

**Heartland Regional Genetics and Newborn Screening Collaborative
Annual Conference
September 28-29, 2006
Omaha, Nebraska**

Agenda:

Wednesday, September 27:

Ancillary Afternoon Meeting:

1:30 – 5:00 Washington City room

PEAS Focus Group: PEAS (Performance Evaluation and Assessment Scheme) for newborn screening programs – focus group to discuss piloting this NBS program/system self-evaluation tool from National Newborn Screening Resource Center (NNSGRC) coordinated by Brad Therrell.

3-7 pm Saint Nicholas Foyer

Registration

Afternoon: **Optional site visit to Munroe-Meyer Genetic and Rehabilitation Institute**, University of Nebraska Medical Center, with Bradley Schaefer, MD, Associate Director and Local Host.

5:30-7:30 Patio (Castle room in case of inclement weather)

Evening Informal Reception: Open to registrants and local individuals who have an interest in genetics and newborn screening. Light refreshments and non-alcoholic beverages will be provided; a cash bar will be available.

Thursday September 28:

Breakfast on your own

7:30-9:30 St Nicholas Foyer: **Registration**

Plenary session - St Nicholas B

8:30 – 8:45: Welcome remarks:

G. Bradley Schaefer, MD, Associate Director -Meyer Genetic and Rehabilitation Institute, University of Nebraska Medical Center, and local host
John J. Mulvihill, MD, Director, Heartland Regional Coordinating Center
Lori Williamson, MS, CGC, Project Manager, Heartland Regional Coordinating Center

Lay Advocate Breakout Session (Merchants Room):

8:45 – 10:00: *Lay advocate breakout session on advocacy and participation in advisory councils with Mark A. Smith, M.S., Consumer/Family Coordinator, Nebraska Center on Disabilities, Munroe Meyer Institute for Genetics and Rehabilitation*

Presentations:

8:45 – 9:30: What are Integrated Data Systems, and Why You Should Participate: Nancy Hoffman, RN, MSN Chief, Bureau of Health Informatics, Missouri Department of Health and Senior Services

9:30 – 10:00: Comparative Genomic Hybridization: Warren G. Sanger, Ph.D., Director, Human Genetics Laboratory, Munroe-Meyer Institute

10:00 – 10:15: Break

Plenary session St Nicholas B

- 10:15 – 10:45: Newborn Screening Update:** Amy Brower, PhD
Executive Director, Medical Informatics & Genetics
Third Wave Technologies, Inc
- 10:45 – 11:15: Newborn Screening Long Term Follow-Up:** Sara Copeland, MD, Medical Director of
Newborn Screening for Iowa, Children's Hospital of Iowa
- 11:15 – 11:45: Medical Transition for Youth with Special Health Care Needs:** Bradley Schaefer, MD,
Associate Director -Meyer Genetic and Rehabilitation Institute, University of Nebraska
Medical Center
- 11:45 – 12:15: Medical Home Model:** Amy Gibson, RN, MS, Assistant Director
Boys Town Institute for Child Health Improvement
- 12:30 – 1:30:** Lunch
Merchants Room Breakout: Newborn Screening Disaster Preparedness lunch meeting,
led by Dr. Fred Schafer

St Nicholas Foyer

- 1:30 – 2:00: Posters** available for viewing:
Updated state posters: Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota,
Oklahoma, and South Dakota
Year 2 pilot projects with representatives at posters:
- Assessing Parenting Capacities and Stress in Neurofibromatosis 1 PI: Larry Mullins, PhD
 - Online CME: A Practical Course in Expanded Newborn Screening PI: Susan E. Palmer, MD, PhD
 - Reduce Disparity of NBS Lab Services in the Heartland Region PI: Stanton Berberich, Ph.D.
- Year 1 pilot projects (listed below)

St Nicholas B Plenary session

- 2:00 – 3:00: Presentations of the year 1 pilot project posters:**
- Online Genetic & Metabolic Education Modules: Sara Copeland
 - Development and Implementation of State Genetics Plans: Technical Assistance: Lisa Butterfield
 - Adherence to National Clinical Guidelines for Down Syndrome: Mark Ferguson
 - Can Telehealth Replace Genetics Outreach Clinics In Rural Missouri: Donna Nale
 - fMRI Studies of Food Motivation in Prader-Willi Syndrome: Merlin Butler
 - Family History Day 2005 in Greater Kansas City: Deb Collins
- 3:00 – 3:15:** Break
- 3:15 – 3:45: Bridging the gap between national and regional family health history initiatives:**
James C. O'Leary, Program Manager, Genetic Alliance, Inc.
- 3:45 - 4:00: National Coordinating Center Update:** Judith Benkendorf, MS, CGC
Project Manager, NCC (call-in)

4:00 - 4:15: **Perspectives on Lay Advocacy:** Mark A. Smith, M.S., Consumer/Family Coordinator, Nebraska Center on Disabilities, Munroe Meyer Institute for Genetics and Rehabilitation

4:15 – 4:35: **Vision for the regional collaboratives:** Michelle Puryear, MD, PhD Health Resources and Services Administration (HRSA)-Genetic Services Branch

4:35 – 5:15: Open discussion and questions with presenters, moderated by John Mulvihill, Heartland Regional Coordinating Center Director

5:15 – 5:30: Closing remarks

Dinner on your own

6:00 – 8:00: Dinner Meeting of State Genetics Coordinators; moderator, Lori Williamson. Location TBD

Friday, September 29

Breakfast on your own

Plenary session - St. Nicholas B

- 8:30 – 9:15:** Advisory Council business meeting
- Heartland Progress report
 - Committee Reports
 - Identify representatives to fill vacancies on the Executive committee
 - Date for Next Conference

Breakout sessions:

- 9:30 – 11:45:** Concurrent Committee breakouts:
- Newborn Screening, Prague room
 - Education, Merchants Room
 - Clinical Services, Paxton room
 - Laboratory services, Mercer room
 - Public Policy, Fontanelle Board room
 - Research, Murray room
 - Hereditary Cancer, Flatiron room

Plenary session – St. Nicholas B

12:00 – 1:30: Lunch and *Highlight Nebraska*:

This session highlights genetics and/or NBS projects or research (not funded by the Heartland collaborative) in Nebraska, our host state, to educate our members and to stimulate intra-regional communication and collaboration. Presentations include:

- 1) Usher syndrome research and pilot project “Usher Syndrome in Children with Cochlear Implants”: William J. Kimberling, Ph.D., Director of the Center for the Study and Treatment of Usher Syndrome, Boys Town Hospital, Professor of Biomedical Sciences, Creighton Medical School
- 2) Molecular Genetics of Dyslexia and Language Disorders: Shelley D. Smith, Ph.D., Director of Human Molecular Genetics, Munroe Meyer Institute
- 3) Autism Genetics Research, Richard Lutz MD, Genetics, Endocrinology & Metabolism, Monroe Meyer Institute

1:30 – 3:00: Committee reports, Discussion, Budget Recommendations

3:00:

Adjourn