

Discretionary Advisory Committee on Heritable Disorders in Newborns and Children September 2014 Meeting

September 11 – 12, 2014
Webinar and In-Person Meeting
NIH Natcher Center
9000 Rockville Pike
Bethesda, Maryland 20892

Thursday, September 11, 2014

9:30 AM – 9:35 AM

Welcome

- Opening Remarks
- Committee Correspondence
- Approval of May 2014 Meeting Minutes **Vote**

Joseph Bocchini, MD
Committee Chair
Louisiana State University

Debi Sarkar, MPH
Designated Federal Official
Health Resources and Services Administration

9:35 AM – 9:45 AM

Pilot Study Workgroup Update

Jeffery Botkin, MD, MPH
Committee Member
University of Utah

9:45 AM – 10:15 AM

The Inborn Errors of Metabolism Collaborative (IBEMC) – Update

Sue Berry, MD
Professor and Director
Division of Genetics and Metabolism
Department of Pediatrics and Genetics, Cell Biology
& Development
University of Minnesota

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Thursday, September 12, 2014 (cont'd)

10:15 AM – 10:45 AM	The Impact, Products, and Future Applications of the Region 4 Stork (R4S) Collaborative Project Piero Rinaldo, MD, PhD Division of Laboratory Genetics Department of Laboratory Medicine and Pathology Mayo Clinic
10:45 AM – 11:00 AM	PUBLIC COMMENTS
11:00 AM – 11:15 AM	BREAK
11:15 AM – 12:00 PM	Condition Review Update – Mucopolysaccharidosis I (MPS I) Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
12:00 PM – 1:15 PM	LUNCH
1:15 PM – 2:15 PM	Condition Review Update – Public Health Systems Impact Assessment Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
2:15 PM – 2:30 PM	BREAK
2:30 PM – 4:30 PM	SUBCOMMITTEE MEETINGS

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9:00 AM – 10:30 AM

Laboratory Procedures and Standards Subcommittee Update – Timely Newborn Screening Project and other projects

Kellie Kelm, PhD
Chair
Committee Member
Food and Drug Administration

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

10:30 AM – 11:30 AM

Electronic Standards for Public Health Information Exchange – National Committee on Vital and Health Statistics Letter to the Secretary

Walter G. Suarez, MD, MPH
Executive Director, Health IT Strategy and Policy
Kaiser Permanente Information Technology
National Committee on Vital and Health Statistics

11:30 AM – 1:00 PM

LUNCH

1:00 PM – 1:30 PM

Report: *Succinylacetone as primary marker to detect tyrosinemia type I in newborns and its measurement by newborn screening programs*
Vote

Joseph Bocchini, MD
Committee Chair
Louisiana State University

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Friday, September 12, 2014 (cont'd)

1:30 PM – 2:00 PM

Follow-up and Treatment Subcommittee Update

Charlie Homer, MD, MPH

Chair

Committee Member

National Institute for Children's Health Quality
(NICHQ)

2:00 PM – 2:30 PM

Education and Training Subcommittee Update

Cathy Wicklund, MS, CGC

Chair

Committee Member

Northwestern University

2:30 PM – 3:00 PM

Future topics (discussion)

3:00 PM

ADJOURN