

The Advisory Committee on Heritable Disorders in Newborns and Children

February
2016

LOCATION: NATIONAL INSTITUTES OF HEALTH, 45 CENTER DRIVE, NATCHER CENTER, ROOM E
IN-PERSON MEETING & WEBCAST
FEBRUARY 11 – 12, 2016

AGENDA

Thursday, February 11, 2016

Time	Topic	Presenter
9:00am – 9:15am	Welcome <ul style="list-style-type: none"> Opening Remarks Committee Correspondence 	Joseph Bocchini, MD Committee Chair Louisiana State University Debi Sarkar, MPH Designated Federal Official Health Resources and Services Administration
NEWBORN SCREENING LONG-TERM FOLLOW-UP (LTFU) PANEL		
9:15am – 9:25am	ACHDNC's Work in Long-Term Follow-Up: A History	Amy Brower, PhD American College of Medical Genetics and Genomics Cindy Hinton PhD, MS, MPH Centers for Disease Control and Prevention
9:25am – 9:45am	California Newborn Screening Long-Term Follow-Up Data Collection	Lisa Feuchtbaum, DrPH, MPH Chief, Program Development & Evaluation Section Genetic Disease Screening Program California Department of Public Health
9:45am – 10:05am	Long-Term Follow-Up after Newborn Bloodspot Screening: Why, How, and What Next?	Sue Berry, MD Professor and Director Department of Pediatrics and Genetics, Cell Biology & Development University of Minnesota
10:05am – 10:25am	Parent Perspective on Long-Term Follow-Up	Christine Brown Executive Director National PKU Alliance
10:25am – 10:40am	BREAK	
10:40am – 11:00am	Panel Discussion – Challenges and Best Practices	PANEL
11:00am – 11:30 am	Discussion	Joseph Bocchini, MD Committee Chair Louisiana State University

Time	Topic	Presenter
11:30am - 12:00pm	PUBLIC COMMENT	
12:00pm - 1:00pm	LUNCH	
1:00pm - 3:00pm	Subcommittee Meetings	
3:00pm - 3:15pm	BREAK	
3:15pm - 5:00pm	Workgroup Meetings*	

*ACHDNC Workgroups will meet from 3:15pm to 5:00pm. More information will be sent by the Workgroup Chairs.

Friday, February 12, 2016

Time	Topic	Presenter
9:30am - 10:00am	Welcome and Roll Call	Joseph Bocchini, MD Committee Chair Louisiana State University
10:00am - 10:30am	Laboratory Procedures and Standards Subcommittee Update	Kellie Kelm, PhD Ex-Officio Committee Member Food and Drug Administration
10:30am - 11:00am	Education and Training Subcommittee Update	Cathy Wicklund, MS, CGC Committee Member Northwestern University
11:00am - 11:30am	Follow-up and Treatment Subcommittee Update	Stephen McDonough, MD Committee Member
11:30am - 12:30pm	LUNCH	
12:30pm - 1:00pm	Discussion/Prioritize Projects	Joseph Bocchini, MD Committee Chair Louisiana State University
1:30pm - 1:45pm	Timeliness Workgroup Update	Kellie Kelm, PhD Ex-Officio Member Food and Drug Administration Cathy Wicklund, MS, CGC Committee Member Northwestern University
1:00pm - 1:15pm	Cost Analysis Workgroup Update	Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
1:15pm - 1:30pm	Pilot Study Workgroup Update	Jeff Botkin, MD, MPH Committee Member University of Utah
1:45 pm - 2:00 pm	New Business	Joseph Bocchini, MD Committee Chair Louisiana State University
2:00pm	ADJOURN	