

# The Advisory Committee on Heritable Disorders in Newborns and Children

May  
2016

LOCATION: 5635 FISHERS LANE ROCKVILLE, MD 20857

IN-PERSON MEETING & WEBCAST

MAY 9 - 10, 2016

## AGENDA

**Monday, May 9, 2016**

Time	Topic	Presenter
<b>9:30am - 10:00am</b>	Welcome <ul style="list-style-type: none"> <li>• Opening Remarks</li> <li>• Committee Correspondence</li> </ul>	Joseph Bocchini, MD Committee Chair Louisiana State University  Debi Sarkar, MPH Designated Federal Official Health Resources and Services Administration
<b>10:00am - 11:00am</b>	Medical Foods for Inborn Errors of Metabolism: Issues in Patient Access	Kathryn Camp, MS, RD, CSP(C) Office of Dietary Supplements National Institutes of Health
<b>11:00am - 12:00pm</b>	Pilot Study Workgroup - Report	Jeff Botkin, MD, MPH Committee Member University of Utah
<b>12:00pm - 1:00pm</b>	<b>LUNCH</b>	
<b>1:00pm - 1:30pm</b>	<b>PUBLIC COMMENT</b>	
<b>1:30pm - 2:30pm</b>	Guanidinoacetate methyltransferase deficiency (GAMT)- Update from the Nomination and Prioritization Workgroup  * <b>Vote on whether or not to move GAMT forward to the Condition Review Team*</b>	Dieter Matern, MD, PhD Committee Member Mayo Clinic
<b>2:30pm - 3:00pm</b>	<b>BREAK</b>	
<b>3:00pm - 5:00pm</b>	Subcommittee Meetings	

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*Tuesday May 10, 2016*

<b>Time</b>	<b>Topic</b>	<b>Presenter</b>
<b>10:00am - 10:10am</b>	Welcome and Roll Call	Joseph Bocchini, MD Committee Chair Louisiana State University
<b>10:10am - 11:00am</b>	Prenatal Education about Newborn Screening and Dried Bloodspots	Jeff Botkin, MD, MPH Committee Member University of Utah
<b>11:00am - 11:30am</b>	Cost Analysis Workgroup Update	Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
<b>11:30am - 11:45am</b>	Follow-up and Treatment Subcommittee Update	Stephen McDonough, MD Committee Member
<b>11:45pm - 12:45pm</b>	<b>LUNCH</b>	
<b>12:45pm - 1:00pm</b>	Timeliness Workgroup Update	Kellie Kelm, PhD Ex-Officio Committee Member Food and Drug Administration  Cathy Wicklund, MS, CGC Committee Member Northwestern University
<b>1:00pm - 1:15pm</b>	Education and Training Subcommittee Update	Cathy Wicklund, MS, CGC Chair Committee Member Northwestern University
<b>1:15pm - 1:30pm</b>	Laboratory Procedures and Standards Subcommittee Update	Kellie Kelm, PhD Chair Ex-Officio Committee Member Food and Drug Administration
<b>1:30pm - 1:45pm</b>	New Business	Joseph Bocchini, MD Committee Chair Louisiana State University
<b>1:45pm</b>	<b>ADJOURN</b>	