

The Advisory Committee on Heritable Disorders in Newborns and Children

August
2015

LOCATION: 5635 FISHERS LANE ROCKVILLE, MD 20857
 IN-PERSON MEETING & WEBCAST
 AUGUST 27-28, 2015

AGENDA

Thursday, August 27, 2015

Time	Topic	Presenter
8:30 AM – 9:00 AM	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
9:00 AM – 10:00 AM	NewSTEPS Data Repository: State of Newborn Screening in the United States	Marci Sontag, PhD Associate Director, NewSTEPS Associate Professor Colorado School of Public Health
10:00 AM – 10:30 AM	PUBLIC COMMENT	
10:30 AM – 10:45 AM	BREAK	
10:45 AM – 11:45 PM	Newborn Screening for X-Linked Adrenoleukodystrophy: A Systematic Review of Evidence	Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
11:45 PM – 1:15 PM	LUNCH	
1:15 PM – 2:15 PM	Newborn Screening for X-Linked Adrenoleukodystrophy: A Systematic Review of Evidence (cont'd)	Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
2:15 PM – 2:45 PM	Committee Report: Newborn Screening for X-Linked Adrenoleukodystrophy (X- ALD)	Don Bailey, PhD, MEd Committee Member RTI International Fred Lorey, PhD Committee Member State NBS Laboratory
2:45 PM – 3:30 PM	Committee Discussion on X-ALD and Vote	Joseph Bocchini, MD Committee Chair Louisiana State University
3:30 PM	END OF DAY 1	

**ACHDNC Workgroups will meet from 3:45pm to 4:45pm. More information will be sent by the Workgroup Chairs.*

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Friday, August 28, 2015

Time	Topic	Presenter
9:00 AM – 9:20 AM	Welcome and Roll Call	Joseph Bocchini, MD Committee Chair Louisiana State University
9:20 AM – 10:20 AM	Updates on Implementation of Screening for Severe Combined Immunodeficiency, Critical Congenital Heart Disease, and Pompe Disease	Jelili Ojodu, MPH Director, Newborn Screening and Genetics Association of Public Health Laboratories Marci Sontag, PhD Associate Director, NewSTEPS Associate Professor Colorado School of Public Health
10:20 AM – 10:35 AM	PUBLIC COMMENT	
10:35 AM – 11:00 AM	Workgroup Updates – Cost Analysis Workgroup	Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
11:00 AM – 11:10 AM	BREAK	
11:10 AM – 11:40 AM	Workgroup Updates (cont'd) – Pilot Study Workgroup	Jeff Botkin, MD, MPH Committee Member University of Utah
11:40 AM – 12:10 PM	Workgroup Updates (cont'd) – Timeliness Workgroup	Kellie Kelm, PhD Ex-Officio Member Food and Drug Administration Cathy Wicklund, MS, CGC Committee Member Northwestern University
12:10 PM – 12:30 PM	New Business	Joseph Bocchini, MD Committee Chair Louisiana State University
12:30 PM	ADJOURN	