

ADVISORY COMMITTEE ON HERITABLE DISORDERS IN NEWBORNS AND CHILDREN

WEBCAST - May 12, 2009
1:00 P.M. – 5:00 P.M. EDT

1:00 P.M. – 1:15 P.M.

WELCOME

R. Rodney Howell, M.D. Committee Chair

- Roll Call
- Approval of minutes from February 26-27, 2009 meeting
- Committee Correspondence

1:15 P.M. – 1:45 P.M.

UPDATE ON THE NOMINATION FOR SEVERE COMBINED IMMUNODEFICIENCY DISORDER

Robert Vogt, Ph.D. - Centers for Disease Control and Prevention (CDC)

- CDC Proposed Pilots
- CDC Proficiency Testing Samples

Duane Alexander, M.D. - National Institutes of Health (NIH)

- National Institute of Child Health and Human
Development (NICHD) Proposed Pilots

R. Rodney Howell, M.D. - Committee Chair

- Committee Discussion to Outline Next Steps

1:45 P.M. – 2:00 P.M.

RESIDUAL BLOOD SPOTS: PROPOSAL FOR A BRIEFING PAPER ON THE TOPIC OF POLICIES AND PROCEDURES FOR THEIR USE AND STORAGE

Jana Monaco - Committee Member

Brad Therrell, Ph.D. - National Newborn Screening and Genetic
Resource Center (NNSGRC)

2:00 P.M. – 2:15 P.M.

COMMITTEE DISCUSSION: BRIEFING PAPER PROPOSAL

R. Rodney Howell, M.D. - Committee Chair

2:15 P.M. – 2:45 P.M.

IMPACT OF THE PRESENT ECONOMY ON THE NEWBORN SCREENING INFRASTRUCTURE

Jane Getchell, Dr.PH. - Committee Representative

2:45 P.M. – 3:00 P.M.

BREAK

3:00 P.M. – 3:45 P.M.

EVIDENCE REVIEW WORKGROUP: PRELIMINARY REPORT ON THE CANDIDATE NOMINATION: KRABBE DISEASE

Alex Kemper, M.D., M.P.H., M.S. - Evidence Review Workgroup

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3:45 P.M. – 4:15 P.M. **COMMITTEE DISCUSSION ON THE NOMINATION OF KRABBE
DISEASE TO THE RECOMMENDED UNIFORM SCREENING PANEL**

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

4:15 P.M. – 4:30 P.M. **PUBLIC COMMENTS**

4:30 P.M. – 5:00 P.M. **COMMITTEE BUSINESS**

R. Rodney Howell, M.D. - Committee Chair

- Calendar for September 2009 Meeting
- Calendar for 2010 meetings

5:00 P.M. **ADJOURN**