

# 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**

<b>TIME</b>	<b>TOPIC</b>	<b>PRESENTER</b>
<b>10:00 AM - 10:15 AM</b>	<ul style="list-style-type: none"> <li>• <b>Welcome</b></li> <li>• <b>Roll Call</b></li> <li>• <b>Opening Remarks</b></li> <li>• <b>Committee Business</b></li> </ul>	<b>Ned Calonge, MD, MPH</b> Committee Chair  <b>Leticia Manning, MPH</b> Acting Designated Federal Official Health Resources and Services Administration (HRSA)
<b>10:15 AM - 10:45 AM</b>	<b>Newborn Screening and Early Intervention</b>	<b>Don Bailey, Jr., PhD, Med</b> RTI International  <b>Elizabeth Reynolds, PhD</b> RTI International
<b>10:45 AM - 11:15 AM</b>	<b>Committee Discussion</b>	
<b>11:15 AM - 11:25 AM</b>	<b>Break</b>	
<b>11:25 AM - 11:45 AM</b>	<b>Research on Benefits and Harms from Uncertain Results</b>	<b>Beth Tarini, MD, MS, MBA</b> Children's National Hospital
<b>11:45 AM - 12:15 PM</b>	<b>Committee Discussion</b>	
<b>12:15 PM - 1:00 PM</b>	<b>Lunch</b>	
<b>1:00 PM - 1:45 PM</b>	<b>Federal Agency Collaboration to Improve Newborn Screening Data Integration</b>	
	<b>Sickle Cell Data Collection (SCDC) Program</b>  <b>Implementing the Blueprint: Implications on Newborn Screening</b>	<b>Mary Hulihan, DrPH</b> Epidemiology and Surveillance Branch of the Division of Blood Disorders Center for Disease Control and Prevention (CDC)  <b>Jeff Brosco, MD, PhD</b> Director, Division of Services for Children with Special Health Needs, Maternal Child Health Bureau, Health Resources Services Administration (HRSA)

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

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

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

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<b>11:30 AM - 12:15 PM</b>	<b>Lunch Break</b>	
<b>12:15 PM - 12:45 PM</b>	<b>Ad-Hoc Topic Group Ideas</b>	<b>Ned Calonge, MD, MPH</b> Committee Chair
<b>12:45 PM - 1:30 PM</b>	<b>New Business</b>	<b>Ned Calonge, MD, MPH</b> Committee Chair
<b>1:30 PM - 1:40 PM</b>	<b>Acknowledgments and Awards</b>	<b>Ned Calonge, MD, MPH</b> Committee Chair
<b>1:40 PM - 1:45 PM</b>	<b>Adjourn</b>	