

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<br>Committee Chair<br>Louisiana State University<br><br>Debi Sarkar, MPH<br>Designated Federal Official<br>Health Resources and<br>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<br>University of Kentucky<br>College of Public Health  |
| <b>11:00 AM – 12:00 PM</b> | <b>Newborn Screening Saves Lives Reauthorization Act of 2014 – Informed Consent Amendment</b>   |  |
| 11:00 AM – 11:05 AM        | Introduction  | Joseph Bocchini, MD<br>Committee Chair<br>Louisiana State University   |
| 11:05 AM – 11:20 AM        | Overview of Newborn Screening Laboratory Processes and Quality Management   | Scott Shone, PhD<br>New Jersey Newborn<br>Screening Program  |
| 11:20 AM – 11:30 AM        | Amendment 12 of the NBS Saves Lives Reauthorization Act of 2014: Landscape and Potential Implications   | Michelle Huckaby Lewis, M.D., J.D.<br>Research Scholar<br>Berman Institute of Bioethics<br>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<br>Committee Member ACHDNC<br>Committee Chair SACHRP<br>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)*

| Time                     | Topic   | Presenter  |
|--------------------------|---|--|
| <b>1:00 PM – 2:30 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<br>Texas Newborn Screening Laboratory            |
| 1:10 PM- 1:20 PM         | Michigan Opt-In Methodology for Sample Storage and Research                                   | Carrie Langbo<br>Michigan Newborn Screening Program                  |
| 1:20 PM – 1:40 PM        | Public Comments   |  |
| 1:40 PM – 2:30 PM        | Committee Discussion and Vote   | Joseph Bocchini, MD<br>Committee Chair<br>Louisiana State University |
| <b>2:30 PM</b>           | End of Day 1  |  |

*Tuesday, May 12, 2015*

| Time                       | Topic  | Presenter   |
|----------------------------|--|---|
| <b>10:00 AM – 10:20 AM</b> | Welcome and Roll Call  | Joseph Bocchini, MD<br>Committee Chair<br>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<br>Project Manager,<br>NBSTRN/NCC<br>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<br>Condition Review Workgroup<br>Duke Clinical Research Institute and Department of Pediatrics |
| <b>12:00 PM</b>            | Adjourn  |   |