



Region 4 Genetics Collaborative

GENETIC EXPERTISE WORKGROUP MEETING – MAY 1ST, 2009

Chicago, Illinois

Agenda

10:00	Introductions and Overview of Region 4	Cameron
10:30	Overview of Genetic Expertise Workgroup	Wedepohl
10:45	Genetic Information and Needs Discussion	Cameron
12:00	Lunch	
1:00	Reconvene to Continue Discussion	Cameron
2:00	Workgroup Goals and Objectives	Mendelsohn
4:00	Adjourn	Wedepohl

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Region 4 Genetics Collaborative Genetic Expertise Workgroup

Workgroup Meeting Purpose: Access to genetic services, including how genetic specialists communicate information to other providers and families and how they coordinate care (e.g., use of a medical home).

Two issues identified at the workgroup's face-to-face meeting on May 1, 2009.

The group is currently exploring:

- Examining practice models and scheduling models to maximize use of genetic specialists/counselors' time:
This process intends to look at how genetic specialists can deliver services more effectively and maximize their time. To do this we are looking at different practice models used by genetic specialists/counselors in our region by identifying genetics clinics in our region then interviewing lead person/coordinating/scheduling person in each clinic about practice models. This applies to pediatric care of genetics patients only.
- Exploring an "ask the geneticists" project (perhaps collaborating with the Southeast region) with primary care providers (not families or patients). This would be a means to expand access to services. Some providers do this already in their hospitals informally, but other primary care providers do not have easy access to a genetic specialist to ask questions, etc. This goal attempts to help reach out to more primary care physicians in our region about genetic services/information. This applies to pediatric genetics questions/topics only.



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State of the Region

Cynthia Cameron, PhD

Director

Region 4 Genetics Collaborative



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Why We Are Together

- To share information about Region 4 activities and opportunities
- To strengthen relationships among stakeholder groups and Region 4
- To provide information on relevant projects at the national level and from other Regions
- To learn what regional activities you would like to initiate, expand or enhance



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History of the Regional Collaboratives

- Established under Title XXVI of the Children's Health Care Act of 2000, "Screening for Heritable Disorders"
- "...The Secretary shall award grants to eligible entities to enhance, improve or expand the ability of State and local public health agencies to provide screening, counseling or health care services to newborns and children having or at risk for heritable disorders..."



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Role of the Regional Collaboratives

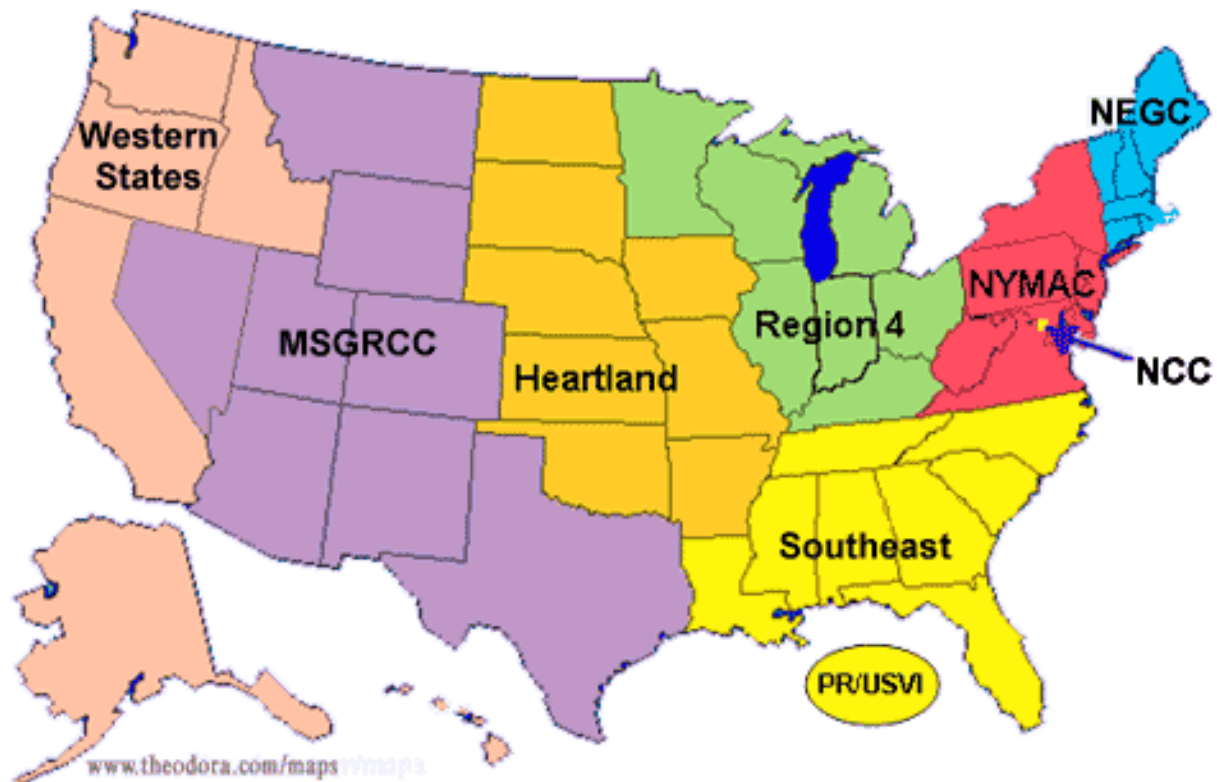
- Ensure that children with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home that provides accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective care.
 - To strengthen communication and collaboration among public health, individuals, families, primary care providers, and genetic medicine and other subspecialty providers.
 - To quantitatively and qualitatively evaluate outcomes of projects undertaken to accomplish their goals.



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Region 4

- One of 7 regional collaboratives
- 2004 start up
- 2007 - Region 4 awarded 5-year, \$5,000,000 grant from HRSA
 - Base funding - \$500,000
 - Priority 1 - \$250,000
 - Priority 2 - \$250,000



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Our Vision

- All newborns will receive state-of-the-art newborn screening and follow-up; children and youth with heritable disorders will have access to genetic expertise and coordinated care in the context of a medical home.



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Our Mission

- Increase access to information about newborn screening and genetic resources, services and family support systems
 - Region 4 website
 - Family is the Center of the Medical Home
 - On-line course



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Our Mission

- Facilitate data collection and analysis to guide decision-making regarding screening cut-offs, diagnosis and long term treatment of heritable disorders
 - Laboratory Quality Improvement of Newborn Screening by MS/MS
 - Inborn Errors of Metabolism Information System
 - CAH disease registry



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Our Mission

- Support state public health agencies in improving infrastructure for genetic service delivery to children with heritable disorders
 - Short term follow up protocols
 - CH follow up project
 - EHDI follow up protocols



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Our Mission

- Provide a forum for families, public health, and clinical providers to share best practices and models for improving newborn screening, follow-up and genetic care coordination
 - Regional meetings
 - Workgroups
 - National Advisory Boards
 - Priority 1
 - Priority 2
 - MEMSCIS



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Our Mission

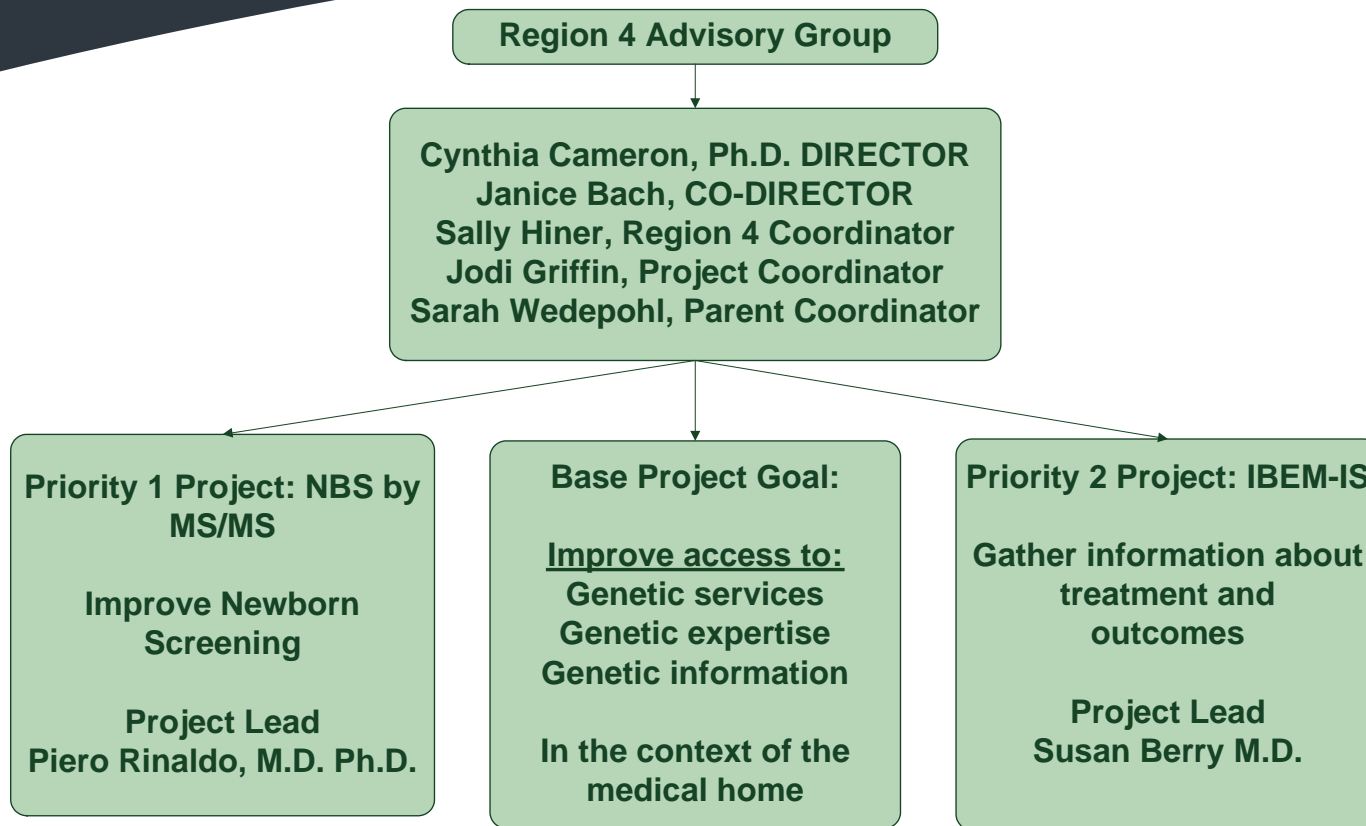
- Link Region 4 states with regional and national initiatives for improving the quality of newborn screening and genetic service delivery
 - Region 4 and Mountain States
 - Interoperability between clinical/public health long-term follow up systems
 - Region 4 and Region 3
 - Survey on reimbursement for medical foods and formulas
 - Secretary's Advisory Committee on Heritable Disorders in Newborns and Children
 - Family Survey on Medical Foods and Formulas
 - Newborn Screening Translational Research Network
 - National Coordinating Center
 - Emergency Preparedness
 - Data Coordination



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Base Project Workgroups

Care Coordination
Endocrine Project
Follow-up
Genetic Expertise

Medical Home Education
Reimbursement
Transition



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Where We Are Going

- Increase collaboration with national partners
 - Genetic Alliance
 - American Academy of Pediatrics
- Cultivate partnerships within Region 4 and across other regions
- Support implementation of processes and products developed by Region 4
- Leverage funds to expand Region 4 projects