

The Advisory Committee on Heritable Disorders in Newborns and Children

HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)
May 11 – 12, 2017

DAY 1 Meeting Agenda: Thursday, May 11, 2017

TIME	TOPIC	PRESENTER
9:00 – 9:20 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • February 2017 Minutes 	<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>
9:20 – 9:40 AM	R4S and CLIR – Interactive Web Tools	Piero Rinaldo, MD, PhD Professor of Laboratory Medicine And Pathology, Mayo Clinic
9:40 – 10:00 AM	CDC's Newborn Screening QA/QC Program	Carla Cuthbert, PhD, FACMG, FCCMG Chief, Newborn Screening and Molecular Biology Branch, National Center for Environmental Health, Centers for Disease Control and Prevention
10:00 – 11:00 AM	Identifying and following up on out of range and borderline results - state perspectives	<p>Panel Presentations:</p> <p>Michele Caggana, Sc.D., FACMG Director, Newborn Screening Program New York State Department of Health</p> <p>Scott Shone, PhD Research Scientist/Program Manager New Jersey Department of Health Newborn Screening</p> <p>Amy Gaviglio, MS, CGC Follow-Up Supervisor/Genetic Counselor, Minnesota Department of Health Newborn Screening Program</p>
11:00 – 11:30 AM	Committee Discussion	

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TIME	TOPIC	PRESENTER
11:30 – 12:00 PM	Public Comments	
12:00 – 1:00 PM	LUNCH	
1:00 – 1:30 PM	SMA Nomination – Summary	Beth Tarini, MD, MS – on behalf of the Nomination and Prioritization Workgroup Committee Member Associate Professor and Division Director General Pediatrics & Adolescent Medicine University of Iowa Hospitals & Clinics
1:30 – 2:00 PM	Committee Discussion <i>VOTE on whether to move SMA forward to a full evidence review</i>	
2:00 – 2:15 PM	A Report on Medical Foods for Inborn Errors of Metabolism	Sue Berry, MD Director, Division of Genetics and Metabolism, Department of Pediatrics, University of Minneapolis
2:15 – 2:45 pm	Committee Discussion <i>VOTE on accepting A Report on Medical Foods for Inborn Errors</i>	
2:45 – 3:00 PM	BREAK	
3:00 – 5:00 PM	Workgroup Meetings <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, May 12, 2017

TIME	TOPIC	PRESENTER
9:00 – 9:30 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Recognition of Service 	<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>
9:30 – 10:30 AM	Implementation of Critical Congenital Heart Defects Newborn Screening	<p>Panel Presentations:</p> <p>Annamarie Saarinen Co-founder, CEO Newborn Foundation</p> <p>Amy Gaviglio, MS, CGC Follow-Up Supervisor/Genetic Counselor, Minnesota Department of Health Newborn Screening Program</p> <p>Careema Yusuf, MPH Manager, NewSTEPS, Newborn Screening and Genetics, APHL</p>
10:30 – 11:00 AM	<p>Consumer Friendly Summaries (MPS-1, ALD, Pompe)</p> <p>Evidence-based Review Process</p> <p>Developing Methods to Assess Costs of Expanding NBS</p>	<p>Alex R. Kemper, MD, MPH, MS Professor of Pediatrics, Duke University Chair, Condition Review Workgroup</p>
11:00 – 11:30 AM	Committee Discussion	

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11:30 - 11:45 AM	BREAK	
11:45 - 12:05 PM	Education and Training Workgroup Update	Cathy Wicklund, MS, CGC Northwestern University Committee Member Chair, Education and Training Workgroup
12:05 - 12:25 PM	Laboratory Standards and Procedures Workgroup Update	Kellie Kelm, PhD Food and Drug Administration Ex-Officio Committee Member Chair, Laboratory Standards and Procedures Workgroup
12:25 - 12:45 PM	Follow-up and Treatment Workgroup Update	Jeffrey P. Brosco, MD, PhD Professor of Clinical Pediatrics University of Miami School of Medicine Committee Member Acting Chair, Follow-up and Treatment Workgroup
12:45 - 1:00 PM	New Business	Joseph Bocchini, MD Committee Chair Louisiana State University
1:00 PM	ADJOURN	