

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

WASHINGTON MARRIOTT AT METRO CENTER, WASHINGTON, D.C.
SEPTEMBER 16-17, 2010

THURSDAY, SEPTEMBER 16, 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 MAY 2010 MEETING
- COMMITTEE CORRESPONDENCE
- CERTIFICATES OF APPRECIATION

R. RODNEY HOWELL, M.D.
COMMITTEE CHAIR

**8:45 A.M. – 9:15 A.M. REPORT ON BRIEFING PAPER FROM THE SICKLE CELL DISEASE
CARRIER SCREENING WORKGROUP- DRAFT**

KWAKU OHENE-FREMPPONG, M.D.
COMMITTEE MEMBER

9:15 A.M. – 9:30 A.M. COMMITTEE DISCUSSION

9:30 A.M. – 10:00 A.M. SACHDNC'S ROLE IN MEANINGFUL USE

SHARON TERRY, M.A.
GENETIC ALLIANCE
CO-CHAIR, HITWG

ALAN ZUCKERMAN, M.D.
HRSA AND NATIONAL INSTITUTES OF HEALTH
CO-CHAIR, HITWG

**10:00 A.M. – 10:30 A.M. DEVELOPMENT OF CODING STANDARDS FOR NEWBORN SCREENING
TESTS**

CARLA CUTHBERT, PH.D.
CENTERS FOR DISEASE CONTROL AND PREVENTION

CLEMENT McDONALD, M.D.
NATIONAL LIBRARY OF MEDICINE, NIH

10:30 A.M. – 10:45 A.M. BREAK

10:45 A.M. – 11:15 A.M. COMMITTEE REPORT ON THE RETENTION AND USE OF RESIDUAL DRIED BLOOD SPOT SPECIMENS AFTER NEWBORN SCREENING

REVIEW OF PUBLIC COMMENTS
REVIEW OF PROPOSED CHANGES TO THE RECOMMENDATIONS

ALISSA JOHNSON, M.A.
JOHNSON POLICY CONSULTING

LISA VASQUEZ, M.A.
HEALTH RESOURCES AND SERVICES ADMINISTRATION
COMMITTEE STAFF

11:15 A.M. – 11:45 A.M. COMMITTEE DISCUSSION

11:45 A.M. – 12:00 P.M. PUBLIC COMMENTS

12:00 P.M. – 1:00 P.M. LUNCH

1:00 P.M. – 1:30 P.M. CLIAC RECOMMENDATIONS FOR DEVELOPMENT OF GOOD LABORATORY PRACTICE GUIDELINES FOR BIOCHEMICAL GENETIC TESTING AND NEWBORN SCREENING

CAROL GREENE, M.D.
PRESIDENT-ELECT, SOCIETY FOR INHERITED METABOLIC DISORDERS

BIN CHEN, PH.D.
CENTERS FOR DISEASE CONTROL AND PREVENTION

1:30 P.M. – 1:45 P.M. REPORT ON THE HRSA-NNSGRC-APHL HEMOGLOBINOPATHY WORKSHOP

BRADFORD THERRELL, JR., PH.D.
NATIONAL NEWBORN SCREENING AND GENETICS RESOURCE CENTER

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

2:00 P.M. – 5:00 PM SUBCOMMITTEE MEETINGS

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

5:00 P.M. ADJOURN

5:15 P.M. – 6:30 PM HEALTH INFORMATION TECHNOLOGY WORKGROUP MEETING

FRIDAY, SEPTEMBER 17, 2010

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

8:30 A.M. – 9:45 P.M. SUBCOMMITTEE AND WORKGROUP 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 HEALTH INFORMATION TECHNOLOGY**

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

9:45 A.M. – 10:30 A.M. EVIDENCE REVIEW WORKGROUP REPORT: REPORT ON THE CANDIDATE NOMINATION CRITICAL CONGENITAL HEART DISEASE

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

10:30 A.M. – 10:45 A.M. BREAK

10:45 A.M. – 11:30 A.M. COMMITTEE INTERNAL EVIDENCE REVIEW PROCESS

NED CALONGE, M.D., PH.D.
COMMITTEE MEMBER

JAMES PERRIN, M.D.
SACHDNC EXTERNAL EVIDENCE REVIEW WORKGROUP

11:30 A.M. – 12:00 PM COMMITTEE DISCUSSION

12:00 – 1:00 P.M. LUNCH

1:00 P.M –1:30 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.
GENETICS AND PUBLIC POLICY CENTER
JOHNS HOPKINS UNIVERSITY

1:30 P.M. – 2:30 P.M.

**ACCESS TO MEDICAL FOODS AND FORMULAS: SUMMARY OF
REGIONAL SURVEYS**

SUSAN BERRY, M.D.
REGION 4 GENETICS AND NEWBORN SCREENING COLLABORATIVE

2:30 P.M. – 2:45 P.M.

PUBLIC COMMENTS

2:45 P.M. – 3:00 P.M.

COMMITTEE DISCUSSION

R. RODNEY HOWELL, M.D.
COMMITTEE CHAIR

3:00 P.M.

ADJOURN