

ADVISORY COMMITTEE ON HERITABLE DISORDERS AND GENETIC DISEASES IN NEWBORNS AND CHILDREN

Marriott Bethesda North Hotel & Conference Center, Bethesda, MD
January 14-15, 2008

MONDAY, JANUARY 14, 2008

8:00 A.M. – 9:00 A.M.

CONTINENTAL BREAKFAST
(Committee Members and Representatives)

9:00 A.M. – 9:30 A.M.
Salon F

ETHICS BRIEFING-NEW MEMBERS

Louise Wagner
Ethics and Personnel Security Specialist
Health Resources and Services Administration

9:30 A.M. – 10:00 A.M.

OPENING REMARKS

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

- Approval of Minutes from September 2007 Meeting
- Approval of Minutes from November 2007 Conference Call

10:00 A.M. – 10:15 A.M.

INTRODUCTION OF NEW MEMBERS

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

10:15 A.M. – 10:30 A.M.

BREAK

10:30 A.M. – 11:45 A.M.

NEWBORN SCREENING SYSTEMS: UTILIZING PARTNERSHIPS FOR FOLLOW-UP

Region 4 Collaborative: Long-Term Follow-Up After Newborn Screening – The Inborn Errors of Metabolism Information System

Susan A. Berry, M.D.
Professor and Director
Division of Genetics and Metabolism
Department of Pediatrics
University of Minnesota

PEDIATRIX and the Nebraska Newborn Screening Program

William S. Slimak

Vice President of Operations
Pediatrix Screening
Pediatrix/Obstetrix Medical Group

**New England Newborn Screening Program: Follow-up Activities
for Massachusetts and Rhode Island**

Roger B. Eaton, Ph.D., M.S.

Director
New England Newborn Screening Program
University of Massachusetts Medical School

**Northwest Regional Newborn Screening Program: Follow-up
Activities for the Northwest Region and the Pacific**

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

Committee Member

11:45 A.M. – 12 NOON

LEGISLATIVE UPDATE: MARCH OF DIMES

Emil Wigode

Director, Federal Affairs
Office of Government Affairs
March of Dimes

12:00 NOON– 1:00 P.M.

LUNCH

1:00 P.M. – 1:30 P.M.

**PERSONALIZED HEALTHCARE WORKGROUP: UPDATE ON
SUBGROUP ON NEWBORN SCREENING**

Stephen M. Downs, M.D., M.S.

Co-Chair, Subgroup on Newborn Screening
Associate Professor and Director
Children's Health Services Research
Indiana University School of Medicine

1:30 P.M. – 5:00 P.M.

SUBCOMMITTEE SESSIONS

- **Subcommittee on Laboratory Standards and Procedures
Brookside A Room**
- **Subcommittee on Education and Training
Brookside B Room**
- **Subcommittee on Follow-up and Treatment
Linden Oak Room**

5:00 P.M.

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TUESDAY, JANUARY 15, 2008

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

8:30 A.M. – 10:30 A.M. SUBCOMMITTEE REPORTS AND DISCUSSION

- **Subcommittee on Laboratory Standards and Procedures**
- **Subcommittee on Education and Training**
- **Subcommittee on Follow-up and Treatment**

10:30 A.M. – 10:45 A.M. BREAK

**10:45 A.M. – 11:15 A.M. SECRETARY’S ADVISORY COMMITTEE ON GENETICS,
HEALTH, AND SOCIETY - ASSESSMENT OF THE IMPACT
OF PATENTS ON ACCESS TO TESTS IN BOTH CLINICAL
PRACTICE AND PUBLIC HEALTH SETTINGS**

James P. Evans, M.D., Ph.D.

Chair, SACGHS Task Force on Gene Patents and Licensing
Practices

Professor of Genetics and Medicine

Director of Clinical Cancer Genetics and the Bryson Program in
Human Genetics

Departments of Medicine & Genetics

University of North Carolina at Chapel Hill

**11:15 A.M. – 12:15 P.M. EVIDENCE REVIEW WORKGROUP: NOMINATION AND
EVALUATION PROCESS FOR CONDITIONS ON THE
UNIFORM SCREENING PANEL**

James Perrin, M.D.

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

12:15 P.M. – 12:30 P.M.

HRSA REVIEW PROCESS

Marie Mann, M.D., M.P.H.

Genetic Services Branch

Maternal and Child Health Bureau

Health Resources and Services Administration

12:30 P.M. – 1:30 P.M.

LUNCH

1:30 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

- **Agenda Items for May 2008 Meeting**
- **Calendar for 2008 Meetings**

3:00 P.M.

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