

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

RENAISSANCE WASHINGTON, DC, DUPONT CIRCLE HOTEL
WASHINGTON, D.C.
MAY 13-14, 2010

THURSDAY, MAY 13, 2010

7:30 A.M. – 8:30 A.M. **CONTINENTAL BREAKFAST (COMMITTEE MEMBERS AND PRESENTERS)**

8:30 A.M. – 8:45 A.M. **COMMITTEE BUSINESS**

- APPROVAL OF MINUTES FROM THE JANUARY 2010 MEETING
- COMMITTEE CORRESPONDENCE
- UPDATE ON COMMITTEE REPORT ON THE RETENTION AND USE OF RESIDUAL BLOOD SPOTS AFTER NEWBORN SCREENING

R. RODNEY HOWELL, M.D.
COMMITTEE CHAIR

8:45 A.M. – 9:45 A.M. **CARRIER SCREENING**

- **REPORT ON BRIEFING PAPER FROM THE SICKLE CELL DISEASE CARRIER SCREENING WORKGROUP**

KWAKU OHENE-FREMPONG, M.D.
COMMITTEE MEMBER

- **PROPOSED TASK FORCE ON CARRIER SCREENING**

SARA COPELAND, M.D.
HEALTH RESOURCES AND SERVICES ADMINISTRATION

9:45 A.M. – 10:00 A.M. **PUBLIC COMMENT: CARRIER SCREENING**

10:00 A.M. – 10:30 A.M. **COMMITTEE DISCUSSION: CARRIER SCREENING**

10:30 A.M. – 10:45 A.M. **BREAK**

10:45 A.M. – 12:15 PM **NEWBORN SCREENING: SYSTEMS, INFORMATION, AND TECHNOLOGY NEEDS**

- **HEALTH INFORMATION TECHNOLOGY WORKGROUP REPORT (HITWG)**

SHARON TERRY, M.A. AND ALAN ZUCKERMAN, M.D.
CO-CHAIRS, HITWG

- **NEWBORN SCREENING TRANSLATIONAL RESEARCH NETWORK AND LONG-TERM FOLLOW-UP DATASETS**

MICHAEL WATSON, PhD
AMERICAN COLLEGE OF MEDICAL GENETICS

- **ASSESSMENT OF NEWBORN SCREENING PROGRAMS DATA AND INFORMATION SYSTEMS**

- **REPORT FROM THE NEWBORN SCREENING CLEARINGHOUSE'S MEETING - INFORMATION AND DATA COLLECTION FOR NEWBORN SCREENING: A NATIONAL APPROACH**

SHARON TERRY, M.A.
GENETIC ALLIANCE

- **SURVEY OF STATE NEWBORN SCREENING PROGRAM**

AMY BROWER, PH.D.
NATIONAL COORDINATING CENTER FOR THE REGIONAL COLLABORATIVES

12:15 P.M. – 1:15 P.M. **LUNCH (COMMITTEE MEMBERS AND PRESENTERS)**

1:15 P.M. – 1:45 P.M. **REPORT ON SECOND SCREEN STUDY**

JELILI OJODU, M.P.H.
ASSOCIATION OF PUBLIC HEALTH LABORATORIES

1:45 P.M. – 2:00 P.M. **COMMITTEE DISCUSSION**

2:00 P.M.—2:30 P.M. **NEWBORN SCREENING CONTINGENCY PLAN**

ALLISON JOHNSON, MPA
CENTERS FOR DISEASE CONTROL AND PREVENTION

2:30 P.M. –2:45 P.M. **BREAK**

2:45 P.M. – 5:15 PM **SUBCOMMITTEE MEETINGS**

- **FOLLOW-UP AND TREATMENT**
- **EDUCATION AND TRAINING**
- **LABORATORY STANDARDS**

5:15 P.M. **ADJOURN**

FRIDAY, MAY 14, 2010

7:30 A.M. – 8:30 A.M. CONTINENTAL BREAKFAST (COMMITTEE MEMBERS AND PRESENTERS)

8:30 A.M. – 9:45 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.
COMMITTEE MEMBERS

- **SUBCOMMITTEE ON FOLLOW-UP AND TREATMENT**

COLEEN BOYLE, PH.D., M.S.
COMMITTEE MEMBER

9:45 A.M. – 10:45 A.M. EVIDENCE REVIEW WORKGROUP REPORT: FINAL REPORT ON THE CANDIDATE NOMINATION HEMOGLOBIN H

ALEX KEMPER, M.D., M.P.H., M.S.
EVIDENCE REVIEW WORKGROUP

10:45 A.M. – 11:00 A.M. BREAK

11:00 A.M. – 11:30 A.M. RESPONSE TO COUNCIL ON BIOETHICS' REPORT ON NEWBORN SCREENING – COMMITTEE DISCUSSION

TRACY L. TROTTER, M.D.
COMMITTEE MEMBER

11:30 A.M. – 12 NOON LYSOSOMAL STORAGE DISEASES—REPORT ON STATE SCREENING PRACTICES

MICHAEL WATSON, PH.D.
AMERICAN COLLEGE OF MEDICAL GENETICS

12 NOON – 1:00 P.M. LUNCH (COMMITTEE MEMBERS AND PRESENTERS)

1:00 P.M. – 2:00 P.M. EVIDENCE REVIEW WORKGROUP REPORT: LITERATURE REVIEW FOR CRITICAL CYANOTIC CONGENITAL HEART DISEASE

ALEX KEMPER, M.D., M.P.H., M.S.
EVIDENCE REVIEW WORKGROUP

2:00 P.M. – 2:30 P.M.

PUBLIC COMMENTS: GENERAL

2:30 P.M. – 3:00 P.M.

COMMITTEE DISCUSSION

3:00 P.M. – 3:30 P.M.

COMMITTEE BUSINESS

- AGENDA ITEMS FOR SEPTEMBER 2010 MEETING

R. RODNEY HOWELL, M.D.

COMMITTEE CHAIR

3:30 P.M.

ADJOURN