

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

*Ronald Reagan Building and International Trade Center
Washington, DC
September 17-18, 2007*

MONDAY, SEPTEMBER 17, 2007

**8:30 A.M. – 9:00 A.M. CONTINENTAL BREAKFAST
(Committee Members and Representatives)**

**9:00 A.M. – 9:15 A.M. OPENING REMARKS
Rotunda Room**

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

- **Approval of Minutes from May 2007 Meeting**
- **Certificates of Appreciation for Departing Members**
- **New Representatives:**
 - American College of Medical Genetics
 - Society of Inherited Metabolic Disorders

**9:15 A.M. – 10:15 A.M. NOMINATION/EVALUATION PROCESS FOR CANDIDATE
CONDITIONS ON THE UNIFORM SCREENING PANEL**

James Perrin, M.D., FAAP

Professor of Pediatrics, Harvard Medical School Director,
Division of General Pediatrics
Director, Center for Child and Adolescent Health Policy,
Harvard Medical School
MassGeneral Hospital for Children

Nancy S. Green, M.D.

Division of Pediatric Hematology
Associate Dean for Clinical Research Operations
Columbia University Medical Center

10:15 A.M. – 10:30 A.M. BREAK

10:30 A.M. – 11:00 A.M. COMMITTEE REVIEW OF NOMINATION FORM

**11:00 A.M. – 11:30 A.M. SECRETARY'S ADVISORY COMMITTEE ON GENETICS,
HEALTH AND SOCIETY: WORKGROUP ON OVERSIGHT OF
GENETIC TESTS**

Andrea Ferreira-Gonzalez, Ph.D.
Professor of Pathology

**11:30 A.M. – 12:30 P.M. UPDATE FROM FEDERAL AGENCIES: RELEVANT TO
NEWBORN SCREENING**

Agency for Healthcare Research and Quality

Denise Dougherty, Ph.D.
Committee Member

Centers for Disease Control and Prevention

William H. Hannon, Ph.D.
Chief, Biochemical Branch
Division of Laboratory Sciences
National Center for Environmental Health

Health Resources and Services Administration (HRSA)

Peter C. van Dyck, M.D., M.P.H., M.S.
Committee Member

National Institutes of Health

Duane Alexander, M.D.
Committee Member

12:30 P.M. – 1:30 P.M. WORKING LUNCH

1:30 P.M. – 2:15 P.M. PUBLIC COMMENTS

2:15 P.M. – 2:30 P.M. BREAK

2:30 P.M. – 5:00 P.M. SUBCOMMITTEE SESSIONS

- **Subcommittee on Laboratory Standards and Procedures
Continental C Room**
- **Subcommittee on Education and Training
Continental B Room**
- **Subcommittee on Follow-up and Treatment
Meridian C Room**

5:00 P.M. ADJOURN

TUESDAY, SEPTEMBER 18, 2007

8:00 A.M. – 8:45 A.M.

**CONTINENTAL BREAKFAST
(Committee Members and Representatives)**

8:45 A.M. – 10:15 A.M.

SUBCOMMITTEE REPORTS AND DISCUSSION

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

10:15 A.M. – 10:30 A.M.

**LEGISLATIVE UPDATE: AMERICAN ACADEMY OF
PEDIATRICS**

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

10:30 A.M. – 10:45 A.M.

BREAK

10:45 A.M. – 11:15 A.M.

WORKGROUP ON RESEARCH AGENDA

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

11:15 A.M. – 11:30 A.M.

GENETIC ALLIANCE

Sharon F. Terry, M.A.
President and Chief Executive Officer
Genetic Alliance

11:30 A.M. – 12:00 P.M.

**CONSUMER PERSPECTIVES IN NEWBORN SCREENING:
HRSA FUNDED INITIATIVES**

Sharon F. Terry, M.A.
President and Chief Executive Officer
Genetic Alliance

12:00 P.M. - 1:00 P.M.

WORKING LUNCH

1:00 P.M. – 1:15 P.M.

**UPDATE FROM THE PERSONALIZED HEALTHCARE
WORKGROUP**

**Gregory J. Downing, D.O., Ph.D.
Project Director
Personalized Health Care
Immediate Office of the Secretary
Department of Health and Human Services**

1:15 P.M. – 2:00 P.M.

COMMITTEE BUSINESS

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

- **Increase in Congenital Hypothyroidism in New York and the United States**
- **Patent on Technologies used in Newborn Screening**
- **Agenda Items for January 2008 Meeting**
- **Calendar for 2008 Meetings**
- **Standard Operating Procedures**

2:00 P.M.

ADJOURN