

Heartland Genetics and Newborn Screening Collaborative Annual Conference October 3-5, 2012—St Louis, Missouri

WEDNESDAY, October 3		
Time	Session	Location
4:00 - 8:00 pm	Registration Open	
5:00 - 8:30 pm	Advisory Board meeting	Wabash Cannonball

THURSDAY, October 4	
7:00 am	Registration Open (Poster and Vendor set-up)

Plenary Session			
Time	Topic	Speakers	Location
7:15 am	Continental Breakfast		Atrium
8:15	Welcome Remarks	Brad Schaefer, MD	New York & Illinois
8:30	Genetics in St Louis	Kathy Grange, MD	New York & Illinois
9:00	Regional Genetics Service Collaboratives; Update and Discussion	Sara Copeland, MD	New York & Illinois
9:30	Project Overview: NCC for the Regional Genetic and Newborn Screening Services Collaboratives	Mike Watson, MS, PhD	New York & Illinois
10:00	Break (Poster session open)		Atrium
10:30	Transition in Practice: A KAP survey of medical genetics health professionals in the Heartland	Jeanine Schulze, MS	New York & Illinois
11:00	Got Transition, A Heartland Experience	Ashley Davis, MS, LGC	New York & Illinois
11:15	Transition Matters: Themes From a Five State Road Trip!	Wendy Parent, PhD	New York & Illinois
12:00 pm	Lunch and Roundtable Discussions*		Grand Hall
1:30	Newborn Screening and Follow-up for Hemoglobinopathies	Monica Hulbert, MD	New York & Illinois
2:15	NewSTEPS, the Newborn Screening Technical Assistance and Evaluation Programs	Marci Sontag, PhD	New York & Illinois
2:30	Newborn Screening Translational Research Network (NBSTRN) Update	Mike Watson, MS, PhD	New York & Illinois
3:00	Break (Poster Session open)		Atrium
3:30	RCC Annual Report <ul style="list-style-type: none"> • HRCC Report • Heartland Evaluation 	Brad Schaefer, MD Barbara Jackson, PhD	New York & Illinois
4:15	Genetic Systems Assessment Project Update	Ann Chou, PhD, MPH	New York & Illinois

5:00 Advocate Work Group Meeting

6:00 **Adjourn**

Time for Networking—Dinner on Your Own

FRIDAY, October 5

Plenary Session

Time	Topic	Speaker	
7:30 am	Continental Breakfast		Atrium
8:30	Lysosomal Storage Disorders—The Missouri Experience	Kathy Grange, MD	New York & Illinois
9:15	Lysosomal Storage Disorder (LSD) Screening Implementation Progress in Missouri to Date	Patrick Hopkins	New York & Illinois
9:45	Cystic fibrosis: hitting the target	Thomas Ferkol, MD	New York & Illinois
10:30	Break (Hotel Check-out)		Atrium
11:00	Providing Newborn Screening Specimens for Research: Legal Issues Faced by State Health Departments	Denise Chrysler, JD	New York & Illinois
12:00 pm	Lunch		Grand Hall
1:00	Work Group meetings	Clinical Services EHDI NBS	
2:30	Real Time Family Support through Social Media	Anne Crotty, MPH	New York & Illinois
2:45	Genetic Counselor and Pediatrician Team	Shobana Kubendran, MS, CGC, MBBS	New York & Illinois
3:15	Wrap-up Session	Klaas Wierenga, MD	New York & Illinois
3:30	Adjourn		

* Roundtable Topics:

- NBS 50th Anniversary
- NICHQ evaluation model
- Prenatal Microarray discussion