

# The Advisory Committee on Heritable Disorders in Newborns and Children

## WEBINAR May 13-14, 2021

Agenda: Thursday, May 13, 2021 from 10:00 AM – 1:45 PM Eastern Time

TIME	TOPIC	PRESENTER
10:00 AM – 10:15 AM	<ul style="list-style-type: none"> <li>• Welcome</li> <li>• Roll Call</li> <li>• Opening Remarks</li> <li>• Committee Business</li> </ul>	<p><b>Cynthia M. Powell, MD, MS, FACMG, FAAP</b> Committee Chair</p> <p><b>Mia Morrison, MPH</b> Designated Federal Official Health Resources and Services Administration (HRSA)</p>
10:15 AM – 10:45 AM	<b>Continuity of Operations Planning (COOP) and COVID-19: Committee Discussion</b>	<p><b>Susan Tanksley, PhD</b> Laboratory Operations Unit Manager Texas Department of State Health Services</p> <p><b>Scott M. Shone, PhD, HCLD(ABB)</b> Committee Member Director North Carolina State Laboratory of Public Health</p> <p><b>Michele Caggana, ScD, FACMG</b> Director, Newborn Screening Wadsworth Center</p> <p><b>Joyal Meyer, RN, MSN</b> Newborn Screening Program Director North Dakota Newborn Screening Program</p>
10:45 AM – 11:45 AM	<b>Association of Maternal &amp; Child Health Programs (AMCHP): Coronavirus Aid, Relief, and Economic Security (CARES) Act - Newborn Screening Telehealth Activities</b>	<p><b>Sabra Anckner, RN, MSN</b> Special Project Director Association of Maternal &amp; Child Health Programs</p> <p><b>Natasha F. Bonhomme</b> Founder, Expecting Health Chief Strategy Officer, Genetic Alliance</p> <p><b>Sulay Rivera Sánchez, MS, PhD</b> Assistant Professor, Department of Pediatrics Associate Director, Puerto Rico Center for Inherited Diseases Puerto Rico Newborn Screening Program University of Puerto Rico Medical Sciences Campus</p>

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		<b>Ginger Nichols, MS, LCGC</b> Genetic Counselor Connecticut Newborn Diagnosis & Treatment Network Connecticut Children's Medical Center
<b>11:45 AM - 12:15 PM</b>	<b>Public Comment: General</b>	
<b>12:15 PM - 12:45 PM</b>	<b>Break</b>	
<b>12:45 PM - 1:15 PM</b>	<b>Mucopolysaccharidosis II (MPS II) Nomination Summary</b>	<b>Scott M. Shone, PhD, HCLD(ABB) - on behalf of the Nomination &amp; Prioritization Workgroup</b> Committee Member Director North Carolina State Laboratory of Public Health
<b>1:15 PM - 1:45 PM</b>	<ul style="list-style-type: none"> <li>• <b>Committee Discussion</b></li> <li>• <b><i>Vote on whether or not to move MPS II forward to full evidence review</i></b></li> </ul>	<b>Cynthia M. Powell, MD, MS, FACMG, FAAP</b> Committee Chair
<b>1:45 PM</b>	<b>End of Day 1</b>	

**Agenda: Friday, May 14, 2021 from 10:00 AM - 1:25 PM Eastern Time**

<b>TIME</b>	<b>TOPIC</b>	<b>PRESENTER</b>
<b>10:00 AM - 10:10 AM</b>	<ul style="list-style-type: none"> <li>• <b>Welcome</b></li> <li>• <b>Roll Call</b></li> </ul>	<b>Cynthia M. Powell, MD, MS, FACMG, FAAP</b> Committee Chair  <b>Mia Morrison, MPH</b> Designated Federal Official HRSA
<b>10:10 AM - 10:40 AM</b>	<b>Overview of the National Survey of Children's Health</b>	<b>Julie Donney, PhD, MPH</b> Public Health Analyst Office of Epidemiology and Research Maternal and Child Health Bureau HRSA  <b>Reem M. Ghandour, DrPH, MPA</b> Director, Division of Epidemiology Office of Epidemiology and Research Maternal and Child Health Bureau HRSA

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<b>10:40 AM – 11:10 AM</b>	<b>Public Comment: Review of the Evidence Review Process</b>	
<b>11:10 AM – 11:40 AM</b>	<b>Break</b>	
<b>11:40 AM – 1:10 PM</b>	<b>Newborn Screening Workforce: Short- and Long-Term Follow-up</b>	<p><b>Miriam G. Blitzer, PhD, FACMG</b> Chief Executive Officer American Board of Medical Genetics and Genomics</p> <p><b>Cate Walsh Vockley, MS, LCGC</b> Senior Genetic Counselor Division of Medical Genetics UPMC Children’s Hospital of Pittsburgh</p> <p><b>Jennifer Kwon, MD, MPH</b> Director, Pediatric Neuromuscular Program Professor of Child Neurology, University of Wisconsin School of Medicine &amp; Public Health</p> <p><b>Marsha J. Treadwell, PhD</b> Professor, UCSF Department of Pediatrics/Division of Hematology Jordan Fund Endowed Chair</p> <p><b>Julie Kanter, MD</b> Associate Professor of Medicine Co-Director, Comprehensive Sickle Cell Center University of Alabama</p>
<b>1:10 PM – 1:25 PM</b>	<b>New Business</b>	<b>Cynthia M. Powell, MD, MS, FACMG, FAAP</b> Committee Chair
<b>1:25 PM</b>	<b>Adjourn</b>	