

2nd Meeting of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

Thursday, September 19, 2013

ADMINISTRATIVE BUSINESS

10:30 AM – 10:45 AM

Welcome

- Committee Correspondence
- Approval of May 2013 Meeting Minutes

Joseph Bocchini, MD
Committee Chair

ADVISORY COMMITTEE, SUBCOMMITTEE, WORKGROUP AND OTHER REPORTS

10:45 AM – 11:45 AM

Assessing the Impact of the Committee's Recommendations on Long-term Follow-up on State Newborn Screening Programs

Beth Tarini, MD, MS, FAAP
American Academy of Pediatrics
Organizational Representative

11:45 AM – 12:00 PM

Newborn Screening Clearinghouse – Baby's First Test CCHD Videos

Natasha Bonhomme, MA
Genetic Alliance
Organizational Representative

12:00 PM – 1:15 PM

LUNCH

2nd Meeting of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

UPDATE ON RUSP CONDITIONS

1:15 PM – 2:15 PM

**Policy impact of the SACHDNC recommendations
regarding sickle cell trait screening in athletes**

Alexis Thompson, MD, MPH
Committee Member

Beth Tarini, MD, MS, FAAP
American Academy of Pediatrics
Organizational Representative

2:15 PM – 2:30 PM

BREAK

2:30 PM – 4:30 PM

Subcommittee Meetings

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

Friday, September 20, 2013

10:00 AM – 11:30 AM

Subcommittee Reports

- Laboratory Standards and Procedures Subcommittee
Kellie Kelm, PhD
Chair
Committee Member

Susan Tanksley, PhD
Co-Chair
Association of Public Health Laboratories
Organizational Representative

2nd Meeting of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

- Education and Training Subcommittee
Don Bailey, PhD, MEd
Chair
Committee Member

Beth Tarini, MD, MS, FAAP
Co-Chair
American Academy of Pediatrics
Organizational Representative

- Follow-up and Treatment Subcommittee
Carol Greene, MD
Chair
Society for Inherited Metabolic Disorders
Organizational Representative

Chris Kus, MD, MPH
Co-Chair
Association of State & Territorial Health Officials
Organizational Representative

11:30 AM – 11:45 AM

Public Comment

11:45 AM – 1:00 PM

LUNCH

[PERTINENT MEETING UPDATES AND TOPICS OF INTEREST](#)

1:00 PM – 2:00 PM

Whole Genome Sequencing in Newborn Screening

Mike Watson, PhD
American College of Medical Genetics
Organizational Representative

2:00 PM – 3:00 PM

Update on MPS 1 Evidence Review

Alex Kemper, MD, MPH, MS
Condition Review Workgroup
Duke Clinical Research Institute and Department of Pediatrics

3:00 PM – 3:10 PM

Open Discussion on Future Meeting Topics

3:10 PM

ADJOURN