

SECRETARY'S ADVISORY COMMITTEE ON
HERITABLE DISORDERS IN NEWBORNS AND CHILDREN

Advisory Committee Meeting

January 27-28, 2011

Renaissance Washington, DC, Dupont Circle Hotel, Washington, D.C.

THURSDAY, JANUARY 27, 2011

7:30 A.M. – 8:30 A.M. Continental Breakfast (Committee Members and Presenters)

8:30 A.M. – 10:30 A.M. Evidence Review Subcommittee-Closed Meeting

10:30 A.M. – 10:45 A.M. Committee Business

- *Approval of Minutes from the September 2010 Meeting*
- *Committee Correspondence*

R. RODNEY HOWELL, M.D.

COMMITTEE CHAIR

10:45 A.M. – 11:00 A.M. Update on NQF measures

SARA COPELAND, M.D.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

11:00 A.M. – NOON Evidence Review Workgroup Report: Preliminary Report On the Candidate Nomination Hyperbilirubinemia

JAMES PERRIN, M.D.

SACHDNC EXTERNAL EVIDENCE REVIEW WORKGROUP

12:00 P.M. – 1:00 P.M. Lunch

1:00 P.M. – 2:00 P.M. Newborn Screening for Severe Combined Immunodeficiency (SCID): State Status

JELILI OJODU, M.P.H. - SESSION LEADER

ASSOCIATION OF PUBLIC HEALTH LABORATORIES

Laboratory Update

Carla Cuthbert PhD, FCCMG, FACMG

Centers for Disease Control and Prevention

Follow-up and Treatment Update

Christine Seroogy, MD

University of Wisconsin

Parent Advocacy/ Educational Material Development

Marcia Boyle

Immune Deficiency Foundation

NBSTRN Update

Michael S. Watson, MS, PhD, FACMG

American College of Medical Genetics

2:00 P.M. – 5:00 PM

Subcommittee Meetings

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

FRIDAY, JANUARY 28, 2011

7:30 A.M. – 8:30 A.M. Continental Breakfast (Committee Members and Presenters)

8:30 A.M. – 10:00 A.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.
COMMITTEE MEMBERS

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

COLEEN BOYLE, PH.D., M.S. AND JEFFREY BOTKIN, M.D., M.P.H.
COMMITTEE MEMBERS

- ***Workgroup on Evidence Evaluation Methods***

R. RODNEY HOWELL, M.D. AND NED CALONGE, M.D., M.P.H.
COMMITTEE MEMBERS

10:00 A.M. – 10:15 A.M. Break

**10:15 A.M. – 10:45 P.M. Efficacy of Newborn Screening from a Family Perspective:
A National Survey of Recent and Prospective Mothers about
Newborn Screening**

DAVID KAUFMAN, PH.D.
JOHNS HOPKINS UNIVERSITY

10:45 A.M. – 11:15 A.M. Overarching Questions for Newborn Screening Long-term Follow-up

CYNTHIA F. HINTON, PH.D., M.S., M.P.H.
SUBCOMMITTEE ON TREATMENT AND FOLLOW-UP

- 11:15 A.M. – 12:15 P.M. Healthcare Reform and Implications for Genetics**
- **Financing and Status of Reimbursement for Genetic Services**

KAY JOHNSON
JOHNSON GROUP CONSULTING, INC.
 - **Current Efforts Related to Improved Financing and Healthcare Reform**

BRENT EWIG
ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS
- 12:15 – 1:15 P.M. Lunch**
- 1:15 P.M.—1:30 P.M. Public Comments**
- 1:30 P.M. – 2:00 P.M. The Committee’s Annual Report to Congress**
- ALAINA HARRIS, M.S.W., M.P.H.**
COMMITTEE STAFF
- 2:00 P.M. – 2:30 P.M. Report from the CCCHD meeting**
- TRACY TROTTER, M.D.**
COMMITTEE MEMBER
- 2:30 P.M. – 3:00 P.M. Committee Discussion**
- R. RODNEY HOWELL, M.D.**
COMMITTEE CHAIR
- 3:00 P.M. Adjourn**