

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

*Hilton Washington Hotel
Washington, DC
December 18-19, 2006*

MONDAY, DECEMBER 18

8:30 a.m. – 9:00 a.m. **Continental Breakfast** (Committee Members and Representatives)

9:00 a.m. – 9:15 a.m. **Health Resources and Services Administration Welcome**

Peter C. van Dyck, M.D., M.P.H., M.S.
Associate Administrator
Maternal and Child Health Bureau

9:15 a.m. – 9:30 a.m. **Opening Remarks**

- **Review of Committee Correspondence**
- **Approval of Minutes from June 2006 Meeting**

R. Rodney Howell, M.D.
Committee Chair

9:30 a.m. – 10:30 a.m. **Nomination/Evaluation Process for Candidate Conditions On the Uniform Screening Panel**

- **Report from the October 2006 Workgroup Meeting, “Process for Evaluation and Gathering Evidence”**

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

10:30 a.m. – 10:45 a.m. **Break**

10:45 a.m. – 11:45 a.m. **Report from the October 2006 Workgroup Meeting, “Process for Evaluation and Gathering Evidence” con’t**

Stephen M. Downs, M.D., M.S.
Associate Professor and Director
Indiana University School of Medicine

Alex Kemper, M.D., M.P.H., M.S.
Associate Professor
Duke University

**11:45 a.m. – 12:15 p.m. Regional Genetic and Newborn Screening Services
Collaboratives: An Update**

Michael S. Watson, Ph.D., FACMG
Executive Director
American College of Medical Genetics

12:15 p.m. – 1:15 p.m. Working Lunch

1:15 p.m. – 1:30 p.m. Federal Legislation: An Update

Cindy Pellegrini
Assistant Director
Department of Federal Affairs
American Academy of Pediatrics

1:30 p.m. – 1:45 p.m. Report on International Newborn Screening Meetings

R. Rodney Howell, M.D.
Committee Chair

**1:45 p.m. – 2:00 p.m. Distribution of Newborn Screening Educational Materials to
Primary Care Providers: ACTION Sheet Survey Report**

Anne Gramiak, M.P.H.
Manager, Screening Programs
American Academy of Pediatrics

**2:00 p.m. – 2:15 p.m. *A Parent's Guide to Newborn Screening*: March of Dimes
Video on Newborn Screening**

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

2:15 p.m. – 2:30 p.m. Break

2:30 p.m. – 5:00 p.m. Subcommittee Meetings

5:00 p.m. Adjourn

8:00 a.m. – 8:30 a.m. **Continental Breakfast** (Committee Members and Representatives)

8:30 a.m. – 10:30 a.m. **The Concepts of Benefit and Treatment**

- **The Early History of Universal Screening for Metabolic Disorders**

Jeffrey P. Brosco, M.D., Ph.D.
Associate Professor of Clinical Pediatrics
Director, Clinical Services, Mailman Center for Child
Development
University of Miami

- **Current Practices and Family Perspectives**

Don Bailey, Ph.D.
Distinguished Fellow
RTI International

Ellen Wright Clayton, M.D., J.D.
Professor of Pediatrics
Professor of Law
Co-Director, Center for Biomedical Ethics and Society
Vanderbilt University

- **Discussion**

10:30 a.m. – 11:00 a.m. **Break**

11:00 a.m. – 12:30 p.m. **Subcommittee Reports and Discussion**

- **Subcommittee on Follow-up and Treatment**
Coleen Boyle, Ph.D., M.S.
- **Subcommittee on Laboratory Standards and Procedures**
Amy Brower, Ph.D.
- **Subcommittee on Education and Training**
Gregory A. Hawkins, Ph.D.

12:30 p.m. – 1:30 p.m. **Working Lunch**

1:30 p.m. – 2:30 p.m. **Public Comments**

2:30 p.m. – 2:40 p.m. **ASSOCIATION OF PUBLIC HEALTH LABORATORIES
UPDATE ON NEWBORN SCREENING ACTIVITIES**

Michael R. Skeels, Ph.D., M.P.H.

2:40 p.m. – 3:00 p.m. **Committee Business**

- **Agenda Items for February 2007 Meeting**
- **Calendar for 2007 Meetings**
- **Standard Operating Procedures for ACHDGDNC**

R. Rodney Howell, M.D.
Committee Chair

3:00 p.m.

Adjourn