

# The Advisory Committee on Heritable Disorders in Newborns and Children

## IN-PERSON/WEBINAR

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

**November 2 - 3, 2023**

**Agenda: Thursday, November 2, 2023, from 10:00 AM – 3:45 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>CDR Leticia Manning, MPH</b> Designated Federal Official Health Resources and Services Administration (HRSA)
<b>10:15 AM – 10:30 AM</b>	<b>NASEM Workshop Update: Next Generation Screening – The Promise and Perils of DNA Sequencing of Newborns at Birth</b>	<b>Natasha Bonhomme</b> Organizational Representative
<b>10:30 AM – 10:50 AM</b>	<b>Committee Discussion</b>	
<b>10:50 AM – 11:45 AM</b>	<b>Public Comments</b>	
<b>11:45 AM – 12:00 PM</b>	<b>ACHDNC Decision Matrix Tool</b>	<b>Ned Calonge, MD, MPH</b> Committee Chair
<b>12:00 PM – 12:20 PM</b>	<b>Committee Discussion</b>	
<b>12:20 PM – 1:00 PM</b>	<b>Lunch</b>	
<b>1:00 PM – 1:15 PM</b>	<b>ACHDNC Conflict of Interest</b>	<b>Jennifer Kwon, MD, MPH</b> Committee Member
<b>1:15 PM – 1:35 PM</b>	<b>Committee Discussion</b>	
<b>1:35 PM – 1:45 PM</b>	<b>Introduction to Listening Session: Considerations for Nomination and Review Processes</b>	<b>Ned Calonge, MD, MPH</b> Committee Chair  <b>CDR Leticia Manning, MPH</b> Designated Federal Official
<b>1:45 PM – 2:15 PM</b>	<b>Break</b>	

**The Advisory Committee on  
Heritable Disorders in Newborns and Children**

---

**IN-PERSON/WEBINAR**

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

**November 2 - 3, 2023**

<b>TIME</b>	<b>TOPIC</b>	<b>PRESENTER</b>
<b>2:15 - 3:45 PM</b>	<b>Listening Session: Considerations for Nomination and Review Processes</b>  <b>Family and Representative Organization Group</b>  <b>Laboratory Group</b>  <b>Clinician Group</b>  <b>Public Health Group</b>	
<b>3:45 PM</b>	<b>End of Day 1</b>	

## The Advisory Committee on Heritable Disorders in Newborns and Children

### IN-PERSON/WEBINAR

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

**November 2 - 3, 2023**

**Agenda: Friday, November 3, 2023, from 9:30 AM – 12:50 PM Eastern Time**

<b>TIME</b>	<b>TOPIC</b>	<b>PRESENTER</b>
<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> Designated Federal Official</p>
<b>9:45 AM – 10:45 AM</b>	<b>Listening Session Group Updates</b>	
	<b>Family and Representative Organization</b>	<p><b>Janine Cody, PhD</b> Committee Member</p> <p><b>Siobhan Dolan, MD, MPH, MBA</b> Organizational Representative</p>
	<b>Laboratory</b>	<p><b>Christine Dorley, PhD</b> Committee Member</p> <p><b>Susan Tanksley, PhD</b> Organizational Representative</p>
	<b>Clinician</b>	<p><b>Jennifer Kwon, MD, MPH</b> Committee Member</p> <p><b>Col. Jacob Hogue, MD</b> Organizational Representative</p>
	<b>Public Health</b>	<p><b>Shawn McCandless, MD</b> Committee Member</p> <p><b>Scott Shone, PhD</b> Organizational Representative</p>
<b>10:45 AM – 11:15 AM</b>	<b>Committee Discussion</b>	
<b>11:15 AM – 11:30 AM</b>	<b>Break</b>	

**The Advisory Committee on  
Heritable Disorders in Newborns and Children**

---

**IN-PERSON/WEBINAR**

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

**November 2 - 3, 2023**

<b>TIME</b>	<b>TOPIC</b>	<b>PRESENTER</b>
<b>11:30 AM - 11:45 AM</b>	<b>Duchenne Muscular Dystrophy Evidence-Based Review: Phase 1 Update</b>	<b>Alex R. Kemper, MD, MPH, MS</b> Lead, Evidence-Based Review Group
<b>11:45 AM - 12:00 PM</b>	<b>Committee Discussion</b>	
<b>12:00 PM - 12:15 PM</b>	<b>Krabbe Disease Expedited Evidence-Based Review: Phase 1 Update</b>	<b>Alex R. Kemper, MD, MPH, MS</b> Lead, Evidence-Based Review Group
<b>12:15 PM - 12:30 PM</b>	<b>Committee Discussion</b>	
<b>12:30 PM - 12:45 PM</b>	<b>New Business</b>	<b>Ned Calonge, MD, MPH</b> Committee Chair
<b>12:45 PM - 12:50 PM</b>	<b>Adjourn</b>	