

The Advisory Committee on Heritable Disorders in Newborns and Children

WEBINAR August 12-13, 2021

Agenda: Thursday, August 12, 2021 10:00 AM – 2:30 PM Eastern Time

TIME	TOPIC	PRESENTER
10:00 AM – 10:15 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Committee Business 	<p>Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair</p> <p>Mia Morrison, MPH Designated Federal Official Health Resources and Services Administration (HRSA)</p>
10:15 AM – 11:15 AM	Mucopolysaccharidosis Type II (MPS II) Evidence Review - Phase 1 Update	Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Review Group
11:15 AM – 12:15 PM	Overview of the Committee's Review of the Evidence Review Process and Proposed Updates	<p>Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Review Group</p> <p>Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair</p>
12:15 PM – 12:45 PM	Public Comment	
12:45 PM – 1:15 PM	Break	
1:15 PM – 1:45 PM	Guanidinoacetate Methyltransferase (GAMT) Deficiency Nomination Summary	Carla Cuthbert, PhD - on behalf of the Nomination & Prioritization Workgroup Ex-Officio Committee Member Chief, Newborn Screening and Molecular Biology Branch National Center for Environmental Health Centers for Disease Control and Prevention (CDC)
1:45 PM – 2:00 PM	<ul style="list-style-type: none"> • Committee Discussion • <i>Vote on whether or not to move GAMT deficiency forward to full evidence review</i> 	Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair

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TIME	TOPIC	PRESENTER
2:00 PM - 2:30 PM	Emerging Issues in Newborn Screening	<p>Shawn E. McCandless, MD Committee Member Professor, Department of Pediatrics Head, Section of Genetics and Metabolism University of Colorado Anschutz Medical Campus Children's Hospital Colorado</p> <p>Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair</p>
2:30 PM	End of Day 1	

Agenda: Friday, August 13, 2021 from 10:00 AM - 1:50 PM Eastern Time

TIME	TOPIC	PRESENTER
10:00 AM - 10:10 AM	<ul style="list-style-type: none"> • Welcome • Roll Call 	<p>Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair</p> <p>Mia Morrison, MPH Designated Federal Official HRSA</p>
10:10 AM - 11:35 AM	National Registries for Hemophilia and Childhood Cancer	<p>Vanessa R. Byams, DrPH, MPH Lead Health Scientist Division of Blood Disorders CDC</p> <p>Judith R. Baker, DrPH, MHSA Public Health Director Center for Inherited Blood Disorders Regional Administrator - Western States/Region IX Hemophilia Network Director, Public Health-Pacific Sickle Cell Regional Collaborative Director, Public Health- Networking California for Sickle Cell</p> <p>Lynne Penberthy, MD, MPH Director, Surveillance, Epidemiology, and End Results Program Associate Director, Surveillance and Research Program Division of Cancer Control and</p>

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TIME	TOPIC	PRESENTER
		Population Sciences/National Cancer Institute
11:35 AM – 12:05 PM	Break	
12:05 AM – 1:35 PM	Newborn Screening Workforce: <ul style="list-style-type: none"> • Laboratory and Follow-up • Audiology • Pediatric Endocrinology • Genetic Metabolic Dietitians 	<p>Scott M. Shone, PhD, HCLD(ABB) Committee Member Director North Carolina State Laboratory of Public Health</p> <p>Marcia Fort, AuD, CCC-A Unit Manager, Genetics and Newborn Screening Division of Public Health, Children and Youth North Carolina Department of Health and Human Services</p> <p>David B. Allen, MD Professor, Division Chief, and Fellowship Program Director Department of Pediatrics University of Wisconsin School of Medicine and Public Health</p> <p>Rani H. Singh, PhD, RD, LD Professor Emory University Department of Human Genetics and Pediatrics</p>
1:35 PM – 1:50 PM	New Business	Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair
1:50 PM	Adjourn	