

# Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children

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*Four Points Sheraton Downtown  
Washington, DC  
June 5-6, 2006*

## **MONDAY, JUNE 5**

8:30 a.m. – 9:00 a.m.      **CONTINENTAL BREAKFAST FOR COMMITTEE MEMBERS AND REPRESENTATIVES**

9:00 a.m. – 9:15 a.m.      **OPENING REMARKS AND WELCOME**

R. Rodney Howell, M.D.  
Committee Chair

### **Introduction of Representatives**

9:15 a.m. – 10:45 a.m.      **AGENCY AND FEDERAL ADVISORY COMMITTEE UPDATE ON ACTIVITIES RELEVANT TO NEWBORN SCREENING**

- **NIH**  
Duane Alexander, M.D., Director, National Institute of Child Health and Human Development
- **CDC**  
Coleen Boyle, Ph.D., M.S., Director, Division of Birth Defects and Developmental Disabilities
- **HRSA**  
Peter C. van Dyck, M.D., M.P.H., M.S., Associate Administrator, Maternal and Child Health Bureau
- **AHRQ**  
Denise Dougherty, Ph.D., Senior Advisor, Child Health
- **SACIM**  
James W. Collins, Jr., M.D., M.P.H., Chairman, Secretary's Advisory Committee on Infant Mortality
- **SACGHS**  
Joseph Telfair, Dr.P.H, M.P.H., M.S.W., Secretary's Advisory Committee on Genetics, Health and Society

10:45 a.m. – 11:00 a.m.      **BREAK**

11:00 a.m. – 11:15 a.m.      **STATUS OF THE STATES**

Brad Therrell, Ph.D.  
Director, National Newborn Screening and Genetics Resource Center

11:15 a.m. – 12:00 p.m.

**FEDERAL LEGISLATIVE UPDATE**

Nancy S. Green, M.D.  
Medical Director, March of Dimes

12:00 p.m. – 1:00 p.m.

**WORKING LUNCH**

1:00 p.m. – 2:45 p.m.

**NOMINATION PROCESS FOR CANDIDATE  
CONDITIONS ON THE UNIFORM SCREENING PANEL**

- **PRESENTATION OF PILOT STUDY**
- **NEXT STEPS**

Nancy S. Green, M.D.  
Medical Director, March of Dimes

2:45 p.m. – 3:00 p.m.

**BREAK**

3:00 p.m. – 5:00 p.m.

**SUBCOMMITTEE MEETINGS**

5:00 p.m.

**ADJOURN**

**TUESDAY, JUNE 6**

- 8:00 a.m. – 8:30 a.m.      **CONTINENTAL BREAKFAST FOR COMMITTEE MEMBERS AND REPRESENTATIVES**
- 8:30 a.m. – 10:00 a.m.      **SUBCOMMITTEE REPORTS AND DISCUSSION**
- 10:00 a.m. – 10:45 a.m.      **POLICIES AND PROCEDURES FOR ADVISORY COMMITTEE PRACTICES**
- Michele A. Lloyd-Puryear, M.D., Ph.D.  
Executive Secretary, ACHDGDNC
- 10:45 a.m. – 11:15 a.m.      **BREAK**
- 11:15 a.m. – 12 noon      **UPDATE FROM COMMITTEE REPRESENTATIVES TO COMMITTEE**
- THE CHILD NEUROLOGY SOCIETY**  
Bennett Lavenstein, M.D.  
Child Neurology Society
- DEPARTMENT OF DEFENSE**  
David S. Louder, III, M.D., Lt Col, USAF, MC  
Chief Consultant for Maternal-Child Medicine and Pediatrics, AFMOA/SGOC
- FOOD AND DRUG ADMINISTRATION**  
Ethan Hausman, M.D.  
Medical Officer, Division of Gastrointestinal Products  
Office of New Drugs, ODE-3  
Center for Drug Evaluation and Research
- 12 noon – 1:00 p.m.      **WORKING LUNCH**
- 1:00 p.m. – 2:00 p.m.      **PUBLIC COMMENTS**
- 2:00 p.m. – 3:00 p.m.      **COMMITTEE BUSINESS**
- R. Rodney Howell, M.D.  
Committee Chair
- 3:00 p.m.      **ADJOURN**