

# The Advisory Committee on Heritable Disorders in Newborns and Children

HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)  
May 9-10, 2018

## AGENDA: Wednesday May 9, 2018

TIME	TOPIC	PRESENTER
9:30 – 10:15 AM	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• Roll Call</li> <li>• Opening Remarks</li> <li>• November 2017 Minutes</li> <li>• February 2018 Minutes</li> </ul>	<p><b>Joseph Bocchini, MD</b> Committee Chair Professor and Chairman, Department of Pediatrics, Louisiana State Univ.</p> <p><b>Catharine Riley, PhD, MPH</b> Designated Federal Official Health Resources and Services Admin.</p>
10:15 – 10:45 AM	<b>Newborn Screening Education and Training Tools: a Communication Aid and an Educational Planning Guide</b>	<b>Beth Tarini, MD, MS, FAAP</b> Committee Member Co-Chair, Education & Training Workgroup
10:45 – 11:15 AM	<b>CDC Quality Assurance and Harmonization Activities</b>	<b>Kostas Petritis, PhD</b> Laboratory Chief, Biochemical Mass Spectrometry Laboratory, Newborn Screening and Molecular Biology Branch, CDC
11:15 – 12:15 PM	<b>Review and Committee Discussion: Cutoffs and Risk Assessment in Newborn Screening</b>	<b>Joseph Bocchini, MD</b> Committee Chair
12:15 – 1:15 PM	<b>LUNCH</b>	
1:15 – 2:20 PM	<b>Working on Timeliness in Newborn Screening: Lessons Learned from States</b>	<p><b>Tonya McCallister</b> Supervisor, Newborn Screening Lab Public Health Laboratory Oklahoma State Department of Health</p> <p><b>Sondi Aponte</b> Education &amp; Outreach Manager Arizona State Laboratory—Office of Newborn Screening</p> <p><b>Stanton L. Berberich, PhD</b> Program Manager Medical Screening State Hygienic Laboratory at The University of Iowa</p>
2:20 – 2:30 PM	<b>Overview: Assessing the Public Health System Impact of Adding Conditions to the RUSP</b>	<b>Joseph Bocchini, MD</b> Committee Chair
2:30 PM	<b>ADJOURN</b>	

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## WORKGROUP MEETINGS: Wednesday May 9, 2018

<b>3:00 – 5:00 PM</b>	<ul style="list-style-type: none"> <li>• <b>Education and Training Workgroup</b></li> <li>• <b>Laboratory Standards and Procedures Workgroup</b></li> <li>• <b>Follow-Up and Treatment Workgroup</b></li> </ul>
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## AGENDA: Thursday May 10, 2018

TIME	TOPIC	PRESENTER
9:30 – 9:45 AM	<ul style="list-style-type: none"> <li>• <b>Welcome</b></li> <li>• <b>Roll Call</b></li> </ul>	<p><b>Joseph Bocchini, MD</b> Committee Chair Louisiana State University</p> <p><b>Catharine Riley, PhD, MPH</b> Designated Federal Official, Health Resources and Services Administration</p>
9:45 – 10:15 AM	<b>Update on Newborn Screening for Guanidinoacetate Methyltransferase (GAMT) Deficiency</b>	<b>Carla Cuthbert, PhD</b> Chief, Newborn Screening and Molecular Biology Branch, Division of Laboratory Sciences, National Center for Environmental Health, CDC
10:15 – 10:45 AM	<b>PUBLIC COMMENT</b>	
10:45 – 11:05 AM	<b>BREAK</b>	
11:05 – 11:25 AM	<b>Education and Training Workgroup Update</b>	<b>Catherine Wicklund, MS, CGC</b> Committee Member Chair, Education & Training Workgroup
11:25 – 11:45 AM	<b>Follow-Up and Treatment Workgroup Update</b>	<b>Jeffrey P. Brosco, MD, PhD</b> Committee Member Chair, Follow up & Treatment Workgroup
11:45 – 12:05 PM	<b>Laboratory Standards and Procedures Workgroup Update</b>	<b>Kellie Kelm, PhD</b> Ex-Officio Committee Member, FDA Chair, Laboratory Standards and Procedures Workgroup
12:05 – 12:50 PM	<b>Committee Discussion: Public Health System Impact Assessment - Survey Tools</b>	<b>Joseph Bocchini, MD</b> Committee Chair
12:50 – 1:00 PM	<b>New Business</b>	<b>Joseph Bocchini, MD</b> Committee Chair
1:00 PM	<b>ADJOURN</b>	