

The Advisory Committee on Heritable Disorders in Newborns and Children

WEBINAR February 11 -12, 2021

Agenda: Thursday, February 11, 2021 from 10:00 AM – 2:25 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>Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair</p> <p>Mia Morrison, MPH Designated Federal Official Health Resources and Services Administration</p>
10:15 AM - 11:15 AM	Processes for the Review of Conditions on the Recommended Uniform Screening Panel (RUSP)	<p>Alex R. Kemper, MD, MPH, MS Lead, Evidence-based Reviews</p> <p>Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair</p>
11:15 AM - 11:55 AM	Condition Nomination Form	<p>Alex R. Kemper, MD, MPH, MS Lead, Evidence-based Reviews</p> <p>Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair</p>
11:55 AM - 12:10 PM	Consumer-Friendly Guidance Materials	Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair
12:10 PM - 12:40 PM	Break	
12:40 PM - 12:55 PM	Public Comment	
12:55 PM - 2:25 PM	Continuity of Operations Planning (COOP) and COVID-19	<p>Susan Tanksley, PhD Laboratory Operations Unit Manager Texas Department of State Health Services</p> <p>Scott M. Shone, PhD, HCLD(ABB) Committee Member Director North Carolina State Laboratory of Public Health</p> <p>Michele Caggana, ScD, FACMG Director, Newborn Screening Wadsworth Center</p>

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		Joyal Meyer, RN, MSN Newborn Screening Program Director North Dakota Newborn Screening Program
2:25 PM	End of Day 1	

Workgroup Meetings: Thursday, February 11, 2021 from 2:40 PM – 3:25 PM Eastern Time

2:40 PM – 3:25 PM	<ul style="list-style-type: none"> • Education and Training Workgroup • Follow-up and Treatment Workgroup • Laboratory Standards and Procedures Workgroup
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Agenda: Friday, February 12, 2021 from 10:00 AM – 1:00 PM Eastern Time

TIME	TOPIC	PRESENTER
10:00 AM – 10:10 AM	<ul style="list-style-type: none"> • Welcome • Roll Call 	Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair Mia Morrison, MPH Designated Federal Official Health Resources and Services Administration
10:10 AM – 10:20 AM	Education and Training Workgroup Update	Jane M. DeLuca, PhD, RN, CPNP Committee Member Chair, Education and Training Workgroup
10:20 AM – 10:30 AM	Follow-up and Treatment Workgroup Update	Jeffrey P. Brosco, MD, PhD Committee Member Chair, Follow-up and Treatment Workgroup
10:30 AM – 10:40 AM	Laboratory Standards and Procedures Workgroup Update	Kellie B. Kelm, PhD Ex-Officio Committee Member Chair, Laboratory Standards and Procedures Workgroup
10:40 AM – 10:55 AM	Discussion: Workgroup Ideas	Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair
10:55 AM – 11:10 AM	Break	
11:10 AM – 12:40 PM	Innovations in Long-Term Follow-up	Jeffrey P. Brosco, MD, PhD Committee Member Professor of Clinical Pediatrics,

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		University of Miami (UM) Title V CYSHCN Director, Florida Department of Health Associate Director, Mailman Center for Child Development Amy Brower, PhD Co-Principal Investigator, Newborn Screening Translational Research Network (NBSTRN) Associate Project Director, American College of Medical Genetics and Genomics Carol Johnson Iowa Newborn Screening Follow- up Coordinator Co-Chair, APHL Short-term Follow-up Workgroup Co-Chair, APHL Workforce Taskforce Workgroup Mary Schroth, MD, FAAP, FCCP Chief Medical Officer Cure SMA
12:40 PM – 1:00 PM	New Business	Cynthia M. Powell, MD, MS, FACMG, FAAP Committee Chair
1:00 PM	Adjourn	