

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

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*Ronald Reagan Building and International Trade Center  
Washington, DC  
April 21-22, 2005*

## **Thursday, April 21**

8:30 a.m. – 9:00 a.m.                    **Continental Breakfast** (for Committee and Ex-Officio Members)

9:00 a.m. – 9:15 a.m.                    **Opening Remarks and Welcome**

- R. Rodney Howell, M.D.  
Committee Chair

9:15 a.m. – 10:30 a.m.                    **American College of Medical Genetics (ACMG) report to HRSA-Update**

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

### **Committee Discussion**

- R. Rodney Howell, M.D.  
Committee Chair

10:30 a.m. – 10:45 a.m.                    **Break**

10:45 a.m. – 12 p.m.                    **Committee Discussion of ACMG report, Continued**

- R. Rodney Howell, M.D.  
Committee Chair

12 noon. – 1:00 p.m.                    **Working Lunch** (for Committee and Ex-Officio Members)

1:00 p.m. – 2:00 p.m.                    **Public Comment Period**

2:00 pm. – 2:45 p.m.                    **Subcommittee meetings**

2:45 p.m. – 3:00 p.m.                    **Break**

3:00 p.m. – 4:30 p.m.                    **Parental Education Session**

**Survey of States for Policies and Procedures for Public and Professional Education**

- Donna Williams  
National Newborn Screening and Genetic Resource Center

**Parental Education Project**

- Terry Davis, Ph.D.  
Louisiana State University at Shreveport

**Sickle Cell Disease Newborn Screening Education Project**

- Janet Ohene-Frempong, M.S.  
President, J. O. Frempong and Associates

4:30 p.m. – 5:00 p.m.

**Committee Discussion**

- R. Rodney Howell, M.D.  
Committee Chair

5:00 p.m.

**Adjourn**

## **Friday, April 22**

8:00 a.m. – 8:30 p.m. **Continental Breakfast** (for Committee and Ex-Officio Members)

8:30 a.m. – 9:30 a.m. **Guidelines for Newborn Screening Follow-up-Addressing the System Performance Evaluation and Assessment System**

- Bradford Therrell, Ph.D.  
National Newborn Screening and Genetic Resource Center

### **Newborn Screening Follow-up Activities and Its Quality Assurance**

- William H. Hannon, Ph.D.  
Centers for Disease Control and Prevention
- Judith Tuerck, R.N., M.S.  
Assistant Professor  
Oregon Health and Science University

9:30 a.m. – 10:30 a.m. **Committee Business-Subcommittee Reports**

### **Education and Training**

- Jennifer Howse, Ph.D.  
President  
March of Dimes Birth Defects Foundation

### **Follow Up**

- Coleen Boyle, Ph.D., M.S.  
Associate Director  
Center for Disease Control and Prevention

10:30 a.m. – 10:45 p.m. **Break**

### **Committee Business-Subcommittee Reports, Continued**

10:45 a.m. – 11:15 a.m. **Laboratory Standards and Procedures**

- Amy Brower, Ph.D.  
Executive Director  
Third Wave Technologies  
Medical Informatics and Genetics

11:15 a.m. – 12 p.m. **Committee Discussion**

- R. Rodney Howell, M.D.

Committee Chair

12 p.m. – 1:00 p.m.

**Working Lunch** (for Committee and Ex-Officio Members)

1:00 p.m. – 2:00 p.m.

**Public Comments**

2:00 p.m. – 3:00 p.m.

**Setting Committee Priorities**

- R. Rodney Howell, M.D.  
Committee Chair

3:00 p.m.

**Adjourn**