

# The Advisory Committee on Heritable Disorders in Newborns and Children

**November  
2015**

LOCATION: WEBINAR

TUESDAY, NOVEMBER 3, 2015

## AGENDA (DRAFT)

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 Committee Chair Louisiana State University  Debi Sarkar, MPH Designated Federal Official Health Resources and Services Administration
<b>10:30 AM – 11:30 AM</b>	Federal Policy for the Protection of Human Subjects Notice of Proposed Rulemaking and the Potential Impact on Newborn Screening Research	Michelle Huckaby Lewis, MD, JD Research Scholar Berman Institute of Bioethics 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 Co-Project Director 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 Vice President of Strategic Partnership Genetic Alliance
<b>2:30 PM – 3:00 PM</b>	Workgroup Update – Pilot Study Workgroup	Jeff Botkin, MD, MPH Committee Member 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 Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
<b>3:30 PM – 3:45 PM</b>	Workgroup Update – Timeliness Workgroup	Kellie Kelm, PhD Ex-Officio Member Food and Drug Administration  Cathy Wicklund, MS, CGC Committee Member Northwestern University
<b>3:45 PM – 4:00 PM</b>	Future meeting topics - discussion	Joseph Bocchini, MD Committee Chair Louisiana State University
<b>4:00 PM</b>	<b>ADJOURN</b>	