

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004**  
**Sorted by Focus Area, Agency, and Progress**  
**October 2009**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research	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)	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	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	
	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)							Yes	NIH issued a second RFA in 2008

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--2**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research (cont'd)	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							
	Provide support and funding for an intramural staffed laboratory committed to CFS research (9/04; 8/05)	X						No	CFS research is co-housed with other research at CDC and NIH
	Promote, encourage, and fund research directed toward the diagnosis, epidemiology, and treatment of CFS in children and adolescents (9/04; 8/05)	X						Expected	RFAs may target these areas
	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	CDC and NIH have sponsored and provided support for several meetings and workshops on CFS
	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						CDC funding remained stable
	CFS be included in the Roadmap Initiative of the NIH (11/06)								

No

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--3**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES	
		HHS	CDC	FDA	HRSA	NIH	SSA			
Research (cont'd)	Restructure CDC effort on CFS to reflect broader expertise on the multifaceted capabilities required to execute a comprehensive program that incorporates the following: --An extramural effort directed by the Office of the Director --Sufficient funds for a program for which the authority and accountability is housed at the level of a coordinating center director --A lab-based component that maintains the current search for biomarkers and pathophysiology --The recommendations of the external CDC Blue Ribbon Panel, including developing, analyzing, and evaluating new interventions and continuing support for longitudinal studies --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 addresses structure <i>[note: each point below was presented as a separate recommendation]</i>	
			X					No		
			X					No		
			X					Yes		CDC's 5-year plan addresses laboratory components
			X					Yes		The Blue Ribbon Panel's recommendations were prioritized in CDC's 5-year plan
			X					No		
	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	
	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								

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--4**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research (cont'd)	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 covered by the Panel
	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: --identification of biomarkers and etiology of CFS --creation of guidelines for adult and pediatric CFS management in full partnership with organizations representing CFS scientific and clinical expertise --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 --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	No					

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--5**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research (cont'd)	Establish progressive leadership at the CDC that can achieve efficient meaningful progress in CFS research, clinical care and education (5/09)	X	X					Expected	CDC's 5 year plan has implications for leadership
	Endorses the planned State of the Knowledge Conference to be developed by NIH (10/08)							Expected	Conference planned for 2010

X

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--6**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Education & Training	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

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--7**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Education & Training (cont'd)	Encourage continuing education for Social Security reviewers and adjudicators. The Secretary of DUIIS [sic] should recommend that adjudicators follow the Social Security Policy ruling 99-2P which specifically clarifies policies regarding CFS (9/04; 8/05) <i>Note: 8/05 recommendation uses "DHHS" in place of "DUIIS"; that abbreviation is not a recognized entity</i>	X		X				Expected	SSA training for its adjudicators is ongoing
	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						
	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				No	

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--8**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Education & Training (cont'd)	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	

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--9**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Care & Services	Encourage the classification of CFS as a "Nervous System Disease" as worded in the ICD-b G93.3 (9/04; 8/05)	X						No	
	Secretary facilitate a task force 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	

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--10**

FOCUS AREA	TEXT/DATE	HHS	CDC	FDA	HRSA	NIH	SSA	PROGRESS	NOTES
CFSAC-Specific	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						Expected	HHS anticipates consideration of additional <i>ex officio</i> members as part of the September 2010 rechartering of CFSAC
	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						Expected	Charter was not revised to reflect addition of AHRQ, but that is being considered for September 2010
	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 <i>Ex Officio</i> representatives report on these issues at each meeting

**CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004--11**

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
CFSAC-Specific (cont'd)	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.