

The Advisory Committee on Heritable Disorders in Newborns and Children

IN-PERSON/WEBINAR

**HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)
November 3-4, 2022**

Agenda: Thursday, November 3, 2022 from 9:30 AM – 3:00 PM Eastern Time

TIME	TOPIC	PRESENTER
9:30 AM – 10:00 AM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • Committee Business 	<p>Ned Calonge, MD, MPH Committee Chair</p> <p>Soohyun Kim, MPH Acting Designated Federal Official Health Resources and Services Administration</p>
10:00 AM – 11:00 AM	Department of Defense Newborn Screening System	<p>Jacob Hogue, MD Lieutenant Colonel, Medical Corps, US Army Chief, Genetics, Madigan Army Medical Center</p>
11:00 AM – 12:30 PM	Roundtable Discussion: State Implementation of Conditions Recently Added to the Recommended Uniform Screening Panel	<p>Lisa Caton, MS, RN Director of Screening and Special Services Oklahoma Department of Health</p> <p>Richard Olney, MD, MPH Division Chief Genetic Disease Screening Program California Department of Public Health</p> <p>Susan M. Tanksley, PhD Deputy Laboratory Director Texas Department of State Health Services Laboratory</p> <p>John D. Thompson, PhD, MPA, MPH Director, Newborn Screening Program Public Health Laboratories Division of Disease Control & Health Statistics Washington State Department of Health</p> <p>Roberto Zori, MD Professor Chief of Clinical Genetics and Metabolism University of Florida Chair, Florida Genetics and Newborn Screening Advisory Council</p>

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12:30 PM – 1:30PM	Lunch	
1:30 PM – 2:10 PM	Public Comment	
2:10 PM – 3:00 PM	Krabbe Disease Evidence-Based Review – Phase 2 Update	Alex R. Kemper, MD, MPH, MS Lead, Evidence-Based Review Group
3:00 PM	End of Day 1	

Workgroup Meetings: Thursday, November 3, 2022 from 3:30 PM – 5:00 PM Eastern Time

3:30 PM – 5:00 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, November 4, 2022 from 9:30 AM - 1:00 PM Eastern Time

TIME	TOPIC	PRESENTER
9:30 AM - 9:45 AM	<ul style="list-style-type: none"> • Welcome • Roll Call 	<p>Ned Calonge, MD, MPH Committee Chair</p> <p>Soohyun Kim, MPH Acting Designated Federal Official Health Resources and Services Administration</p>
9:45 AM - 11:00 AM	Blueprint for Change: Access to Care for Children and Youth with Special Health Care Needs and their Families	<p>Dennis Kuo, MD, MHS Professor of Pediatrics Chief, Division of Developmental and Behavioral Pediatrics University of Rochester Medicine / Golisano Children's Hospital</p>
11:00 AM - 11:10 AM	Follow-up and Treatment Workgroup Update	<p>Kyle Brothers, MD, PhD Committee Member Chair, Follow-up and Treatment Workgroup</p>
11:10 AM - 11:20 AM	Laboratory Standards and Procedures Workgroup Update	<p>Kellie B. Kelm, PhD Ex-Officio Committee Member Chair, Laboratory Standards and Procedures Workgroup</p>
11:20 AM - 11:30 AM	Education and Training Workgroup Update	<p>Jane M. DeLuca, PhD, RN, CPNP Committee Member Chair, Education and Training Workgroup</p>
11:30 AM - 12:00 PM	Break	
12:00 PM - 12:55 PM	Committee Discussion on Action Items on Advancing Newborn Screening System	<p>Ned Calonge, MD, MPH Committee Chair</p>
12:55 PM - 1:00 PM	New Business	
1:00 PM	Adjourn	