

The Advisory Committee on Heritable Disorders in Newborns and Children

**HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)
August 1 - 2, 2019**

AGENDA: Thursday, August 1, 2019 from 10:00AM to 3:15PM

TIME	TOPIC	PRESENTER
10:00AM – 10:15AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • April 2019 Minutes 	<p>Cynthia Powell, MD, MS, FACMG, FAAP Committee Chair</p> <p>Catharine Riley, PhD, MPH Designated Federal Official Health Resources and Services Administration (HRSA)</p>
10:15AM – 10:45AM	Improving Detection of Newborns at Risk for Homocystinuria and Congenital Adrenal Hyperplasia	Carla Cuthbert, PhD Ex-officio Member Centers for Disease Control and Prevention (CDC)
10:45AM – 11:30AM	Public Comment - Condition Nomination and Evidence Review Process	
11:30AM – 12:30PM	Lunch	
12:30PM – 2:00PM	RUSP Condition Nomination and Evidence Review Process	<p>MODERATOR: Cynthia Powell, MD, MS, FACMG, FAAP Committee Chair</p> <p>Panel Presenters - Evidence-based Review Group Members: Alex R. Kemper, MD, MPH, MS Lisa A. Prosser, PhD, MS Jelili Ojodu, MPH Scott Grosse, PhD</p>
2:00PM – 2:15PM	Break	
2:15PM – 3:15PM	RUSP Condition Nomination and Evidence Review Process (continued)	
3:15PM	Adjourn*	

**Workgroups meet on Thursday, August 1, 2019 from 3:30pm – 5:00pm
at 5600 Fishers Lane, Rockville, MD.*

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**HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)
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AGENDA: Friday, August 2, 2019 from 9:30AM to 2:00PM

TIME	TOPIC	PRESENTER
9:30AM - 9:45AM	<ul style="list-style-type: none"> • Welcome • Roll Call 	Cynthia Powell, MD, MS, FACMG, FAAP Committee Chair Catharine Riley, PhD, MPH Designated Federal Official, HRSA
9:45AM - 10:15AM	International Rare Disease Research Consortium (IRDiRC)	Anne R. Pariser, MD Director, Office of Rare Diseases Research National Center for Advancing Translational Sciences, National Institutes of Health
10:15AM - 11:00AM	Implementation of RUSP Conditions Report	Alex R. Kemper, MD, MPH, MS Lead, Evidence-based Reviews
11:00AM - 11:30AM	Linking Data Resources: Interoperability for Newborn Screening Programs	Ashleigh Ragsdale, MPH Newborn Screening Epidemiologist Office of Newborn Screening Washington State Department of Health
11:30AM- 12:30PM	Lunch	
12:30PM - 1:00PM	Public Comment	
1:00PM - 1:10PM	Ad-Hoc Workgroup - Interpreting NBS results	Mei Baker, MD Committee Member
1:10PM - 1:20PM	Follow Up and Treatment Workgroup Update	Christopher Kus, MD, MPH Co-Chair, Follow up & Treatment Workgroup
1:20PM - 1:30PM	Education and Training Workgroup Update	Beth Tarini, MD Chair, Education & Training Workgroup
1:30PM - 1:40PM	Laboratory Standards and Procedures Workgroup Update	Kellie Kelm, PhD Chair, Laboratory Standards and Procedures Workgroup
1:40PM - 1:55PM	Discussion: Workgroup Ideas	Cynthia Powell, MD Committee Chair
1:55PM - 2:00PM	New Business	Cynthia Powell, MD Committee Chair
2:00PM	Adjourn	