

ADVISORY COMMITTEE ON HERITABLE DISORDERS IN NEWBORNS AND CHILDREN

Capital Hilton, 1001 16th Street, NW, Washington, DC 20036
General Session – Federal A/B Room, 2nd Floor

WEDNESDAY, OCTOBER 1, 2008

1:30 P.M. – 1:45 P.M.

WELCOME

R. Rodney Howell, M.D.
Committee Chair

- Approval of Minutes from August 2008 Meeting

1:45 P.M. – 2:15 P.M.

DECISION CRITERIA AND PROCESS WORKGROUP

Nancy S. Green, M.D.
Committee Consultant Workgroup Member

2:15 P.M. – 3:15 P.M.

EVIDENCE REVIEW WORKGROUP: REPORT ON THE CANDIDATE NOMINATION: (POMPE DISEASE)

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

Piero Rinaldo, M.D., Ph.D.
Committee Member

3:15 P.M. – 3:30 P.M.

BREAK

3:30 P.M. – 4:00 P.M.

PUBLIC COMMENTS

4:00 P.M. – 5:00 P.M.

**FINANCIAL REIMBURSEMENT AND INSURANCE COVERAGE FOR
MEDICAL FOODS**

- **MEDICAL FOODS WORKGROUP**

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

- **STATE POLICIES ON PAYMENT FOR DIETARY
TREATMENT OF DISORDERS IDENTIFIED THROUGH
NEWBORN SCREENING, A REPORT BY THE REGIONAL
COLLABORATIVES' NATIONAL COORDINATING CENTER
(NCC)**

Alissa L. Johnson, M.A.
Principal Consultant
Johnson Policy Consulting

5:00 P.M.

ADJOURN

THURSDAY, OCTOBER 2, 2008

**7:30 A.M. – 8:00 A.M. CONTINENTAL BREAKFAST
(Committee Members and Representatives)**

8:00 A.M. – 10:30 A.M. SUBCOMMITTEE SESSIONS

- **Laboratory Standards and Procedures**
Ohio Room, 2nd Floor
- **Education and Training**
Federal A/B Room, 2nd Floor
- **Follow-up and Treatment**
New York Room, 2nd Floor

10:30 A.M. – 11:00 A.M. BREAK

**11:00 A.M. – 12:00 P.M. PERSONALIZED HEALTHCARE WORKGROUP: UPDATE ON
SUBGROUP ON NEWBORN SCREENING**

- **NEWBORN SCREENING HEALTH IT STANDARDS AND USE
CASE RECOMMENDATIONS**

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

- **USE CASE PROCESS AND COMMUNITY INPUT**

Alan E. Zuckerman, M.D.
Consultant, AHIC Personalized Healthcare Workgroup
Co-Chair CCHIT Interoperability Workgroup
Primary Care Informatics Program Director
Georgetown University School of Medicine

12:00 P.M. – 1:00 P.M. LUNCH

1:00 P.M. – 1:45 P.M.

**EMERGENCY PREPAREDNESS AND CONTINGENCY PLANNING
FOR NEWBORN SCREENING**

- **HHS NATIONAL CONTINGENCY PLAN FOR
NEWBORN SCREENING**

Susan McClure

Associate Director for Program and Partnership
Development
Division of Laboratory Sciences
National Center for Environmental Health
Centers for Disease Control and Prevention

Mark E. Austin

Plans Section Lead
Division of Emergency Operations
Coordinating Office of Terrorism Preparedness and Emergency
Response
National Center for Environmental Health
Centers for Disease Control and Prevention

- **NEWBORN SCREENING PREPAREDNESS/CONTINGENCY
PLANNING FRAMEWORK: A WHITE PAPER BY THE
ASSOCIATION OF PUBLIC HEALTH LABORATORIES
(APHL)**

Jane Getchell, Dr.PH

APHL Organization Representative to the Committee

- **EMERGENCY PREPAREDNESS FOR NEWBORN
SCREENING AND GENETIC SERVICES: A REPORT BY THE
REGIONAL COLLABORATIVES' NATIONAL
COORDINATING CENTER (NCC)**

Michael S. Watson, Ph.D., FACMG

Executive Director
American College of Medical Genetics
Representative to the Committee

1:45 P.M. – 2:30 P.M.

SUBCOMMITTEE REPORTS

- **Subcommittee on Laboratory Standards and Procedures**

Gerard Vockley, M.D., PH.D.

Committee Member

- **Subcommittee on Education and Training**

**Jana Monaco and
Tracy L. Trotter, M.D., F.A.A.P.**
Committee Members

- **Subcommittee on Follow-up and Treatment**

Coleen Boyle, Ph.D., M.S.
Committee Member

2:30 P.M. – 3:00 P.M.

COMMITTEE BUSINESS

R. Rodney Howell, M.D.
Committee Chair

- **Agenda Items for the Next Meeting**
 - November 24, 2008 Meeting (Webcast)
 - February 26-27, 2009 Meeting
- **Calendar for 2009 Meetings**

3:00 P.M.

ADJOURN