

The Advisory Committee on Heritable Disorders in Newborns and Children

HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)
August 3 - 4, 2017

DAY 1 Meeting Agenda: Thursday, August 3, 2017

TIME	TOPIC	PRESENTER
9:30 – 9:45 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • May 2017 Minutes 	<p>Joseph Bocchini, MD Committee Chair Professor and Chairman, Department of Pediatrics, Louisiana State University</p> <p>Catharine Riley, PhD, MPH Acting Designated Federal Official Health Resources and Services Administration</p>
9:45 – 10:15 AM	SMA Evidence Review – Phase 1 Report	<p>Alex R. Kemper, MD, MPH, MS Lead, Evidence-based Review Group Division Chief, Ambulatory Pediatrics, Nationwide Children’s Hospital</p>
10:15 – 10:45 AM	Q&A and Committee Feedback – SMA Evidence Review	
10:45 – 11:30 AM	Quality Measures in Newborn Screening to Promote Long Term Follow-up	<p>Jeffrey P. Brosco, MD, PhD Committee Member Chair, Follow up and Treatment Workgroup Professor of Clinical Pediatrics, University of Miami School of Medicine</p> <p>Alan Zuckerman, MD Member, Follow Up and Treatment Workgroup Assistant Professor, Community and Family Medicine and Department of Pediatrics, Georgetown University</p>
11:30 – 11:50 PM	Public Comments	
11:50 – 12:50 PM	LUNCH	
12:50 – 1:20 PM	Establishing and Revisiting Newborn Screening Cutoffs - Lessons Learned from States	<p>Susan Tanksley, PhD Organizational Representative, Association of Public Health Laboratories</p>
1:20 – 1:40 PM	Establishing and Revisiting Newborn Screening Cutoffs – Summary and Next Steps	<p>Joseph Bocchini, MD Committee Chair Professor and Chairman, Department of Pediatrics, Louisiana State University</p>
1:40 – 2:30 PM	Committee Discussion – Establishing and Revisiting Newborn Screening Cutoffs	
2:30 – 3:00 PM	BREAK	
3:00 – 5:00 PM	<p>Workgroup Meetings</p> <ul style="list-style-type: none"> • Education and Training Workgroup • Laboratory Standards and Procedures Workgroup • Follow up and Treatment Workgroup 	
5:00 PM	ADJOURN	

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DAY 2 Meeting Agenda: Friday, August 4, 2017

TIME	TOPIC	PRESENTER
9:30 – 9:50 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Recognition of Service – Dr. Coleen Boyle, CDC 	<p>Joseph Bocchini, MD Committee Chair Louisiana State University</p> <p>Catharine Riley, PhD, MPH Acting Designated Federal Official Health Resources and Services Administration</p>
9:50 – 10:20 AM	Overview of Newborn Screening Technology	<p>Alex R. Kemper, MD, MPH, MS Lead, Evidence-based Review Group Division Chief, Ambulatory Pediatrics, Nationwide Children’s Hospital</p>
10:20 – 10:40 AM	Education and Training Workgroup Update	<p>Cathy Wicklund, MS, CGC Committee Member Chair, Education and Training Workgroup Northwestern University</p>
10:40 – 11:00 AM	Follow Up and Treatment Workgroup Update	<p>Jeffrey P. Brosco, MD, PhD Committee Member Chair, Follow up and Treatment Workgroup Professor of Clinical Pediatrics University of Miami School of Medicine</p>
11:00 – 11:30 AM	BREAK	
11:30 – 11:50 AM	Laboratory Standards and Procedures Workgroup Update	<p>Kellie Kelm, PhD Ex-Officio Committee Member, Food and Drug Administration Chair, Laboratory Standards and Procedures Workgroup</p>
11:50 – 12:05 PM	Committee Discussion - Workgroup Activities	
12:05 – 12:50 PM	Clinical and Public Health Implications of Critical Congenital Heart Defects Newborn Screening	<p>Scott Grosse, PhD Research Economist Office of the Director, National Center on Birth Defects and Developmental Disabilities, CDC</p> <p>Matt Oster, MD, MPH Director, Children’s CORPS (Cardiac Outcomes Research Program at Sibley Heart Center), Emory University School of Medicine</p>
12:50 – 1:00 PM	New Business	<p>Joseph Bocchini, MD Committee Chair Professor and Chairman, Department of Pediatrics, Louisiana State University</p>
1:00 PM	ADJOURN	