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-FREMPONG, 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

CLEMONT 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