

The Advisory Committee on Heritable Disorders in Newborns and Children

IN-PERSON/WEBINAR

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

May 4 - 5, 2023

Agenda: Thursday, May 4, 2023, from 10:00 AM - 3:50 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>Leticia Manning, MPH Acting Designated Federal Official Health Resources and Services Administration (HRSA)</p>
10:15 AM - 10:45 AM	Newborn Screening and Early Intervention	<p>Don Bailey, Jr., PhD, MEd RTI International</p> <p>Elizabeth Reynolds, PhD RTI International</p>
10:45 AM - 11:15 AM	Committee Discussion	
11:15 AM - 11:25 AM	Break	
11:25 AM - 11:45 AM	Research on Benefits and Harms from Uncertain Results	<p>Beth Tarini, MD, MS, MBA Children's National Hospital</p>
11:45 AM - 12:15 PM	Committee Discussion	
12:15 PM - 1:00 PM	Lunch	
	Federal Agency Collaboration to Improve Newborn Screening Data Integration	
1:00 PM - 1:45 PM	<p>Sickle Cell Data Collection (SCDC) Program</p> <p>Implementing the Blueprint: Implications on Newborn Screening</p>	<p>Mary Hulihan, DrPH Epidemiology and Surveillance Branch of the Division of Blood Disorders Center for Disease Control and Prevention (CDC)</p> <p>Jeff Brosco, MD, PhD Director, Division of Services for Children with Special Health Needs, Maternal Child Health Bureau, Health Resources Services Administration (HRSA)</p>

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	CDC's Ed3N Project	<p>Carla Cuthbert, PhD Division of Laboratory Sciences Center for Disease Control and Prevention (CDC)</p> <p>Amy Gaviglio, MS, CGC Division of Laboratory Sciences Centers for Disease Control and Prevention (CDC)</p>
1:45 PM – 2:30 PM	Committee Discussion	
2:30 PM – 2:40 PM	Break	
2:40 PM – 3:40 PM	Public Comments	
3:40 PM – 3:50 PM	Acknowledgments and Awards	
3:50 PM – 4:00 PM	End of Day 1	Ned Calonge, MD, MPH Committee Chair

Agenda: Friday, May 5, 2023, from 9:30 AM – 1:45 PM Eastern Time

TIME	TOPIC	PRESENTER
9:30 AM – 9:45 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Committee Business 	<p>Ned Calonge, MD, MPH Committee Chair</p> <p>Leticia Manning, MPH Acting Designated Federal Official Health Resources and Services Administration (HRSA)</p>
9:45 AM – 10:00 AM	Prioritization and Capacity Workgroup Interim Update	Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Review Group
10:00 AM – 10:15 AM	Committee Discussion	
10:15 AM – 10:45 AM	ACHDNC Decision Matrix	<p>Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Review Group</p> <p>Ned Calonge, MD, MPH Committee Chair</p>
10:45 AM – 11:30 AM	Committee Discussion	

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11:30 AM - 12:15 PM	Lunch Break	
12:15 PM - 12:45 PM	Ad-Hoc Topic Group Ideas	Ned Calonge, MD, MPH Committee Chair
12:45 PM - 1:30 PM	New Business	Ned Calonge, MD, MPH Committee Chair
1:30 PM - 1:45 PM	Adjourn	