

The Advisory Committee on Heritable Disorders in Newborns and Children

HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)
November 8-9, 2017

DAY 1 Meeting Agenda: Wednesday, November 8, 2017

TIME	TOPIC	PRESENTER
9:30 – 9:45 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • August 2017 Minutes 	<p>Joseph Bocchini, MD Committee Chair Professor and Chairman, Department of Pediatrics, Louisiana State University</p> <p>Catharine Riley, PhD, MPH Designated Federal Official Health Resources and Services Administration</p>
9:45 – 10:30 AM	Working Toward Newborn Screening Timeliness Goals	<p>Joshua Miller, MPH Research Instructor, Colorado School of Public Health Data Specialist, NewSTEPS</p>
10:30 – 11:00 AM	Q&A and Committee Discussion Regarding NBS Timeliness Goals	
11:00 – 11:30 AM	PUBLIC COMMENTS	
11:30 – 12:30 PM	LUNCH	
12:30– 1:45 PM	Implications of Detecting Carriers Through Newborn Screening	<p>Michael Watson, PhD, FACMG Executive Director American College of Medical Genetics</p> <p>Aaron Goldenberg, PHD, MPH Associate Professor of Bioethics and Director of Research, Dept of Bioethics, Case Western Reserve University</p> <p>Michele Caggana, Sc.D., FACMG Director, Newborn Screening Program New York State Department of Health</p>
1:45– 2:15 PM	SMA Evidence Review – Phase 2 Report	<p>Alex R. Kemper, MD, MPH, MS Lead, Evidence-based Review Group</p>
2:15 – 2:45 PM	Q&A and Committee Feedback – SMA Evidence Review	
2:45 PM	ADJOURN	

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 	
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November 8-9, 2017

DAY 2 Meeting Agenda: Thursday, November 9, 2017

TIME	TOPIC	PRESENTER
9:30 – 9:45 AM	<ul style="list-style-type: none"> • Welcome • Roll Call 	<p>Joseph Bocchini, MD Committee Chair Louisiana State University</p> <p>Catharine Riley, PhD, MPH Designated Federal Official, Health Resources and Services Administration</p>
9:45 – 10:05 AM	Education and Training Workgroup Update	Beth Tarini, MD, MS, FAAP Committee Member Co-Chair, Education & Training Workgroup
10:05 – 10:25 AM	Committee Discussion	
10:25 – 10:45 AM	Follow-Up and Treatment Workgroup Update	Jeffrey P. Brosco, MD, PhD Committee Member Chair, Follow up & Treatment Workgroup
10:45 – 11:05 AM	Committee Discussion	
11:05 – 11:25 PM	Laboratory Standards and Procedures Workgroup Update	Kellie Kelm, PhD Ex-Officio Committee Member, FDA Chair, Laboratory Standards and Procedures Workgroup
11:25 – 11:45 AM	Committee Discussion	
11:45 – 12:45 PM	LUNCH	
12:45 – 1:00 PM	Prioritizing 2018 Workgroup Activities	
1:00 – 2:15 PM	Clinical and Public Health Impact of SCID Screening	<p>Sikha Singh, MHS, PMP Manager, Newborn Screening and Genetics Operations, Association of Public Health Laboratories</p> <p>Adrienne Manning Division Director, Newborn Screening Connecticut Department of Public Health</p> <p>Lisa Kobrynski, MD, MPH Associate Professor of Pediatrics Marcus Professor of Immunology Section, Allergy/Immunology</p>
2:15 – 2:30 PM	New Business	Joseph Bocchini, MD Committee Chair
2:30 PM	ADJOURN	