

The Advisory Committee on Heritable Disorders in Newborns and Children

**August
2016**

LOCATION: 5635 FISHERS LANE ROCKVILLE, MD 20857
 IN-PERSON MEETING & WEBCAST
 AUGUST 25-26, 2016

AGENDA

Thursday, August 25, 2016

Time	Topic	Presenter
9:00am - 9:15am	Welcome <ul style="list-style-type: none"> Opening Remarks New Committee Members - Introductions 	Joseph Bocchini, MD Committee Chair Louisiana State University Debi Sarkar, MPH Designated Federal Official Health Resources and Services Administration
9:15am - 10:15am	Pilot Study Workgroup Recommendation on Required Data Elements <ul style="list-style-type: none"> Discussion Vote 	Joseph Bocchini, MD Committee Chair Louisiana State University Scott M. Shone, PhD Program Manager New Jersey Department of Health, Newborn Screening
10:15am - 10:45am	PUBLIC COMMENT	
10:45am - 11:00am	BREAK	
11:00am - 12:00pm	Introduction to Sequencing and Potential Impact on Newborn Screening	Michele Caggana, ScD, FACMG Deputy Director of the Division of Genetics Director of the Newborn Screening Program New York Department of Health
12:00pm - 1:00pm	LUNCH	
1:00pm - 2:15pm	Newborn Sequencing in Genomic Medicine and Public Health (NSIGHT) Panel Discussion	<i>Panel Lead:</i> Don Bailey, PhD, M.Ed Committee Member <i>Panelists:</i> David Dimmock, MD Robert Green, MD, MPH Barbara Koenig, PhD Cynthia Powell, MD, MS

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2:15pm - 2:45pm	Committee Discussion	Joseph Bocchini, MD Committee Chair Louisiana State University
2:45pm	END OF DAY ONE	

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Time	Workgroup	Location
2:45pm - 4:45pm	Education and Training Workgroup Meeting	5635 Fishers Lane (Main Committee Room)
3:30pm - 5:30pm	Follow-up and Treatment Workgroup Meeting	5600 Fishers Lane Building Room 5W07
3:30pm - 5:30pm	Laboratory Procedures and Standards Workgroup Meeting	5600 Fishers Lane Building Room 5N54

Friday, August 26, 2016

Time	Topic	Presenter
9:00am - 9:05am	Welcome and Roll Call	Joseph Bocchini, MD Committee Chair Louisiana State University
9:05am - 9:50am	Newborn Screening Timeliness – Collaborative Improvement & Innovation Network (CoIIN)	Yvonne Kellar-Guenther, PhD Evaluator, NewSTEPS 360 University of Colorado, School of Public Health
9:50am - 10:35am	Robert Wood Johnson Project on Newborn Screening Timeliness	Beth Tarini, MD, MS, FAAP Committee Member University of Iowa Amy Cochran, PhD Research Assistant Professor University of Michigan
10:35am - 10:45am	BREAK	
10:45am - 11:30am	Missouri’s Experience Implementing Lysosomal Storage Disorders Screening and Follow-up for Pompe, Gaucher, Fabry and MPS-I and Krabbe Disorders	Sharmini Rogers, MBBS, MPH Chief, Bureau of Genetics and Healthy Childhood Missouri Department of Health and Senior Services
11:30am - 12:00pm	Long Term Follow Up for Pompe Disease	Jennifer M. Kwon, MD, MPH FAAN Associate Professor, Neurology, Pediatrics, Pathology and Laboratory Medicine Golisano Children's Hospital University of Rochester

Time	Topic	Presenter
12:00pm - 1:00pm	LUNCH	
1:00pm-1:15pm	Cost Analysis Workgroup Update	Alex Kemper, MD, MPH, MS Condition Review Workgroup Duke Clinical Research Institute and Department of Pediatrics
1:15pm - 1:30pm	Education and Training Workgroup Update	Cathy Wicklund, MS, CGC Committee Member Northwestern University
1:30pm - 1:45pm	Follow-up and Treatment Workgroup Update	Stephen McDonough, MD Committee Member
1:45pm - 2:00pm	Laboratory Procedures and Standards Workgroup Update	Kellie Kelm, PhD Chair Ex-Officio Committee Member Food and Drug Administration
2:00pm - 2:15pm	New Business	Joseph Bocchini, MD Committee Chair Louisiana State University
2:15pm	ADJOURN	