

# **29<sup>th</sup> Meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children**

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**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 Decision Matrix**

Alex Kemper, MD, MPH, MS

*\* Vote on application of 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.

**Population Based Carrier Screening**

Meredith Weaver, PhD, ScM, CGC

*\* Vote on SACHDNC Affirmation of Value*

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

# **29<sup>th</sup> Meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children**

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**Friday, February 1, 2013**

9:30 A.M. – 10:15 A.M.

**Update on State Implementation of Screening and Data  
Collection for CCHD and SCID**

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.

**Update on MDA Muscle Disease Symposium on  
Newborn Screening for Duchenne Muscular Dystrophy**

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  
Carla Cuthbert, PhD  
CDC Ex-Officio (alternate)
- Subcommittee on Education and Training  
Don Bailey, PhD, MEd  
Committee Chair
- Subcommittee on Follow-up and Treatment  
Carol Greene, MD  
Organizational Representatives

1:15 P.M.

**ADJOURN**