

Agenda
Heartland Regional Genetics and Newborn Screening Collaborative
Annual Conference
September 5-7, 2007
Hilton Skirvin
Oklahoma City, OK

Wednesday September 5, 2007

| Time | Topic | Location |
|-------------|-------------------------------|----------------------|
| 4-8 pm | Registration Open | Grand Ballroom Foyer |
| 3-9 pm | Lay Advocate Training session | Crystal Room |
| 6 pm | Dinner break | Hilton Honors Lounge |

Thursday Morning, September 6, 2007

| Time | Topic | Presenter | Location |
|-------------|---|---|----------------------|
| 7:30 | Breakfast; Registration Open | | Grand Ballroom Foyer |
| | Plenary Session | | Grand Ballroom |
| 8:15 | Welcome and Introductory remarks | John J. Mulvihill , MD Director, Heartland Regional Coordinating Center | |
| 8:30 | Health Resources Services Administration Maternal Child Health Bureau Genetic Services Branch | Jill Shuger, MS Genetic Services Branch HRSA/Maternal Child Health Bureau | |
| 8:45 | National Coordinating Center | Michal Watson, PhD Project Director, National Coordinating Center for Genetics and Newborn Screening Regional Collaborative Groups | |
| 9:00 | Q&A time for Shuger and Watson | | |
| 9:20 | Annual Report of the Regional Coordinating Center and Heartland Collaborative | Lori Williamson Dean, MS, CGC Project Manager Heartland Regional Coordinating Center | |
| 9:45 | Legislative Update | James C. O'Leary Program Manager Genetic Alliance | |
| 10:15 | BREAK | | Grand Ballroom Foyer |
| 10:40 | LEND (Leadership Education in Neurodevelopmental Disabilities) <ul style="list-style-type: none"> • Introduction to LEND in our region • LEND and Genetics: a natural fit | Linda M. Wilson, PhD Oklahoma LEND Training Director Bradley Schaefer, MD Associate Director Monroe-Meyer Genetics and Rehabilitation Institute | |
| 11:10 | Long-term follow-up after NBS: the Inborn Errors of Metabolism Information System (IBEM-IS) | Sue Berry, MD Division Director of Pediatric Genetics and Metabolism University Minnesota | |
| 11:45 | The Future of Newborn Screening | Amy Brower, PhD Executive Director Medical Informatics and Genetics Third Wave Technologies | |
| 12:00 | How genetics can strengthen the medical home | Gina DiRenzo-Coffey, MD Director of Pediatric Place Bergan Mercy Hospital Omaha, NE | |

Thursday Afternoon, September 6, 2007

| 12:15 | LUNCH | | | Centennial Ballroom |
|-------------|--|---|---|---|
| 12:15 | Lay Advocate Lunch Meeting | | | Henry Overholser Suite |
| 12:15 | Disaster Preparedness Lunch Meeting | | | Perle Mesta Suite |
| Time | Newborn Screening Workgroup Ballroom B-C Facilitator: Williamson | Presenters | Education Workgroup Ballroom A Facilitator: Vaz | Presenters |
| 1:30 | <p>Laboratory workshop: expansion/harmonization</p> <p>Disaster preparedness project</p> <p>New Iowa HRSA project</p> <p>Maple syrup urine disease in Mennonites</p> <p>Town hall meetings</p> | <p>Stan Berberich, PhD Program Manager, Univ. Iowa Hygienic Lab</p> <p>Kimberly Noble Piper, RNC, BS, CPH State Genetics Coordinator Iowa Department of Public Health</p> <p>Charlotte Phillips, PhD Associate Professor, Departments of Biochemistry and Child Health University of MO</p> <p>Gene Hallford, MA, ABD Clinical Instructor, Pediatrics/Genetics, Oklahoma Univ. Health Sciences Center</p> | <p>Town hall meetings</p> <p>New Iowa HRSA project</p> <p>Family history campaign—next steps</p> <p>Teratogen resource project</p> | <p>Gene Hallford, MA, ABD Clinical Instructor Pediatrics/Genetics OUHSC</p> <p>Kimberly Noble Piper, RNC, BS, CPH, State Genetics Coordinator Iowa Department of Public Health</p> <p>James C. O’Leary Program Manager Genetic Alliance</p> <p>Bradley Schaefer, MD Associate Director Monroe-Meyer Genetics and Rehabilitation Institute</p> |
| 3:15 | BREAK | | | |
| 3:30 – 5:30 | <p>Genome disorders</p> <p>Cystic fibrosis mutations in American Indian populations</p> <p>Kansas-Nebraska Telemedicine Project</p> <p>Genetic Alliance Newborn Screening Grants</p> <p>Save Babies Foundation</p> | <p>Susan J. Hassed, MS, CGC Clinical Assoc. Professor Pediatrics, OUHSC</p> <p>Shibo Li, MD Professor Pediatrics OUHSC</p> <p>Bradley Schaefer, MD Associate Director, Monroe-Meyer Genetics and Rehabilitation Inst.</p> <p>James C. O’Leary Program Manager Genetic Alliance</p> <p>Ryan McLaughlin Mrs. Oklahoma</p> | <p>Discussion</p> <p>--web-based health provider education</p> <p>--reaching minority populations</p> <p>--developing an educational strategy</p> <p>Planning</p> <p>Begin to work!</p> | |
| 5:30 | Adjourn | | | |
| 6:00 | Oklahoma City Museum of Art: tour, hors d’oeuvres, cash bar | | | |
| 8:00 | Oklahoma City Museum of Art: Dinner | | | |

Friday, September 7, 2007

| Time | Topic | Presenter | Location |
|-------------|--|---|----------------|
| 7:30 | BREAKFAST | | Foyer |
| | Plenary Session | | Grand Ballroom |
| 8:15 | Opening remarks | John J. Mulvihill, MD | |
| 8:20 | Public Health Genomics Scholarship—Report | Jamie S. Kim, MPH, Epidemiologist Bureau for Children, Youth and Families Kansas Department of Health and Environment | |
| 8:30 | State reports <ul style="list-style-type: none"> • SD • OK • ND • NE • MO • IA • KS • AR | <p>Kayla Tinker, RN South Dakota Department of Health</p> <p>Sharon Vaz MS, RN Genetic Counselor State Genetics Education Coordinator Oklahoma State Department of Health</p> <p>Jayne Brown, BA Human Services Information Coordinator School Medicine University of North Dakota</p> <p>Julie Miller Program Manager Newborn Screening & Genetics Nebraska Department of Health & Human Services</p> <p>Dr. Sharmini V. Rogers, MBBS, MPH Chief, Bureau of Genetics and Healthy Childhood Section for Healthy Families and Youth Division of Community and Public Health Missouri Dept Health and Senior Services</p> <p>Kimberly Noble Piper, RNC, BS, CPH State Genetics Coordinator Iowa Department of Public Health</p> <p>Linda Kenney Director, Bureau Children Youth and Family Kansas Dept Health and Environment</p> <p>Jo Ann Bolick, APN, CPNP, MA, CPM, CPH Section Chief, Child & Adolescent Health Arkansas DHHS Division of Health</p> | |
| 9:45 | Genetics Report Card Project | John J. Mulvihill , MD Director, Heartland Regional Coordinating Center Mulvihill and Ann Chou, PhD, Assistant Professor, College Public Health, OU Health Sciences Center | |
| 10:15-10:30 | BREAK | | Foyer |

Friday, September 7, 2007

| | CLINICAL SERVICES Work Group Centennial Ballroom 1 Facilitator: Byerly | Presenters | NEWBORN SCREENING Work Group Centennial Ballroom 2 Facilitator: Williamson | Presenters |
|-----------------|---|---|--|--------------------------|
| 10:30 | <ul style="list-style-type: none"> • Neurofibromatosis parental stress project • Transition model in Sickle Cell • Genome disorders • Kansas – Nebraska telemed project • Discussion • Planning • Begin to work! | <p>Larry Mullins, PhD Professor, Department of Psychology Oklahoma State University</p> <p>Delphine Dorsey RN, BSN, MPH Transition Coordinator and Educator Oklahoma Pediatric Sickle Cell Program</p> <p>Susan J. Hassed, MS, CGC Clinical Assoc. Professor, Pediatrics OUHSC</p> <p>Bradley Schaefer, MD Associate Director, Monroe-Meyer Genetics and Rehabilitation Institute</p> | <p>Continued discussion; planning</p> <p>Follow up on current NBS Committee Projects</p> | |
| 12:30 – 1:45 | LUNCH | | | Grand Ballroom |
| 12:30 | Lunch Meeting: State Genetics Coordinators meet with Chou and Mulvihill | | | Perle Mesta Suite |
| 1:45 | Closing Plenary Session: <ul style="list-style-type: none"> • Presentation of Work Group plans • Budget • Discussion | | | Grand Ballroom |
| 3:00 | ADJOURN | | | |