

The Advisory Committee on Heritable Disorders in Newborns and Children

**HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion)
November 1-2, 2018**

AGENDA: Thursday, November 1, 2018 from 1:30PM to 5:30PM

TIME	TOPIC	PRESENTER
1:30PM – 1:45PM	<ul style="list-style-type: none"> • Welcome • Roll Call • Opening Remarks • August 2018 Minutes 	<p>Joseph Bocchini, MD Committee Chair Professor and Chairman, Department of Pediatrics, Louisiana State University</p> <p>Catharine Riley, PhD, MPH Designated Federal Official Health Resources and Services Administration</p>
1:45PM – 2:15PM	Public Comment	
2:15PM – 3:00PM	Condition Nomination for Cerebrotendinous Xanthomatosis (CTX)	Scott Shone, PhD Committee Member
3:00PM – 3:15PM	Break	
3:15PM – 4:00PM	Baby's First Test	Natasha Bonhomme Chief Strategy Officer, Genetic Alliance
4:00PM – 5:45PM	Education Activities in Newborn Screening - PANEL	<p>Beth Tarini, MD, MS, FAAP(Moderator) Committee Member Associate Director, Center for Translational Science, Children's National Health System</p> <p>Jackie Seisman, MPH Assistant Director of Maternal & Child Health, Genetic Alliance</p> <p>Debra Freedenberg, MD, PhD Medical Director, Newborn Screening and Genetics, Texas Dept of State Health Services</p> <p>Susan Berry, MD Committee Member Professor and Director, Division of Genetics and Metabolism, University of MN</p> <p>Kimberly Noble Piper, RN Executive Officer, Center for Congenital and Inherited, Iowa Dept of Public Health</p>
5:45PM	ADJOURN	

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AGENDA: Friday, November 2, 2018 from 9:30AM to 2:15PM

TIME	TOPIC	PRESENTER
9:30AM - 9:45AM	<ul style="list-style-type: none"> • Welcome • Roll Call 	<p>Joseph Bocchini, MD Committee Chair</p> <p>Catharine Riley, PhD, MPH Designated Federal Official, HRSA</p>
9:45AM - 11:15AM	<p>Genomic Sequencing in Newborn Screening: Ethical, Legal, and Social Implications - PANEL</p>	<p>Cynthia Powell, MD (Moderator) Committee Member Professor of Pediatrics and Genetics, Pediatric Genetics and Metabolism, The University of North Carolina at Chapel Hill</p> <p>Josephine Johnston, MS Director of Research The Hastings Center</p> <p>John Lantos, MD Director of Pediatric Bioethics and Professor of Pediatrics, University of Missouri-Kansas City, School of Medicine</p> <p>Barbara Koenig, PhD Professor of Medical Anthropology & Bioethics and Director of Bioethics, University of California at San Francisco</p>
11:15AM - 11:45AM	<p>Ethical, Legal, Social & Policy considerations for Newborn Screening Pilot Studies</p>	<p>Jeffrey Brosco, MD, PhD Committee Member</p>
11:45 AM- 12:45PM	<p>Lunch</p>	
12:45PM - 1:10PM	<p>Education and Training Workgroup Update</p>	<p>Beth Tarini, MD Committee Member Chair, Education & Training Workgroup</p>
1:10PM - 1:35PM	<p>Follow Up and Treatment Workgroup Update</p>	<p>Jeffrey Brosco, MD, PhD Committee Member Chair, Follow up & Treatment Workgroup</p>
1:35PM - 1:50 PM	<p>Laboratory Standards and Procedures Workgroup Update</p>	<p>Kellie Kelm, PhD Ex-Officio Committee Member, FDA Chair, Laboratory Standards and Procedures Workgroup</p>
1:50PM - 2:15 PM	<p>Ad-Hoc Workgroup - Interpreting NBS results</p>	<p>Mei Baker, MD Committee Member</p>
2:15PM - 2:30 PM	<p>New Business</p>	<p>Joseph Bocchini, MD Committee Chair</p>
2:30PM	<p>Adjourn</p>	

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*Please note: Workgroups will meet prior to the ACHDNC meeting on
Thursday, November 1, 2018 from 10:30am – 12:30pm at 5600 Fishers Lane, Rockville, MD.
Please see information below.*

WORKGROUP MEETINGS

- Follow up and Treatment Workgroup will meet in Room 5W07
- Education and Training Workgroup will meet in Room 5N54
- Laboratory Standards and Procedures Workgroup will meet in Room 5N76