

Gray= HHS updates

Blue = NIH updates

CFSAC RECOMMENDATIONS SINCE SEPTEMBER 2004
 Sorted by Focus Area, Agency, and Progress
 Last Updated: February 11, 2011

FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE								PROGRESS	NOTES
		HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ		
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; 8/05)	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 2 Funding Opportunity Announcements in 2008 (PA-08-246 & PA-08-247)

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE								PROGRESS	NOTES
		HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ		
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								Yes	CFS research is co-housed with other research at CDC and NIH. Intramural NIH (NIAID, NCI and NHLBI) are working on CFS-related projects.
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 program announcements PA-08-246 & PA-08-247 specifically invite CFS research proposals on these patients
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	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.
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	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ		
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 [note: each point below was presented as a separate recommendation] 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.

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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	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ		
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	X		X						Yes	See notes concerning the same recommendations made again in October 2009 (1.q.10.09).

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	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)										
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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE								PROGRESS	NOTES
		HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ		
<p>Research (cont'd) 1.q.10.09</p>	<p>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]):</p> <p>--Identification of biomarkers, with increasing efforts in viral etiology of CFS:</p> <p>--Creation of updated guidelines for adult and pediatric CFS management in full partnership with organizations representing CFS scientific and clinical expertise;</p> <p>--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</p>			X						<p>Yes</p> <p>Yes</p> <p>Yes</p> <p>Yes</p>	<p>The 5-year plan currently has adequate funds to implement priority items.</p> <p>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.</p> <p>CDC will continue to rely on science-based, peer-reviewed published studies to continue updating guidelines for adult and pediatric CFS.</p> <p>CDC does provide guidelines and comprehensive information concerning CFS on its website. The website is in top 30 of all CDC</p>

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FOCUS AREA	TEXT/DATE	AGENCY RELEVANCE								PROGRESS	NOTES
		HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ		
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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		HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ		
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	
3.c.5.10	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.
3.d.5.10	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		HRSA recognizes the 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.
3.e.5.10	CFSAC rejects proposals to classify CFS as a psychiatric condition in U.S.	X								Yes	*DFO Note: The ICD 10-CM is scheduled for

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	<p>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)</p>									<p>implementation on October 1, 2013. In that classification, two mutually exclusive codes exist for chronic fatigue:</p> <ul style="list-style-type: none"> • post-viral fatigue syndrome (in the nervous system chapter), and • chronic fatigue syndrome, unspecified (in the signs and symptoms chapter). <p>HHS has no plans at this time to change this classification in the ICD 10-CM. (5/10)</p>
<p>3.g.10.10</p>	<p>Adopt the term "ME/CFS" across HHS programs. (10/10)</p>	<p>X</p>								

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		HHS	CMS	CDC	FDA	HRSA	NIH	SSA	AHRQ		
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								Yes	Charter was renewed in September 2010 to include AHRQ. AHRQ representative has been identified.
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 Ex Officio representatives report on these issues at each meeting

