

AGENDA

*Monday, May 11, 2015*

Time	Topic	Presenter
<b>10:00 AM – 10:30 AM</b>	Welcome <ul style="list-style-type: none"> <li>• Opening Remarks</li> <li>• Advisory Committee’s Authorization</li> <li>• Nomination Process for Prospective Committee Members</li> <li>• Committee Correspondence</li> </ul>	Joseph Bocchini, MD Committee Chair Louisiana State University  Debi Sarkar, MPH Designated Federal Official Health Resources and Services Administration
<b>10:30 AM – 11:00 AM</b>	<i>Impact of the Affordable Care Act’s Coverage Mandate on State Newborn Screening Programs</i> – Project funded by the Office of the Assistant Secretary for Planning and Evaluation	Julia Costich, JD University of Kentucky College of Public Health
<b>11:00 AM – 12:15 AM</b>	<b>Newborn Screening Saves Lives Reauthorization Act of 2014 – Informed Consent Amendment</b>	
11:00 AM – 11:05 AM	Introduction	Joseph Bocchini, MD Committee Chair Louisiana State University
11:05 AM – 11:20 AM	Overview of Newborn Screening Laboratory Processes and Quality Management	Scott Shone, PhD New Jersey Newborn Screening Program
11:20 AM – 11:30 AM	Background	Michelle Huckaby Lewis, M.D., J.D. Research Scholar Berman Institute of Bioethics Johns Hopkins University
11:30 AM – 12:00 PM	Summary of the Secretary's Advisory Committee on Human Research Protections Meeting on the NBS Informed Consent Amendment	Jeff Botkin, MD Committee Member ACHDNC Committee Chair SACHRP University of Utah
<b>12:00 PM – 1:00 PM</b>	Lunch	

# The Advisory Committee on Heritable Disorders in Newborns and Children

**May  
2015**

*Monday, May 11, 2015 (continued)*

<b>Time</b>	<b>Topic</b>	<b>Presenter</b>
<b>1:00 PM – 2:15 PM</b>	<b>Newborn Screening Saves Lives Reauthorization Act of 2014 – Informed Consent Amendment</b>	
1:00 PM – 1:10 PM	Texas Opt-In Methodology for Sample Storage and Research	Susan Tanksley, PhD Texas Newborn Screening Laboratory
1:10 PM- 1:20 PM	Michigan Opt-In Methodology for Sample Storage and Research	Carrie Langbo Michigan Newborn Screening Program
1:20 PM – 1:40 PM	Public Comments	
1:40 PM – 2:30 PM	Conclusion	Joseph Bocchini, MD Committee Chair Louisiana State University
<b>2:30 PM</b>	End of Day 1	

*Tuesday, May 12, 2015*

<b>Time</b>	<b>Topic</b>	<b>Presenter</b>
<b>10:00 AM – 10:20 AM</b>	Welcome and Roll Call	Joseph Bocchini, MD Committee Chair Louisiana State University
<b>10:20 AM – 11:00 AM</b>	Long-Term Follow-Up in Newborn Screening: An Update on ACMG’s Work on the NBSTRN and NCC	Amy Brower, PhD Project Manager, NBSTRN/NCC American College of Medical Genetics and Genomics
<b>11:00 AM – 11:15 AM</b>	Public Comments	
<b>11:15 AM – 12:00 PM</b>	Update on ALD	Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
<b>12:00 PM</b>	Adjourn	