

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

Webinar and In-Person Meeting
U.S. Pharmacopeial Convention (USP) Headquarters
12601 Twinbrook Parkway
Rockville, Maryland 20852

Thursday, May 29, 2014

9:30 AM – 9:45 AM

Welcome

- Opening Remarks
- Committee Correspondence
- Approval of January 2014 Meeting Minutes
Vote

Joseph Bocchini, MD
Committee Chair
Louisiana State University

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

9:45 AM – 11:45 AM

Public Health Impact

Joseph Bocchini, MD
Committee Chair
Louisiana State University

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

Jelili Ojodu, MPH
Newborn Screening and Genetics
Association of Public Health Laboratories

11:45 AM – 12:00 PM

Public Comments

12:00 PM – 1:15 PM

LUNCH

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

Thursday, May 29, 2014 (cont'd)

1:15 PM – 2:00 PM

Impact of Electronic Health Records Implementation on the Early Hearing Detection and Intervention Programs

Coleen Boyle, PhD, MSHyg
Committee Member
Centers for Disease Control and Prevention (CDC)

John Eichwald, MA
Branch Chief
Child Development and Disability
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention (CDC)

2:00 PM – 2:30 PM

BREAK

2:30 PM – 4:30 PM

Subcommittee Meetings

4:30 PM

End of Day 1

Friday, May 30, 2014

9:00 AM – 9:45 AM

Conducting research on population-based screening (discussion)

Jeff Botkin, MD, MPH
Committee Member
University of Utah

9:45 AM – 10:00 AM

Pilot Study Data Needed for Condition Reviews (discussion)

Joseph Bocchini, MD
Committee Chair
Louisiana State University

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

Friday, May 30 (*cont'd*)

10:00 AM – 10:15 AM

Public Comments

10:15 AM – 11:00 AM

New CPT codes established for molecular diagnostics and their impact on genetic testing laboratories and patient access

Michael S. Watson, PhD, MS, FACMG
Organizational Representative
American College of Medical Genetics

11:00 AM – 11:30 AM

Subcommittee Reports

Laboratory Standards and Procedures

Kellie Kelm, PhD

Chair

Committee Member

Food and Drug Administration (FDA)

Susan Tanksley, PhD

Co-Chair

Organizational Representative

Association of Public Health Laboratories

11:30 AM – 12:30 PM

LUNCH

12:30 PM – 1:00 PM

Subcommittee Reports

Follow-up and Treatment

Carol Greene, MD

Chair

Organizational Representative

Society for Inherited Metabolic Disorders

Chris Kus, MD, MPH

Co-Chair

Organizational Representative

Association of State & Territorial Health Officials

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

Friday, May 30 (*cont'd*)

1:00 PM – 1:30 PM

Subcommittee Reports

Education and Training

Beth Tarini, MD, MS, FAAP

Co-Chair

Organizational Representative

American Academy of Pediatrics

1:30 PM

Future topics (discussion)

1:45 PM

ADJOURN