# DAY 1 Meeting Agenda: Thursday, August 3, 2017 – DRAFT as of July 18, 2017

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<tr>
<th>TIME</th>
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| 9:30 – 9:45 AM | • Welcome  
• Roll Call  
• Opening Remarks  
• May 2017 Minutes | **Joseph Bocchini, MD**  
Committee Chair  
Professor and Chairman, Department of Pediatrics, Louisiana State University  

**Catharine Riley, PhD, MPH**  
Acting Designated Federal Official  
Health Resources and Services Administration |
| 9:45 – 10:15 AM | SMA Evidence Review – Phase 1 Report | **Alex R. Kemper, MD, MPH, MS**  
Lead, Evidence-based Review Group  
Professor of Pediatrics, Duke University |
| 10:15 – 10:45 AM | Q&A and Committee Feedback – SMA Evidence Review |  |
| 10:45 – 11:30 AM | Quality Measures in Newborn Screening to Promote Long Term Follow-up | **Jeffrey P. Brosco, MD, PhD**  
Committee Member  
Chair, Follow up and Treatment Workgroup  
Professor of Clinical Pediatrics, University of Miami  
School of Medicine  

**Alan Zuckerman, MD**  
Member, Follow Up and Treatment Workgroup  
Assistant Professor, Community and Family Medicine and Department of Pediatrics, Georgetown University |
| 11:30 – 12:00 PM | Public Comments |  |
| 12:00 – 1:00 PM | LUNCH |  |
| 1:00 – 1:30 PM | Establishing and Revisiting Newborn Screening Cutoffs - Lessons Learned from States | **Susan Tanksley, PhD**  
Organizational Representative, Association of Public Health Laboratories |
| 1:30 – 1:50 PM | Establishing and Revisiting Newborn Screening Cutoffs – Summary and Next Steps | **Joseph Bocchini, MD**  
Committee Chair  
Professor and Chairman, Department of Pediatrics, Louisiana State University |
| 1:50 – 2:40 PM | Committee Discussion – Establishing and Revisiting Newborn Screening Cutoffs |  |
| 2:40 – 3:00 PM | BREAK |  |
| 3:00 – 5:00 PM | Workgroup Meetings  
• Education and Training Workgroup  
• Laboratory Standards and Procedures Workgroup  
• Follow up and Treatment Workgroup |  |
| 5:00 PM | ADJOURN |  |
# The Advisory Committee on Heritable Disorders in Newborns and Children

**HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)**  
**August 3 - 4, 2017**

## DAY 2 Meeting Agenda: Friday, August 4, 2017 - DRAFT as of July 18, 2017

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| 9:30 – 9:45 AM | Welcome  
Roll Call  
Recognition of Service  
Introduce New Ex-Officio Member | Joseph Bocchini, MD  
Committee Chair  
Louisiana State University  
Catharine Riley, PhD, MPH  
Acting Designated Federal Official  
Health Resources and Services Administration |
| 9:45 – 10:15 AM | Overview of Newborn Screening Technology | Alex R. Kemper, MD, MPH, MS  
Lead, Evidence-based Review Group  
Professor of Pediatrics, Duke University |
| 10:15 – 10:30 AM | Public Comments | | |
| 10:30 – 10:50 AM | Education and Training Workgroup Update | Cathy Wicklund, MS, CGC  
Committee Member  
Chair, Education and Training Workgroup  
Northwestern University |
| 10:50 – 11:10 AM | Follow Up and Treatment Workgroup Update | Jeffrey P. Brosco, MD, PhD  
Committee Member  
Chair, Follow up and Treatment Workgroup  
Professor of Clinical Pediatrics  
University of Miami School of Medicine |
| 11:10 – 11:30 AM | BREAK | | |
| 11:30 – 11:50 AM | Laboratory Standards and Procedures Workgroup Update | Kellie Kelm, PhD  
Ex-Officio Committee Member, Food and Drug Administration  
Chair, Laboratory Standards and Procedures Workgroup |
| 11:50 – 12:05 PM | Committee Discussion - Workgroup Activities | | |
| 12:05 – 12:50 PM | Clinical and Public Health Implications of Critical Congenital Heart Defects Newborn Screening | Scott Grosse, PhD  
Research Economist  
Office of the Director, National Center on Birth Defects and Developmental Disabilities, CDC  
Matt Oster, MD, MPH  
Director, Children’s CORPS (Cardiac Outcomes Research Program at Sibley Heart Center), Emory University School of Medicine |
| 12:50 – 1:00 PM | New Business | Joseph Bocchini, MD  
Committee Chair  
Professor and Chairman, Department of Pediatrics, Louisiana State University |
| 1:00 PM | ADJOURN | |