

29th Meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

Thursday, January 31, 2013

9:30 A.M. – 10:00 A.M.

Committee Business

- Approval of September 2012 Meeting Minutes

Joseph Bocchini, MD
Committee Chair

10:00 A.M. – 11:00 A.M.

Condition Review Matrix –
Alex Kemper, MD, MPH, MS

** Vote on application of Condition Review Decision Matrix*

11:00 A.M. – 11:15 A.M.

BREAK

11:15 A.M. – 11:45 A.M.

Public Comments

11:45 A.M. – 12:30 P.M.

LUNCH

12:30 P.M. – 1:45 P.M.

Update on Pompe Condition Nomination

Alex Kemper, MD, MPH, MS

1:45 P.M. – 2:30 P.M.

Carrier Screening Final Report

Meredith Weaver, PhD, ScM, CGC

** Vote on SACHDNC support for project*

2:30 P.M. – 2:45 P.M.

BREAK

2:45 P.M. – 5:00 P.M.

Subcommittee Meetings

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

28th Meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

Friday, February 1, 2013

9:30 A.M. – 10:15 A.M.

**Update on State CCHD Screening, SCID, and Data
Collection Implementation**

Marci Sontag, PhD and Amy Brower, PhD

10:15 A.M. – 10:45 A.M.

**Update on NIH Genomic Sequencing and Newborn
Screening Disorders Initiative**

Tiina Urv, PhD

10:45 A.M. – 11:30 A.M.

Duchenne Muscular Dystrophy NBS Symposium

Jerry Mendell, MD

11:30 A.M. – 11:45 A.M.

BREAK

11:45 A.M. – 1:15 P.M.

Subcommittee Reports

- Subcommittee on Laboratory Standards and Procedures
Fred Lorey, PhD
Committee Member
- Subcommittee on Education and Training
Don Bailey, PhD, MEd
Organizational Representative
- Subcommittee on Follow-up and Treatment
Carol Greene, MD
Organizational Representatives

1:15 P.M.

ADJOURN