

# The Advisory Committee on Heritable Disorders in Newborns and Children

**November  
2015**

LOCATION: WEBINAR

TUESDAY, NOVEMBER 3, 2015

## AGENDA

| Time                       | Topic  | Presenter  |
|----------------------------|--|--|
| <b>10:00 AM – 10:30AM</b>  | Welcome <ul style="list-style-type: none"> <li>Opening Remarks</li> <li>ACHDNC Bylaws – Vote</li> <li>August Meeting Minutes - Vote</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 Services<br>Administration |
| <b>10:30 AM – 11:30 AM</b> | Overview of the Implications of the Federal Policy for the Protection of Human Subjects Notice of Proposed Rulemaking for Newborn Screening    | Michelle Huckaby Lewis, MD, JD<br>Research Scholar<br>Berman Institute of Bioethics<br>Johns Hopkins University  |
| <b>11:30 AM – 12:00 PM</b> | <b>PUBLIC COMMENT</b>  |  |
| <b>12:00 PM – 1:00 PM</b>  | <b>LUNCH</b>   |  |
| <b>1:00 PM – 1:45 PM</b>   | Transition Models from Pediatric to Adult Health Care: Innovative Strategies   | Patience White, MD, MA<br>Co-Project Director<br>Got Transition/Center for Health Care Transition  |
| <b>1:45 PM – 2:30 PM</b>   | Raising Awareness in Newborn Screening: Strategies and Updates   | Natasha Bonhomme<br>Vice President of Strategic Partnership<br>Genetic Alliance  |
| <b>2:30 PM – 3:00 PM</b>   | Workgroup Update – Pilot Study Workgroup   | Jeff Botkin, MD, MPH<br>Committee Member<br>University of Utah   |
| <b>3:00 PM – 3:15 PM</b>   | <b>BREAK</b>   |  |
| <b>3:15 PM – 3:30 PM</b>   | Workgroup Update – Cost Analysis Workgroup   | Alex Kemper, MD, MPH, MS<br>Condition Review Workgroup<br>Duke Clinical Research Institute and Department of Pediatrics  |
| <b>3:30 PM – 3:45 PM</b>   | Workgroup Update – Timeliness Workgroup  | Kellie Kelm, PhD<br>Ex-Officio Member<br>Food and Drug Administration<br><br>Cathy Wicklund, MS, CGC<br>Committee Member Northwestern University                               |
| <b>3:45 PM – 4:00 PM</b>   | Future meeting topics - discussion   | Joseph Bocchini, MD<br>Committee Chair<br>Louisiana State University   |
| <b>4:00 PM</b>             | <b>ADJOURN</b>   |  |