or educate health care providers under health reform. (5/10)	X	-	-	-	-	-	-	-	No	-	-

TEXT/DATE	HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ	PROGRESS	NOTES	COMPLETED
<b>CARE AND SERVICES</b>											
Encourage the classification of CFS as a "Nervous System Disease" as worded in the ICD-b G93.3. (9/04; 8/05)	X	-	-	-	-	-	-	-	No	The science of CFS does not support this action at this time.	-
CFSAC rejects proposals to classify CFS as a psychiatric condition in U.S. disease classification systems. CFS is a multi-system disease and should be retained in its current classification structure, which is within the "Signs and Symptoms" chapter of the International Classification of Diseases 9-Clinical Modification (ICD 9-CM). (5/10)	X	-	-	-	-	-	-	-	Yes	*DFO Note: The ICD 10-CM is scheduled for implementation on October 1, 2013. In that classification, two mutually exclusive codes exist for chronic fatigue:  --post-viral fatigue syndrome (in the nervous system chapter), and --chronic fatigue syndrome, unspecified (in the signs and symptoms chapter).  HHS has no plans at this time to change this classification in the ICD 10-CM. (5/10)	✓
CFSAC rejects current proposals to code CFS in Chapter 18 of ICD-10-CM under R53.82: Chronic fatigue, unspecified > Chronic fatigue syndrome NOS. CFSAC continues to recommend that CFS should be classified in ICD-10-CM in Chapter 6 under "diseases of the nervous system" at G93.3, in line with ICD-10 and ICD-10-CA (the Canadian Clinical Modification), and in accordance with the Committee's recommendations of August 2005. CFSAC considers CFS to be a multi-system disease and rejects any proposals to classify CFS as a psychiatric condition in US disease classification systems. (NOTE: no disease classification system under HHS' control proposes to move or to include CFS in or among psychiatric conditions.) (5/11)	X	-	-	-	-	-	-	-	No	-	-
CFSAC recognizes that much can be done to ensure that every child with CFS has the best possible access to support and treatment and asks that the Secretary facilitate a taskforce or working group to establish an ongoing interagency and interdepartmental effort to coordinate school, family, financial, and health care support for children and young adults with CFS. (10/08)	X	-	-	-	-	-	-	-	No	-	-

TEXT/DATE	HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ	PROGRESS	NOTES	COMPLETED
The Secretary should ask the blood community to defer indefinitely from donating any blood components, any person with a history of chronic fatigue syndrome. (5/10)	X	-	-	-	-	-	-	-	Yes	HHS is working with the AABB Task Force to coordinate activities including communication and interim guidance for donor selection. In the absence of definitive data, guidance to the blood community directs them to educate potential donors that persons with CFS should not donate blood.	✓
The Secretary should direct CMS, AHRQ, and HRSA to collaborate on developing a demonstration project focused on better value and more efficient and effective care for persons with CFS. This can be a public-private effort, and monitoring outcomes and costs should be part of the overall evaluation. (5/10)	X	X	-	-	X	-	-	X	No	HRSA recognizes importance of efficient and effective health care management of individuals with CFS. However, before that can be pursued, additional knowledge about potential causes, practice and care coordination, and appropriate treatment for CFS is needed.	-
	-	-	-	-	-	-	-	-	-	-	✓
Adopt the term "ME/CFS" across HHS programs. (10/10)	-	-	-	-	-	-	-	-	No	-	-

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<b>CFSAC-SPECIFIC</b>											
Consider participation of the Department of Defense, Department of Veterans Affairs, Agency for Healthcare Research and Quality, and the National Institute of Disability and Rehabilitation Research (NIDRR) as ex-officio members of the CFSAC for future deliberations of recommendations. (9/04)	X	-	-	-	-	-	-	-	Yes	HHS received approval for an AHRQ and CMS <i>ex officio</i> member as part of the September 2010 rechartering of CFSAC.	Partial
Add a representative of AHRQ as an ex officio member effective immediately, but at least in advance of the next CFSAC meeting [May 2008]. (11/07)	X	-	-	-	-	-	-	-	Yes	Charter was renewed in September 2010 to include AHRQ. AHRQ representative has been identified and is currently on board.	✓
Chair and Executive Secretariat to seek information from 3 <sup>rd</sup> party providers as to classification and coverage for CFS. Ask representatives of major medical insurance providers to present to the Committee how companies process claims for CFS. Specifically, information as to standards for diagnosis of CFS and documentation of associated disability; what treatments are covered and to what extent; and, how rehabilitation and disability are assessed and covered. Invite representatives of the companies to provide the Committee a presentation on how they address these issues. (5/07)	X	-	-	-	-	-	-	-	No	-	-
Request a report from each relevant HHS agency on existing resources and programs for provider education that might be useful in disseminating information to providers on CFS diagnosis and management. (5/07)	X	-	-	-	-	-	-	-	Expected	Agency Ex Officio representatives report on these issues at each meeting.	-
DHHS [should] solicit the Department of Education's cooperation on issues relating to pediatric CFS. (10/08)	X	-	-	-	-	-	-	-	Yes	Dept of Education representative addressed 5/09 CFSAC on accommodation issues in schools.	✓
		-	-	-	-	-	-				
		-	-	-	-	-	-				
Transition report to the new Administration and Secretary include the background of the CFSAC and CFS and a list of the recommendations that have been developed by this Committee over the past two chartered periods, with any action taken on each point. (10/08)	X	-	-	-	-	-	-	-	Yes	Transition document included a brief summary of CFSAC. Performance Web (for all FACA Committees) collects summary data on implementation of recommendations.	✓

TEXT/DATE	HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ	PROGRESS	NOTES	COMPLETED
Multiple case definitions currently are used for CFS. The CFSAC rejects the empirical case definition and the terminology of “chronic unwellness”, both of which are endorsed by the CDC, and recommends that DHHS recognize a need for and commit to support a national effort to arrive at a consensus definition of CFS that is accurate, standardized, and reflective of the true disease. (10/09)	X	-	-	-	-	-	-	-	Yes	The CDC uses the 1994 International Research Case definition. The term “chronic unwellness” is not a CFS case definition component and is not used as such by the CDC.	-
The Secretary should ask the Designated Federal Officer to explore adding a web-based meeting to conduct CFSAC business. (5/10)	X	-	-	-	-	-	-	-	Yes	Webinars may be used for critical topic updates in between CFSAC meetings. Several models identified.	-
Engage the expertise of CFSAC as HHS moves forward to advance policy and agency responses to the health crisis that is ME/CFS. (10/10)	X	-	-	-	-	-	-	-	Yes	Several members tapped by NIH to serve on the planning committee for SoK. Several members volunteered to assist CDC in reviewing its "website content".	Ongoing