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National Center on Birth Defects and Developmental Disabilities

Records of the Meeting of the

National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect

June 15-16, 2005

Meeting held at the
Doubletree Buckhead Hotel
Atlanta, Georgia

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Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect

Minutes of the Meeting
June 15-16, 2005

Wednesday, June 15, 2005
A meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) was convened on June 15-16, 2005, in Atlanta, GA, by the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD).

Opening Comments
The meeting was called to order at 8:45 a.m. by Chair, Dr. Jean A. Wright. Dr. Wright introduced and welcomed the Task Force's newest member, Carole Brown, EdD.

Dr. Brown is a research associate professor for the Department of Education at Catholic University of America. In addition to teaching courses in special education and early intervention, she is currently Project Director for the Collaborative Professional Development Schools in Washington, DC offering professional development support to school leadership and faculty in a variety of areas including special education. Dr. Brown has had a variety of leadership positions in education including research and professional development projects, and supervision of a child development center serving children with and without special needs. Dr. Browne also worked with the Department of Education's Office of Special Education Programs on the initial regulations for the Infant and Toddlers with Disabilities Early Intervention Program, Part C (then Part H) of the Individuals with Disabilities Education Act (IDEA) and spearheaded a number of technical assistance efforts, including the development of *Guidelines and Recommended Practice for Individualized Family Service Plans* (IFSPs).

In addition, Dr. Wright also noted that Dr. Sterling Clarren was substituting as the American Academy of Pediatrics (AAP) liaison on behalf of George Brennamen. Dr. Clarren is currently with the Division of Developmental Paediatrics and the Child Development and Rehabilitation Program at the University of British Columbia. He is also Professor of Pediatrics and Head of the Division of Hospital Medicine at the University of Washington School of Medicine and Division of Genetics and Development at the University of Washington in Seattle. Currently, Dr. Clarren is providing leadership in the area of FASD in British Columbia and Western Canada. He is CEO and Scientific Director of the Canada Northwest FASD Research Network which is a joint initiative of the Western provinces and Northern Territories.

Dr. Wright then introduced those who were presenting at the Task Force meeting: Hani Atrash, MD, MPH, Associate Director for Program Development at CDC's National Center on Birth Defects and Developmental Disabilities; Grace Chang, MD, MPH, Associate Professor of Psychiatry at Harvard Medical School, Department of Psychiatry, Brigham and Women's Hospital in Boston, MA; and Susan Rich, MD, MPH, a member-in-training trustee of the

American Psychiatric Association Board of Trustees and currently working at Children's National Medical Center in Washington, DC.

Speaking on behalf of Dr. Cordero, Executive Secretary, Coleen Boyle congratulated Task Force members on their efforts regarding the recent release of the Surgeon General's Advisory on Alcohol Use in Pregnancy. Dr. Deborah Cohen suggested that the Task Force send a thank you letter to Dr. Kenneth Warren for his work on this. Dr. Warren, Director of Scientific Affairs at the National Institutes of Alcohol Abuse and Alcoholism (NIAAA) agreed to update the 1981 advisory incorporating recent scientific progress made regarding FAS and alcohol use during pregnancy. Ms. Weber, the Task Force's new Designated Federal Official, indicated that a thank you letter will be sent to Dr. Warren on behalf of the Task Force. Ms. Weber then welcomed Task Force members and asked for introductions of members and attendees.

Introduction of Task Force Members, Liaisons, and Attendees

Acting Executive Secretary:	Coleen Boyle, PhD, Division on Birth Defects & Developmental Disabilities (DBDDD), NCBDDD, CDC
Designated Federal Official:	Mary Kate Weber, MPH, Fetal Alcohol Syndrome Prevention Team, DBDDD, NCBDDD, CDC
Chair:	Jean A. Wright, MD, Backus Children's Hospital, Savannah, GA
Standing Member:	Faye J. Calhoun, DPA, MS, National Institute for Alcohol Abuse and Alcoholism, National Institutes of Health

Task Force Members present:

Kristen L. Barry, PhD, Department of Veterans Affairs, Ann Arbor, MI
James E. Berner, MD, Alaska Native Tribal Health Consortium, Anchorage, AK
Carole W. Brown, EdD, Catholic University of America, Washington, DC
Raul Caetano, MD, PhD, MPH, University of Texas School of Public Health, Dallas, TX
Deborah E. Cohen, PhD, New Jersey Department of Human Services, Trenton, NJ
Mark B. Mengel, MD, MPH, Saint Louis University School of Medicine, St. Louis, MO
Lisa A. Miller, MD, Department of Public Health and Environment, Denver, CO
Raquelle Myers, JD, National Indian Justice Center (NIJC), Santa Rosa, CA
Melinda M. Ohlemiller, MPH, Saint Louis Arc, St. Louis, MO
Heather Carmichael Olson, PhD, University of Washington Fetal Alcohol Syndrome Diagnostic Clinic, Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network, Seattle, WA (by phone: June 15, 2005, 1:00-4:30pm)

Task Force members absent:

Colleen A. Morris, MD, University of Nevada School of Medicine, Las Vegas, NV

Liaison Representatives present:

American Academy of Pediatrics (AAP): Sterling Clarren, MD, Division of Developmental Paediatrics and the Child Development and Rehabilitation Program at the University of British Columbia

American College of Obstetrics and Gynecology (ACOG): Robert J. Sokol, MD, Department of Obstetrics and Gynecology, C.S. Mott Center for Human Growth and Development, School of Medicine, Wayne State University, Detroit, MI
March of Dimes (MOD): Karla Damus, RN, PhD, Senior Research Associate
The Arc: Sharon Davis, PhD, Professional and Family Services, Silver Springs, MD
Center for Science in the Public Interest (CSPI): George A. Hacker, JD, Alcohol Policy Project, Washington, DC.

Liaison Representatives absent:
National Organization on Fetal Alcohol Syndrome: Kathleen T. Mitchell, Washington, DC.

Guest Speakers:
Hani Atrash, MD, MPH, Associate Director for Program Development, NCBDDD, CDC
Grace Chang, MD, MPH, Associate Professor of Psychiatry, Harvard Medical School, Department of Psychiatry, Brigham and Women's Hospital, Boston, MA
Susan Rich, MD, MPH, member-in-training trustee, American Psychiatric Association Board of Trustees; fellow, Children's National Medical Center, Washington, DC.

Other Attendees:
Ammie Akyere Bonsu, MPH, DKASI/Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration
Jacquelyn Bertrand, PhD, FAS Prevention Team, DBDDD, NCBDDD, CDC
Sherry D. Ceperich, PhD, FAS Prevention Team, DBDDD, NCBDDD, CDC
Yvette Dominique, MISM, Programmer, FAS Prevention Team, Batelle Contractor
Louise Floyd, DSN, RN, FAS Prevention Team, DBDDD, NCBDDD, CDC
Elizabeth Parra Dang, MPH, FAS Prevention Team, DBDDD, NCBDDD, CDC
Shahul Ebrahim, MD, PhD, FAS Prevention Team, DBDDD, NCBDDD, CDC
Callie Gass, FASD Center for Excellence, Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration
Patricia Price-Green, MPH, FAS Prevention Team, DBDDD, NCBDDD, CDC
Jacqueline Vowell, Committee Management Specialist, FAS Prevention Team, DBDDD, NCBDDD, CDC

Update on Activities to Promote Surgeon General's Advisory
After introductions, Mary Kate Weber provided an update on the Surgeon General's advisory. Weber applauded Task Force efforts regarding the advisory. She noted that, almost from its inception, the Task Force recommended restatement of the advisory. Thanks went out again to Dr. Ken Warren who drafted the new advisory incorporating the scientific progress since publication of the 1981 advisory. Ms. Weber also expressed her thanks to past and current Task Force members for their support of these efforts. Appreciation was also given to the lead agencies (CDC, NIAAA, and SAMHSA) that were involved in reviewing the advisory and communicating with Surgeon General representatives, NCBDDD policy staff, and many others. Ms. Weber also acknowledged the hard work of a few individuals who helped to move the advisory forward, Dr. Faye Calhoun, Dr. Ken Warren, and Dr. Louise Floyd. They worked together to respond to specific scientific questions posed by the Surgeon General's Office and obtained support from agency leadership. Dr. José Cordero was also instrumental in working

with the Surgeon General's Office on this request. NCBDDD Policy, Planning and Evaluation staff, especially Alison Kelly, Peter Rzeszotarski, Maggie Kelly, and Joan Altman, also helped shepherd the request through the system and worked with members of the CDC FAS Prevention team, Louise Floyd, Elizabeth Parra Dang, and Ms. Weber, to prepare materials for the Surgeon General once the advisory was approved. Bob Williams and Craig Stevens, from the Surgeon General's Office, worked with CDC leadership to make sure that this request remained on the radar screen. Finally, thanks was given to Surgeon General Richard Carmona for recognizing the importance of raising awareness about alcohol use during pregnancy and the prevention of fetal alcohol spectrum disorders.

Reports from Agency Representatives, Task Force members and Liaisons on Activities to Promote the Surgeon General's Advisory

The following reports were provided:

- Sharon Davis, from the Arc, said the Arc's executive director distributed the Surgeon General's advisory on the Arc's listserv which includes over 700 members. Additionally, an article will appear in the Arc's news magazine, *Insight*, which reaches over 100,000 people.

- Raquelle Myers indicated that NIJC disseminated the new advisory to those who have participated in the NIJC FAS curriculum trainings. It will be distributed at a California conference targeting tribal communities. Ms. Myers will be ordering the Surgeon General advisory cards as well.

- Deborah E. Cohen distributed the advisory to New Jersey's FAS Task Force and others in the perinatal network. Information about the advisory will be disseminated to agencies and at regional conferences. Information is also being given to treatment centers and addiction specialists.

- George Hacker said that CSPI distributed the advisory to over 85,000 contacts. CSPI has also worked with members of Congress to propose language in an upcoming Labor, Health and Human Services appropriations bill to identify FASD and the new advisory. This could provide funding to support promotion efforts and other FASD-related activities. CSPI is waiting to hear if the language was accepted. In addition, CSPI and NOFAS discussed forming a committee to promote the advisory. CSPI also spoke with March of Dimes (MOD) about this collaboration. In summary, CSPI is progressing with activities to increase advisory visibility.

- Kristen Barry distributed the advisory to primary care and behavioral health departments within her organization. Her team is currently conducting a study in emergency departments in Michigan on people meeting alcohol/drug abuse/dependence criteria. The study helps people get treatment and asks childbearing aged women about contraceptive use or non-use.

- Robert Sokol will provide activity updates related to the advisory during his presentation on the following day.

- James Berner indicated that the Surgeon General's advisory has been widely distributed in Alaska. Feedback he has received included the following questions, "Why did this have to be said again? What is new about this?" In these instances, Dr. Berner explains that the issue dropped off the federal radar screen. The recent release of the advisory reminds people that drinking alcohol during pregnancy continues to be a problem.

- Ms. Weber mentioned that CDC has produced 5 x 8 pink cards containing the advisory message and relevant web resources. Cards can be ordered through the CDC website (www.cdc.gov/ncbddd/fas). In addition, the advisory was announced through an MMWR Notice to Readers and a downloadable version is available on the CDC website. CDC also put together a matte release which is a free non-copyrighted preformatted news article made available to newspapers (typically 2nd tier papers) looking for stories. This service is available to over 10,000 newspapers across the country. To date, the matte release has generated 80 newspaper articles and has been printed in 8 different states (WI, NC, MN, NY, CA, IN, FL, WV), representing a readership of 2.9 million.

- Faye Calhoun promised to provide an update on the advisory during her ICCFAS report. Dr. Calhoun reiterated that efforts to reissue the advisory were truly collaborative with several federal agencies working together. She also asked Task Force members to think about different kinds of ways to promote the advisory such as including the key messages in pregnancy test instructions.

- Mark Mengel distributed the advisory to healthcare professionals who have received training through the St. Louis University FAS Regional Training Center and through other continuing education events.

- Carole Brown said there is much attention in DC on this issue. A maternal and child health priority setting meeting recently placed FAS on their priorities list.

- Dr. Clarren said that the AAP had no particular activities to report at this time related to the advisory.

- Lisa Miller reported that the advisory was widely distributed to Colorado multidisciplinary groups interested in FAS.

- Melinda Ohlemiller said that the advisory was distributed through a Missouri coalition addressing FAS. The advisory was also distributed to the Perinatal Substance Abuse Committee and their constituents.

Dr. Wright concluded updates by stating there is still denial around the issue's significance. Thus, the release of the 2005 advisory is an opportunity to raise awareness.

Report on ICCFAS Activities
Faye Calhoun, DPA, MS
The Task Force then focused on Dr. Calhoun's update on the activities of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS).

The ICCFAS was created to improve communications and cooperation among disciplines and federal agencies that address health, education, developmental disabilities, alcohol research, and social services and justice. The issue of alcohol use and pregnancy had fallen between the cracks until 1996 when an Institute of Medicine (IOM) report suggested that NIAAA convene an interagency coordinating council to improve communication across relevant federal agencies.

Dr. Calhoun explained that three federal departments make up the ICCFAS. They are the Department of Education (Office of Special Education and Rehabilitation Services), the Department of Justice (Office of Juvenile Justice and Delinquency Prevention), and the Department of Health and Human Services (includes Indian Health Service; CDC; Health Resources and Services Administration – Maternal and Child Health Bureau; Agency for Healthcare Research and Quality; National Institutes of Health – NIAAA and National Institute of Child Health and Human Development; and SAMHSA – Center for Substance Abuse Prevention and Center for Substance Abuse Treatment). Dr. Calhoun also hopes to include the Department of Agriculture in the future.

Dr. Calhoun explained each department's role and said many agencies participated in the promotion of the Surgeon General's advisory. Once the advisory was approved by the Surgeon General, ICCFAS members identified 12 proposed venues for presentation of the advisory by the Surgeon General and generated six ideas for message promotion. CDC and SAMHSA's Center for Excellence posted the advisory on their websites, NIAAA highlighted the advisory in the 2005 Spring Newsletter (printed version and on website), and NIAAA and SAMHSA included the advisory in information packets for their media contacts on National Alcohol Screening Day on April 7th. This resulted in national and local press coverage (e.g., healthnewsdigest.com, Evanville Courier & Press).

In the past five years, there have been strong efforts to increase interaction between the federal agencies. Dr. Calhoun explained the ICCFAS's "four Cs." Collaboration consists of co-funded conferences, grants, contracts, and outreach activities. Consulting/advisory includes activities such as service on committees, assisting in development of requests for proposal, and reviewing proposals. Cooperation includes speaking at meetings and writing articles for newsletters. Communication means sharing ideas at joint meetings and reporting on activities to other members. Dr. Calhoun said ICCFAS is now reaching true collaboration. Interactions have increased dramatically.

She identified the themes around which the ICCFAS bases its work: prevention of drinking during pregnancy, intervening with children and families affected by prenatal alcohol exposure, improving methods for diagnosis and case identification, increasing research on etiology and pathogenesis, and increasing information dissemination.

Dr. Calhoun reported that in April 2005 NIH received a letter from the co-chairs of the Congressional Caucus on FASD, Jim Ramstad and Frank Pallone, Jr. The letter requested that the ICCFAS submit a report to Congress on recent accomplishments and a 5-year strategic plan for FY2006-2010. Approximately 25 members of Congress have joined the caucus to promote the cause of FASD. While there is an interest in FASD, agency budgets are flat. ICCFAS will work to increase effectiveness of agency activities with respect to current budgets.

Dr. Calhoun also outlined various "shareable" FAS educational resources funded by agencies of the ICCFAS. These include products on general information about FASD (curricula, videos, web-based) and publications on prevention, treatment and diagnosis. Audiences include families affected by FASD, healthcare and community providers, tribal leaders and social service workers, medical and allied health professionals, and education and justice professionals.

Dr. Calhoun noted that in the past the Department of Education (DOE) chaired the ICCFAS Education Workgroup. While they haven't met recently, the new DOE representative, Anne Smith, will convene the subcommittee to determine how to get FAS information to educators in ways they can use it. Dr. Smith is leading a survey to evaluate existing assets that could be utilized for education and training. In February, Anne sponsored a focus group on FASD at the OSERS Alliance Parent Training and Information Center and the OSERS Early Childhood Project Directors Meeting.

Dr. Karen Stern, from the Office of Juvenile Justice and Delinquency Prevention (OJJDP) at the Department of Justice, has been active with ICC for years. The economic cost of FAS was mentioned in the Spring 2005 OJJDP newsletter, "NEWS@ a Glance. OJJDP staff participated in a December 2004 SAMHSA meeting for juvenile court grantees. They shared OJJDP's work and resources that may be helpful to the project grantees as they implement their programs. There is a request for proposals for field-initiated research currently in development (Fall 2005 release) that is soliciting for FASD prevalence and intervention studies. Also, a panel on FASD is planned for the OJJDP National Conference in January 2006.

In Spring 2004, the U.S. Preventive Services Task Force, which is sponsored by the Agency for Healthcare Research and Quality (AHRQ), recommended screening and behavioral counseling interventions to reduce alcohol misuse by adults, including pregnant women in primary care settings. Findings supporting the effectiveness of these interventions were released by AHRQ. AHRQ also funded an information dissemination conference in Michigan, "Best Practices in FAS Prevention and Intervention," in August 2004. The AHRQ ICCFAS representative is Charlotte Mullican.

The Maternal and Child Health Bureau within the Health Resources and Services Administration is another agency involved in the ICCFAS. Dr. Ellen Hutchins has been the representative for a number of years but she is leaving the Bureau. Dr. Hutchins authored a chapter in *Health and Welfare for Families in the 21st Century* (2004) called "Providing Substance Abuse Services for Families." In addition, an MCHB funded grantee funded the evaluation of the 4Ps Plus screen and brief intervention tool by healthcare professionals at Healthy Start Sites (Chasnoff, et al. "The 4Ps Plus Screen for Substance Use in Pregnancy: Clinical Applications and Outcomes," *Journal of Perinatology*. June 2005). Another MCHB-funded study found that allowing site staff to customize substance use assessment tools and protocols to their specific settings resulted in increased use due to a greater comfort of site staff with the program (Kennedy, et al., Maternal and Child Health Journal, 8(3):137-147, 2004.) Also, Kathy Mitchell was the keynote speaker at a recent MCHB meeting of Healthy Start Directors. Kathy did a fabulous job. Dr. Calhoun described Kathy Mitchell as an excellent asset and spokesperson on FASD.

The Indian Health Service has been quite active in the area of FASD. A working group on FASD was formed in 2004 and is made up of 9 Canadian members and 12 U.S. members. IHS recently did a scan and identified several gaps in providing health services to native peoples in the U.S. and Canada. The working group proposed a Spring 2006 conference to share information and to provide a mechanism to bridge or translate knowledge into practice. IHS representatives are Tammy Clay and Judy Thierry.

The National Institute of Child Health and Human Development (NICHD) published several RFAs which included FASD. NICHD is also collaborating with the ICCFAS on prenatal alcohol exposure and pregnancy outcomes relating to SIDS and stillbirths. The NICHD representative on the ICCFAS is Lynn Haverkos.

Discussion:
Raquelle Myers noted that the Bureau of Justice, Victims Assistance Group, Bureau of Justice, Statistics, and the Bureau of Prisons could be additional ICC partners at the Department of Justice. Also, the National Council of Juvenile Court Judges is another ideal candidate for collaboration. Council members interact with women at risk for alcohol use because of stressful family situations. The ICCFAS should consider contacting this Council. Dr. Calhoun will put Ms. Myers in touch with Karen Stern at OJJDP at the Department of Justice.

Dr. Calhoun expressed interest in establishing an executive committee including ICC members (including the Department of Agriculture), and then creating separate working groups. Currently, there are 2 ICC working groups focused on education and juvenile justice issues. Another working group could address prevention and treatment of alcohol abusing and dependent women of childbearing age. The ICC needs assistance with working group meetings. Grantee research results and projects could be discussed and information exchanged.

Dr. Damus recommended that there should be a national speakers bureau on FASD. Perhaps the Center for Excellence could be involved in this.

Dr. Wright asked what the will of the ICCFAS is to get something done after they convene. Dr. Calhoun replied that ICCFAS agencies exchange information with each other and encourage each other; however, there does need to an advocate within each organization for the issue to remain on the agency's radar. CDC, NIAAA, and SAMHSA have targeted funding allocated for FASD. However, other agencies such as the DOJ and DOE do not. They do advocate to have FASD included in RFAs to spur projects and research. The dynamics of the ICC are good.

Federal Updates
National Institute on Alcohol Abuse and Alcoholism
Faye Calhoun, DPA, MS
Next, Dr. Calhoun provided an update on the NIAAA research portfolio. NIAAA convenes the ICCFAS. Sally Anderson coordinates the activities of this group. NIAAA supports research on etiology, pathogenesis, and prevention and treatment of FASD. The agency currently has 104 grants related to FASD in the amount of approximately $25 million. The majority of the research focuses on exploring mechanisms for alcohol-induced fetal injury. They fund research to identify biomarkers of susceptibility and molecular targets and to explore repair and

regeneration options to ameliorate FASD. This new research area is called fetal programming. Supported MRI research is also underway using MRI technology. MRI findings indicate that there are reductions in overall brain size and certain brain structures when ethanol is present. NIAAA also funds research on personal and environmental risk factors of women at risk for an alcohol-exposed pregnancy.

NIAAA funded a large portfolio on FASD prevention efforts which include studies on prenatal alcohol screening, gender-specific treatment programs, and alcohol training. The agency has supported efforts to post signs in bars and has explored brief intervention methods.

Next, Dr. Calhoun gave an overview of the international collaborative research program. This program is building a multidisciplinary international team aimed at increasing capacity to address FASD and to advance research and knowledge on FASD in this country by learning what other countries are doing. The program considers different methods for assessing and addressing developmental disabilities, affected children living in different environments, and prevention strategies.

Dr. Calhoun briefly spoke about international partnerships as well. The NIAAA Collaborative Initiative focuses on differential diagnosis, maternal interview techniques, imaging, informatics, and integration of behavioral research. Dr. Ed Riley, San Diego University, is the lead on these projects. Current partnerships are with the U.S., Russia, Finland, Italy, Chile, South Africa, and the Ukraine.

Dr. Calhoun highlighted an article by Dr. Phil May appearing in the July 2005 issue of the *American Journal of Public Health*. The article highlights an excellent study done in the Western Cape of South Africa on 53 first graders with FAS. NIAAA evaluated protective factors such as larger body size, lower parity, higher income, educational attainment, religiosity, adequate nutrition, and women with a non-drinking partner. Dr. Calhoun spent a day working with these children in South Africa. She had the children draw self portraits and showed slides of the portraits to the Task Force. Drawing abilities reflected a three-year developmental lag in some cases. The Western Cape is an area where large numbers of FAS children and parents can be assembled for study. In this study, each child was diagnosed by at least four professionals. NIAAA is undertaking similar studies in Russia.

Substance Abuse and Mental Health Services Administration
FASD Center for Excellence
Ammie Akyere Bonsu and Callie Gass

Ammie Bonsu and Callie Gass presented on recent agency activities. Ms. Bonsu expressed gratitude for the CDC's work and pleasure at collaborating with sister agencies. She also recognized Dr. Calhoun for her support.

The Center was mandated through the Child Health Act of 2001. The Center has five direct Congressional mandates. Their main charges are to get the FASD research findings out into the field, to provide training, and to maintain the Information Resource Center on the Center's website. The Center also has a viewing library of 5,000 items that is open to the public. Materials can be reviewed on-site and materials can be photocopied.

Initially, the Center was asked to inventory the systems of care addressing FASD. They found no comprehensive systems of care focused on FASD. Center tasks include information dissemination, training and technical assistance, materials development, managing the Information Resource Center, and partnering with CDC, NIAAA, and OJJDP. The Center also coordinates the Building FASD State Systems meetings

Activities around the Surgeon General's advisory were highlighted. The Advisory was posted on the FASD Center's website, published in their newsletter, and sent to thousands of individuals on their distribution list. A materials package promoting the advisory is being developed by SAMHSA and CDC for distribution through CDC's FAS regional training centers and other venues.

Callie Gass provided an update on Center activities since the last Task Force meeting in December. These include the awarding of 35 subcontracts, launch of an initiative targeting American Indian/Alaskan Natives, and materials development.

The goals of the Center subcontracts are to integrate evidence-based prevention or treatment activities into an existing service delivery system, to find ways to continue the project after the funding ends, and to document process and outcome measures. These subcontracts were solicited as competitive proposals and were advertised in both traditional and nontraditional venues. The Center received close to 70 applications but could only funded up to 35. There were 20 community subcontractors, 10 state subcontractors, and 5 juvenile court subcontractors that are located across the country. The subcontractors' diversity ranges from urban to isolated rural communities. States throughout the U.S. are represented. Distribution is also excellent in terms of expertise ranging from very experienced to novice. Subcontract goals focus either on reducing alcohol-affected pregnancies or demonstrating that interventions improved the lives of individuals affected by FASD.

Lessons learned from these projects: there are high levels of awareness about FASD in local communities around prenatal care, social services, foster care, and substance abuse; there is a perception that addressing FASD may reduce relapse and recidivism; and there is a willingness to integrate appropriate interventions. There have been definite barriers as well, including the absence of cost-effective, validated screening tools, confusion over the relationship between IOM and new CDC guidelines, and insufficient diagnostic capacity. In June, a panel will convene to discuss the topic of FASD screening in juvenile courts.

Ms. Gass provided a brief overview highlighting the following publications and products:

- Center website www.fasdcenter.samhsa.gov -- online items include "Grab and go" fact sheets. These are heavily used by parents and providers. The Center recommends using these in child study team meetings.
- "The Basics," an FASD slide show is also available online. This successful resource grew out from a Task Force recommendation. It can be downloaded or cut and pasted into user documents.
- "Recovering Hope-Mothers Speak Out" video and discussion guide.

- "Brandon slide" – This slide illustrates all of the resources required for one child with FASD. This is also free and downloadable and can be taken to a child's school to help describe the various services a child may need.

The FASD Center for Excellence began the American Indian/Alaskan Native Initiative to provide web-based, culturally appropriate training materials, to convene four women's summits in Indian country, to convene two institutes, and to identify promising practices.

Ms. Gass also commented that the Center, in collaboration with NOFAS, created a curriculum for addiction professionals, utilizing the competencies outlined in the CDC regional training centers' curriculum framework. The Center is also working on developing the "Tools for Success Curriculum." This is a follow-up to the NIAAA-funded "Tools for Success" resource guide and is targeted to professionals in the juvenile justice system. This will be pilot-tested in summer or fall 2005.

Next, Ammie Bonsu discussed the Center's evaluation project. Evaluation of the Center depends on perceptions of its value as an information resource and its role as a catalyst for changes in behavior of priority audiences. The evaluation asked three key questions: (1) Does the Center effectively reach appropriate audiences with information? (2) Do consumers perceive that the Center makes a significant difference? and (3) Do audiences change behavior following exposure to Center resources?

The Center is monitoring the evolution of state and community-level FASD infrastructure, the evolution of state and national organizations fostered by the Center, and the pace of legislative initiatives. Essentially, the main purpose of the evaluation is to develop state-level baselines of FASD service delivery using a set of capacity indicators (including infrastructure, reporting guidelines, service delivery and planning, prevention communication and advocacy), and to perform annual review of capacity indicators.

The infrastructure indicator evaluated 52 states from 2003 to 2004. During this time, one-fifth of states strengthened infrastructure. There was an increase in states indicating that they have reporting guidelines specific to cases of diagnosed FASD. In terms of service delivery and planning, the number of states collecting data on the incidence of FASD/fetal substance abuse exposure doubled.

Ms. Bonsu said the indicators on prevention are progressing slowly. However, one-fifth of states adopted policies discouraging pregnant women from drinking alcohol. Forty-one states made positive changes in FASD service delivery. Ms. Bonsu concluded that states with little or no service capacity made swift changes once they were involved in Center-sponsored meetings. She noted that six states experienced negative changes such as decreased funding, overlooking FASD activities, or changes in policymakers.

The Center is also conducting evaluations on subcontracted work. Results should be available by October 2005.

Discussion:
When asked whether a survey might determine if positive changes can be attributed to the Center or negative changes improved, Ms. Bonsu said a written survey has not been done. However, the evaluator speaks directly with all states. This issue will be discussed with the Center's evaluator.

When asked if the Center plans to evaluate fetal outcome indicators following up on capacity changes, Ms. Bonsu replied that a long term evaluation will take place. Outcomes for specific projects will be considered; however, fetal indicators will not.

Preconception Care: A Strategy for Prevention
Hani Atrash, MD, MPH
Dr. Atrash indicated that it was a moral, legal, and ethical obligation to care about preconception care (PCC) and to provide effective prevention. He presented data highlighting maternal and infant health indicators including maternal mortality, infant mortality, low birthweight, and preterm delivery. Dr. Atrash said pregnancy outcome improvements have been highlighted as one of the ten major achievements in public health in the U.S. However, racial gaps continue and are worse today than in the 1940s. In fact, since 1980, improvements have stagnated or declined. There has been almost no change in maternal mortality rates. Some rates, including preterm birth and low birth weight, have increased. Low birth weight, according to Dr. Atrash, is an issue of increasing prevalence and concern. While there is improved survival in these babies, affects on babies and on the healthcare system must continue to be measured. Negative birth outcomes also impact the number of children born with developmental disabilities.

Dr. Atrash contended that early prenatal care is too late. There is scientific evidence that preconceptional interventions are effective and clinical practice guidelines already exist to inform health care delivery during the preconceptional period. The American College of Obstetricians and Gynecologists (ACOG) and the American Academy of Pediatrics (AAP) have established the main components of preconception care under four intervention categories which include (1) maternal assessment (e.g., family history, health behavior, obstetric history, physical exam), (2) vaccinations (e.g., rubella, varicella, and hepatitis B), (3) screening (e.g., HIV, STD, genetic disorders), and (4) counseling (e.g. folic acid, smoking and alcohol cessation, weight management).

Commenting that the incidence of adverse pregnancy outcomes is unacceptably high, Dr. Atrash said that 3.3% of births have major health effects resulting from these outcomes. Analyses also indicate that nearly 31% of women have pregnancy complications.

Preconception care (PCC) is comprised of biomedical and behavioral interventions that improve pregnancy outcomes. Preconceptional interventions are designed to reduce perinatal risk factors, and for optimal effectiveness, must be successfully implemented before the start of pregnancy. According to Dr. Atrash, the usual intervention typically occurs around 8-10 weeks after pregnancy. This is sometimes too late to repair damage done to the fetus. Scientific evidence indicates that preconceptional interventions are effective, so it's wise to start care prior to pregnancy.

Dr. Atrash doesn't understand why, if PCC works, it isn't common practice. He indicated surprise that no one with an FAS baby has sued their physician. Commonly, women are told, "Get pregnant, come back, and then we'll discuss care." In fact, over half of the obstetrics textbooks published over the past forty years state that some alcohol consumption during pregnancy is okay.

Dr. Atrash highlighted some of the effective preconception interventions. These include:

- Folic acid supplements (reduces the occurrence of neural tube defects by two thirds)
- Rubella sero-negativity (rubella immunization provides protective sero-positivity and prevents the occurrence of congenital rubella syndrome)
- Diabetes (there is a 3-fold increase in the prevalence of birth defects among infants of women with type 1 and type 2 diabetes)
- Hypothyroidism (levothyroxine requirement increases in early pregnancy; the dosage should be adjusted to maintain adequate hormone levels needed for neurological development)
- HIV/AIDS (identification of HIV infection prior to conception can help in making pregnancy planning decisions and prevent adverse infant outcomes)
- Maternal PKU (a low phenylalnine diet starting before preconception and continued throughout pregnancy prevents mental retardation in infants born to mothers with PKU)
- Oral anticoagulants (warfarin has been shown to be a teratogen; medications can be switched to non-teratogenic anti-coagulant before the onset of pregnancy)
- Anti-epileptic drugs (some anti-epileptic drugs are known teratogens; medications can be switched to non teratogenic anti-epileptic drug before pregnancy)
- Accutane use (use of accutane in pregnancy results in miscarriage and birth defects: pregnancy planning is advised in women using Accutane)
- Smoking (preterm birth, low birth weight, and other adverse perinatal outcomes associated with maternal smoking in pregnancy can be prevented if a woman stops smoking in early pregnancy)
- Alcohol use (FAS and other alcohol-related birth defects can be prevented if alcohol binge drinking and/or frequent drinking behavior is controlled before pregnancy begins)
- Obesity (adverse perinatal outcomes associated with maternal obesity include neural tube defects, preterm delivery, diabetes, cesarean section, hypertensive and thromboembolic disease)

Dr. Atrash said there is consensus that PCC should be provided to all women. An objective for preconception care was included in Healthy People 2000; however, the objective was removed in 2010 because it was not being monitored. Instead of removing the objective, monitoring should have begun.

In 2002, ACOG and AAP summarized their position on preconception care by stating that all health encounters during a woman's reproductive years, particularly those that are a part of preconceptional care, should include counseling on appropriate medical care and behavior to optimize pregnancy outcomes. Dr. Atrash noted that, of the 82 million women of reproductive age, this goal is ambitious and unrealistic. He believes that it should first focus on at-risk populations.

Currently, preconception care is not being delivered, mainly because most providers don't provide PCC (there is no billing code), most insurers don't pay for it, and most consumers don't ask for it. A March of Dimes study revealed that only 20% of ob/gyns who provide any prenatal care offer a PCC visit prior to pregnancy. Dr. Atrash added that ACOG had just completed a CDC-funded PCC survey.

Major challenges to implementing PCC include:

- Absence of a national policy supporting implementation
- Lack of national/state/local model programs
- Lack of tools and practical guidelines for practice (who does it, who gets it, how much, what is it, why do it, how to do it, where to do it, when to do it, etc?)
- Inadequate education of providers and consumers
- Lack of demonstrated practicality, feasibility, and effectiveness of preconception "programs"

Dr. Atrash suggested several approaches for tackling the problem:

- Service at-risk populations first, then move forward.
- Offer assistance to the nearly 60 community-based PCC programs.
- Create a "cookbook" for providing services.
- Develop tool kits.
- Develop practical guidelines.
- Consider conception at every prenatal visit. Most consumers aren't aware they need to act before becoming pregnant.

Other challenges and barriers to PCC include:

- 50% of pregnancies are unplanned
- Lack of guidelines for implementing comprehensive PCC
- Better definition of target populations is needed
- Provision of training and education of providers, policy makers, and consumers
- Policy development and implementation
- Ensuring financial support/reimbursement

Dr. Atrash discussed packaging PCC and said many silos exist. Suggested approaches to "packaging" preconception care include:

- Comprehensive versus packaged/integrated
- Universal versus targeted
- Age-appropriate services
- Clinical versus community-based
- Behavioral versus medical
- Individual versus group

These approaches could incorporate behavior modification, screening, exams, and age-specific approaches.

Dr. Atrash provided a brief overview of the CDC PCC Initiative. Launched in September 2003, the Initiative is partnering with CDC/ATSDR programs and national organizations. The PCC work group reviewed current evidence for effectiveness of PCC components and consulted with

practitioners regarding current knowledge, attitudes, and practices. The Initiative also hopes to develop and evaluate the effectiveness of tools for the delivery of comprehensive PCC. The Initiative also aims to create marketing strategies for implementation and develop training programs and materials for providers and consumers.

The Initiative's main goals are to: make the scientific case and the business case that interventions work, develop consensus within and outside of CDC, develop recommendations, promote a national policy, develop guidelines and tools for implementation, develop marketing strategies to implement recommendations, enhance knowledge and skills of providers, and educate consumers.

Dr. Atrash updated the Task Force on PCC activities to date. Two work groups were established to address PCC, one comprised of CDC/ATSDR programs and the other made up of external partner organizations. A literature review on PCC was undertaken as well. Discussions and collaborations have occurred with MOD, ACOG, AAP, CityMatch, Maternal and Child Health Epidemiology Program (MCHEP), Council of State and Territorial Epidemiologists (CSTE), National Association of County and City Health Officials (NACCHO), the Association of State and Territorial Health Officers (ASTHO) and others. A PCC Summit is planned in a few weeks; 400 are scheduled to attend. The National Summit on Preconception Care will address issues related to policy, programs, marketing, communications, data/research, and financing.

Following the Summit, an expert panel will convene. Panel members will make recommendations for translating science into action. The recommendations will be published in spring 2006. This panel will also generate 30 articles on PCC, which will be an excellent resource.

Discussion:
Dr. Karla Damus highlighted the need for scientific and business evidence and having ways to bill for PCC. A recent paradigm shift within MOD arose around spontaneous preterm births. A paper recently suggested that most spontaneous preterm birth are related to chronic conditions like diabetes or heart disease. Dr. Damus agreed with the need to shift thinking away from not treating women until they're pregnant. We should promote an objective that 60% of women receive PCC and should support research that says, by investing in PCC, you prevent problems later. She felt the Summit would be a critical juncture. Dr. Damus made a comparison to heart disease. People in the U.S. now accept that you don't wait until age 70 to treat heart disease.

Dr. Susan Rich was encouraged by these efforts. She noted that infertility doctors, for example, still approve of some alcohol consumption during pregnancy. To shift the treatment paradigm, national policies must also shift. Funding must shift toward child bearing aged women in substance abuse programs. Screenings could help women who may not realize even small amounts of alcohol are harmful.

Dr. Calhoun acknowledged the challenge of developing comprehensive care for 82 million women. She suggested that young healthy women be given PCC information during annual pap smears. This might be an excellent capture point. A question could also be added to future PRAMS surveys, such as, "Did you see your provider before becoming pregnant?" A third idea

was posting a simple self-screening form on the Internet. Any encounter with target populations at health care clinics, STD clinics and the like, could be potential capture points.

Defining which group of women to begin focusing on and from there, move toward securing comprehensive care for all women seems to be the most reasonable strategy. One target group could be women requesting birth control.

Brief Intervention for Prenatal Alcohol Use
Grace Chang, MD, MPH
Dr. Chang provided an overview of two NIAAA studies she has overseen. She began by acknowledging funding sources and her investigative team.

There is no universally safe level of alcohol consumption. Prenatal alcohol exposure is associated with a range of defects and problems (subtle developmental problems to FAS to death). Research indicates that women who drink are typically older than 35, non-Hispanic, educated, and employed. Binge drinkers were generally younger than 30, single, white, and cigarette smokers.

Identifying use is difficult because women may alter patterns of consumption once pregnancy is known. Even moderate drinkers may underreport consumption. Screening hasn't been effective. Dr. Chang described the screening tool used for her study. The T-ACE method was developed by Dr. Sokol. This questionnaire was based on the CAGE and has been validated in diverse patient samples (Detroit, MI and Boston, MA). T-ACE questions are:

T - How many drinks does it take to make you feel high (effects)?
(Dr. Chang noted that this key question reflects pattern of use. People don't know the socially correct answer and therefore, answer truthfully.)
A - Have people ever annoyed you by criticizing your drinking?
C - Have you ever felt you ought to cut down on your drinking?
E - Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hang-over?

Dr. Chang reviewed the T-ACE scoring as well. The screen is positive with a score of 2 or more. The "T" question is given 2 points if the woman reports more than 2 drinks. The other questions each get 1 point for each affirmative reply. In terms of which screening instrument to use, Dr. Chang felt that any screening instrument is better than the usual physician question, "You're not drinking, are you?"

Dr. Chang noted that brief interventions (BI) and prenatal alcohol use are well suited for each other. Brief interventions are meant to reduce drinking in nondependent drinkers. The common ingredients for a brief intervention include an assessment of alcohol use, provision of feedback to patient, and clear advice from the provider. Pregnant women infrequently have severe drinking problems and are highly motivated to change behaviors.

Dr. Chang reported on her first randomized control trial (RCT) on prenatal alcohol use and brief intervention. The study sought pregnant women who drank alcohol in the previous 6 months and

who were T-ACE positive. Dr. Chang screened 1,165 women and ultimately enrolled 250 pregnant women. Women were randomized into either the comprehensive assessment group or comprehensive assessment + BI. There was a 99% follow-up rate. Findings indicated that both groups reduced their alcohol consumption. The risk of prenatal drinking increased 3-fold if the woman had reported any prenatal alcohol use. Those who were abstinent at enrollment were more likely to maintain their abstinence if given the brief intervention. Additional findings showed that current pregnant drinkers drank less if they chose abstinence as a goal and if they identified FAS as a reason not to drink.

The purpose of the second RCT was to test the effectiveness of a brief intervention for prenatal alcohol use that included a support partner chosen by the pregnant woman. The hypotheses were that both controls and BI subjects would drink less and that the BI subjects would have greater reductions in alcohol use. The T-ACE was also used in this study. Inclusion criteria consisted of a positive T-ACE screen, any alcohol use while pregnant, drinking during a previous pregnancy, drinking > 1 drink daily pre-pregnancy, and gestation < 28 weeks. Subjects were to consent to study terms which included randomization to treatment, selecting a support partner, and diagnostic and follow-up interviews. The diagnostic interview for pregnant subjects consisted of Timeline Follow Back (TLFB), the alcohol abstinence self-efficacy scale, the ASI, and Healthy Pregnancy Facts. Partners were asked self and collateral drinking history and Healthy Pregnancy Facts. Healthy Pregnancy Facts consist of 7 true/false statements on prenatal smoking, caffeine use, marijuana use, cocaine exposure, and alcohol use.

Randomization was done by computer assignment. The study group received a brief intervention consisting of assessment and feedback on Healthy Pregnancy Facts, development of a contract and goal setting, behavior modification, and summary of progress. Post-partum follow-up interviews were conducted.

In total, 2,927 women were screened and ultimately 304 women and their partners were eligible to participate. The median age of the group was 31 years. 80.5% were in a married or committed relationship. 78.6% were white, 7.6% were African American, and 13.8% were Other race. Ninety-five percent completed postpartum follow-ups. Dr. Chang indicated that the two groups were comparable in terms of pre-pregnancy indicators: mean % days drinking (20.9% - BI vs. 20.3% - Control), mean drinks per drinking day (1.85 – BI vs. 1.82 – Control); and prenatal use at enrollment (less than 20% abstinent, 30% consumed more than 2 drinks at a time), mean % days drinking (5.4% - BI vs 5.0% -- Control), and mean drinks per drinking day (1.6 – BI vs. 1.6 – Control). There was an interaction effect between the BI and level of alcohol use at enrollment. Brief intervention was more effective in reducing alcohol consumption among the heavy drinkers. The study noted that other factors had a significant impact on prenatal drinking after enrollment. These included: increased education, more temptation in social situations, and more previous alcohol use. A decreased risk occurred when women had confidence in managing social situations. The study also showed that brief intervention was more effective for the heavier drinking woman when her partner was involved.

The study did have potential limitations which include assembly bias (e.g., particularly motivated women, able to include partner), education and income factors (increase the risk of

consumption), under-reporting, interviewers not blinded to treatment assignment, and treatment fidelity (assessed with treatment notes).

A review of self report data vs. medical record data was also conducted. It was found that 82% of women who physicians did not consider at risk for alcohol use actually drank alcohol. Also, doctors were less likely to document that white women were at risk for prenatal drinking, even controlling for income, education, and pre-pregnancy consumption. Other findings indicate that self report generally exceeds collateral reports of prenatal alcohol use, social support is not predictive of prenatal alcohol use, and couples do not agree on healthy habits during pregnancy.

In summary, the study identified several conclusions and recommendations. These were as follows:

- Consistent screening with a validated instrument embedded in a general patient questionnaire may provide valuable information to the clinician.
- A diagnostic interview triggered by a positive screen appears to result in reduced consumption subsequently.
- Screening and assessment may be the most parsimonious approach to the management of prenatal alcohol use.
  - Brief interventions involving a partner of her choice may be especially effective for women who are drinking more prenatally.
  - Social situations seem to pose the greatest risk for prenatal alcohol use. Techniques are needed to improve management of this risk.
- Abstinence is the most prudent course.
- Without a universally safe limit, some patients and their doctors may believe low levels of consumption are safe. Note that less than 20% of obstetric textbooks published after 1990 had a consistent message about abstinence. 52% of the textbooks published after 1990 condoned prenatal alcohol use.

Women are motivated and concerned about their health and that of their baby but there isn't enough visibility around the dangers of alcohol use during pregnancy.

Discussion:
Dr. Rich commented that the tolerance question is the most nonjudgmental way to address the alcohol use issue. She suggested training healthcare and human service providers to use the T-ACE. Screening coupled with education is more effective. Dr. Wright noted that something as simple as talking with patients can make a difference and said it is encouraging to see solid evidence supporting the effectiveness of this approach.

Dr. Chang also mentioned an ongoing study of women with health problems exacerbated by drinking. She noted her forthcoming article in the *American Journal on Addictions* on infertility and risk drinking. She acknowledged the challenge between reality and the perfect study. Pragmatic studies may not pass review because of scientific standards. This was clearly an efficacy study.

Federal Updates (continued)
CDC Update
Louise Floyd and Mary Kate Weber

The afternoon session began with an update of CDC activities since the last Task Force meeting. Louise Floyd reported on recent findings from Project CHOICES. This project began in 1997. The goals were to identify settings with high proportions of women at risk for an alcohol-exposed pregnancy (AEP), characterize the population to identify the level of risk and predictors of risk, and design and implement an intervention aimed at risk reduction and prevention of AEPs.

The Project CHOICES intervention consists of a dual focus. Motivational interventions were conducted offering the choice of reducing alcohol use, using effective contraception, or doing both. CDC partnered with universities in Florida, Texas, and Virginia. High-risk settings included: treatment centers; a jail, gynecology services at a large metropolitan hospital, and primary care settings. A feasibility study was conducted from 1997-2001. The intervention consists of four counseling sessions, a family planning visit, and pre and post assessments. Women received a battery of assessment instruments assessing temptation, confidence, readiness for change, and decisional balance (weighing pros/cons). Findings from this study indicate that at 6 months post-intervention, 68% of the participants were at reduced risk for an alcohol-exposed pregnancy. In terms of routes to risk reduction, 18% of women reduced their drinking, 34% of women used effective contraception, and 48% did both. Dr. Floyd noted the value of mentioning contraception use in this study and that this contributes to research in this area.

Dr. Floyd then briefly described the Project CHOICES randomized control trial conducted from 2001-2004. The analyses for the RCT are currently underway. Preliminary findings suggest a promising tool for translation. Women were randomized into either the information plus counseling group or the information only (control) group. The intervention group received fact sheets, 4 counseling sessions, and a family planning consultation visit. Controls received a brochure on healthy lifestyle behaviors, and referral sources for primary care, gynecology, and drug/alcohol treatment. Follow-up of study participants occurred at 3, 6, and 9 months post intervention. Cross-sectional analyses indicate that 9 months after participating in the study, two-thirds of the women were at reduced risk for an alcohol-exposed pregnancy. While the information-only participants positively changed behavior, women in the information-plus counseling group did significantly better. Researchers are also evaluating whether diagnostic interviews have their own effect on changes in behavior.

Dr. Floyd indicated that CDC continues to monitor the patterns of alcohol consumption among childbearing aged women aged 18-44 through the Behavioral Risk Factor Surveillance System. Rate of alcohol consumption have remained relatively stable from 2001-2003. In 2003, 53.7% of women of childbearing age reported drinking any alcohol, 13.6% reported frequent drinking, and 13% reported binge drinking.

In other developments, the CDC has funded seven state-based FAS prevention projects. These projects are in Colorado, Wisconsin, Oregon, Minnesota, Missouri, South Dakota/North Dakota, and Michigan. States are targeting high risk communities and are utilizing evidence-based prevention strategies. In addition, states are monitoring prenatal alcohol use and are conducting

FAS surveillance to measure the impact of prevention programs. Also, states are working to identify children already affected by prenatal alcohol and to secure needed services.

Another project Dr. Floyd described was the CDC Intervening with Children consortium. This consortium is comprised of five intervention sites: UCLA, the Marcus Institute in Atlanta, GA, the University of Oklahoma Health Science Center, Chicago Research Triangle, and University of Washington. The interventions are randomized control studies and a core database has been developed so that data can be pooled across sites. A mid-course review of these projects was presented and they are seeing positive effects so far. An RFA to adapt these tested interventions at the community level will be published soon. Dr. Jacqui Bertrand is the CDC contact for these studies.

Louis Floyd briefly outlined additional CDC activities and updates. These included:

- CDC recently released an RFA targeting prevention activities in South Africa's Northern Cape region. This project is separate from NIAAA's efforts.
- The CDC reorganization of the past two years placed the NCBDDD FAS Prevention Team under the Coordinating Center for Health Promotion (CoCHP). Shahul Ebrahim, a member of the FAS Prevention team, received a grant from CoCHP to examine the impact of alcohol use on the health of women and children globally. The objective is to develop the science base to support global alcohol activities by analyzing demographic and health survey data and developing reports on alcohol's impact on HIV/STD transmission, pregnancy exposure, and social systems. In June 2005, an information gathering meeting will take place to discuss major concerns around alcohol and maternal child health populations.

Discussion:
Dr. Faye Calhoun asked about the cohorts in the Intervening projects. It was explained that the teams are running multiple cohorts of these sessions—nine groups of 10 through 14 sessions, for example. All children are diagnosed with full or partial FAS or exposure is strongly suspected. Nearly 500 children participated in the study. Dr. Jacquelyn Bertrand said the team is evaluating analysis parameters and a programmer is assembling the data.

Mary Kate Weber provided a brief update on CDC's health education materials.

- CDC funded four non-profit organizations (the ARC, Double ARC, National Indian Justice Center, Educational Development Center) to develop, implement, and evaluate education curriculum for parents, school staff, law enforcement and social service personnel regarding FAS and ARND. These curricula were tested in 30 states with over 2,000 participants. Materials are now available through each of the four sites. Visit the CDC website (www.cdc.gov/ncbddd/fas) which will direct you to each of the grantee sites for ordering information.
- Evaluation findings indicate that each project showed significant increases among training participants in awareness and understanding of FAS and increased confidence of participants in how to work more effectively with children with FAS and their families.
- As a way to get the word out about the Surgeon General's advisory, CDC created a pink 5x8 card containing the key points of the advisory along with relevant websites on alcohol use and pregnancy. These cards can be ordered through the CDC website.

- In 2004, more than 8,000 copies of FAS Guidelines for Diagnosis and Referral were distributed across the country. The development of this report was a collaborative effort with the National Task Force, experts in the field, parents, and relevant federal agencies. The Guidelines have also been endorsed by AAP, March of Dimes, ACOG, and NOFAS. The Guidelines are available for order and can also be downloaded from the CDC website as a .pdf document.
- The "Think Before Your Drink" brochure, developed in 1999 by CDC and the Arc, has been graphically enhanced and will soon be available in Spanish. This brochure provides information about FAS and offers key prevention messages regarding drinking during pregnancy. CDC has additional brochures (known as the Karen and Wanda materials) which are also available for order through the CDC website.
- Examples of materials developed as a result of three CDC-funded targeted media campaign research projects were presented. CDC is currently looking into ways to make some of these materials more widely available for use as health education products. Evaluation results from two of these projects are still pending. Results from the St. Louis campaign indicated that the campaign had no effects on FAS knowledge. However, they did find that FAS knowledge was higher among women in the target group who saw campaign messages 10 or more times suggesting the importance of having messages appear repeatedly.
- Materials currently under development include materials from the CDC FAS Regional Training Centers, which include a curriculum framework for medical and allied health education, an instruction resource handbook, and a health provider's toolkit.
- CDC is also working with ACOG to develop quick-reference materials for OB/Gyns to screen and intervene with women at risk for an alcohol-exposed pregnancy.
- NOFAS is collaborating with CDC on a number of health education projects, including the development of a K-12 curriculum, a community guide, and media materials for the Cherokee Nation in Oklahoma.
- Finally, Black Hills State University in Spearfish, South Dakota has been funded through CDC to develop training materials for teachers working with K-8 students who have FAS and to prepare K-12 teachers to teach children about alcohol use, pregnancy, and FAS. This work is being done in collaboration with the Aberdeen Area Tribal Chairmen's Health Board.

Discussion:
Dr. Caetano asked if CDC will be adapting the training materials designed for medical personnel for use by public health workers. In some cases, there is considerable information overlap. However, public health has its own identity and this should be acknowledged. Ultimately, public health workers need to know about screening. It was recommended that more work should be done to raise awareness about FAS among schools of public health.

Dr. Bertrand said that CDC is working on an MMWR highlighting the FAS referral and diagnostic guidelines. The MMWR is disseminated widely to public health departments and others. It was also mentioned that the CDC regional training centers are reaching out to a variety of health professionals.

The Task Force brainstormed different ways the Surgeon General's advisory might be disseminated. In France, the warning appears in at-home pregnancy test literature. Other ideas considered were inclusion of information in tampon packaging. It was suggested that the Task

Force write product manufacturers to suggest including the advisory in packaging. This kind of effort could be a multi-year process. Dr. Damus said the Folic Acid Task Force tried placing warnings on products such as condoms and tampons. Manufacturers resisted, explaining that consumers misconstrue warnings to mean that products won't work or that they will have a child with a birth defect.

Dr. Rich suggested including the warning in the section of a pregnancy test that outlines steps to be taken if a woman tests positive. Consumers are apt to read further if they test positive. She advised working with manufacturing associations to promote this idea. It was suggested that this issue be considered by the Prevention Working Group.

Public comment was solicited but there were no comments offered.

Task Force members and liaison representatives convened into **Working Group Sessions** for the remainder of the afternoon.

Thursday, June 16, 2005
The second day of the National Task Force meeting was called to order at 8:30 a.m. by Dr. Wright. Dr. Wright turned the floor over to Dr. Susan Rich.

Report on FASD Action Paper to the American Psychiatric Association
Susan Rich, MD, MPH
Dr. Rich and her colleagues drafted an action paper to include FASD in the DSM for consideration by the American Psychiatric Association (APA). Dr. Rich also presented this information to the Post Exposure Working Group on the previous day.

Dr. Rich began noticing problems in diagnosing fetal alcohol related disorders when she was working in rural North Carolina where she was developing substance abuse programs for pregnant and parenting women and their children. What she saw was that pediatric dysmorphologists were reluctant to diagnose these children's problems as alcohol related, and that other mental health providers were ill-equipped to handle the complicated problems children had. Fetal alcohol syndrome was included in the DSM-III at one time but then was removed in the DSM-IIIR. Dr. Rich was not sure why this was. Regardless, psychiatrists and other mental health providers do treat children with fetal alcohol spectrum disorders every day. However, there is currently no consistent way to code fetal alcohol spectrum disorders, which is problematic.

The FASD Action Paper was drafted by Drs. Rich and Peele with assistance from NOFAS and Kieran O'Malley. There have been studies to show linkages between mental illness and FASD. Dr. Ann Streissguth and Kieran O'Malley have written a great deal about this. It is their work that Dr. Rich highlighted for the psychiatric community. ADHD is one example of a disorder that is co-morbid with fetal alcohol spectrum disorders. A clinical subtype of FASD may exist within the population of individuals with ADHD. Claire Coles has done some research in this area. Psychiatric medications often do not help many children. Well-controlled clinical trials in this population of children do not exist; partly due to the fact that there is not a DSM code.

Autism, obsessive-compulsive disorder, and Tourette's syndrome have all been shown to be common in children with FASD.

Another important question to address is "What is ARND (alcohol-related neurodevelopmental disorder)?" This is important to communicate to the psychiatric community because these are the children presenting in the psychiatric community. Also, more children have ARND than FAS (perhaps 3-10 times more prevalent). Learning more about these children will help psychiatrists better treat these children and help determine which medications are most appropriate. For example, psychiatrists need to understand that prenatal alcohol exposure may affect the child's organs. This needs to be understood especially when prescribing certain medications. Acquired brain injury is probably a very different kind of problem for children with prenatal alcohol exposure. For example, medication could be administered in small doses combined with environmental supports for children with FASD.

Perhaps we need to sell FAS itself instead of ARND? This question was raised during the working group session yesterday. The problem is that if you just go by facial dysmorphology you will be missing a large number of children. Dr. Rich contends that we need to educate psychiatrists about this issue and to stress the importance of taking a prenatal history. There are also safety issues related to decreased seizure threshold for certain medications.

The action paper outlines the issues related to FASD and offers the following alternatives to the APA for consideration: (1) continue to omit fetal alcohol-related disorders from DSM, and (2) explore having fetal alcohol-related disorders included in the DSM-IV CR/DSM-V and subsequent editions. The CR is a code revision to the DSM, while TR is a text revision to the DSM. The difference between CR and TR is that a CR will come into play if ICD-10 is adopted by insurance companies and others. It is not likely that they will update with the CR. It will be less expensive to wait for ICD-11 (to be adopted in 2012) which will coincide with DSM-V. This is most likely what will occur.

Dr. Rich informed the APA Assembly that a Congressional bill went through last year to recommend that FASD be in the DSM. It did not pass but will go through again this year. During her presentation, Dr. Rich asked the Assembly, "Why should we wait for an act of Congress to have this happen?" The American Academy of Child and Adolescent Pyschiatry endorsed this unanimously at their Assembly and the APA Assembly did as well.

The action paper went through the Committee on Psychiatric Diagnosing and Assessment (CPDA) and the CPDA is required to report back to the Assembly with next steps. Based on previous experience: the estimated cost for exploration of this issue includes the costs of subcommittee exploration (author: $10,000) and costs for development of diagnostic criteria and field trials (APA: $300-350,000). This action paper was submitted for consideration by Dr. Rich and Dr. Roger Peele, along with Dr. Michael Houston, Dr. Catherine May, and Dr. Lawrence Kline. The group has received endorsements from NOFAS, the Washington Psychiatric Society, APA Area 3 Council, APA Area Committee of Members in Training, American Academy of Child and Adolescent Psychiatry Assembly, NIAAA, and the American Psychiatric Association Assembly.

This action paper goes back to the Committee on Psychiatric Diagnosing and Assessment. They will convene a workgroup to explore this issue. Dr. Rich may be able to be on this workgroup. The main reason the paper was submitted was to get this issue on the APA radar screen. Eventually this workgroup will report back to CPDA who would then report back to the APA Board of Trustees. There is a possibility that later this year they might go ahead and submit and try to get this into the DSM-TR. Possible outcomes include updating DSM-IV TR when sleep disorders are revised later this year. They could also introduce FASD if DSM-IV CR is published (if ICD-10 is adopted). However, it is most likely that DSM-V will coincide with the adoption of ICD-11 (2012). By 2008, a compilation of the diagnostic criteria based on a literature review will be done and then field trials would begin.

Discussion:
Dr. Sterling Clarren recommended a slightly different approach to thinking about this. Dr. Clarren has worked at the Seattle Children's Home, which is a lock-up facility for children with serious problems who are not criminals. Children here had failed in system after system. A psychiatrist at the home wondered if their failures were due to brain differences and maybe they should be assessed as children are in the fetal alcohol clinic. Dr. Clarren began multidimensional evaluations on speech, occupational therapy, and neurodevelopmental assessments similar to those done for children with FAS. Eighty-five percent of the children had cognitive behavioral profiles like children exposed to alcohol. These findings will be published now that they have assessed 100 children. About a third of the children were found to have a history of prenatal alcohol exposure. A range of disorders was found. In all cases, understanding fundamental dysfunctions changed the psychiatric treatment plan dramatically. It also changed Dr. Clarren's purview of what should go in the DSM.

The real issue may not be codifying ARND but maybe ND (neurodevelopmental disorder). What is needed in the DSM is a description of a modern view of minimal brain dysfunction, which we may want to call cognitive behavioral disorder or something. Under this, perhaps list the things that cause it, including alcohol. This gets psychiatrists out of the box when brain damage is discovered but alcohol history can't be obtained. Alcohol leads the way to understanding a huge population of children psychiatrists need to work on. However, Dr. Clarren isn't sure targeting alcohol is what is needed to diagnose the problem. It also makes it more compatible to the DSM to use descriptors of a functional nature to build the diagnosis rather than an etiology.

Dr. Rich responded that a committee within APA is looking at developmental disabilities and providing input into redevelopment of the DSM in ways Dr. Clarren has mentioned. Dr. Rich's group recognizes that whatever disability a child has is the primary problem, but then with prenatal alcohol exposure or secondary to prenatal alcohol exposure. Highlighting the alcohol issue leads the way to understanding and diagnosing children.

Dr. Clarren urged linkages between developmental pediatricians and the APA. They both work on similar issues. Dr. Rich explained that when children may have developmental disabilities, once an OT/PT evaluation is done, they are referred to a geneticist or developmental pediatrician, depending on the child's age.

According to Dr. Sokol, most FAS diagnoses are made by developmental pediatricians and geneticists, not psychiatrists. Linkages with these groups would be very helpful. Secondly, he noted that the Task Force approved a definition of FASD as a non-medical diagnosis. FASD is not a diagnostic term and it includes more than FAS and ARND (e.g., ARBD). Dr. Sokol is concerned about diagnoses written into DSM that do not include these other categories. He again encouraged consultation with professionals like Dr. Clarren who have been writing about these definitions for a long time. This will encourage breadth of scope and not just a psychiatric focus. Getting FASD in the DSM will not be a simple process. At the moment, FASD is still a loose term. Not everyone is using it the same way.

Dr. Rich explained that the group wasn't suggesting FASD be considered as a diagnosis. What they are recommending is that you give a diagnosis of the problem identified within the spectrum. They are using the term FASD as it is used in autism. You don't give a child the diagnosis of autism spectrum disorder, rather you give them the diagnosis of the specific condition (e.g. PDD, Asberger's). FAS and ARND are problems that children have that psychiatrists need to understand better and underneath there are an array of other problems that the children have, such as learning disabilities. This is also in keeping with the way that alcohol use disorders are designated in the DSM. For example dementia is secondary to alcoholism. Also, this would include a multidisciplinary, comprehensive approach similar to what is already being done to treat these children.

Dr. Sokol commented that developmental psychologists would also be an important group to link with. They come at this from a very different perspective than developmental pediatricians.

Dr. Clarren recommended having someone speak to the Task Force about the history of the term, "minimal brain damage," describing the origin of the term, how it evolved, and how it was destroyed. This type of brain damage is what we are talking about. It is the diffuse, complex mild brain damage that leads to a litany of different functions in different people. It is what Strauss and Laetner were looking at in the 1940s. They tried a team approach to diagnosis. The problems they faced in the 50s and 60s led to the destruction of the term in the 70s. This needs to be understood or we will go down that exact same road again. This story has not been told nearly enough in FAS circles and it needs to be.

Dr. Wright then turned Task Force attention to Working Group reports.

Post-Exposure Working Group Update
Deborah Cohen, PhD, Co-Chair

Dr. Deborah Cohen presented recommendations from the Post-Exposure Working Group. She began by describing Dr. Rich's work as an incredible step forward in getting FASD before the APA. The fact that the APA has recognized that alcohol can cause these types of brain insults is a tremendous step forward. She acknowledged NOFAS for pushing this agenda as well. Also, echoing Dr. Rich's comments, we are finally getting FASD on psychiatrists' radar screens.

The working group put forth a number of recommendations needing follow-up on the APA issue. Dr. Cohen noted that Heather Carmichael Olson participated in working group deliberations via

conference call. Based on the discussions, Dr. Olson put forward several recommendations for consideration which the working group endorsed.

1) The first was that the Task Force write and send a letter to APA in support of their inclusion of FAS in the DSM. The working group acknowledged that the term ARND opens up a very broad area that is still unclear. Also, the working group recommends that CDC endorse this by sending a letter of support to APA. NIAAA has already done this. SAMHSA will most likely do this as well.
2) The working group also recommends that support be provided for field trials. While this is an issue that is still down the road, we do ask that the federal agencies consider in their budgets a way that we can support these field trials. Additionally, the working group thought that other organizations should also weigh in on this issue and write letters of endorsement to APA.
3) One other issue that the group felt that the Task Force could move on was to educate psychiatrists about FAS (e.g., disseminating guidelines for residency programs, brief reports in psychiatric journals) and stimulate discussion among psychiatrists.
4) Finally, the working group recommends that the Task Force set a research agenda on ARND and recommends convening a summit in 2006-2007 to discuss key issues related to diagnosis of ARND.

Discussion:
Dr. Boyle raised the concern that the focus of the action steps leaned heavily on psychiatrists only and not other mental health professionals who may encounter children and families that are affected. It was explained that the working group was responding specifically to APA. APA is a leader for those in the mental health field. Others in the field also use the DSM for their coding so it is an important issue.

The following motion was made by Dr. Cohen:

> **A letter should be sent from the Task Force endorsing APA's consideration of FAS in the DSM.**

This motion was approved unanimously.

The Post Exposure working group will come up with a plan to present at the December 2005 meeting regarding the other action items related to the DSM issue. The group will be meeting via email and conference call.

The second issue of the Post Exposure working group deals with the reauthorization of the IDEA regulations. At their last meeting, the Post-Exposure group decided to send a letter to Secretary Margaret Spellings at the Department of Education. The IDEA legislation had already been reauthorized by Congress. This letter will request recognition or inclusion of FAS to the regulations that are now being promulgated. A draft of the letter was distributed and reviewed.

Proposed Changes and Comments:

- In the first paragraph, Dr. Clarren suggested changing "learning disabilities" to "problems of memory, executive functioning, and adaptive difficulties" because in the fourth paragraph

learning disabilities and mental retardation are described and are, in fact covered, so it should be suggested that there is a different pattern that's being missed.

- Dr. Boyle said adding data to back up what is proposed would make the letter stronger. Dr. Streissguth's work could possibly be used.

- Dr. Sokol mentioned that at one point the Task Force tried to get FAS listed in IDEA but was turned down and it was recommended to wait and try to get it listed as part of the regulations. He stressed that it will be important to get this letter to the right person.

- CDC staff are working with an individual at CDC who has worked at the Department of Education. He will provide advice on the best person to send this to at the Department of Education. It is recommended that this issue be acted on immediately. The Department of Education is currently holding public hearings regarding the IDEA regulations from late June-July.

- Dr. Brown noted that new legislation has changed the definition of learning disabilities. How this will be written into the legislation remains unclear. Local education agencies can eliminate the discrepancy of achievement and ability as the criteria for learning disabilities. Instead, they can use up to a two year period where children receives scientifically-based reading instruction or other instruction. Some jurisdictions may take a "wait and see" approach to the diagnosis of learning disabilities which could be harmful to this population.

- Dr. Karla Damus suggested that the letter begin with what the Task Force wants. She also suggested moving the third to last paragraph to the beginning. Start by saying, "We are writing to ask your consideration. . ." Begin the second paragraph with, "As you are aware, prenatal alcohol is one of the leading . . ." At the end, insert "We are certain that the inclusion will help to clarify the issues . . ." Also, it may be a good idea to copy Dr. Carmona on this letter.

- The CDC process was briefly discussed. CDC will decide on the best way to send this letter forward. Dr. Cohen suggested that a copy of the FAS Referral and Diagnostic Criteria, the mission of the Task Force, and Dr. Carmona's release be included with the letter.
- Dr. Brown recommended Troy Justesen, Acting Director of the Office of Special Education Programs (OSEP), as a good contact. OSEP is taking the lead on this effort.

- Dr. Boyle recommended that the letter be as concrete as possible and that information supporting the benefits of early intervention, cost savings incurred, etc. would make the letter stronger.

- Dr. Cohen agreed to send the letter out for one more review and noted that within the next three weeks the letter must move forward. She asked CDC for their help with this. A discussion of where the letter should originate followed. It was decided to begin the process and have the letter reviewed at CDC to determine the best person to send the letter to and any next steps that need to be taken in the process.

- It is anticipated that the IDEA regulations will be published in December 2005 so there is some urgency in terms of how quickly this information can get to the Department of Education. Also, the Task Force may be asked for endorsement by other agencies. The Task Force may want to take this into consideration ahead of time.

Dr. Wright asked about the Post Exposure working group's research agenda and asked for clarification on what they want to achieve. Over the next year, does the working group plan to articulate recommendations on this issue to federal agencies and others? Dr. Cohen said yes to this but also that prior to the development of this agenda, the working group would also like to sponsor a meeting or summit to gather experts to help develop these recommendations.

Dr. Cohen reported that previously Charles Schad met with individuals at the Department of Education about fetal alcohol syndrome. To follow up on this meeting, a package of materials does need to be developed and disseminated to state special education directors and other education-related organizations to raise awareness about this issue. The working group has agreed to work on this. The concern articulated by Department of Education representatives focus on identifying and diagnosing FAS. The working group can include the diagnostic guidelines in this package of materials.

Prevention Working Group Update
Lisa Miller, MD, Co-Chair
Dr. Lisa Miller presented her group's report. Since the last meeting, the Prevention working group developed an outline for the background document regarding the prevention of FAS and alcohol-exposed pregnancies. The outline was approved by the working group during a conference call about six weeks ago.

Representatives from the group spoke with a scientific writer to help assemble the prevention report. The writer has been involved in developing several U.S. Preventive Task Force Service reports. The writer pointed out several issues warranting attention by the working group before they move forward with writing the report. These included: What do we want this report to accomplish? Who are key stakeholders? What kind of report is it? and What do we want the writer to produce?

The working group decided that they would like to identify those "things that work" in prevention, identify current gaps, and highlight best practices, but will refrain from recommending implementation strategies at this point. They also discussed that they would need a consultant or two to conduct a structured literature review of individual and population-based prevention strategies. The group wants to look at the full breadth of interventions including population-based approaches and individual-level interventions strategies that are.

Stakeholders include funders, private and public policymakers, public health officials, and clinicians. Dr. Miller asked for any ideas for possible consultants. These can be sent to Dr. Miller and Ms. Weber.

The Prevention working group has not yet decided how to disseminate this report until they have a draft in front of them. Perhaps there will be a summary and a more detailed version. This will

depend on the audience the Task Force wants to reach. Ms. Weber explained that the report will help the Task Force gathered information to assist the group in making an informed decision regarding Task Force recommendations on prevention. After identifying consultant(s), the group will provide resources and feedback to the writer as needed. The FASD Center for Excellence volunteered their resources and possible referrals for writers. The working group will follow up with Callie Gass for this information.

The project timeline is one year which would include the deliberations regarding Task Force recommendations as well as the literature review. It was felt that once the information gathering is completed, the recommendations should flow from it quickly.

The draft letter to Abercrombie and Fitch was on the Prevention working group agenda; however, the group did not have time to discuss it.

Liaison Updates
The following liaison updates were provided:

American College of Obstetricians and Gynecologists
Dr. Sokol reported on ACOG activities. Task Force guidelines were officially endorsed by ACOG and a letter documenting the endorsement was sent to Dr. Floyd at CDC. Dr. Sokol is also working with ACOG on a new document reflecting appropriate practice applications related to alcohol screening and brief intervention. This project is being actively worked on and both CDC and ACOG have contributed resources to this process. The group had a very productive one-day meeting in March in Washington, DC.

Two papers are also underway. Louise Floyd is first author on a brief that will be published in the *Green Journal*, the most widely read OB/Gyn journal in world. The paper makes evidence-based recommendations for practicing doctors regarding alcohol screening and brief intervention. A revision is currently being submitted. The second paper is lengthier and provides the science behind these issues. It may be submitted to Alcohol, Clinical, and Experimental Research.

Dr. Sokol highlighted Kathleen Mitchell's program at Northwestern University in Chicago. He taught a few sessions to medical students there. This is a very effective program and should be recognized as an excellent initiative.

The Arc
The next update was from Dr. Sharon Davis from the Arc. Her organization was one of the four grantees to receive a CDC awareness and education grant. While this project has ended, the curriculum is still available. The curriculum is for parents of FASD children and health/human services professionals and teachers who work with these families. The Arc conducted 11 train-the-trainer workshops and trained more than 200 people and hopes they, in turn, will train others. Several Arc chapters were involved in developing this curriculum.

Program results have been excellent. The curriculum is available via the Arc website, http://www.thearc.org/fasproject/thecurriculum.htm. In additional efforts, the Arc has

maintained their website and is receiving requests for follow-up training. The Arc's network of approximately 900 chapters is essential to getting work out into the field. Dr. Davis shared success stories of how Arc chapters have connected with groups who are interested in getting the word out about FAS.

Melinda Ohlemiller, from the Saint Louis, Missouri Arc, said that about 5 years ago a prevention committee was started within her agency and was awarded a $5,000 grant from the March of Dimes. In January 2005, this committee received $330,000 from a local foundation to do primary prevention with high school students related to drinking during pregnancy. The project will last three years. The committee also just started a diagnostic clinic in Missouri with the help of the Arc.

Dr. Davis also described the Nine Zero campaign, a campaign initiated by the Arc Riverside in California. She distributed Nine Zero bracelets to Task Force members, and encouraged them to visit www.ninezero.org for more information. The campaign involves teenagers in primary prevention activities. This Arc chapter developed a program called FASTRAC, a curriculum in which junior and senior high school students are trained to teach ninth and tenth graders about FAS prevention. This curriculum also includes information about the Nine Zero campaign. In the Nine Zero campaign, teenagers are encouraged to pledge "Nine months. Zero alcohol." They can make this pledge on the Internet. When 90% of a school's student population have registered, they become a Nine Zero school. Dr. Davis said this activity might fit into the Prevention working group's list of possible prevention activities. Other chapters are also carrying out activities regarding FASD.

Dr. Davis indicated that the Social Security Administration announced an advanced notice of proposed rule making in April regarding the revision of criteria used to determine disability for children and adults with neurological impairments. These criteria do not include FAS. The last time these criteria were revised was in 1985, over 20 years ago. Her office will recommend adding FAS as one of the things to consider in the revisions. Many people with FAS never qualify for disability benefits. They are requesting public comments to point Social Security in the right direction for specific issues that should be considered. The deadline for public comment was June 13th. A public meeting is scheduled for July 28-29, 2005 in New York City. Attorney Marty Ford is spearheading this issue at the Arc. If people are interested, Ms. Ford can be reached at 202-783-2229. More information can be found at www.thearc.org. Dr. Davis gave Ms. Ford the FAS guidelines for more information.

Center for Science in the Public Interest

George Hacker provided an update on recent activities at the Center for Science in the Public Interest. His agency attempted to include report language in both House and Senate bills. This language recognizes the issue of FAS, commends the Surgeon General for updating the advisory, and urges CDC to work more aggressively with partner organizations to generate awareness regarding the new advisory. He distributed copies of what CSPI proposed to the House and Senate. Mr. Hacker said the language was overlooked in a recent mark up. However, a short paragraph will be included in the manager's amendment to be included in the full committee mark up. This paragraph recognizes the problem of FAS, acknowledges the advisory, and urges CDC to work with partner organizations, like NOFAS, to raise awareness about the advisory

especially among high risk communities. This is a done deal in the House and CSPI is still working this on the Senate side. No funding was attached to this, but the action keeps FAS on the radar screen and perhaps gives CDC an opportunity to be more aggressive than it might have been.

Mr. Hacker distributed a package of information to Task Force members. He discussed a brochure for the CSPI effort on alcohol-free advertising during college sports events on TV. About 230 universities have pledged to help eliminate alcohol advertising during their local sports, conference sports, and the NCAA telecasts of college sports. As a result of that action and a House resolution (by Tom Osborne), NCAA ultimately put this issue on its agenda. In April, the NCAA board of directors requested that its executive committee adopt a new comprehensive policy on alcohol advertising. The executive committee meets in early August. CSPI is hoping that the NCAA makes some revisions to their current policies.

The Stop Act (Sober Truth on Preventing Underage Drinking), which is bipartisan in both houses, is progressing. The Act has 44 sponsors in the House and 15 in the Senate. It aims to amend a bill that includes SAMHSA reauthorization, which is up this year. If approved, there is an excellent opportunity to amend the bill with at least some parts of the Stop Act. Mr. Hacker distributed information describing the Stop Act.

Three weeks ago, the Center sent Congress a declaration by a group of 60 economists, including 4 Noble Prize winners, advising on alcohol excise taxes. The group opposes the reduction of taxes and proposes an increase in taxes both for public health and revenue purposes.

After many years, the Alcohol and Tobacco Tax and Trade Bureau issued an advance notice of proposing rule making and a request for comments on issues regarding ingredient, calories, alcohol facts and other nutritional labeling. Thirty-three years and two lawsuits later, the actual rule is coming together again. It asks whether the alcohol industry can promote products on the basis of no fat or low carbohydrates and whether important information should include alcohol content and calories on the labels. More information is available on the Center's website – www.cspinet.org/booze.

American Academy of Pediatrics

Dr. Sterling Clarren is substituting for Dr. George Brenneman as the representative of the American Academy of Pediatrics. The Academy of Pediatrics has a specific organizational structure that makes it difficult for any specific disease to have a specific home within the Academy. Dr. Clarren mentioned a paper being drafted by the Committee on Substance Abuse, the Committee on the Fetus and the Newborn, and the Council on Children with Disabilities. The committees are issuing a new policy statement on fetal alcohol syndrome in the context of prenatal alcohol exposure and long-term effects. This will replace their 2000 policy statement. The new Surgeon General's advisory will be helpful to them in their final paper.

In other AAP updates, Dr. Sheila Gahagen is leading a team of authors from the AAP, CDC, and the FAS Regional Centers for the Education and Training of Medical and Allied Health Students and Professions. The team is developing an article based on their 2003 survey of members of the Academy. The survey queried pediatricians' knowledge of prenatal alcohol disorders. Also, the

journal of *Pediatrics* has recently published two articles related to this field. The first paper, *A Practical and Clinical Approach to Diagnosis of Fetal Alcohol Spectrum Disorders: Clarification of the Institute of Medicine Criteria*, addressed the clinical approach to FASD diagnosis (January 2005, Hoyme, et al). The second was a basic science paper entitled, *Effects of Alcohol Intake During Pregnancy on Docosahexaenoic Acid and Arachidonic Acid in Umbilical Cord Vessels of Black Women* (February 2005).

Dr. Floyd asked what content will be addressed in the new policy statement that the Academy is working on and what the timeline is. Dr. Clarren was not certain but suggested that Dr. Floyd follow up with the Academy. Dr. Sokol requested an email version of this policy statement so that he could keep ACOG informed since the AAP and ACOG often collaborate on issues like these.

March of Dimes

Dr. Karla Damus said her organization was proud to have endorsed the FAS guidelines. MOD has been involved in efforts around prenatal alcohol exposure for quite some time. She felt the MOD National Prematurity Campaign, which has been expanded until 2010, could be leveraged to support these efforts as well. Prematurity is the number one obstetrical problem. Despite treatments known to be of great value, such as folic acid and smoking cessation, only about 50% of obstetricians are offering evidence-based interventions to women. The campaign's focus is preventing preventable preterm birth through risk reduction, strategies, and messages that empower communities. They are focusing on provider education and awareness, and more research funding for other agencies (e.g., CDC, HRSA, and NIH) to do these types of important research.

Dr. Damus also discussed impacts of preterm birth. Her agency has stressed messages focused on the continuum of reproductive healthcare. Many issues are interrelated and impact preterm birth. Related to this, Dr. Damus reminding the audience about the renewal of the Violence Against Women Act.

According to Dr. Damus, MOD is sending a strong message about the overlap in low birth weight, preterm birth, and birth defects. They used to treat preterm birth with ethanol. To increase public interest, MOD talks about cost—the national bill for preterm births is $15.5 billion. We need to address the issues that are preventable and work to identify attributable risk. Preterm birth rates are increasing. They are rising due to advanced maternal age, substance abuse, and other factors. MOD focuses on that which is preventable. A major issue is substance abuse prevention. MOD continues to work strongly with partners such as ACOG, AAP, AAWON and others on smoking cessation. Polysubstance and alcohol abuse are always mentioned during these discussions of smoking.

Dr. Damus commended an ACOG and Dartmouth website: www.interactivemedialab.dartmouth.edu. The site contains a downloadable antismoking program to be implemented in clinical practice. MOD hopes a similar model will become available for alcohol. Physicians can obtain CMEs with this. They could also address FASD and polysubstance abuse in their discussions.

Dr. Damus said MOD has many fact sheets on alcohol and other substances, updated statistics, and a wealth of materials for the public, nurses, and doctors. In fact, healthcare providers can receive free CMU and CME credits through MOD materials. One course addresses perinatal impact of alcohol tobacco and other drugs. This course is being updated to incorporate the new FAS guidelines.

MOD constantly promotes polysubstance abuse at grand rounds emphasizing that these are preventable, modifiable issues. The MOD website provides extensive information on prenatal alcohol and related issues. It links to SAMHSA substance abuse treatment facilities. MOD also recently funded several efforts that will be exploring mechanisms and pathways related to prematurity.

A paper originating from a MOD scientific advisory committee has been accepted. This paper sets forth a national research agenda targeting specific areas related to preterm delivery and will appear sometime in October 2005 in the *American Journal of Obstetrics and Gynecology*. An accompanying cartoon in the article explains pathways that represent interactions among behavior, psychosocial, and other issues in the external environment, along with family history, genetic, nutrition, etc. This evidence provides MOD a framework to promote the role of substance abuse and its impact on preterm births.

Dr. Damus discussed another paper's findings regarding weekly progesterone injections for eligible women. Published in the *Green Journal*, the paper stated that preterm birth would decrease by 2% if all eligible women received a weekly injection of progesterone. MOD is working with ACOG and other groups to explore this further. It is not going to be one intervention that will make a difference but a variety of different preventative approaches.

MOD is also working with family medicine to create a prevention model. The alcohol message is surfacing in this area, too. MOD is also doing multi-national research on preterm birth issues. MOD takes a comprehensive approach to working with partners. The NICU Family Support links families to services during difficult time and in between pregnancies and before they are pregnant again.

Dr. Damus summarized that preterm birth is a common, complex disorder that requires active involvement along the continuum of reproductive health. The approach must be multi-disciplinary and comprehensive.

MOD Peristats website http://www.marchofdimes.com/peristats/ provides free online access to U.S., state, county, and city maternal & infant health data. MOD Peristats now links directly to PubMed (National Library of Medicine) which brings up articles about alcohol and pregnancy and other issues. Dr. Damus noted that www.MedLinePlus.gov has interactive tutorials on many health issues. MedLinePlus should be encouraged to include FAS in their lineup of interactive tutorials. The Task Force may want to consider using the public library system to do community outreach on FASD.

New Business

Abercrombie and Fitch Letter

With Task Force updates complete, discussion turned to new business. The first item up for discussion was the Abercrombie and Fitch letter. A letter was drafted for Task Force review which commended the company for removing t-shirts from their clothing line that promoted excessive drinking. The process involved in writing a letter of this kind was discussed. The question was raised if it would be feasible to proceed with the letter given the time constraints in providing a response.

Dr. Sokol indicated that if the Task Force does decide to write this letter it should relate to FAS. Something that mentions that drinking among young women can result in adverse pregnancy should be added to the letter. He also asked why this is something this group should pursue?

Since the company has already taken action by removing the t-shirts from the shelves, it may not be worth writing a letter. It was suggested that when these kinds of requests for action occur that the best way to respond would be through the Task Force's liaison groups.

It was also suggested that the Task Force may want to think differently about how to respond to concerns of this nature. Are there other strategies besides letter writing that would be more productive? The key question is how can the Task Force and other groups communicate concerns to the alcoholic beverage industry and others about the inappropriateness of promoting excessive drinking among vulnerable populations?

Abercrombie and Fitch are looking for continued press and to continue this attention would just give them more press. In addition, singling them out when there are other companies guilty of similar actions may become problematic from a legal standpoint.

It was also suggested that perhaps recognizing good responsible practices would be a better strategy than identifying "the bad guys." However, again, recognizing one company versus others may be problematic for the Task Force from legal standpoint.

In lieu of this discussion, the Task Force decided against writing a letter to Abercrombie and Fitch.

Melinda Ohlemiller asked if the NTFFAS listserv should be used for these kinds of action items? Ms. Weber indicated that information can be sent out as an FYI but requests for actions cannot be made. Government policy prohibits CDC employees from forwarding action items on political issues but can forward informational and administrative items via listserv. It was suggested that action requests such as the Abercrombie and Fitch item could be handled through other email lists and listservs and possibly addressed by relevant liaison groups. George Hacker offered to add interested individuals to the CSPI email distribution list.

Speakers/Topics for Upcoming Task Force Meetings

Dr. Jim Berner asked if the Task Force would consider inviting a liaison from the World Health Organization (WHO) to a future Task Force meeting. This could provide an international perspective on how other countries address prenatal alcohol exposure prevention strategies.

WHO headquarters in New York could probably provide possible speakers. Pan American Health Organization is another organization that may be appropriate. Dr. Clarren offered to present information on the Western Canadian effort at a later date. His team will be preparing recommendations at the end of this year.

Melinda Ohlemiller asked if a speaker on the history of minimal brain dysfunction should be added to the December meeting agenda. Dr. Cohen also agreed with Dr. Clarren's suggestion that learning this history would be helpful. Dr. Clarren offered to speak on the topic, but felt better speakers could be found at the Kennedy Krieger Institute. He said Strauss' papers from 1950s are remarkable in that they read like papers being written now about FAS. It is a cautionary tale that should be understood.

Louise Floyd thought dialogue with the AAP Committee on Substance Abuse would be helpful for the Task Force. What clinical issues are pediatricians struggling with and what is the direction for the future. The Task Force has been directly involved in these conversations and have harmonized with other groups regarding diagnosis and referral. This dialogue could be mutually beneficial to both groups. Dr. Clarren offered to email the AAP committee to find out what they are doing. This might be a topic at a future Task Force meeting.

Ms. Weber requested that the Task Force submit any ideas for future meetings via email to Dr. Wright or herself.

Dates and Times for Next Meeting

Dr. Cohen requested that working groups have more than two hours to meet and deliberate. The Prevention working group felt they didn't need additional time. However, they may need time during the upcoming meeting if the draft prevention document is ready for review. As work progresses in the coming months, accommodations will be made if possible. Any changes in the current format of the meetings will be proposed to the committee before any decisions are made.

Ms. Weber will forward via email possible dates for the December 2005 meeting as soon as possible.

No public comment was offered. Thus, the Task Force adjourned at 12:40 p.m.

Minutes approved on 09/21/2005
by Jean A. Wright, MD, MPH
Chair, National Task Force on FAS/FAE

Appendix A: Motions Passed, Action Items, Future Agenda Items

Motions Passed:

- The following motion was made by Dr. Cohen:
  A letter should be sent from the Task Force endorsing APA's consideration of FAS in the DSM. This motion was approved unanimously.

Key Action Items:

- Send a thank you letter to Dr. Warren on behalf of the Task Force recognizing the work he did on revising and updating the advisory to reflect current scientific research.
- Finalize and approve the letter to be sent to the Department of Education regarding inclusion of FAS in the IDEA regulations.
- The Post Exposure working group will draft a letter of endorsement from the Task Force to the American Psychiatric Association.
- The Post Exposure working group will put together a package of materials to send to the Department of Education representatives who met with Charles Schad last year.
- The Prevention working group will identify consultant(s) to draft background information on prevention strategies to inform working group recommendations. Consultants to prepare draft document by next Task Force meeting.

Topics for Future Task Force Meetings:

- Invite a liaison from the World Health Organization or the Pan American Health Organization to discuss prevention of prenatal alcohol exposure from an international perspective.
- Dr. Sterling Clarren could return to the Task Force to present on FASD activities in Western Canada once his team finalizes their recommendations.
- Invite a speaker to present to the Task Force on the topic of minimal brain dysfunction.
- Invite a representative from the AAP Committee on Substance Abuse and/or related committees that are working to revise the AAP policy statement on FASD.