

Key: **Yellow** = CDC updates

Blue = NIH updates

CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004
Sorted by Focus Area, Agency, and Progress
May 10, 2010

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research 1.a.9.04	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				X		No	
1.b.5.07	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	
1.c.5.09	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	
1.d.10.09	Establish Regional Centers funded by DHHS for clinical care, research, and education on CFS. (10/09)	X						No	
1.e.11.06	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 a second RFA in 2008

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research (cont'd) 1.f.9.04	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							
1.g.9.04	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
1.h.9.04	Promote, encourage, and fund research directed toward the diagnosis, epidemiology, and treatment of CFS in children and adolescents (9/04; 8/05)	X						Expected	NIH standing CFS program announcement invites and has funded research in this area
1.i.9.04	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
1.j.11.06	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.
1.k.11.06	CFS be included in the Roadmap Initiative of the NIH (11/06)					X		Yes	CFS researchers have applied to standard roadmap and infrastructure initiatives

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research (cont'd) 1.1.11.07	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> CDC's 5-year plan addresses laboratory components The Blue Ribbon Panel's recommendations were prioritized in CDC's 5-year plan CDC's 5-year plan includes an expanded educational outreach effort that was endorsed by the Blue Ribbon Panel.
			X					No	
			X					No	
			X					Yes	
			X					Yes	
1.m.5.08	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.
1.n.10.08	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.

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research (cont'd) 1.o.5.08	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.
1.p.5.09	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					Yes	See notes concerning the same recommendations made again in October 2009 (1.q.10.09).

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRES S	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Research (cont'd) 1.q.10.09	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]):		X					Yes	The 5-year plan currently has adequate funds to implement priority items.
	--Identification of biomarkers, with increasing efforts in viral etiology of CFS:							Yes	The CDC in its 5-year strategic plan has outlined its continued research into the biomarkers and etiology of CFS. CFS program has partnered with the 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 does provide 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

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	--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)						Yes	public health field. CDC will continue to provide comprehensive information based on science-based, peer-reviewed published studies for its public communications.
1.r.5.09	Establish progressive leadership at the CDC that can achieve efficient meaningful progress in CFS research, clinical care and education (5/09)	X	X				Yes	CDC continues its long tradition of leadership as evidenced in the CFS Research Program's 5 year plan.
1.s.10.09	Establish progressive leadership at the CDC that can achieve efficient, meaningful progress in CFS research, clinical care, and education. (10/09)		X				Yes	CDC continues its long tradition of leadership as evidenced in the CFS Research Program's 5 year plan.
1.t.10.08	Endorses the planned State of the Knowledge Conference to be developed by NIH (10/08)					X	Yes	NIH initiated the internal mechanisms necessary to have the State of the Knowledge meeting to be held in 2011 and planned with input from CFSAC.
1.u.10.09	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	No	

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Education & Training 2.a.9.04	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	
2.b.5.07	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	
2.c.5.08	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

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Education & Training (cont'd) 2.d.9.04	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
2.e.9.04	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
2.f.11.06	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.
2.g.5.08	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	

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Education & Training (cont'd) 2.h.10.08	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	

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
Care & Services 3.a.9.04	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.
3.b.10.08	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--11

FOCUS AREA	TEXT/DATE	HHS	CDC	FDA	HRSA	NIH	SSA	PROGRESS	NOTES
CFSAC-Specific 4.a.9.04	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
4.b.11.07	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
4.c.5.07	Chair and Executive Secretariat to seek information from 3 rd 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	
4.d.5.07	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--12

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE						PROGRESS	NOTES
		HHS	CDC	FDA	HRSA	NIH	SSA		
CFSAC-Specific (cont'd) 4.e.10.08	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
4.f.10.08	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.
4.g.10.09	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.