

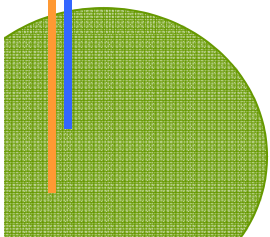


# Mountain States Genetics Regional Collaborative Center

Celia Kaye, MD, PhD  
Project Director, MSGRCC

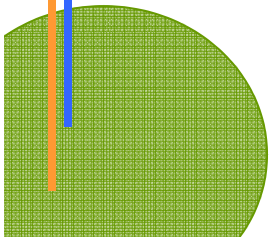
Mountain States Genetics Foundation Annual Meeting and  
Education Conference

July 15, 2010



# The MSGRCC

- One of seven regional collaborative centers covering the nation
- Federally funded by the US. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Genetic Services Branch
- Administered by Texas Health Institute



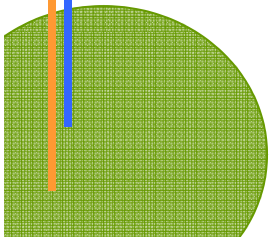
# The Mountain States

- Arizona
- Colorado
- Montana
- New Mexico
- Nevada
- Texas
- Utah
- Wyoming



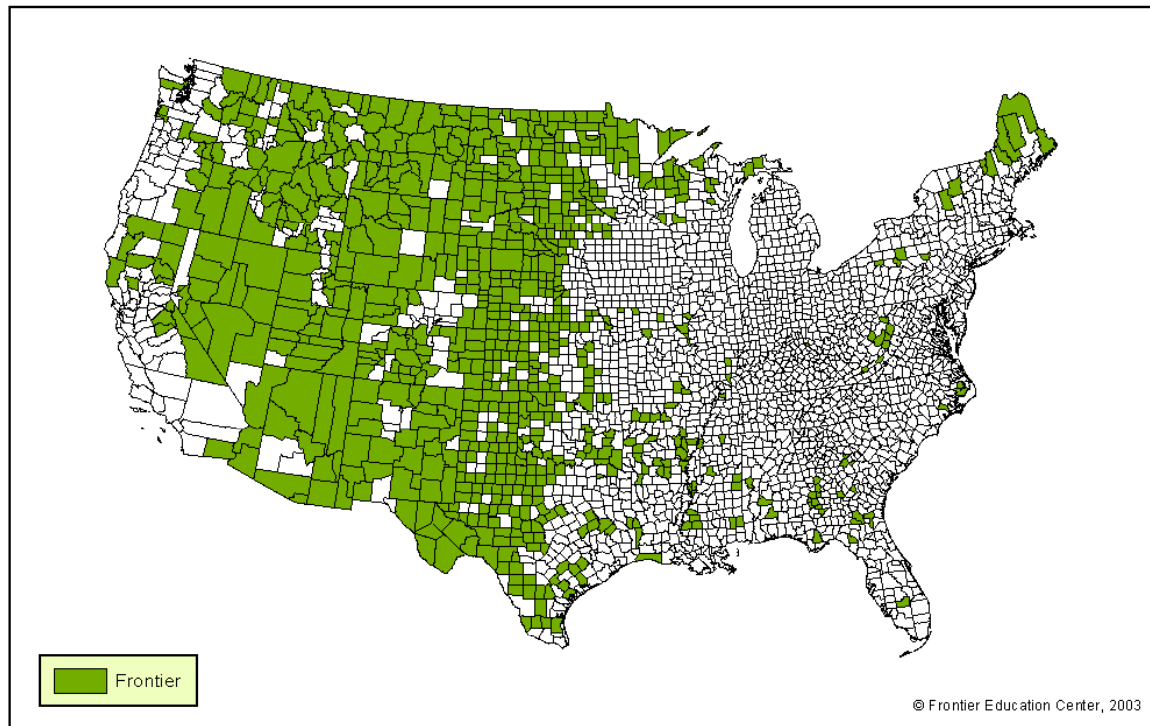
# A Look at the Mountain States

- 1,081,813 sq miles (almost 1/3 of U.S.)
- Population over 44M (15% of U.S. population)
- Annual births more than 600,000 (15% of U.S. births, projected to increase to 20% by 2025)
- Arizona, Nevada, New Mexico, Texas have higher than U.S. Hispanic/Latino populations
- Region has higher percentage of Native Americans than overall U.S. rates



# More About the Mountain States

USA Frontier Counties, 2000 Consensus



"ZIP code areas whose calculated population centers are more than 60 minutes or 60 miles along the fastest paved road trip to a short-term non federal general hospital of 75 beds or more, and are not part of a large rural town with a concentration of over 20,000 population."

# Economics\*

	<b>% below FPL</b>	<b>% Medicaid enrollment</b>	<b>Median Annual Income</b>
<b>Arizona</b>	19.7	23	\$47,750
<b>Colorado</b>	12.8	11	\$57,333
<b>Montana</b>	15.1	12	\$41,852
<b>Nevada</b>	14.4	10	\$53,008
<b>New Mexico</b>	20.5	25	\$42,295
<b>Texas</b>	21.5	17	\$44,861
<b>Utah</b>	13.3	11	\$55,974
<b>Wyoming</b>	13.4	15	\$48,205
<b>United States</b>	<b>17.2</b>	<b>20</b>	<b>\$49,901</b>

\*US Census Data, Access from [www.statehealthfacts.org](http://www.statehealthfacts.org), Kaiser Family Foundation

# Economics, continued

- 5 states had at least 10% increase in Medicaid enrollment from June 2008 to June 2009 <sup>1</sup>
- All states had Medicaid enrollment increases of at least 5% from June 2008 to June 2009 <sup>1</sup>
- 7 of 8 states are projected to have a budget shortfall in FY2010 <sup>2</sup>
- 3 states have experienced at least 2.5% increase in unemployment <sup>3</sup>

<sup>1</sup> Kaiser Family Foundation. *Medicaid enrollment % change, June 2008 to June 2009*. Retrieved June 16, 2009 from <http://www.statehealthfacts.org/comparemaptable.jsp?ind=796&cat=4>.

<sup>2</sup> McNichol, E. & Johnson, N. (2010). *Recession continues to batter state budgets; state responses could slow recovery*. Center on Budget and Policy Priorities. Retrieved March 17, 2010, from <http://www.cbpp.org/cms/?fa=view&id=711>.

<sup>3</sup> Bureau of Labor Statistics. (2010). *Over-the-year change in unemployment rates for states*. Retrieved March 17, 2010, from <http://www.bls.gov/web/laumstch.htm>.

# Distribution of NBS and Genetic Services

- Four states have at least one state lab performing Newborn Screening (NBS) tests
- Four states contract with an out of state lab for NBS tests
- Six states have single major program offering or coordinating genetic services
- One state is served exclusively by out of state geneticists

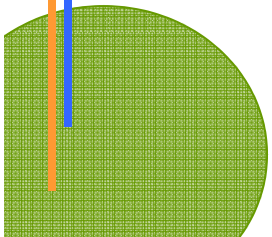
# MSGRCC Goals

- To capitalize on our strengths to **serve**\* this large, diverse, dispersed population of individuals affected with or at risk for hereditary disorders
- To use collaboration to ensure these individuals have **access** to quality care and appropriate genetic expertise and information in the context of a medical home

\* through sustainable infrastructure development, not direct services

# Regional Assets

- Premier children's hospitals and university centers
- Outstanding clinicians
- World class training programs for genetic counselors, physician assistants, nurses
- Committed families and communities



# MSGRCC Priorities

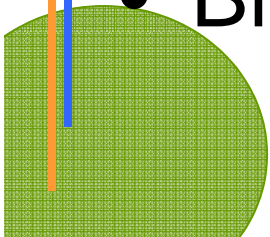
- All newborns will be screened for the American College of Medical Genetics (ACMG) panel of disorders
- NBS services will be of high quality and accessible to all
- All individuals with genetic disorders will be served through a medical home
- Transition plans will be in place for all individuals

# MSGRCC Priorities

- Distance strategies (e.g. telemedicine, telehealth) to provide care will be used appropriately
- Emergency preparedness plans will be in place
- Clinicians and families will participate in setting priorities, solving problems, evaluating outcomes
- We will contribute to the development of new knowledge and its translation to high quality care

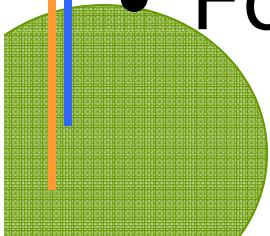
# MSGRCC Strategies

- Facilitate communication and information exchange between stakeholders
- Leverage MSGRCC base funding to bring additional resources to the region
- Recruit active members and listen to them
- Collaborate with other regions and federal agencies
- Bring good ideas home



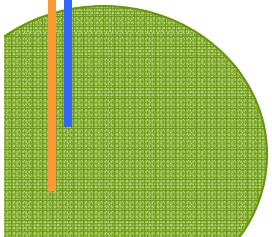
# MSGRCC Structure

- Advisory Council
- Four Core Staff Members
  - Project Director: Celia Kaye, MD, PhD
  - Project Administrator: Camille Miller, President/CEO, Texas Health Institute
  - Project Manager: Joyce Hooker
  - Project Coordinator: Liza Creel
- Seven Projects
- Four Workgroups



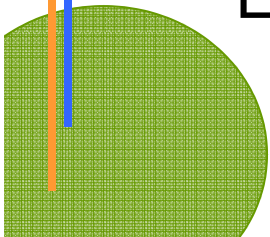
# MSGRCC Advisory Council

- Larry Goodmay, Wyoming
- Celia Kaye, Colorado
- Lynn Martinez, Utah
- Summer Pierson, Arizona
- Ken Pool, Texas
- Trish Thomas, New Mexico
- Johan Van Hove, Colorado



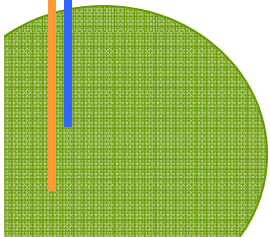
# MSGRCC Projects

- Metabolic Newborn Screening Long-term Follow-Up Study  
Lead: Janet Thomas, MD
- Improving Medical Homes and Transition Outcomes for Youth Served in IMD Clinics  
Lead: Laura Pickler, MD, MPH
- Hemoglobinopathies Newborn Screening and Follow-Up Project  
Lead: Kathryn Hassell, MD
- Laboratory Quality Assurance  
Lead: Marzia Pasquali, PhD



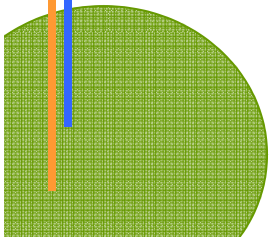
# MSGRCC Projects, Cont.

- Community Conversations on Genetics  
Leads: Murray Brilliant, PhD, Yolanda Sandoval-Nez
- Emergency Preparedness Planning Project  
Lead: Johan Van Hove, MD, PhD, MBA
- Quality Improvement in Clinical Genetics  
Lead: Marc S. Williams, MD



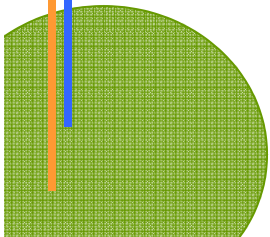
# New Projects

- Genetic Alliance Newborn Screening Clearinghouse, funded by HRSA
- Genetic Alliance Congenital Conditions Program, funded by HRSA
- Innovative projects in telemedicine and telehealth



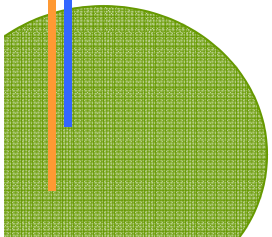
# MSGRCC Workgroups

- Consumer Advocacy Workgroup  
Chairs: Joe Martinec (TX) & Rod Slaght (CO)
- Newborn Screening Workgroup  
Chairs: Susan Tanksley (TX) & Jeffrey Botkin (UT)
- Telemedicine Workgroup  
Chairs: Thelma McClosky-Armstrong (MT) & Brad Thompson (TX)
- Emergency Preparedness Workgroup  
Chairs: Donna Williams (TX) & Lynette Borgfeld (TX)



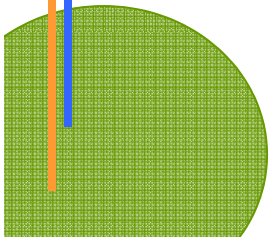
# Annual Events & Activities

- Annual meeting
- Mid-year workgroup meetings
- Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) meetings (4x per year)
- NCC PI calls and in person meetings (monthly)
- NCC workgroup meetings
- Quarterly calls with project leads
- Ad hoc workgroup calls
- Bi-weekly management team calls



# Evaluation

- MSGRCC
  - Contracted evaluator
  - Updated five year logic model
  - Data collection underway
- NCC
  - Eleven tracked outcomes
  - Annual data collection

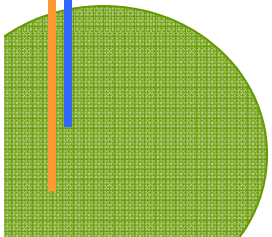


# Other Regional Projects

- **Colorado Sickle Cell Care Network** (PI: Karen Chacko, M.D.; Kathy Hassell, M.D. is key staff on project)
- **Texas Newborn Screening Performance Measures Project** (project contact: Susan Tanksley, Ph.D.)
- **Evaluation and Implementation of Second Tier Testing for Disorders Identified by MS/MS in Newborn Blood Spots in the Mountain States Region** (PI: Marzia Pasquali, Ph.D.)
- **Colorado Effective Follow-up in Newborn Screening Project** (PI: Chris Wells, MS)
- **Utah Newborn Screening Clinical Health Information Exchange** (PI: Richard Harward, Au.D., CCC-A)
- **Promoting Public Dialogue on the Use of Residual Newborn Screening Samples** (PI: Jeffrey Botkin, M.D.)

# Acknowledgement

*The Mountain States Genetics Regional Collaborative Center (MSGRCC) is supported by cooperative agreement #U22MC10761 with the United States Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau, Genetic Services Branch.*



# Thank You!

Celia Kaye, MD, PhD, MSGRCC PD

## Mountain States Genetics Regional Collaborative Center

8501 N. MoPac Expressway, Suite 300

Austin, Texas 78759

512-279-3906

NEW Website: [www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)

