

The Advisory Committee on Heritable Disorders in Newborns and Children

IN-PERSON/WEBINAR

HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)

August 8 - 9, 2024

Agenda: Thursday, August 8, 2024, from 10:00 AM - 3:00 PM Eastern Time

TIME	TOPIC	PRESENTER
10:00 AM - 10:15 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • Committee Business 	<p>Ned Calonge, MD, MPH Committee Chair</p> <p>CDR Leticia Manning, MPH Designated Federal Official</p>
10:15 AM - 10:30 AM	ACHDNC Nomination and Evidence Review Process	Ned Calonge, MD, MPH Committee Chair
10:30 AM - 10:45 AM	Committee Discussion	
10:45 AM - 11:05 AM	ACHDNC Decision Matrix Tool: Public Health System Assessment	Ned Calonge, MD, MPH Committee Chair
11:05 AM - 11:35 PM	Committee Discussion <i>Vote on whether or not to adopt the Decision Matrix as a tool to evaluate evidence presented to it and in making recommendations regarding addition of the condition to the RUSP.</i>	
11:35 AM - 11:45 AM	Break	
11:45 AM - 12:00 PM	Standardized Reporting of Newborn Screening Outcomes (STAR-NBS)	Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Review Group
12:00 PM - 12:15 PM	Committee Discussion	
12:15 PM - 12:25 PM	Including the Voices that Matter	
	ACHDNC Review of Research Focusing on Lived Experience Perspectives	Ned Calonge, MD, MPH Committee Chair
12:25 PM - 12:45 PM	Committee Discussion	
12:45 PM - 1:45 PM	Lunch	
1:45 PM - 2:25 PM	Approaches to Population-Based Screening in Newborns and Children	Stephen Patrick, MD, MPH, MS Professor and Chair Rollins School of Public Health Emory University
		Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Review Group
2:25 PM - 2:55 PM	Committee Discussion	
2:55 PM - 3:00 PM	End of Day 1	

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August 8 - 9, 2024

Agenda: Friday, August 9, 2024, from 10:00 AM - 1:05 PM Eastern Time

TIME	TOPIC	PRESENTER
10:00 AM - 10:15 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • Committee Business 	<p>Ned Calonge, MD, MPH Committee Chair</p> <p>CDR Leticia Manning, MPH Designated Federal Official</p>
10:15 AM - 11:15 AM	Public Comments	
11:15 AM - 11:30 AM	Metachromatic Leukodystrophy (MLD) Nomination Process	<p>Michele Caggana, ScD Committee Member</p> <p>Chanika Phornphutkul, MD FACMG Committee Member</p>
11:30 AM - 11:45 AM	Committee Discussion <i>Vote on whether or not to move MLD forward to full evidence review.</i>	
11:45 AM - 12:00 PM	Break	
12:00 PM - 12:20 PM	Naming/Counting Condition ACHDNC Ad Hoc Topic Groups (ATG): Updates and Next Steps	<p>Susan Tanksley, PhD Chair, Association of Public Health Laboratories Naming/Counting Condition ATG, (Laboratorian)</p> <p>Susan A. Berry, MD Member, Association of Public Health Laboratories Naming/Counting Condition ATG, (Clinician)</p>
12:20 PM - 12:50 PM	Committee Discussion	
12:50 PM - 1:00 PM	New Business	
1:00 PM - 1:05 PM	Adjourn	