



**10TH ANNUAL
CONFERENCE**



HEARTLAND

GENETICS

SERVICES

COLLABORATIVE

APRIL 23 -25, 2014

KANSAS CITY, MO



TENTH ANNUAL CONFERENCE

APRIL 23-25, 2014
KANSAS CITY, MISSOURI

Dear Colleagues and Partners,

Welcome to the tenth regional conference for the Heartland Genetics Services Collaborative. During this meeting, you will learn about the exciting work occurring in the regional collaboratives and learn more about topics that will challenge and inspire. We invite you to visit our exhibitors, poster presentations, to participate in the work group sessions on Friday, and, of course, to network with your colleagues. We warmly welcome the many newcomers this year and hope that you become involved in the collaborative.

Thank you for your attendance, participation, and contribution to the Collaborative's mission.

Warmest Regards,

Heartland Regional Coordinating Center Team:

Brad Schaefer
Klaas Wierenga
Lori Williamson Dean
Anayeli Herrera Morales
Dustin Foster

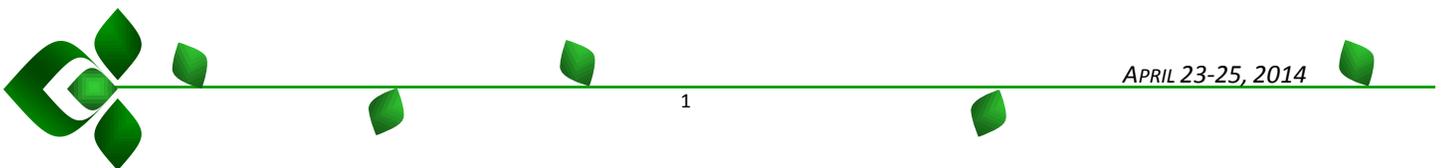
Conference Planning Committee:

JoAnn Bolick
Kim Piper
Heather Smith
Jeanne Egger

Heartland Advisory Board:

JoAnn Bolick
Holly Johnson
Joni Bosch
Michelle Black
Jakica Tancabelic
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Becky Bailey
Leisha Suckstorf
Judy Kellogg
Amy Brower
Barbara Jackson
Barb Hemmelman





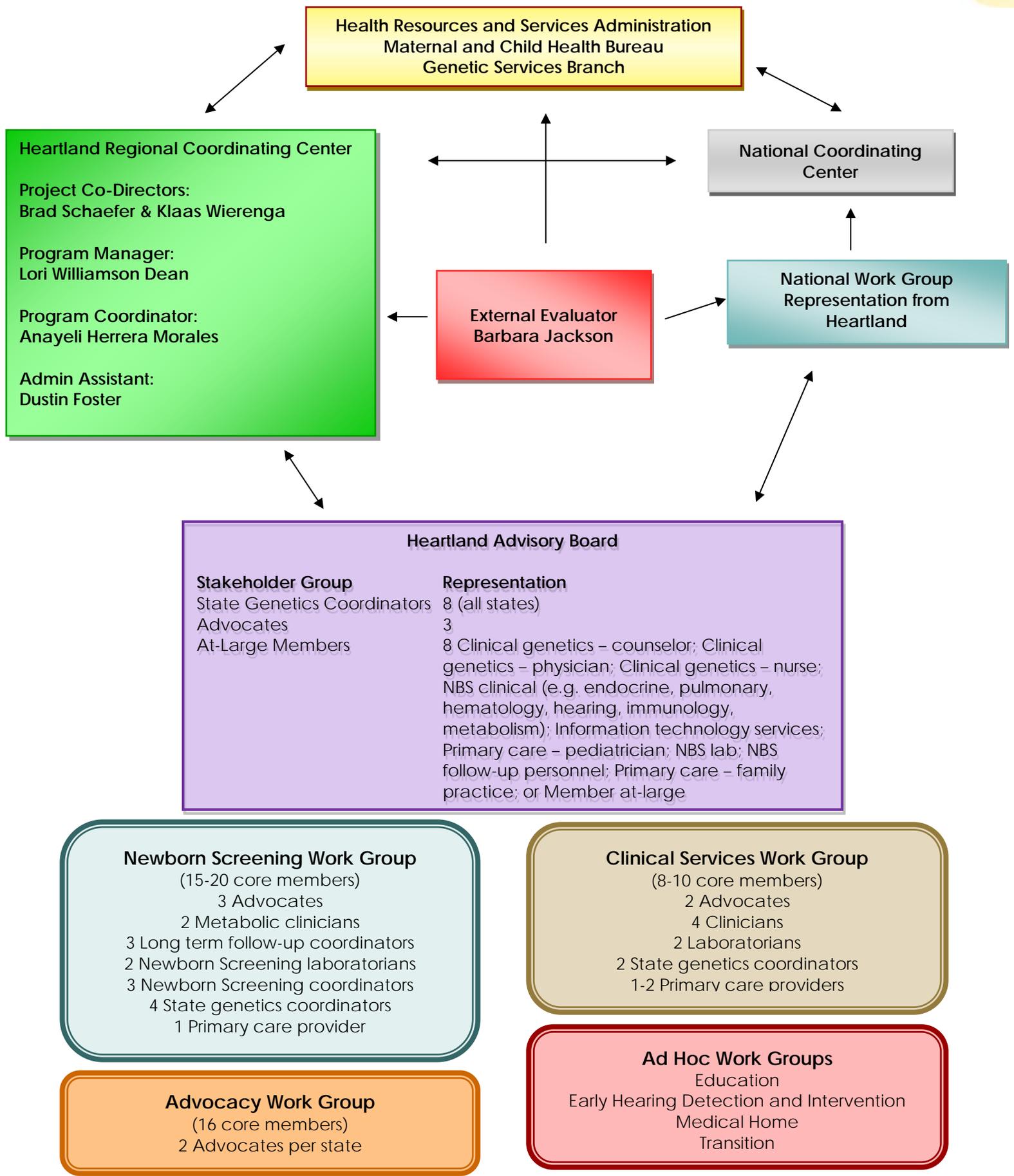
MISSION STATEMENT

February 2010

The Heartland Genetics and Newborn Screening Collaborative is focused on ensuring the best possible outcome for individuals with heritable disorders and optimizing the health of the population throughout the life cycle by improving understanding and awareness of genetics; expanding access to health care; and translating new findings to improve the quality of care within an eight-state region.



ORGANIZATIONAL CHART





2014 CONFERENCE SPONSORS AND EXHIBITORS

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Begbroke, Oxfordshire

OX5 1PF, UK

www.ogt.com

Prevention Genetics, LLC

3800 South Business Park Dr.

Marshfield, WI 54449

www.preventiongenetics.com

The Heartland Genetics and Newborn Screening Collaborative is supported by a grant from the Genetic Services Branch of the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA). Grant Number: H46MC24089





HEARTLAND GENETICS SERVICES COLLABORATIVE ANNUAL CONFERENCE AND ANCILLARY MEETINGS

APRIL 23 – 25, 2014
AIRPORT MARRIOTT
KANSAS CITY, MISSOURI
AGENDA

| Wednesday, April 23 | | |
|----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|
| Time | Event | Location |
| 09:15 – 04:30 | NBS Workshop (designated invitees) | Salon C |
| 08:00 – 04:00 | Healthcare Transition Learning Collaborative (designated invitees) | Salon A |
| 03:00 – 05:00 | Heartland Advocates Meeting (designated invitees) <i>Light refreshments provided</i> | Arkansas / Illinois |
| 04:00 – 08:00 | Annual Meeting Registration Open | Salon A – C Hallway |
| 05:30 – 08:30 | Heartland Advisory Board Meeting <i>Dinner provided for Advisory Board members and invited guests</i> | Salon B |
| Thursday, April 24 | | |
| 07:00 | Registration open | Salon A – C Hallway |
| 07:00 | Poster set up | Salon D |
| 07:00 – 08:00 | Breakfast | Salon A - C |
| 08:00 – 08:10 | Welcome remarks <i>Brad Schaefer, MD</i> <i>Heartland Co-director</i> | Salon A - C |
| 08:10 – 08:30 | Perspectives from HRSA <i>Joan Scott, MS, CGC</i> <i>Chief, Genetics Services Branch</i> | Salon A - C |
| 08:30 – 09:00 | National Coordinating Center (NCC) report <i>Alisha Keehn, MPA</i> <i>NCC Program Manager</i> <i>and</i> <i>David Flannery, MD, FACMG, FAAP</i> <i>ACMG Medical Director</i> | Salon A - C |
| 09:00 – 09:30 | National Genetics Education and Consumer Network (NGECN) <i>Sharon Romelczyk, MPA</i> <i>NGECN Program Manager</i> | Salon A - C |
| 09:30 – 10:00 | State of the Heartland region <i>Lori Williamson Dean, MS, CGC</i> <i>Heartland Program Manager</i> | Salon A - C |





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| 10:00 – 10:15 | Regional Health and Human Services offices: role & resources <i>CDR Nancy Miller, APRN, CCNS, MSHS, MBA, MSN</i> <i>Regional Nurse Consultant Title X</i> | Salon A - C |
| 10:15 – 10:30 | Break | Salon D |
| 10:30 – 10:45 | NewSTEPS updates <i>Marci Sontag, PhD</i> <i>Associate Professor, MPH Concentration Director,</i> <i>Colorado School of Public Health</i> | Salon A - C |
| 10:45 – 12:00 | Genomic sequencing as part of the newborn screen <i>Amy Brower, PhD</i> <i>NCC and the American College of Medical Genetics</i> <i>and</i> <i>Laurel Willig, MD and Joshua Petrikin, MD</i> <i>Children's Mercy Hospital</i> | Salon A - C |
| 12:00 – 01:15 | Lunch provided | Salon A - C |
| 01:15 – 03:15 | Priority initiatives in the Heartland region <ul style="list-style-type: none"> Individualized Health Plan project <i>Heather Smith, MPH</i> Healthcare transition for our patients <i>Wendy Parent-Johnson, PhD</i> <i>Richard Parent-Johnson, PhD</i> | Salon A - C |
| 03:15 – 03:30 | Break | Salon D |
| 03:30 – 04:30 | Are we making a difference? <i>Barb Jackson, PhD</i> | Salon A - C |
| 04:30 – 05:30 | Poster session with authors <i>Light refreshments and optional cash beverages</i> | Salon D |
| <i>Dinner on your own—see meeting packet for shuttle services and restaurants</i> | | |
| Friday, April 25 | | |
| 07:00 – 08:00 | Breakfast provided | Salon A - C |
| 08:00 – 09:30 | Genetics in Primary Care <ul style="list-style-type: none"> American Academy of Pediatrics' Genetics in Primary Care Institute <i>Ingrid Larson, FNP</i> Sickle Cell trait education—pilot project <i>James L. Harper, MD</i> Residency training in healthcare transition <i>Sara Gardner, MD</i> | Salon A - C |
| 09:30 – 10:00 | Health system considerations for the growing population of Hispanic children with special healthcare needs in Arkansas <i>Eduardo Ochoa Jr., MD</i> | Salon A - C |





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|----------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| 10:00 – 01:00 | Breakout sessions | |
| | <ul style="list-style-type: none">• Clinical Services Work Group Salon C<ul style="list-style-type: none">○ Medical Home○ Hispanic Access○ Transition○ IHP• Newborn Screening Work Group Salon A• Early Hearing Detection and Intervention Work Group Salon B | |
| 11:45 – 01:00 | Lunch Buffet | Outside Salon A–C |
| 01:15 – 02:45 | Exhilarating Family Partnerships <i>Eileen Forlenza</i> <i>National Expert and Speaker</i> | Salon A - C |
| 02:45 – 03:00 | Closing remarks <i>Klaas Wierenga, MD</i> <i>Heartland Co-Director</i> | Salon A - C |
| 03:00 | Adjourn | |





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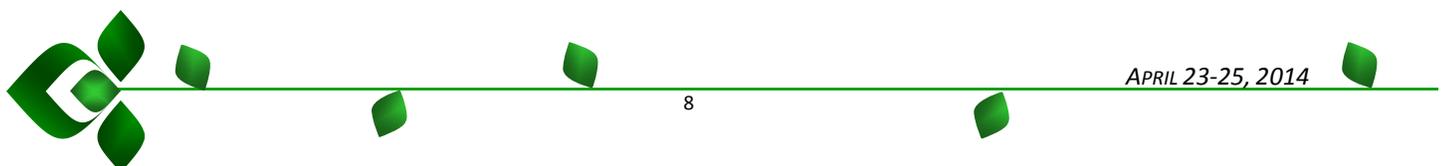
G. Bradley Schaefer, MD, FAAP, FACMG
Professor of Genetics and Pediatrics
Founding Director, Division of Medical Genetics
University of Arkansas for Medical Sciences
SchaeferGB@uams.edu

BIO: Dr. Schaefer moved from the University of Nebraska to the University of Arkansas for Medical Sciences in 2008. He is the Founding Director of the Division of Medical Genetics and the Chief of the Section of Genetics and Metabolism in the Department of Pediatrics. He holds the Committee-for-the-Future Endowed Chair in Medical Genetics.

He has authored 250 scientific articles, book chapters, and invited reviews. He is on the editorial board of the Journal of Child Neurology and the National Advisory Board for the Sotos Syndrome Support Association. His clinical practice focuses on the genetics of neurologic conditions, neurosensory abnormalities, and craniofacial malformations. His research is in clinical genetics with emphasis in neurogenetics and neurodevelopmental disabilities.

TOPIC: Welcome to the 10th Annual Heartland Genetics Services Collaborative Conference

NOTES:





NAME:

Joan A. Scott, MS, CGC
Chief, Genetic Services Branch
Division of Services for Children with Special Health Needs
Maternal and Child Health Bureau
jscott2@hrsa.gov

Bio: Ms. Scott is Chief, Genetic Services Branch in the Division of Children with Special Health Needs (DSCSHN), Maternal and Child Health Bureau (MCHB) at Health Resources and Services Administration (HRSA). She is a certified genetic counselor with more than 35 years' experience in clinical genetics, genetics education, laboratory medicine, the biotechnology industry, and the ethical, legal, social, and policy implications of advances in genomics. Ms. Scott's career has focused on the application of genomic discoveries to health care. Prior to coming to HRSA, she was Executive Director of the National Coalition for Health Professional Education in Genetics (NCHPEG), where she led a national effort to promote health professional education and access to information about advances in human genetics, and a Research Scientist in the Berman Institute of Bioethics at The Johns Hopkins University where she studied public and stakeholder attitudes about genomics.

Prior to NCHPEG, Ms. Scott was Director of the Genetics and Public Policy Center at Johns Hopkins University which was established to fill an important niche in the science policy landscape. There she led the Center's efforts to address policy issues related to advances in genetics, genetic testing quality and oversight, and public engagement in genetic research. Prior to coming to the Center in 2002, Ms. Scott was a director in GeneLogic, Inc. overseeing the operations of a large biorespository for use in genomic discovery. She also has served as general manager and director of Genetic Services at the clinical diagnostic lab OncorMed from 1994-1998. Clinically, she has practiced in a variety of academic, outreach, and private practice settings, including pediatric, adult, and reproductive genetic clinics.

Ms. Scott is a past president of the National Society of Genetic Counselors and founding member of the American Board of Genetic Counseling. She has served on numerous national committees and work groups including the IOM Roundtable on Translation Genome-based Research into Health; the Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group; the Secretary's Advisory Committee on Genetics, Health, and Society Task Force on DTC Genetic Testing; the Maryland Insurance Administration Workgroup on Genetic Testing; the National Cancer Institute's CaHUB Advisory Committee; and the Genetic Alliance Biobank Advisory Board. Ms. Scott holds an M.S. (Human Genetics Program) from Sarah Lawrence College and a B.A. in Anthropology and Zoology from Kent State University. She has been certified by the American Board of Medical Genetics with a subspecialty in Genetic Counseling, and was recertified by the American Board of Genetic Counseling in 2006.

TOPIC: HRSA, MCHB, Genetics Services Branch





NAME:

Alisha Keehn, MPA
Project Manager, NCC
American College of Medical Genetics and Genomics
akeehn@acmg.net

Bio: Since 2008, Ms. Keehn has served as the Project Manager for the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (NCC) housed at the American College of Medical Genetics and Genomics (ACMG). Prior to joining ACMG, Ms. Keehn was the Project Director of the Southeast Regional NBS and Genetics Collaborative. Ms. Keehn received her Master of Public Administration from the Georgia State University Andrew Young School of Policy Studies with a concentration in Policy Analysis and Evaluation.

TOPIC: National Coordinating Center (NCC) Report

NOTES:





NAME:

David Flannery, MD, FACMG, FAAP
Medical Director
American College of Medical Genetics and Genomics
dflannery@acmg.net

Bio: Dr. David Flannery is Medical Director of the American College of Medical Genetics and Genomics, as well as Medical Director for the NCC. He received his BA in Psychology from Columbia University and his medical degree from Emory University. He began his residency in Pediatrics at Emory University Affiliated Hospitals, completing it at the University of Virginia. He completed his Fellowship in Human Genetics at the Medical College of Virginia. He also received a certificate in health services research and health economics from Medical College of Georgia in 1999. He is board-certified in both Clinical Genetics and Pediatrics.

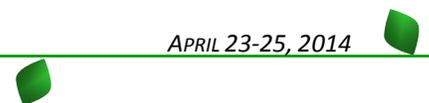
Dr. Flannery joined ACMG in February of this year from the Medical College of Georgia (MCG) of Georgia Regents University where he served in a succession of clinical, academic and medical staff leadership positions since 1984 including Professor of Pediatrics, Chief of the Genetics Division, Vice Chair for Administration and Medical Director for Pediatric Ambulatory Care, President of the Medical Staff, Board of Directors of the MCG Health System, and Chair of the Board of Trustees of the Physicians Practice Group. At MCG he started telemedicine genetics clinics in 1995, which are considered to have been the longest continually running telegenetics services in the nation.

Dr. Flannery has published extensively in clinical genetics and dysmorphology and is a frequent presenter at national meetings.

Dr. Flannery has served on the Boards of numerous health care, academic, and non-profit organizations and received a number of awards including the US Department of Health and Human Services Superior Performance Award, recognition by Castle Connolly's Top Doctors in America, the Columbia University Dean's Award and was elected to the American Pediatric Society.

TOPIC: National Coordinating Center (NCC) Report

NOTES:





NAME:

Sharon Romelczyk, MPA
Program Manager
National Genetics Education
and Consumer Network
Genetic Alliance
sromelczyk@geneticalliance.org

Bio: Sharon serves as the Program Manager for the National Genetics Education and Consumer Network, a three year initiative led by Genetic Alliance in conjunction with the efforts of the National Coordinating Center for the seven Regional Genetics Collaboratives. In this role, Sharon contributes to several projects aimed at improving access to genetic services through education and outreach and consumer engagement. Prior to this role, Sharon served as a Senior Project Specialist coordinating technical assistance activities for seven CDC-funded state based public health grants.

TOPIC: National Genetics Education and Consumer Network (NGECN)

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NAME:

Lori Williamson Dean, MS, CGC
Department Chair and
Assistant Professor,
Department of Genetic Counseling
University of Arkansas for Medical Sciences
Program Manager,
Heartland Genetics Services Collaborative
LWDean@uams.edu

BIO: Lori has worked as a prenatal and pediatric genetic counselor at Arkansas Children's Hospital ('92-'93); and at the University of Missouri Department of Pediatrics and the Southern Missouri Regional Genetics Program ('93 – '03). In 2004, she began teaching genetic counseling students at the University of Oklahoma Health Sciences Center and is now chairman of the Department of Genetic Counseling at the University of Arkansas for Medical Sciences.

Lori has served as Program Manager for the Heartland Genetics Collaborative since its inception in 2004. Public health genetics, teaching, and supporting individuals and families affected by genetic conditions are the hallmarks of her career. Lori has spent her life and career in the Heartland region. She was born and raised in the Ozarks of southern Missouri and spends weekends on her farm outside of Willow Springs, Missouri.

TOPIC: State of the Heartland Region

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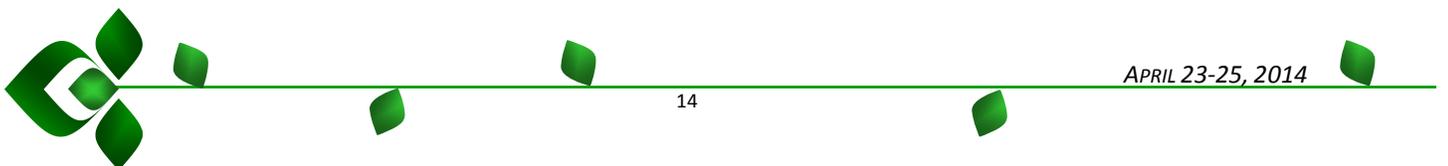
CDR Nancy Miller
APRN, CCNS, MSHS, MBA, MSN
Regional Nurse Consultant Title X
Office of Population Affairs-Region 7
Kansas City, MO
Nancy.Miller@hhs.gov

Bio: CDR Nancy Miller is Commissioned Officer in the United States Public Health Service. CDR Miller completed her BSN at Eastern Kentucky University and worked as an ICU/ER nurse at Wake Forest University-Baptist Medical Center in Winston-Salem, North Carolina for 10 years prior to joining the U.S. Air Force in 1999. During her tenure with the USAF, she served as Critical Care nurse and Clinical Nurse Specialist while earning her Master of Science in Health Administration, Master of Business Administration and Master of Nursing, as well as certification as Acute Care Nurse Practitioner (ACNP), Certified Clinical Nurse Specialist (CCNS) and Critical Care Registered Nurse Certification (CCRN).

CDR Miller transferred to the USPHS-CC in 2009 and serves as the Regional Program Consultant for the Office of Population Affairs-Office of Family Planning in the Regional Health Administrators Office in Kansas City.

TOPIC: Regional Health and Human Services offices: role & resources

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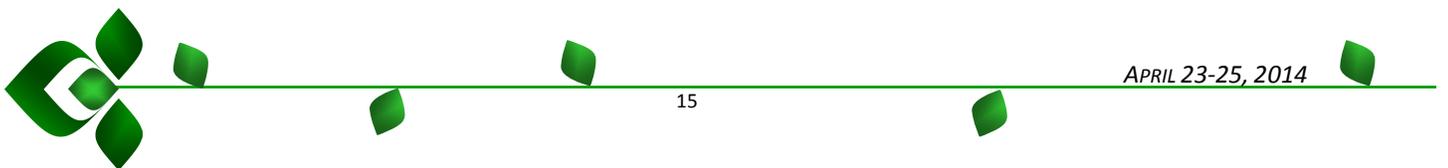
Marci Sontag, PhD
Associate Professor
MPH Concentration Director
Colorado School of Public Health
Marci.Sontag@ucdenver.edu

BIO: Marci Sontag is an Associate Professor of Epidemiology and Pediatrics at the Colorado School of Public Health and the University of Colorado Anschutz Medical Center, and the Associate Director of Epidemiology of NewSTEPS (the Newborn Screening Technical assistance and Evaluation Program), a program designed to support newborn screening programs across the U.S. through an innovative data repository and quality improvement initiatives. She has a PhD in Epidemiology and an MS in Biometrics from the University of Colorado Health Sciences Center.

Dr. Sontag has studied clinical outcomes and newborn screening in cystic fibrosis since 1995. Her research in CF has resulted in a better understanding of longitudinal progression of pancreatic damage and a new algorithm for CF newborn screening. Dr. Sontag is helping to lead the efforts to implement CCHD newborn screening in Colorado and working on a pilot study of Spinal Muscular Atrophy Newborn Screening. Other research interests include characterizing the epidemiology of chronic lung disease associated with prematurity and the respiratory tract microbiome in pediatrics.

TOPIC: NewSTEPS

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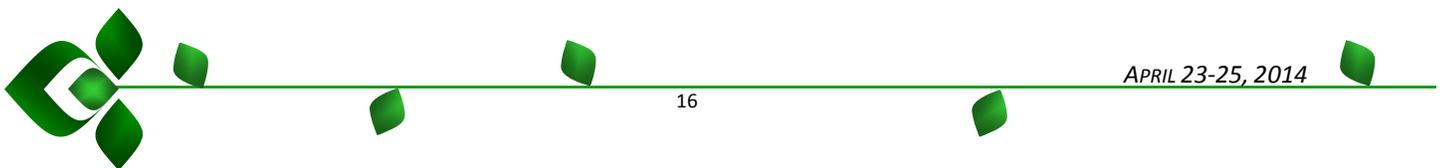
Amy M. Brower, PhD
National Coordinating Center
and Newborn Screening Translational
Research Network
American College of Medical Genetics
and Genomics
& ACMG Foundation
abrower@acmg.net

BIO: Dr. Brower works on several projects at the American College of Medical Genetics and Genomics focused on translational research and public health in newborn screening, informatics and genomics. She has a background in medical genetics, genomics and bioinformatics, and was a member of the Human Genome Project team.

Dr. Brower is a former member of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children and received her doctorate degree in Medical Genetics at the University of Nebraska Medical Center. She led development of molecular diagnostics that are utilized in newborn screening, clinical care, and genomic research.

TOPIC: Genomic Sequencing as Part of the Newborn Screen

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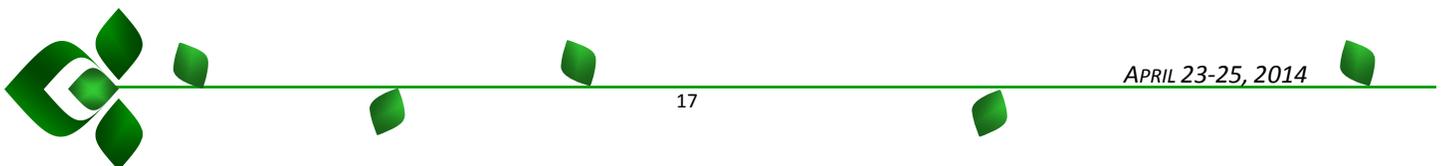
Laurel Willig, MD, MS
Assistant Professor,
University of Missouri
Pediatric Nephrologist,
Children's Mercy Hospital
Assistant Medical Director,
Center for Pediatric Genomic Medicine
lkwillig@cmh.edu

Bio: Dr. Willig is an Assistant Professor at University of Missouri, Kansas City, a pediatric nephrologist at Children's Mercy Hospital, Kansas City and assistant medical director of the Center for Pediatric Genomic Medicine. She received her medical training at the University of Iowa, completed her pediatric residency at Oregon Health Science University and pediatric nephrology fellowship at Seattle Children's Hospital. She also completed her master's degree in genetic epidemiology at the University of Washington.

Dr. Willig's current research involves the study of clinical application of whole genome sequencing to infants and neonates with a special focus on those with congenital renal anomalies.

TOPIC: Genomic Sequencing as Part of the Newborn Screen

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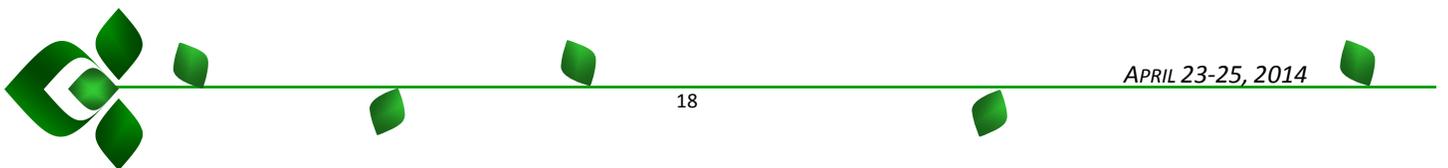
Joshua E. Petrikin, MD
Assistant Professor of Pediatrics
Director of Neonatal Genomics
Children's Mercy Hospital Center
for Pediatric Genomic Medicine
jepetrikin@cmh.edu

Bio: Joshua E. Petrikin, MD, a Neonatologist at Children's Mercy Hospital in Kansas City, Missouri since 2009, received his MD from the University of Oklahoma College of Medicine. He performed his post-graduate education and training at the Mayo Graduate School of Medicine in Rochester, Minnesota, and completed his fellowship in Neonatology at Children's Mercy Hospital.

Dr. Petrikin's clinical practice and research interests are neonatology, bioethics, child advocacy, and infant immunology. His primary research focuses on genome sequencing and ethical issues in neonatal genomics.

TOPIC: Genomic Sequencing as Part of the Newborn Screen

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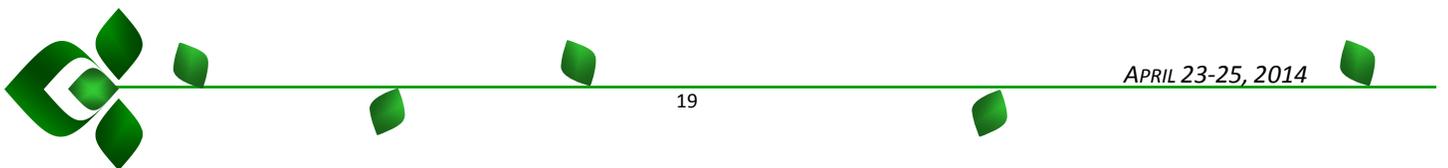
Heather Smith, MPH
Director, Special Health Services
Kansas Department of Health and Environment
hsmith@kdheks.gov

Bio: Mrs. Smith has worked in the health care field in some capacity for nearly 15 years, beginning in a family physician's office, moving to a hospital outpatient surgery unit and then to home health and inpatient care on a transitional care unit throughout college. Working with Children's Miracle Network as the Directors of Special Projects and Children's Services created a passion to serve the special health care needs population. Upon graduate from Missouri State University with a Master's in Public Health and an internship with the Kansas City, MO Health Department, she began working for the Children and Youth with Special Health Care Needs (CYSHCN) at the Kansas Department of Health and Environment (KDHE) as the Project Coordinator an Integrated Community Systems grant in September 2009.

Holding various positions within the CYSHCN program, participating in the Kansas Public Health Leadership Institute and working closely with the Director to align the program's state objectives and activities with national performance measures and national initiatives provided opportunities for advancement. In February of 2013, Mrs. Smith had the opportunity to lead staff within the Kansas Special Health Services section at KDHE. As Director, she oversees the Kansas Metabolic Newborn Screening, Early Hearing Detection and Intervention, Infant/Toddler Early Intervention (Part C), and Special Health Care Needs programs. Additionally, Mrs. Smith has been the lead consultant on the Heartland Genetics Individualized Health Planning project.

TOPIC: Individualized Health Plan Project

NOTES:





NAME:

Wendy Parent-Johnson, PhD, CRC, CESP
Executive Director, Center for Disabilities
Professor, Department of Pediatrics
Sanford School of Medicine
University of South Dakota
Wendy.ParentJohnson@usd.edu

Bio: Dr. Wendy Parent-Johnson is Professor, Department of Pediatrics, and Executive Director of the Center for Disabilities, a Center for Excellence in Developmental Disabilities, at the Sanford School of Medicine, University of South Dakota (USD). She recently took this position approximately one year ago and in that role is responsible for administration and oversight of multiple grants, research, teaching, and supervision of 35 staff.

Her educational background includes a Masters Degree in Rehabilitation Counseling and a Ph.D. in Education with an emphasis on Transition for Individuals with severe Disabilities, both from Virginia Commonwealth University. She has thirty years experience in the areas of supported and customized employment and transition from school to work for individuals with severe disabilities.

Dr. Parent-Johnson has conducted presentations and published numerous book chapters, peer-reviewed journal articles, curricula, and informal written and electronic products related to transition and supported/customized employment and has co-authored several books on supported employment with a current one under contract with Paul Brookes Publishing Co. Most recently, her research and teaching has focused on health care transition, health disparities, and interdisciplinary health science education.

TOPIC: Healthcare Transition for Our Patients

NOTES:



NAME:

Richard Parent-Johnson, PhD
Clinical Research Coordinator
University of South Dakota
Sanford School of Medicine
Richard.ParentJohnso@usd.edu

BIO: Dr. Richard Parent-Johnson is a Clinical Research Coordinator in the Sanford School of Medicine. Prior to this new position, he was a Senior Research Associate in the Center for Research on Learning at the University of Kansas and held a courtesy appointment in the Department of Special Education at KU. His doctorate is in Sociology from the University of Kansas.

Dr. Parent-Johnson has been the PI, Co-PI or project coordinator on multiple state and federal grants. For the past 12 years, his work has focused on the iterative development and implementation of “universal design” educational products and processes that serve the individualized transition needs of persons with mild to severe disabilities. Other recent work involved design and development of on-line tools that support the work of job coaches as they transition their clients with significant disabilities into real-world employment.

Dr. Parent-Johnson’s focus on the models and practices of more inclusive learning environments provides him the opportunity to look concretely at the specifics of individual learning content as well as at the social systems in which that learning takes place. He has a special interest in social determinants of health and how social capital works to bridge gaps in health care transitions for special needs populations.

Dr. Parent-Johnson is knowledgeable of mixed methods research methodologies with particular expertise in qualitative data analysis.

TOPIC: Healthcare Transition for Our Patients

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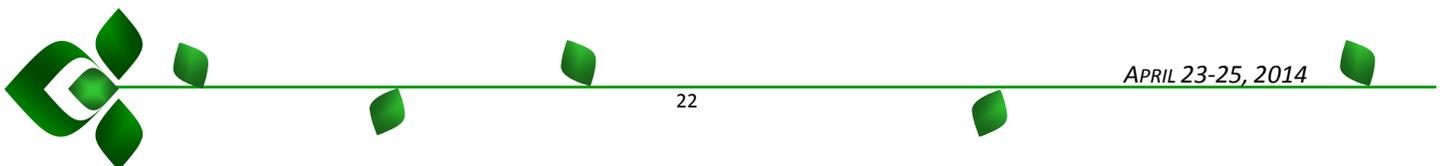
NAME:

Barbara Jackson, PhD
Munroe-Meyer Institute,
University of NE Medical Center
985450 Nebraska Medical Center
bjjackso@unmc.edu

BIO: Dr. Jackson is the Director of the Department of Education and Interdisciplinary Center of Program Evaluation (ICPE) and Professor at Munroe-Meyer Institute at the University of Nebraska Medical Center. Dr. Jackson is the program evaluator for multiple federal, regional and state funded projects, including such projects that focus on: national literacy and parent education, newborn screening, mental health consultation in child care settings, school based early childhood, and home visitation. In her role as an evaluation consultant she has experience with a variety of assessment measures that can effectively measure child, family, and early child teacher outcomes. The ICPE has established systematic quality assurance procedures and an effective process for continuous improvement as a key aspect of the evaluation process.

TOPIC: Are we making a difference?

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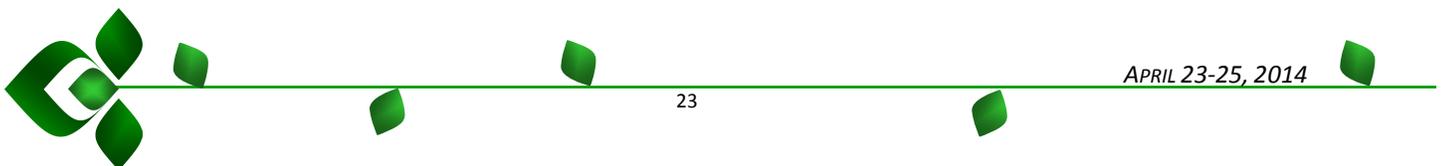
NAME:

Ingrid Larson, BA, MSN, MBA, RN, APRN, CPNP
Director – Beacon Program
Children's Mercy Clinics on Broadway
ialarson@cmh.edu

Bio: Ingrid received her MBA with an emphasis in healthcare administration from Avila University, her MSN and BSN equivalent from Vanderbilt University and a bachelor's in biology, with a minor in chemistry, from William Jewell College. Ingrid joined Children's Mercy Hospital in 2008 initially working in biochemical genetics. She then joined the Pediatric Care Center (PCC) in 2011, an outpatient primary care clinic. Ingrid became the Director of the Beacon Program in 2013, which is a comprehensive medical home for children and youth with special health care needs and their siblings. She continues to be a genetics content expert, is active professionally and presents locally and nationally about genetics, newborn screening, the medical home and the care of a child with complex health needs.

TOPIC: American Academy of Pediatrics' Genetics in Primary Care Institute

NOTES:





NAME:

James Harper, MD
Associate Professor,
Pediatric Hematology-Oncology
University of Nebraska Medical Center
jharper@unmc.edu

BIO: Dr. Harper is an associate professor of pediatric hematology and oncology at the University of Nebraska Medical Center. He is also a member of Nebraska's Newborn Screening Advisory Committee and a consultant to the Newborn Screening Committee. His scholarly interests lie in continuing medical education, where he is the Director of Continuing Medical Education at Omaha's Children's Hospital and Medical Center. Dr. Harper is also involved in CME as the CME Section Leader for the Central Group on Educational Affairs of the AAMC and as the chair of the Certification and Continuing Education Committee for the American Society of Pediatric Hematology-Oncology.

His active projects include online CME at Children's (Grand Rounds online, and Just in Time CME), and as a member of the AAP PREP Editorial committee for Pediatric Hematology-Oncology.

TOPIC: Sickle Cell Trait Education

NOTES:





NAME:

Sara Gardner, MD
Interim Section Chief,
Medicine/Pediatrics
Program Director, Internal
Medicine-Pediatrics Residency
Children's Mercy Hospital
segardner@cmh.edu

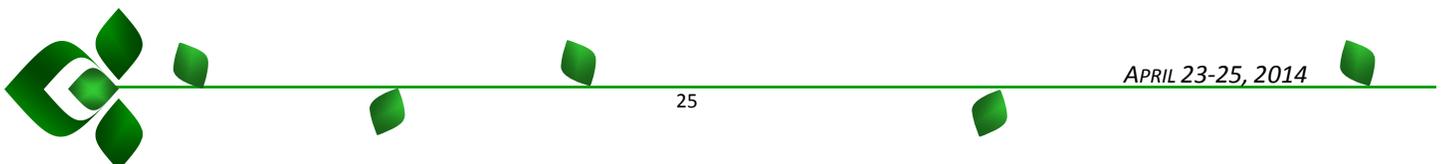
BIO: Sara Gardner received her combined BA/MD degree from the University of Missouri – Kansas City School of Medicine. She then remained in Kansas City to complete a combined Internal Medicine – Pediatrics residency.

Currently, Dr. Gardner is an Assistant Professor of Internal Medicine and Pediatrics at UMKC. She serves as program director for the combined residents and is in her final months as interim section chief for a new section of Internal Medicine and Pediatrics for Children's Mercy Hospital and Truman Medical Center.

Dr. Gardner's passion for transition medicine was cultivated during her residency as she cared for young adults with chronic conditions of childhood in crisis in adult healthcare facilities. She is working to build a collaboration of adult health care providers in the KC region who are excited to provide outstanding primary and specialty care for this unique population of patients.

TOPIC: Residency training in healthcare transition

NOTES:





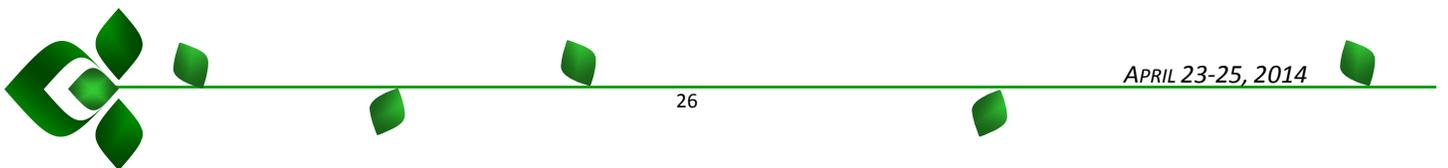
NAME:

Eduardo Ochoa, MD
Associate Professor
University of Arkansas
for Medical Sciences
OchoaEduardoR@uams.edu

BIO: Dr. Eduardo Ochoa is both a pediatrician and an advocate in the emergent Latino community of Arkansas. He is an Associate Professor of Pediatrics at the University of Arkansas for Medical Sciences (UAMS) and the Assistant Dean for Minority Affairs at the UAMS College of Public Health. Ochoa practices pediatrics at Arkansas Children's Hospital (ACH) in Little Rock, where he began the Latino Clinic for special needs children at ACH in May 2009. He is an alumnus of the Open Society Institute's Soros Advocacy Fellowship for Physicians. He received his AB in Religion from Princeton University and his MD from Texas Tech University Health Sciences Center. He is the past President of the Arkansas Chapter of the American Academy of Pediatrics (AAP), has been named to the Best Doctors in America list since 2003 and has been voted Mejor de lo Mejor (Best of the Best) doctor by the readers of El Latino, Central Arkansas' Spanish weekly newspaper.

TOPIC: Health System Considerations for the Growing Population of Hispanic Children with Special Healthcare Needs in Arkansas

NOTES:





NAME:

Eileen Forlenza

Speaker, Author, Trainer

www.EileenForlenza.com

BIO: Eileen Forlenza is a motivational speaker/leader/performer who is recognized nationally for her work on family engagement. Eileen gently encourages individuals to live each day through the lens of possibility, especially those dedicated to cultivating the potential of children living with unique needs. Eileen is the parent of young adult with disabilities, lending authenticity to her extensive experience embedding strategies for effective parent engagement.

Eileen has served on state and national advisory councils including National Center for Healthcare Transition – Got Transition, National Committee on Quality Assurance (NCQA), National Initiative for Child Health Quality (NICHQ), Association of Maternal and Child Health Programs (AMCHP) and Family Voices National and has served as faculty for the Institute for Patient and Family Centered Care and as a curriculum consultant for University of North Carolina – Chapel Hill. In Colorado, Eileen has held Governor appointed positions on the Colorado Interagency Coordinating Council and the Colorado Developmental Disabilities Council and served as a Colorado delegate to attend the national Family Policy Academy. Eileen holds credentials in family leadership development, including curriculum design and implementation and is a fellow of the Maternal and Child Health Public Health Leadership Institute as well as Colorado’s Leadership and Education for Neurodevelopmental Disabilities (LEND).

TOPIC: Exhilarating Family Partnerships

NOTES:





NAME:

Klaas J. Wierenga, MD, MSc, FACMG
Associate Professor, Department of Pediatrics,
Division of Genetics
Director of Medical Genetics Residency Program
klaas-wierenga@ouhsc.edu

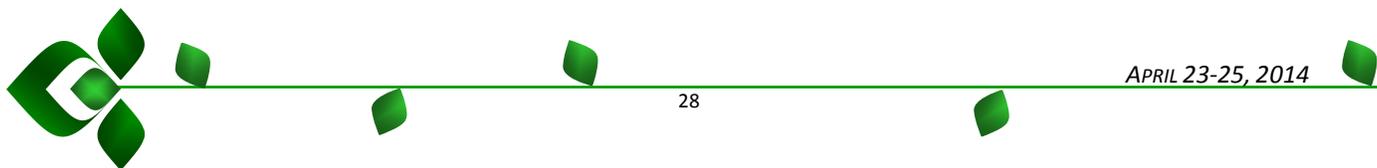
BIO: Dr. Klaas J. Wierenga is a medical geneticist at the University of Oklahoma Health Sciences Center (OUHSC) in Oklahoma City, OK, with degrees in Biology and Medicine from the Groningen State University in the Netherlands. He is Board-certified in Clinical and Biochemical Genetics. His clinical focus is to provide care, both diagnostic and therapeutic, to children with genetic disorders or suspected of having genetic or metabolic disorders.

At OUHSC, he is Director of the Specialty Clinic, and Program Director of the Medical Genetics Residency Program. He is also director of the 1st year Medical School course 'Molecular and Cellular Systems' for OU Medicine. Together with Dr. G. Bradley Schaefer, he is co-Director of the HRSA-funded 'Heartland Regional Genetics Collaborative.' He also serves as Medical Director of the Master's Program for Genetic Counseling.

His research interest focuses on the diagnostic process for individuals with rare Mendelian disorders, using information technology and novel technical genetic breakthroughs to aid in this process; and to empower the geneticist involved in patient care to access and utilize complex data, by making analysis of these data more accessible and user-friendly.

TOPIC: Closing Remarks

NOTES:





BECOMING A CORE WORK GROUP MEMBER

Core Work Group Member:

Core members of the Heartland Work Groups agree to a two-year commitment to work group membership, including participating in teleconferences, scheduled every one to two months, email communications and a work group project. Core members may also be asked to represent Heartland on national committees or groups. Attendance at the annual in-person meeting and, if needed, one additional mid-year meeting, will be funded by the Heartland Regional Coordinating Center.

Please check all that apply:

___ **YES!** I would like to become a core work group member of the following work group (s):

___ Advocate

___ Clinical Services

___ Early Hearing Detection and Intervention

___ Newborn Screening

___ Medical Home

Please provide your name and email address below:

Name: _____

Email: _____

Contact the Heartland Regional Coordinating Center:

Email: hrcc@uams.edu





DEFINING ADVOCATE WORK GROUP MEMBERSHIP

Core Work Group Member

Core members of the Heartland Work Groups agree to a two year commitment to work group membership, including participating in teleconferences, scheduled every one to two months, email communications and a work group project. Core members may also be asked to represent Heartland on national committees or groups. For core members, attendance at the annual in-person meeting, and if needed, one additional mid-year meeting, will be funded by the Heartland Regional Coordinating Center.

Work Group Members

Other members of a work group may wish to receive work group communications but not commit to active attendance and participation, or may wish to participate only on a specific project.

Advocate Core Work Group Members:

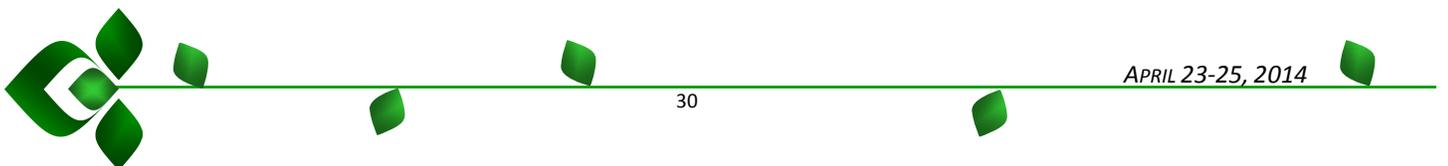
| Name | Email |
|------------------------|------------------------------------------------------------------------------|
| Holly Johnson (AR) | hajohnson2@uams.edu |
| Jeanne Egger (NE) | jeanne.egger@nebraska.gov |
| Mark Smith (NE) | msmitha@unmc.edu |
| Larry Weatherford (OK) | learryweatherford@gmail.com |
| Michelle Black (KS) | mblack_75@yahoo.com |
| Kendra Gottsbelen (SD) | kegotts@gmail.com |
| Donene Feist (ND) | fvnd@drtel.net |

Other Work Group Members:

| Name | Email |
|-----------------------|--------------------------------------------------------------------|
| Leisha Suckstorf (NE) | jmsgng49@msn.com |
| Julie Briggs (SD) | juliabriggs3@yahoo.com |

Core Membership Status: The listing above reflects work group members' status at the beginning of the project year.

Becoming a Core Work Group Member: If you are interested in becoming a Core Work Group Member, please contact: Dustin Foster (dmfoster@uams.edu).





HEARTLAND GENETICS SERVICES COLLABORATIVE

ADVOCATE WORK GROUP MEETING

WEDNESDAY, APRIL 23, 2014

3:00 – 5:00 PM

ARKANSAS / ILLINOIS

AGENDA

| | |
|--------------------------------------|---------------------------------------------------------------------------------------------|
| 1. Welcome and Introductions | Egger |
| 2. ACMG Experience | Egger, Black, Weatherford, Smith |
| 3. NGECCN Update | Weatherford, Smith, Romelczyk |
| 4. Hispanic Access Project Update | Coffman and Herrera Morales |
| 5. Individualized Health Plan Update | Coffman |
| 6. Mentoring | Herrera Morales or Williamson Dean |
| 7. Face Forward | Herrera Morales or Williamson Dean |
| 8. Work Group Assignments | All |
| 9. Future Monthly Meeting Time | All |
| 10. Other | |
| Next Meetings: | May 7th, 2014 at 10:00 AM June 4th, 2014 at 10:00 AM |





NOTES



DEFINING CLINICAL SERVICES WORK GROUP MEMBERSHIP

Core Work Group Member

Core members of the Heartland Work Groups agree to a two year commitment to work group membership, including participating in teleconferences, scheduled every one to two months, email communications and a work group project. Core members may also be asked to represent Heartland on national committees or groups. For core members, attendance at the annual in-person meeting, and if needed, one additional mid-year meeting, will be funded by the Heartland Regional Coordinating Center.

Work Group Members

Other members of a work group may wish to receive work group communications but not commit to active attendance and participation, or may wish to participate only on a specific project.

Clinical Services Work Group Members:

| Name | Email |
|------------------------|------------------------------------------------------------------------------------|
| Kim Piper (IA) | kimberly.piper@idph.iowa.gov |
| Joni Bosch (IA) | ioni-bosch@uiowa.edu |
| Shobana Kubendran (KS) | shobana.kubendran@wesleymc.com |
| Robin Troxell (MO) | troxellr@gmail.com |
| Carol Johnson (IA) | carol-johnson@uiowa.edu |

Other Work Group Members:

| Name | Email |
|-----------------------|--------------------------------------------------------------------------------|
| Merlin Butler (KS) | mbutler4@kumc.edu |
| Erin Youngs (MO) | eyoungs@saint-lukes.org |
| Mary Riske (ND) | mary.riske@sanfordhealth.org |
| Jeanne Egger (NE) | jeanne.egger@nebraska.gov |
| Melissa Hall (OK) | mhall@breastok.com |
| Quinn Stein (SD) | quinn.stein@sanforhealth.org |
| Suzanne Huetter (AR) | shuetter@uams.edu |
| Jennifer Roberts (KS) | jroberts6@kumc.edu |

Core Membership Status: The listing above reflects work group members' status at the beginning of the project year.

Becoming a Core Work Group Member: If you are interested in becoming a Core Work Group Member, please contact: Dustin Foster (dmfoster@uams.edu).





HEARTLAND GENETICS SERVICES COLLABORATIVE

CLINICAL SERVICES WORK GROUP

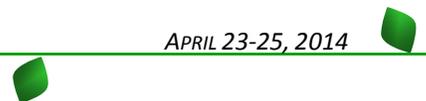
FRIDAY, APRIL 25, 2014

10:00 AM – 1:00 PM

SALON C

AGENDA

| | |
|--------------------------------------------|----------------------|
| 1. Welcome and Introductions | Schaefer |
| 2. Review of Activities for 2012 – Present | |
| a. Medical Home | Larson and Schaefer |
| b. Hispanic Access | Coffman |
| c. Healthcare Transition | Wendy Parent-Johnson |
| d. Individualized Health Plan | Coffman |
| 3. Proposed Activities for 2014-2015 | Schaefer |
| a. Genomics Centers Webinar | |
| b. Epilepsy Education Project (KU/AAP/HHS) | |





NOTES



DEFINING NEWBORN SCREENING WORK GROUP MEMBERSHIP

Core Work Group Member

Core members of the Heartland Work Groups agree to a two year commitment to work group membership, including participating in teleconferences, scheduled every one to two months, email communications and a work group project. Core members may also be asked to represent Heartland on national committees or groups. For core members, attendance at the annual in-person meeting, and if needed, one additional mid-year meeting, will be funded by the Heartland Regional Coordinating Center.

Work Group Members

Other members of a work group may wish to receive work group communications but not commit to active attendance and participation, or may wish to participate only on a specific project.

Newborn Screening Core Work Group Members:

| Name | Email |
|--------------------------|--------------------------------------------------------------------------------------------|
| Leslie Himstedt (AR) | leslie.himstedt@arkansas.gov |
| Stan Berberich (IA) | sue.routledge@minostateu.edu |
| Julie Raburn-Miller (MO) | julie.raburn-miller@dhss.mo.gov |
| Dawn Peck (MO) | peckda@health.missouri.edu |
| Patrick Hopkins (MO) | patrick.hopkins@dhss.mo.gov |
| Sharmini Rogers (MO) | sharmini.rogers@dhss.mo.gov |
| Karen Eveans (NE) | karen.eveans@nebraska.gov |
| Krystal Baumert (NE) | krystal.baumert@nebraska.gov |
| Julie Luedtke (NE) | julie.luedtke@nebraska.gov |
| Tonya McCallister (OK) | tonyaj@health.ok.gov |
| Sarah Groeneveld (SD) | sarah.groeneveld@sanfordhealth.org |
| Lucy Fossen (SD) | lucy.fossen@state.sd.us |
| Stephen Kahler (AR) | kahlerstepheng@uams.edu |
| JoAnn Bolick (AR) | jabolick@uams.edu |
| Patricia Scott (AR) | patricia.scott@arkansas.gov |
| Kim Piper (IA) | kimberly.piper@idph.iowa.gov |
| Carol Johnson (IA) | carol-johnson@uiowa.edu |
| Jamey Kendall (KS) | jkendall@kdheks.gov |
| Becky Bailey (ND) | bbailey@nd.gov |
| Jami Kiesling (MO) | jami.kiesling@health.mo.gov |
| Sue Haddad (OK) | soheilah@health.ok.gov |
| Jena Callen-Scholz (KS) | jcallen-scholz@kdheks.gov |

Core Membership Status: The listing above reflects work group members' status at the beginning of the project year.

Becoming a Core Work Group Member: If you are interested in becoming a Core Work Group Member, please contact: Dustin Foster (dmfoster@uams.edu).





HEARTLAND GENETICS SERVICES COLLABORATIVE

NEWBORN SCREENING WORK GROUP

FRIDAY, APRIL 25, 2014

10:00 AM – 1:00 PM

SALON A

AGENDA

| | |
|--------------------------------------------------------------|-----------------|
| 1. NewSTEPs Update | Sontag |
| 2. Collaborative Partners Project | Herrera Morales |
| 3. Long-Term Follow-Up Project Update | Rogers |
| 4. SCID Testing Methodologies | Vaz |
| 5. Other | |
| Next Meetings: May 28 th , 2014 at 2:00 PM | |
| June 25 th , 2014 at 2:00 PM | |





NOTES



DEFINING EHDI WORK GROUP MEMBERSHIP

Core Work Group Member

Core members of the Heartland Work Groups agree to a two year commitment to work group membership, including participating in teleconferences, scheduled every one to two months, email communications and a work group project. Core members may also be asked to represent Heartland on national committees or groups. For core members, attendance at the annual in-person meeting, and if needed, one additional mid-year meeting, will be funded by the Heartland Regional Coordinating Center.

Work Group Members

Other members of a work group may wish to receive work group communications but not commit to active attendance and participation, or may wish to participate only on a specific project.

EHDI Core Work Group Members:

| Name | Email |
|-----------------------|----------------------------------------------------------------------------------------|
| Tammy O'Hollearn (IA) | tammy.ohollearn@idph.iowa.gov |
| Liz Abbey (KS) | eabbey@kdheks.gov |
| Sue Routledge (ND) | sue.routledge@minostateu.edu |
| Kathy Northrop (NE) | kathy.northrop@nebraska.gov |
| Jeff Hoffman (NE) | jeffhoffman.ehdi@gmail.com |
| Patricia Burk (OK) | patriciaab@health.ok.gov |
| Lucy Fossen (SD) | lucy.fossen@state.sd.us |
| Cathy Harbison (MO) | catherine.harbison@health.mo.gov |
| Jerusha Olthoff (ND) | jerusha.olthoff@minostateu.edu |

Other Work Group Members:

| Name | Email |
|-------------------|----------------------------------------------------------------------------------|
| Tariq Ali (AR) | saiyed.ali@arkansas.gov |
| Wendy Thomas (ND) | wendy.thomas@minostateu.edu |
| Kim Hrubby (ND) | krhrubby@nd.gov |
| Quinn Stein (SD) | quinn.stein@sanfordhealth.org |

Core Membership Status: The listing above reflects work group members' status at the beginning of the project year.

Becoming a Core Work Group Member: If you are interested in becoming a Core Work Group Member, please contact: Dustin Foster (dmfoster@uams.edu).





HEARTLAND GENETICS SERVICES COLLABORATIVE

EARLY HEARING DETECTION AND INTERVENTION WORK GROUP

FRIDAY, APRIL 25, 2014

10:00 AM – 1:00 PM

SALON B

AGENDA

| | |
|----------------------------------------------------------------------------------------------------------------------------------|-----|
| 1. EHD Conference Review | All |
| a. EHD conference ideas for Heartland | |
| 2. EHD exchange data | All |
| a. EHD conference ideas for Heartland | |
| 3. 2014 work goals | All |
| a. 2013 Audiology survey, webinar training, Gallaudet course | |
| b. Topics/ activities: Education, Access, Linking resources, Demonstration Pilot and Building on previous work at another region | |
| c. Possible goals: Border States: Compiling state activities, working to share data, Data process and sharing agreements | |
| 4. Update Heartland EHD Programs Excel Spreadsheet | All |
| a. New information | |
| b. Expand information to facilitate program links | |
| Next Meetings: | |
| May 25th, 2014 at 3:00 PM | |
| June 28th, 2014 at 3:00 PM | |





NOTES



HEARTLAND COLLABORATIVE BIBLIOGRAPHY (2006-2014)

PEER-REVIEWED JOURNAL ARTICLES

DAACK-HIRSCH S, JACKSON B, BELCHEZ CA, ELDER B, HURLEY R, KERR P, NISSEN MK. Intergrating genetics and genomics into nursing curricula: you can do it too!. *Nurs Clin North Am*. 2013 Dec;48(4):661-9.

CARLETON SM, PECK DS, GRASELA J, DIETIKER KL, PHILLIPS CL. DNA carrier testing and newborn screening for maple syrup urine disease in Old Order Mennonite communities. *Genet Test Mol Biomarkers*. 2010 Apr;14(2):205-8.

CHOU AF, NORRIS AI, WILLIAMSON L, GARCIA K, BAYSINGER J, MULVIHILL JJ. Quality assurance in medical and public health genetics services: A systematic review. *Am J Med Genet*. 2009; Part C Semin Med Genet 151C:214–234.

FERGESON MA, MULVIHILL JJ, SCHAEFER GB, DEHAAI KA, PIATT J, COMBS K, BRIGHT BC, NEAS BR: Low adherence to national guidelines for thyroid screening in Down syndrome. *Genet Med*. 2009; 11(7):548-51.

HOLSEN LM, ZARCONI JR, CHAMBERS R, BUTLER MG, BITTEL DC, BROOKS WM, THOMPSON TI, SAVAGE CR: Genetic subtype differences in neural circuitry of food motivation in Prader-Willi syndrome. *Int J Obes*. 2008; 33: 273-283.

HOLSEN LM, ZARCONI JR, BROOKS WM, BUTLER MG, THOMPSON TI, AHLUWALIA JS, NOLLEN NG, SAVAGE CR: Neural mechanisms underlying hyperphagia in Prader-Willi syndrome. *Obesity*. 2006;14:1028-1037.

MULTIMEDIA

PARENT-JOHNSON R., PARENT-JOHNSON W. Social Capital: Making Transitions Possible. Webinar. January 10, 2014. Accessible at <https://www.youtube.com/watch?v=9Br3uXL0g0o>

PARENT-JOHNSON R., PARENT-JOHNSON W. Heartland Region Transition Projects: Overview and Findings. Webinar. November 25, 2013. Accessible at https://www.youtube.com/watch?v=G8Oa_36ImTg

SWEARINGEN C. Arkansas Newborn Screening Long term Follow up Database. Webinar. November 20, 2013. Accessible at <https://www.youtube.com/watch?v=0ovRZ1mF-B4>

PARENT-JOHNSON R., PARENT-JOHNSON W. Heartland Transition Learning Collaborative. Webinar. October 25, 2013. Accessible at <https://www.youtube.com/watch?v=9CI9HIMyJr8>





WHITE M., BOWEN-EUBANKS M. HIPAA and FERPA Working Together While Keeping the Privacy of the Student in Mind. Webinar. August 22, 2013. Accessible at <https://www.youtube.com/watch?v=nC7qO72o9Sw>

BIGLER K. Comparing School-Based Plans for CYSHCN and/or Genetic Conditions. Webinar. July 9, 2013. Accessible at <https://www.youtube.com/watch?v=oeclgrax1GU>

KEMPER A. Weighing the Evidence for Newborn Screening. Webinar. April 24, 2013. Accessible <https://www.youtube.com/watch?v=DQkCOz6B12I>

KIMBERLING W., JOLMA C. Hearing Loss and Deafness. April 2013. Accessible at <http://www.medicalhomeportal.org/>

PRESENTATIONS

INVITED PLATFORM PRESENTATIONS

KUBENDRAN S, SARONWALA A, SCHAEFER. A novel approach in telegenetics services- geneticist, pediatrician and genetic counselor team. ACMG March 27, 2014 Nashville, TN.

PARENT-JOHNSON W., WILLIAMSON-DEAN L. Transitioning and Medical Home: Role of the Genetic Counselor. Pre-Conference Symposium, National Society of Genetic Counselors Annual Education Conference, October 2013; Anaheim, CA.

MROCH A. Sanford Children's Hearing Loss Clinic: Start-up, Successes, and Challenges. Early Hearing Detection and Intervention Annual Meeting; March 2012; St Louis, MO.

KUBENDRAN S. Telegenetics in the Heartland Regional Collaborative. American Telemedicine Association Conference; May 2011; Tampa, FL.

WILLIAMSON L. Access to Services is a Local Issue: NBS initiatives of the Regional Collaboratives. National Society of Genetic Counselors Annual Education Conference; October, 2010; Dallas, TX.

KUBENDRAN S. Telehealth: Heartland Regional Genetics & Newborn Screening Collaborative Telemedicine Services. Genetic Alliance Annual Conference; July, 2010; Bethesda, MD.

WILLIAMSON L. The Regional Newborn Screening and Genetics Services Collaboratives. Sarah Lawrence College Public Health Genomics Certificate Program; June 2010; Bronxville, NY.

WILLIAMSON L. The Genetic Counselor's Role in Newborn Screening. Sarah Lawrence College Public Health Genomics Certificate Program; June 2010; Bronxville, NY.

HOPKINS PV. The Heartland newborn screening back-up testing project: Quality assurance findings. Association of Public Health Laboratories Conference; November 2008; San Antonio, TX.

WILLIAMSON L. Role of genetic counselors in the newborn screening system: The Oklahoma





experience: Association of Public Health Laboratories Conference; November 2008, San Antonio, TX.

BENDURE WB, SCHAFFER GB: Regional evaluation of telemedicine use and availability for clinical genetic service. American Telemedicine Association Conference; May 2007; Nashville, TN.

POSTER PRESENTATIONS

PARENT-JOHNSON R. *Transitioning and Medical Home: The Role of the Geneticist*. Got Transition? and Health Care Transition: Research Symposium; October 2013; Houston, TX.

MULVIHILL J, HOPKINS P, BERBERICH S. *Interstate Compatibility and Emergency Preparedness of Newborn Screening Laboratories at the Interface of Clinical Medicine and Public Health*. American Society of Human Genetics Annual Meeting; November 2012; San Francisco, CA.

SCHULZE J, WILLIAMSON DEAN L. *Transition in Practice: A KAP Survey of Medical Genetics Health Professionals in the Heartland and Mountain States Regional Genetics and Newborn Screening Collaboratives*. American College of Medical Genetics Annual Meeting; March 2012; Charlotte, NC.

DAVIS, A, VAZ S. *Newborn Screening Education for Parents*. Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium. November 2011; San Diego, CA.

MULVIHILL J, WHITEHEAD S, CHOU A. Genetics Systems Assessment Working Group. *Weighted Metrics for Assessing Quality of Regional Public Health and Clinical Genetics Services*. 12th International Congress of Human Genetics/61st Annual Meeting of The American Society of Human Genetics; October, 2011; Montreal, Canada.

CREEL LM, KUBENDREN, S, LANDGREN, S, KAYE, CI, HOOKER, J, SCHAEFER, B. *Use of Telemedicine to Deliver Genetics Education in Two Regional Genetics Collaboratives*. National Coalition for Health Professional Education in Genetics, 14th Annual Conference; September 2011; Bethesda, MD.

CHOU AF, AU S, WILLIAMSON L, ET AL: *Developing a Comprehensive Quality Metrics Set for Genetics Service Delivery*: Academy Health; June 2011; Seattle, WA.

MCCALLISTER T, HIMSTEDT L, ROSS L, ET AL: *The Heartland good spot/bad spot project*: Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium; May 2010; Orlando, FL.

WILLIAMSON L, JACKSON B, MULVIHILL JJ, NBS Work Group of the Heartland Regional Genetics and NBS Collaborative. A regional approach to enhancing quality and service capacity of NBS Programs. Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium; May 2010; Orlando, FL.





ROGERS SV. Knowledge and attitudes of the public on storage of dried blood spots. Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium; May 2010; Orlando, FL.

ROGERS SV. Newborn screening – What providers and parents need to know. Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium; May 2010; Orlando, FL.

BERBERICH SL, VALBRACHT M, RAMIREZ M, ET AL. *Enlarging national newborn screening backup capacity by establishing a network of harmonized newborn screening programs.* Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium; May 2010; Orlando, FL.

NORRIS A, CHOU A, WILLIAMSON L, WHITEHEAD S, MULVIHILL JJ. Metrics development for quality assessment of state genetics programs. American College of Medical Genetics Annual Meeting; March 2010; Albuquerque, NM.

MILES J, NALE D, TROXELL R, ET AL. Can teleHealth replace genetics outreach clinics in rural Missouri? American Telemedicine Association Annual Conference; April 2009; Las Vegas, NV.

HATFIELD J, CHOU A, WILLIAMSON L, ET AL. Developing of quality indicators to assess state genetics services and education: A Pilot Study. American College of Medical Genetics Annual Meeting; March 2009; Tampa, FL.

CONOVER E, SCHAEFER GB. Heartland Multi-State Teratogen Education Project. American College of Medical Genetics Annual Meeting; March 2009; Tampa, FL.

PHILLIPS C, COPELAND S. Genetic testing for maple syrup urine disease in Mennonite communities. Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium; November 2008; San Antonio, TX.

KIM J, OLNEY R, YANG Q. Trends in tuberous sclerosis deaths in the United States, 1983-1997. American Public Health Association Annual Meeting; October 2008; San Diego, CA.

SAVAGE CR, HOLSEN L M, CHAMBERS RJ, ET AL. Brain activation to food pictures in overweight and healthy weight children during high and low food motivation states. The Obesity Society Annual Scientific Meeting; October 2007; New Orleans, LA.

SAVAGE CR, HOLSEN LM, CHAMBERS RJ, BROOKS WM, BUTLER MG, & ZARCONE JR. Brain activation to food pictures in obese and healthy weight adults during high and low food motivation states. The Obesity Society Annual Scientific Meeting Annual Scientific Meeting; October 2006; Boston, MA.



Heartland Goals

1. Continue to ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and other subspecialty expertise;
2. Apply the translation of genome-based knowledge, genomics best practices, and new technologies to education and training, services, and dissemination to improve population health; and
3. Quantitatively and qualitatively evaluate through program evaluation outcomes of projects undertaken to accomplish the goals.

| HRSA PRIORITY AREA | HEARTLAND OBJECTIVES | OVERALL STRATEGIES | STATUS | YEAR 3 STRATEGIES | PROPOSED REVISION | RESPONSIBLE PARTY for PROJECT COMPLETION |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------|
| Treat in the context of a medical home that provides accessible, family-centered continuous, comprehensive, coordinated, compassionate, and culturally effective care. | Obj. 1: Increase the number and diversity of the referral indications for telemedicine patient visits in the Heartland. | 1: Prioritize pilot project funding for telemedicine clinic expansion. | Baseline data collection to be completed before May 31, 2014 Purchasing equipment for new sites | Ongoing | None | HRCC Team; Clinical Services Work Group |
| | | 2: Provide technical assistance to new users of telemedicine for the delivery of public health or clinical genetics services. | | Ongoing | None | HRCC: Brad Schaefer |
| | | 3: Educate genetics residents, genetic counseling students, and those in practice less than five years in partnership with Western States region. | Cohort #1 being recruited. On-site training to occur June 23-24 in AR and AZ. | Continue the project; Revise, as needed, after Cohort #1 complete; recruit Cohort #2 | None | HRCC: Lori Williamson Dean |
| | Obj. 2: Use the Individualized Health Plan to enhance coordinated, continuous and family-centered care for children with genetic conditions in the school setting. | Build on the IHP efforts from the Kansas Integrated Community Systems (D-70) grant. | Learning Collaborative phase completed. Analysis of data, creating values, formulating recommendations and next steps. | Continue the project; pilot implementation of new strategies; parent-professional partnership workshop; activity hub; IHP education | None | Consultants: Charlotte Burt, Wendy Parent-Johnson HRCC: Mary Ann Coffman; Medical Home Work Group |
| | Obj. 3: Increase Heartland pediatric genetics providers' knowledge of and practice behaviors in | Learning collaborative | Learning collaborative will be complete by May 31, 2014. | Continue the project; pilot implementation of new strategies; qualitative study of adult care providers; | Explore adult care providers needs and perceptions of the role of the geneticist in transition and the | Consultant: Wendy Parent-Johnson, Richard Parent-Johnson |

| HRSA PRIORITY AREA | HEARTLAND OBJECTIVES | OVERALL STRATEGIES | STATUS | YEAR 3 STRATEGIES | PROPOSED REVISION | RESPONSIBLE PARTY for PROJECT COMPLETION |
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| | healthcare transition for youth with genetic conditions. | | | complete products and disseminate | transition process | HRCC: Lori Williamson Dean; Medical Home Work Group |
| | Obj 4: Increase access to genetics services for patients from Hispanic communities in the Heartland region. | Conduct interviews to learn about barriers, facilitators, and patient experiences. | Ongoing | | None | HRCC: Klaas Wierenga, Mary Ann Coffman, Gene Hallford and Anayeli Herrera Morales; Medical Home Work Group |
| | Obj 5: Explore role of geneticist in the medical home | Write a white paper delineating the issues | Ongoing | Qualitative study of PCP, geneticists, and patient/family perceptions of the role of the geneticist in the medical home | | HRCC: Brad Schaefer, Gene Hallford; Medical Home Work Group |
| Expand the pool of the genetic service workforce by determining needs and gaps across sectors to provide education and training, with emphasis on allied health providers, other subspecialties and educators. | Obj. 1: Increase primary care providers' access to tools and resources for the initial evaluation, follow-up and monitoring of patients with genetic disorders | Strategy 1: Disseminate results, tools, and resources of the pilot project (A Novel Approach in Telegenetic Services: Pediatrician and Genetic Counselor Team) currently underway to train a community pediatrician in the preliminary evaluation of the genetics patient through a presentation at the 2012 Heartland annual meeting, to Heartland states' American Academy of Pediatrics (AAP) chapters, to the MedHome Portal (Mountain States region), and on the Heartland website. | Manuscript in progress; to be completed by May 31, 2014. | None | None | HRCC: Brad Schaefer |
| | | Strategy 2: Heartland Coordinating Center will update Heartland | Shared survey data with NCC and national GPCI project | Will use data to inform a PCP project around FHH and | Combine the effort to provide and promote decision support tools | HRCC: Anayeli Herrera Morales; Medical Home |

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| | | Collaborative members about national efforts in developing templates for management of patients with genetic conditions. We are aware of ongoing efforts, as well as published printed and online resources. These resources and updates will be provided to Heartland members through work group meetings, at the annual meeting, and made available on the Heartland website | coordinator. | decision support tools. | with the FHH project. | Work Group |
| | | Strategy 3: Complete the “Heartland Collaborative Partners Program” | Completed | Renew project in Year 3 based on success of first cohort. | None | HRCC: Anayeli Herrera Morales; NBS Work Group |
| | | Strategy 4: Family Health History implementation of NCHPEG tool into Heartland clinical practices | | Add NCHPEG pediatric tool | Redesign project to include aspects of the AAP’s GPCI project and the Heartland’s clinical decision support project | HRCC: Anayeli Herrera Morales; Clinical Services Work Group and Medical Home Work Group |
| | Obj 2: Enhance the Heartland’s Early Hearing Detection and Intervention (EHDI) programs through resource sharing and education. | Strategy 1: Complete the EHDI exchange program. | ND and SD to arrange exchanges in 2014-2015 | | None | HRCC: Anayeli Herrera Morales; EHDI Work Group |
| | | Strategy 2: Support genetics education of EHDI coordinators, for audiologists, educators, speech/language pathologists, otolaryngologists, parents, patients, and advocates in the region. | Schedule webinars re: genetics evaluation for hearing loss and resources/genetic counseling | | None | HRCC: Anayeli Herrera Morales; EHDI Work Group |
| Build capacity in state public health | Obj 1: Heartland will initiate an information | Strategy 1: Develop an implementation toolkit for | Toolkit components are established. SCID | Add disorders, as needed | None | HRCC: Anayeli Herrera Morales; |

| HRSA PRIORITY AREA | HEARTLAND OBJECTIVES | OVERALL STRATEGIES | STATUS | YEAR 3 STRATEGIES | PROPOSED REVISION | RESPONSIBLE PARTY for PROJECT COMPLETION |
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| departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services. | system to facilitate Heartland states' adoption of SACHDNC recommendations related to newborn and child screening and genetic follow-up and treatment services. | Heartland states | toolkit completed. Pompe drafted. | | | NBS Work Group |
| | | Strategy 2: Monitor local, regional and national activities related to new conditions and SACHDNC recommendations to identify opportunities for Heartland states to participate in pilots, clinical practice guidelines, short and long-term follow-up of newborn screen identified patients. Once a SACHDNC recommendation is published, begin to work with clinicians to identify newborns who are clinically diagnosed prior to adoption of newborn screening to provide a cohort for comparison with newborn screen identified cases. | Ongoing | Continue to send 1 to 2 state representatives to national work group meetings. | None | HRCC; State Genetics Coordinators; NBS Program Coordinators |
| Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access. | Obj. 1: Improve state systems to reflect best practices in LTFU by increasing the specificity of newborn screening, establishing an approach to the long-term follow-up of patients, incorporating electronic health information, and expanding the number of conditions for which screening tests are available. | Strategy 1: Conduct regional NBS workshops for key stakeholders (public health, clinical services, patients and advocates). | Workshop planned for April 23, 2014 | None | | HRCC: Anayeli Herrera Morales and NBS Work Group |
| | | Strategy 2: Facilitate states' adoption of case definitions for the recommended uniform screening panel. | Ongoing | Use time during NBS and Advisory Board monthly meetings | | HRCC Team; NBS Work Group; Advisory Board |
| | | Strategy 3: Link Heartland clinicians to clinical, LTFU databases, such as IBEM-IS | Arkansas and Iowa added | Ongoing | | HRCC Team; NBS Work Group |

| HRSA PRIORITY AREA | HEARTLAND OBJECTIVES | OVERALL STRATEGIES | STATUS | YEAR 3 STRATEGIES | PROPOSED REVISION | RESPONSIBLE PARTY for PROJECT COMPLETION |
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| Any other program priority that addresses the needs of the region and the program goals. | Obj. 1: Expand the implementation of the Genetic Systems Assessment | Strategy 1: Revise GSA tool based on Heartland implementation experience in 2012. | Manuscripts in progress. Meeting with expert panel in May 2014 | Revise tool (Version 2) | | Consultants: Ann Chou HRCC: John Mulvihill and Lori Williamson Dean |
| | | Strategy 2: Sustain GSA in the Heartland | | | | |
| | | Strategy 3: Plan and execute national rollout of the GSA tool. | | Implement in other states/regions. | | Consultant: Ann Chou; HRCC Team |
| | Obj. 2: Pilot Project Program | Tool for soliciting novel strategies to address specific problems | As needed | No plans for RFP in Year 3 | | |
| | Obj. 3: Sustain Emergency Preparedness in the Heartland region (<i>HRSA priority 9</i>) | Strategy 1: The Heartland Region has demonstrated the ability to back up other states during events that would prevent a NBS laboratory from screening. During the next five years, it will be important to maintain this preparedness through drills conducted every other year (2014 and 2016). Repeating the drills will assure readiness and capacity as well as further harmonize systems and processes within the states. | Drill to be conducted in 2014. | Analysis of 2014 drill and recommendations for 2016 drill. | | Consultants: Stan Berberich and Patrick Hopkins HRCC: Lori Williamson Dean |
| | | | | | | |
| | Obj 4: Facilitate communication and linkages of Heartland providers through a variety of methods. | Strategy 1: Heartland Annual Meeting | Spring 2014 | None | | HRCC Team; Advisory Board |
| | | Strategy 2: The Heartland website | Survey results being analyzed | Continue newsletter; add social media | | HRCC: Anayeli Herrera Morales and Illuminage (CareSource) |

| HRSa PRIORITY AREA | HEARTLAND OBJECTIVES | OVERALL STRATEGIES | STATUS | YEAR 3 STRATEGIES | PROPOSED REVISION | RESPONSIBLE PARTY for PROJECT COMPLETION |
|--------------------|-----------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|-------------------------------------------------------------------------------------------------------|-------------------|------------------------------------------|
| | | Strategy 3: Participate in key national or other regional work groups or meetings that keep the Heartland linked to and represented. | Ongoing | Ongoing | | HRCC Team and Heartland liaisons |
| | Obj. 5: Education and facilitate implementation of the Affordable Care Act | Strategy 1: Convene stakeholders | Webinar and Forum to be completed by May 31. | Analyze results of forum to plan next steps. Maintain current ACA information on Heartland website | | HRCC: Anayeli Herrera Morales |



2014 CONFERENCE ATTENDEES

| LAST NAME | FIRST NAME | E-MAIL | ORGANIZATION |
|----------------------|------------|--------------------------------|-----------------------------------------------------|
| ABBEY | Elizabeth | eabbey@kdheks.gov | Kansas Department of Health & Environment |
| ABRAHAM | Michael | Michael.Abraham@hyperiontx.com | Hyperion Therapeutics |
| ATHERTON | Andrea | amatherton@cmh.edu | Children's Mercy Hospital |
| BAILEY | Becky | bbailey@nd.gov | North Dakota Department of Health |
| BARNETT | Sarah | barnetts@health.missouri.edu | University of Missouri Health Care |
| BAUMERT | Krystal | Krystal.Baumert@Nebraska.gov | Nebraska Department of Health & Human Services |
| BENTZ | Katie | kbentz@nd.gov | North Dakota Department of Health |
| BERBERICH | Stan | stanton-berberich@uiowa.edu | State Hygienic Laboratory at The University of Iowa |
| BIRD | Susan | birdsk@umkc.edu | Advocate |
| BLACK | Michelle | mblack_75@Yahoo.com | Advocate |
| BLANCHARD | M. Esther | maria-blanchard@uiowa.edu | State Hygienic Laboratory |
| BOLICK | JoAnn | JABolick@uams.edu | University of Arkansas for Medical Sciences |
| BOOTHE | Emily | eboothe@uams.edu | University of Arkansas for Medical Sciences |
| BOSCH | Joni | joni-bosch@uiowa.edu | University of Iowa |
| BOYLAN | Deborah | Deborah_Boylan@ssmhc.com | Cardinal Glennon Children's Medical Center |
| BRIDGES | Dana | dabridge@childrensnational.org | Children's National Medical Center |
| BROWER | Amy | abrower@acmg.net | American College of Medical Genetics |
| BUTLER | Merlin | mbutler4@kumc.edu | Kansas University Medical Center |
| CALLEN-SCHOLZ | Jena | jcallen-scholz@kdheks.gov | Kansas Department of Health & Environment |
| CASAS | Kari | kari.casas@sanfordhealth.org | Sanford Health |
| CATON | Lisa | lisarc@health.ok.gov | Oklahoma State Department of Health |
| CHACE | Carol | cchace@childrensnational.org | Children's National Medical Center |





| | | | |
|------------------------|-----------|--------------------------------------|------------------------------------------------------------|
| CHEN | She-Hang | shehang-chen@ouhsc.edu | University of Oklahoma Health Sciences Center |
| CHIN | Ephrem | ephrem.chin@ogt.com | Oxford Gene Technology |
| CHOU | Ann | ann-chou@ouhsc.edu | University of Oklahoma Health Sciences Center |
| COFFMAN | Mary Ann | mcoffman5@cox.net | Heartland Regional Coordinating Center |
| COLBERT | Amber | misscolbert17@gmail.com | Advocate |
| COLLINS | Jessica N | collinsjess@att.net | Advocate |
| COX | Devin | dcox2@uams.edu | University of Arkansas for Medical Sciences |
| CRIST | Rachel | rachel.crist@preventiongenetics.com | Prevention Genetics |
| DEUTSCH | Patricia | Patricia_Deutsch@ssmhc.com | Cardinal Glennon Children's Medical Center |
| DORSEY | Delphine | delphine-dorsey@ouhsc.edu | University of Oklahoma Health Sciences Center |
| DUNCAN | Amy | Amy-Duncan@oklahomafamilynetwork.org | Oklahoma Family Network |
| EGGER | Jeanne | jeanne.egger@nebraska.gov | Advocate |
| EIKEN | Darla | darla.eiken@health.mo.gov | Missouri Department of Health & Senior Services Laboratory |
| EVANGELISTA | Armand | | Hyperion Therapeutics |
| EVEANS | Karen | karen.eveans@nebraska.gov | Nebraska Department of Health & Human Services |
| FANNING | Elizabeth | elizabeth-fanning@ouhsc.edu | University of Oklahoma Health Sciences Center |
| FIGUEROA | Shirelle | sfigueroa2@uams.edu | University of Arkansas for Medical Sciences |
| FLANNERY | David | dflannery@acmg.net | American College of Medical Genetics |
| FONT-MONTGOMERY | Esperanza | fontmontgomerye@missouri.edu | University of Missouri Health Care |
| FORLENZA | Eileen | EileenForlenza@comcast.net | National Expert & Speaker |
| FOSSEN | Lucy | lucy.fossen@state.sd.us | South Dakota Department of Health |
| FOSTER | Dustin | dmfoster@uams.edu | Heartland Regional Coordinating Center |
| FRYDRYK | Susanna | | Hyperion Therapeutics |
| GARDNER | Sara | segardner@cmh.edu | Children's Mercy Hospital |
| GREFE | Rosemary | rgrefe@cnmc.org | Childrens National Medical Center |





| | | | |
|-------------------------|-----------|------------------------------------|-----------------------------------------------|
| GROENEVELD | Sarah | Sarah.Groeneveld@SanfordHealth.org | South Dakota Newborn Screening Program |
| GUARINI | Ludovico | lguarini@maimonidesmed.org | New York-Mid-Atlantic Consortium |
| HADDAD | Sue | soheilah@health.ok.gov | Oklahoma State Department of Health |
| HALLFORD | Gene | Gene-Hallford@ouhsc.Edu | University of Oklahoma Health Sciences Center |
| HANSEN | Tricia | Tricia.Hansen@sde.ok.gov | Oklahoma State Department of Education |
| HARPER | James | jlharper@unmc.edu | University of Nebraska Medical Center |
| HARRIS | Catharine | harriscath@health.missouri.edu | University of Missouri Health Care |
| HARRIS | Katharine | kbh02@health.state.ny.us | New York-Mid-Atlantic Consortium |
| HEESE | Bryce | baheese@cmh.edu | Children's Mercy Hospital |
| HENRY | Travis | travis-henry@uiowa.edu | University of Iowa |
| HERRERA | Erica | Erica-herrera@ouhsc.edu | Oklahoma Family Network |
| HERRERA MORALES | Anayeli | AHerreraMorales@uams.edu | Heartland Regional Coordinating Center |
| HICKAM | Teresa | thickam@cmh.edu | Children's Mercy Hospital |
| HIMSTEDT | Leslie | Leslie.Himstedt@arkansas.gov | Arkansas Department of Health |
| HOBERT-MELLECKER | Melody | m-hobert-mellecker@uiowa.edu | University of Iowa |
| HOFFMAN | Jeff | jeffhoffman.ehdi@gmail.com | ECHO, NCHAM |
| HOPKINS | Patrick | Patrick.Hopkins@health.mo.gov | Missouri State Public Health Laboratory |
| HOWELL | Jenny | jenny-howell@ouhsc.edu | University of Oklahoma Health Sciences Center |
| JACKSON | Barbara | bjjackso@unmc.edu | Munroe-Meyer Institute |
| JENIOUS | Molika | jusalex25@gmail.com | Advocate |
| JOHANNES | Mike | mjohanne@kdheks.gov | Kansas Department of Health & Environment |
| JOHNSON | Carol | carol-johnson@uiowa.edu | University of Iowa |
| JOHNSON | Catherine | braydenandemmasmommy@yahoo.com | Advocate |
| JOHNSON | Holly | hajohnson2@uams.edu | Advocate |
| JOHNSON | Jacquelyn | jjohnson4@uams.edu | University of Arkansas for Medical Sciences |
| JOHNSON | Tammie | tamjohnson@nd.gov | North Dakota Department of Health |





| | | | |
|----------------------|----------|--------------------------------------|-------------------------------------------------|
| KAERCHER | Kate | katherine.kaercher@sanfordhealth.org | Sanford Health |
| KEEHN | Alisha | akeehn@acmg.net | National Coordinating Center - ACMG |
| KENDALL | Jamey | jkendall@kdheks.gov | Kansas Department of Health & Environment |
| KETCHER | Jason | jmketcher@uams.edu | University of Arkansas for Medical Sciences |
| KIESLING | Jami | Jami.Kiesling@health.mo.gov | Missouri Department of Health & Senior Services |
| KOO | Hang Mo | hang-mo-koo@uiowa.edu | University of Iowa |
| LARSON | Ingrid | ialarson@cmh.edu | Children's Mercy Hospital |
| LEONHARD | Jennifer | jrleonhard@uams.edu | University of Arkansas for Medical Sciences |
| LEPARD-TASSIN | Tiffany | tlepard@uams.edu | Arkansas Children's Hospital |
| LUEDTKE | Julie | julie.luedtke@nebraska.gov | Nebraska Department of Health & Human Services |
| MCCALLISTER | Tonya | tonyaj@health.ok.gov | Oklahoma State Department of Health |
| MCCURRY | Donna | donna.mccurry@tmcmcd.org | Truman Medical Center |
| MELLICKER | Brena | brenna-mellicker@ouhsc.edu | University of Oklahoma Health Sciences Center |
| MILLER | Nancy | nancy.miller@hhs.gov | Department of Health & Humans Services, RHA |
| MOORE | Tiffany | tpmoore@uams.edu | University of Arkansas for Medical Sciences |
| MYERS | Jessica | myersjl@health.missouri.edu | University of Missouri Health Care |
| NORTHROP | Kathryn | kathy.northrop@nebraska.gov | Nebraska Department of Health & Human Services |
| OCHOA | Eduardo | ochoaeduardor@uams.edu | University of Arkansas for Medical Sciences |
| O'CONNOR | Gavin | | Advocate |
| O'CONNOR | Greg | | Advocate |
| O'CONNOR | Jenni | jenniporras0312@gmail.com, | Advocate |
| O'HOLLEARN | Tammy | tammy.ohollearn@idph.iowa.gov | Iowa Department of Public Health |
| OSUNKWO | Ify | ifyosunkwo@gmail.com | Levine Cancer Institute |
| PARENT- | Richard | richard.parentjohnson@usd.edu | University of South Dakota |





| | | | |
|-----------------------|----------|-----------------------------------|--------------------------------------------------------|
| JOHNSON | | | |
| PARENT-JOHNSON | Wendy | wendy.parentjohnson@usd.edu | University of South Dakota |
| PECK | Dawn | peckda@health.missouri.edu | University of Missouri Health Care |
| PEDERSON | Nicole | npederson@uams.edu | University of Arkansas for Medical Sciences |
| PENNANT | Yana | ypennant@brookdale.com | New York-Mid-Atlantic Consortium |
| PERKINS | Janet | janet.perkins@perkinelmer.com | PerkinElmer |
| PETERSON | Colleen | ckpeters@kdheks.gov | Kansas Department of Health & Environmental Laboratory |
| PETRIKIN | Joshua | jepetrik@cmh.edu | Children's Mercy Hospital |
| PHILLIPS | Emily | emily-phillips@uiowa.edu | University of Iowa |
| PIPER | Kim | kimberly.piper@idph.iowa.gov | Iowa Department of Public Health |
| RABURN-MILLER | Julie | julie.raburn-miller@health.mo.gov | Missouri Department of Health & Senior Services |
| RICH | Corinn | corinn.rich@perkinelmer.com | PerkinElmer |
| ROGERS | Sharmini | sharmini.rogers@health.mo.gov | Missouri Department of Health & Senior Services |
| ROMELCZYK | Sharon | sromelczyk@geneticalliance.org | Genetic Alliance |
| SCHAEFER | Bradley | SchaeferGB@uams.edu | Heartland Regional Coordinating Center |
| SCHAEFFER | Traci | traci-schaeffer@ouhsc.edu | OU Children's Physicians |
| SCHARPE | Neil | neil.scharpe@minotstateu.edu | Minot State University |
| SCHROEDER | Melissa | moeschroederiii@yahoo.com | Family Voices of North Dakota |
| SCOTT | Joan | jscott2@hrsa.gov | Genetic Services Branch, HRSA |
| SMITH | Heather | hsmith@kdheks.gov | Kansas Department of Health & Environment |
| SMITH | Laurie | ldsmith@cmh.edu | Children's Mercy Hospital |
| SMITH | Mark | msmitha@unmc.edu | The Munroe-Meyer Institute |
| SONTAG | Marci | marci.sontag@ucdenver.edu | Colorado School of Public Health |
| STRENK | Meghan | mestrenk@cmh.edu | Children's Mercy Hospital |
| TROXELL | Robin | robin.troxell@mercy.net | Mercy Hospital Springfield |
| VAN ZEE | Valerie | valerie-vanee@uiowa.edu | State Hygienic Laboratory at the University of Iowa |





| | | | |
|----------------------------|--------|----------------------------|-------------------------------------------|
| VAZ | Sharon | sharonav@health.ok.gov | Oklahoma State Department of Health |
| WEATHERFORD | Andrew | physco@me.com | Advocate |
| WEATHERFORD | Larry | larryweatherford@gmail.com | Advocate |
| WIERENGA | Klaas | klaas-wierenga@ouhsc.edu | Heartland Regional Coordinating Center |
| WILLIAMSON DEAN | Lori | lwdean@uams.edu | Heartland Regional Coordinating Center |
| WILLIG | Laurel | lkwillig@cmh.edu | Children's Mercy Hospital |
| WITHERINGTON | Sarah | switherington@ambrygen.com | Ambry Genetics |





CONFERENCE EVALUATION

(NOTE ADDITIONAL QUESTIONS ON OTHER SIDE OF PAGE)

| TOPIC | 1 | 2 | 3 | 4 | 5 |
|-----------------------------------------------------------------------------------------------------------|-----------------------|--------------|-------------------|-----------------|--------------------------|
| | Strongly Agree | Agree | No Opinion | Disagree | Strongly Disagree |
| I. Pre-Conference Communications | | | | | |
| 1. Travel and lodging arrangements were made without difficulty. | | | | | |
| 2. Pre-conference e-mail and list serve communications were clear. | | | | | |
| 3. Website information about conference was helpful. | | | | | |
| 4. Registration instructions were clear. | | | | | |
| II. Conference Agenda | | | | | |
| 1. There was sufficient time for networking during the meeting. | | | | | |
| 2. There was time to address specific regional issues of concern. | | | | | |
| 3. Topics chosen for discussion were relevant for the future of Genetics and NBS in the Heartland states. | | | | | |
| 4. Information regarding the national agenda (from Copeland) was clearly presented. | | | | | |
| 5. I learned something from a speaker or colleague that I intend to try in my state or practice. | | | | | |





III. Conference Location, Accommodations and Booths

1. The KC Airport Marriott accommodations met my needs.

2. Vendor booths contributed to the overall resources at the conference and are worth having at a future meeting.

3. Staff at the Heartland Registration table was friendly, efficient, and helpful.

Comments: Please use this space to comment on questions above or to provide other comments.





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