

# 2008 Current Fiscal Year Report: National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect

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<b>1. Department or Agency</b>		<b>2. Fiscal Year</b>	
Department of Health and Human Services		2008	
<b>3. Committee or Subcommittee</b>		<b>3b. GSA Committee No.</b>	
National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect		9491	
<b>4. Is this New Fiscal Year?</b>	<b>5. Current Charter</b>	<b>6. Expected Renewal Date</b>	<b>7. Expected Term Date</b>
No	05/17/2006	05/17/2008	10/25/2007
<b>8a. Was Terminated During Fiscal Year?</b>	<b>8b. Specific Termination Authority</b>		<b>8c. Actual Term Date</b>
Yes	Section 399J [280f-3]		10/25/2007
<b>9. Agency Recommendation for Next Fiscal Year</b>	<b>10a. Legislation Req to Terminate?</b>	<b>10b. Legislation Pending?</b>	
Terminate	Yes	Enacted	
<b>11. Establishment Authority</b> Statutory (Congress Created)			
<b>12. Specific Establishment Authority</b>	<b>13. Effective Date</b>	<b>14. Committee Type</b>	<b>14c. Presidential?</b>
42 USC 241, 399(d) PHS Act 280f (Mandated)	05/24/2000	Continuing	No
<b>15. Description of Committee</b> Scientific Technical Program Advisory Board			
<b>16a. Total Number of Reports</b> 1			
<b>16b. Report Date</b>	<b>Report Title</b>		
08/01/2008	Report to Congress Preventing and Reducing FAS and Other FASDs		
<b>Number of Committee Reports Listed:</b> 1			

17a. 1 17b. Closed 0 17c. Partially Closed 0 Other Activities 0 17d. Total 1  
Open

## Meetings and Dates

Purpose	Start	End
The objective of this conference call was to provide an update on the Task Force report, Reducing Alcohol-exposed Pregnancies, and to call for a vote on this report. Various content revisions within the report were reviewed at this time. These were based on suggestions made by Task Force members at the previous Task Force meeting in September 2007. The final report recommendations were reviewed and discussed as well. After these deliberations, a unanimous vote was obtained to accept the report recommendations. Also, a vote was taken to approve the report as written, with the understanding that there may be additional minor editorial revisions made prior to publication. This motion was supported unanimously. An update on the Call to Action report was also presented during this call along with some discussion regarding the timelines for the final Task Force report publications and possible dissemination strategies.	10/24/2007	10/24/2007

## Number of Committee Meetings Listed: 1

	Current FY	Next FY
<b>18a(1). Personnel Pmts to Non-Federal Members</b>	\$3,000.00	\$0.00
<b>18a(2). Personnel Pmts to Federal Members</b>	\$0.00	\$0.00
<b>18a(3). Personnel Pmts to Federal Staff</b>	\$66,988.00	\$0.00
<b>18a(4). Personnel Pmts to Non-Member Consultants</b>	\$0.00	\$0.00
<b>18b(1). Travel and Per Diem to Non-Federal Members</b>	\$0.00	\$0.00
<b>18b(2). Travel and Per Diem to Federal Members</b>	\$0.00	\$0.00
<b>18b(3). Travel and Per Diem to Federal Staff</b>	\$0.00	\$0.00
<b>18b(4). Travel and Per Diem to Non-member Consultants</b>	\$0.00	\$0.00

<b>18c. Other(rents,user charges, graphics, printing, mail, etc.)</b>	\$3,500.00	\$0.00
<b>18d. Total</b>	\$73,488.00	\$0.00
<b>19. Federal Staff Support Years (FTE)</b>	0.55	0.00

**20a. How does the Committee accomplish its purpose?**

The main goals of the Task Force are to advise governmental agencies, academic bodies, and community groups that conduct or support fetal alcohol syndrome and fetal alcohol effect research, programs, and surveillance and to meet the general needs of populations actually or potentially impacted by FAS and FAE. In the final year of the Task Force, approvals from Task Force members were obtained on the document, "Reducing Alcohol-exposed Pregnancies." Minor editorial revisions were also made to each of the Task Force documents and appropriate agency clearances are being obtained prior to submission to the HHS Secretary. Task Force deliberations in FY 2008 included the October 24, 2007 conference call that took place to undergo final deliberations and approvals of both Task Force reports along with discussion of dissemination strategies for these products.

**20b. How does the Committee balance its membership?**

The Task Force is comprised of 13 members including the Chair selected and appointed by the Secretary of the Department of Health and Human Services, from authorities knowledgeable in the field of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) and includes clinicians, researchers, parents or legal guardians of individuals with FAS/FAE, federal agencies representatives, state program directors, and state

representatives, and educators, and representatives from advocacy and research organizations that brings together a broad spectrum of individuals who are involved with and affected by FAS/FAE to consider issues and develop a more comprehensive view of what is needed. The Chairperson of the Interagency Coordinating Committee on Fetal Alcohol Syndrome of the Department of Health and Human Services was mandated to serve as a standing member to coordinate its efforts with the Task Force. The task force also includes seven liaison representatives from the following organizations: American Academy of Pediatrics; American Academy of Family Physicians; American College of Obstetrics and Gynecology; March of Dimes; National Organization on Fetal Alcohol Syndrome; The Arc of the United States; and the Center for Science in the Public Interest. Members are appointed to serve for overlapping terms of up to four years and emphasis is placed on equitable geographic location, racial/ethnic background, gender, minority and female representation, and areas of expertise.

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

The Task Force met one time via conference call in FY 2008 since the committee terminated on October 25, 2007. The Executive Secretary, Designated Federal Official, and writing group members continue to communicate via email regarding agency clearance processes and preparation of final reports for submission to the HHS Secretary. A Task Force listserv is available for discussions among Task Force members on particular topics or to alert members of new information, upcoming events, or special requests.

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

The Secretary is mandated under Section 399H of the Public Health Service Act, as amended (42 U.S.C. Section 280f), as amended by Public Law 105-392), to establish a National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect: (1) to foster coordination among all governmental agencies, academic bodies, and community groups that conduct or support fetal alcohol syndrome and fetal alcohol effect research, programs, and surveillance; and, (2) to otherwise meet the general needs of populations actually or potentially impacted by fetal alcohol syndrome (FAS) and fetal alcohol effect (FAE). The National Task Force includes clinicians, researchers, parents or legal guardians of individuals with FAS and FAE, federal agencies representatives, state program directors, and educators, and representatives from advocacy and research organizations that brings together a broad spectrum of individuals who are involved with and affected by FAS/FAE to consider issues and develop a more comprehensive view of what is needed. The Interagency Coordinating Committee on Fetal Alcohol Syndrome of the Department of Health and Human Services consists of Federal agencies only and is focused on interagency collaboration and elimination of duplication. Through its mandate, the Task Force works to 1) develop strategies to disseminate recommendations at Federal, State, and local levels; 2) partners with governmental and non-governmental agencies to adopt recommendations; and 3) assists agencies in their ongoing efforts to implement the recommendations. Implementation of these recommendations fulfill the mandate of the Task Force and result in enhanced programs and

research concerning the effectiveness of public health messages about drinking during pregnancy, to increase the knowledge and skills of health and social service providers in recognizing and intervening with women at risk for an alcohol-exposed pregnancy, to support and develop effective strategies for preventing and treating FAS and FAE, and to assure that efforts across agencies and organizations are coordinated and comprehensive. This mandate is not served by any existing Task Force or Committee.

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

The Task Force did not have any closed meetings during FY 2008. All meetings of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect are open to the public.

**21. Remarks**

In October 2007, the CDC Fetal Alcohol Syndrome Prevention Team received a Congressional request to outline the contributions of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect since its inception in 2000. The request, from Senate Report 110-107, is as follows: Senate--Fetal Alcohol Spectrum Disorders- The Committee is concerned by the prevalence of fetal alcohol spectrum disorders [FASD] in the United States and notes that drinking during pregnancy is the Nation's leading known preventable cause of mental retardation and birth defects. To publicize and promote awareness of this critical public health information, the Committee has provided sufficient resources to continue these activities. The Committee notes that the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol

Effect is due to expire in October 2007. The Committee requests that the CDC submit a progress report within six months on the Task Force's contributions to preventing and reducing fetal alcohol spectrum disorders. The report should outline future plans for the Task Force, including programmatic and funding priorities. A Report to Congress entitled, Preventing and Reducing Fetal Alcohol Spectrum Disorders, was signed by the Director of CDC in August 2008 and forwarded to HHS. This report highlights CDC's FASD-related prevention activities and future priorities (a separate Congressional request made in the House) in addition to describing the goals and accomplishments of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. Part O, Section 399H(d)(1) of the Public Health Service Act (42 U.S.C. Section 280f-3) directs the establishment of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. This legislation also includes a Sunset Provision (Section 399K) that reads "this part shall not apply on the date that is 7 years after the date on which all members of the National Task Force have been appointed under section 399H(d)(1)." The initial appointments took effect October 24, 2000, therefore, the committee officially terminated October 25, 2007.

### **Designated Federal Officer**

R. Louise Floyd Acting, Executive Secretary

Committee Members	Start	End	Occupation	Member Designation
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Barry, Kristen	10/16/2003	05/31/2007	Associate Director, Health Services Research and Development, Serious Mental Illness Treatment Research and Evaluation Center, Ann Arbor, Michigan	Special Government Employee (SGE) Member
Berner, James	10/19/2003	05/31/2007	Director, Office of Community Health Services, Alaska Native Tribal Health Consortium, Anchorage, Alaska	Special Government Employee (SGE) Member
Brenneman, George	10/20/2000	10/24/2007	Chair, Committee on Native American Child Health, American Academy of Pediatrics, Elkridge, Maryland	Representative Member
Brown, Carole	06/01/2005	05/31/2008	Research Associate Professor, Department of Education, Catholic University of America, Washington, D.C.	Special Government Employee (SGE) Member
Caetano, Raul	06/01/2005	05/31/2007	Professor of Epidemiology and Regional Dean, The University of Texas School of Public Health, Dallas, Texas	Special Government Employee (SGE) Member
Chang, Grace	06/01/2006	05/31/2008	Associate Physician in Psychiatry, Department of Psychiatry, Brigham and Women's Hospital, Boston, Massachusetts	Special Government Employee (SGE) Member
Damus, Karla	10/20/2000	10/24/2007	Senior Research Associate, March of Dimes, White Plains, New York	Representative Member



Davis, Sharon	10/20/2000	10/24/2007	Member, National Health Promotion and Disability Prevention Committee, Reston, Virginia	Representative Member
DeJoseph, Mary	06/01/2006	05/31/2009	Faculty, Department of Osteopathic Manipulative Medicine, Philadelphia College of Osteopathic Medicine, Philadelphia, Pennsylvania	Special Government Employee (SGE) Member
Hacker, George	10/20/2000	10/24/2007	Director, Alcohol Policies Project, Center for Science in the Public Interest, Washington, D.C.	Representative Member
Miller, Lisa	10/17/2003	05/31/2007	Division Director, Disease Control and Environmental Epidemiology Division, Department of Public Health and Environment, Denver, Colorado	Special Government Employee (SGE) Member
Mitchell, Kathleen	10/20/2000	10/24/2007	Program Director and National Spokesperson, National Organization on Fetal Alcohol Syndrome, Washington, D.C.	Representative Member
Morris, Colleen	04/13/2004	05/31/2008	Chief, Genetics Division, University of Nevada School of Medicine, Las Vegas, Nevada	Special Government Employee (SGE) Member

O'Connor, Mary	06/01/2006	05/31/2009	Adjunct Professor, Department of Psychiatry and Biobehavioral Sciences, David Geffen School of Medicine at the University of California, Los Angeles	Special Government Employee (SGE) Member
Ohlemiller, Melinda	04/13/2004	05/31/2008	Director, Early Childhood, Prevention and Advocacy Services, Saint Louis Arc, Saint Louis, Missouri	Special Government Employee (SGE) Member
Olson, Heather	04/18/2004	05/31/2008	Psychologist and Clinical Supervisor, University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network, Seattle, Washington	Special Government Employee (SGE) Member
Sokol, Robert	10/20/2000	10/24/2007	Director, Department of Obstetrics and Gynecology, C.S. Mott Center for Human Growth and Development, School of Medicine, Wayne State University, Detroit, Michigan	Representative Member
Warren, Kenneth	04/27/2006	10/25/2007	Associate Director for Basic Science Research, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Rockville, Maryland	Regular Government Employee (RGE) Member
Wright, Jean	10/15/2003	05/31/2007	Executive Director, Backus Children's Hospital, Savannah, Georgia	Special Government Employee (SGE) Member

## **Number of Committee Members Listed: 19**

### **Narrative Description**

The Secretary is mandated under Section 399H of the Public Health Service Act, as amended (42 U.S.C. Section 280f, as added by Public Law 105-392), to establish the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. The Task Force (a) advises federal, state, and local programs and research concerning fetal alcohol syndrome (FAS) and fetal alcohol effect (FAE), including programs and research concerning education and public awareness for relevant service providers, school-age children, women at risk, and the general public medical diagnosis, interventions for women at risk of giving birth to children with FAS and FAE, and beneficial services for individuals with FAS and FAE and their families; (b) coordinate its efforts with the Interagency Coordinating Committee on Fetal Alcohol Syndrome of the Department of Health and Human Services; and (c) report, on a biennial basis, to the Secretary and relevant committees of Congress on the current and planned activities of the participating agencies. Since its inception, this Task Force has worked to identify priorities and put forth recommendations in the areas of FAS diagnosis, prevention, and service provision (for both women at risk for an alcohol-exposed pregnancy and children and families affected). This Task Force also promotes interagency and liaison member information sharing and collaboration in its efforts. The Task Force completed its final year in 2007, terminating on October 25, 2007. Current activities are focused on the finalization of two important Task Force products. The first is entitled, "Reducing Alcohol-exposed Pregnancies" and it is a report that describes evidence-based strategies to reduce alcohol misuse and alcohol-exposed pregnancies. This report puts forth recommendations to support the development, implementation, and expansion of evidence-based strategies to prevent alcohol-exposed pregnancies; to stress the importance of alcohol screening and provider education; and to promote further research on how best to intervene with women at greatest risk for alcohol-exposed pregnancies. The Task Force also puts forward several topics for consideration as future research directions in the

FASD prevention arena. The prevention report was reviewed and approved by the Task Force on October 24, 2007. Additionally, the Task Force reviewed and approved another important report, entitled "A Call to Action: Advancing Essential Services and Research on Fetal Alcohol Spectrum Disorders," which highlights recommendations to improve and expand efforts regarding early identification, diagnostic services, and quality research on interventions for individuals with FASDs and their families. Both of these reports are currently being prepared for submission to the HHS Secretary. Once vetted, these documents will be disseminated to relevant stakeholders including researchers, clinicians, decisionmakers, state and local health and social service entities, professional organizations, and caregivers interested in FASD prevention and interventions for children and families affected by FASDs.

**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 type="checkbox"/>
Major policy changes	<input type="checkbox"/>
Advance in scientific research	<input checked="" type="checkbox"/>
Effective grant making	<input checked="" 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**

NA

**What are the cost savings associated with this committee?**

	Checked if Applies
None	<input type="checkbox"/>
Unable to Determine	<input checked="" 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?**

16

### **Number of Recommendations Comments**

1. To recommend approval with revisions to the document, Reducing alcohol-exposed pregnancies (10/24/2007). Report is currently being prepared for submission to HHS. Completed. 2. To recommend approval with revisions to the document, A Call to Action: Advancing Essential Services and Research on Fetal Alcohol Spectrum Disorders (FASDs). (09/12/07). Report is currently being prepared for submission to HHS. Completed. 3. Recommend that Task Force representatives attend the FASD Leadership Institute to be convened by the Marcus Institute in October 2007. (02/13/07). Several Task Force members attended and participated in this meeting, October 22-24, 2007. The Call to Action document and recommendations were presented and discussed. Completed. 4. To endorse the work of the Post-Exposure Working Group and the document put before the Task Force during the February 2007 meeting for further work, development, discussion, and finalization. (02/13/07). Completed. 5. To recommend that CDC provide a "Community Guide" approach for prevention interventions for FASD and that they have input into this process. (02/17/06). Based on the evidence presented by RTI, the Task Force decided not to proceed in using the Community Guide approach to systematically review the evidence of FASD studies since prevention studies at this time are limited. The Task Force did decide to prepare a report reviewing the evidence to date and to develop recommendations based on these. Completed. 6. To convene an adhoc working group to discuss how to advise the Secretary and/or other appropriate entities on the promotion of a productive research agenda on FASDs (09/27/06). A smaller group from the Post-Exposure working group prepared the Call to Action document which was approved with revisions by the Task Force on 09/12/07). Completed. 7. To direct CDC to investigate the feasibility of convening a meeting of appropriate stakeholders and clinicians involved

in the diagnosis and treatment of individuals with FASDs to begin the process of formulating diagnostic criteria or guidelines for alcohol-related neurodevelopmental disorders. (09/27/06). Initial plans to coordinate such a meeting have begun with involvement from CDC and NIAAA. Completed.8. To explore how the Task Force can commend the Substance Abuse and Mental Health Services Administration (SAMHSA) FASD Center for Excellence on their work and express concern regarding the discontinuation of Center activities. (09/27/06). SAMHSA Center was refunded; no Task Force action taken. Not completed.9. To approve a letter to the Department of Education requesting that FAS be included in the list of conditions in the administrative regulations based on the reauthorization of the Individuals with Disabilities Education Act (IDEA) regulations. (08/22/05). Completed.10. To recommend that a letter be sent from the Task Force endorsing the American Psychiatric Association's consideration on including FAS in the Diagnostic and Statistical Manual of Mental Disorders (DSM). (06/16/05). Not completed; tabled until the next revision of DSM in 2011.11. To recommend that the Surgeon General reissue the advisory on alcohol use in pregnancy -- a motion to request this reissuance of the advisory was made in April 2001. The advisory was reviewed and approved by the Task Force and received key federal agency support. The Surgeon General's Advisory on Alcohol Use in Pregnancy was released in February 2005. Completed.12. To recommend that FAS be included in the reauthorization of IDEA under "other health impairments." (12/9/04). Completed.13. To recommend that teachers complete a course on FAS as part of their teacher certification. (12/9/04). One federal agency funded a project to develop a program and curriculum to address this issue. Partially completed.14. To endorse the definition of Fetal Alcohol Spectrum Disorders (FASD) developed and approved by the Summit convened by the National Organization on FAS. (6/17/04). Completed.15. To approve the Fetal Alcohol Syndrome Guidelines for Referral and Diagnosis Report. (5/13/04). Completed.16. To recommend that the Center for Science in the Public Interest (CSPI) drafted a letter on behalf of the Task Force to support the CSPI's petition to revise the design specifications for alcoholic beverage warning labels. The CSPI liaison to the Task Force also recommended communication by the DHHS Secretary to the Treasury Secretary about this labeling issue. (09/20/02). The letter was drafted; however, it was later determined that this issue was no longer a priority at the agency directing these efforts. Partially completed.

**What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?**

75%

**% of Recommendations Fully Implemented Comments**

NA

**What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?**

13%

**% 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 Task Force is provided with frequent communication at full committee meetings, working group meetings, conference calls, and/or e-mails, to address pending action items and to discuss works in progress and issues that may arise between meetings. A Task Force listserv is available for discussions among Task Force members on particular topics or to alert members of new information, upcoming events, or special requests. CDC's National Center on Birth Defects and Developmental Disabilities; the Interagency Coordinating Committee on Fetal Alcohol Syndrome of the Department of Health and Human Services, and other federal agencies provide formal presentations and updates during Task Force meetings to keep the membership abreast of ongoing activities at the federal level.

**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**

NA

**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

The meetings, minutes, Charter, membership roster, and mission of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) can be accessed through CDC's National Center on Birth Defects and Developmental Disabilities web site. A web page for the Task Force has been designed to keep the membership, advocacy and research organizations, parents or legal guardians of individuals with FAS and FAE, the general public, and other Federal agencies abreast of ongoing activities.