



## Message from the Project Director Celia I. Kaye, MD, PhD

August, 2011

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### Greetings!

I'm enjoying a quiet Sunday afternoon in my office at home in Parker, Colorado. It's pleasant to think about what you may be doing with your few discretionary hours. I suspect it's a combination of pleasure and duty, too!

As promised last month, we'd like to share with you some highlights about our Annual Meeting, which was held July 12-14 in Denver, Colorado. This makes for a fairly long message, but it's difficult to leave out any of the wonderful activities that we shared with so many of you.

On Tuesday, July 12th, we hosted several project meetings. The first was the annual gathering for the Metabolic Consortium. The Consortium members, led by Dr. Janet Thomas, discussed screening and treatment issues related to metabolic diseases and the collection and use of data for long-term follow-up. They also participated in an emergency preparedness tabletop exercise that looked at emergency response from the clinical perspective. Many thanks to Bill Perry and Dr. Hans Andersson for leading such an informative and enlightening session. The Hemoglobinopathies group also met to review numerous topical areas, including sickle cell trait, Bart's hemoglobin, and NCAA testing. They also discussed the [Primary Care On-line Trait Education Module](#), which was developed by Dr. Kathy Hassell and her team with funds from the National Newborn Screening and Genetics Resource Center. Finally, the group involved with laboratory quality assurance issues in the region heard from Marzia Pasquali, PhD about the next educational challenge that will be sent to laboratories participating in her quality assurance project originally funded by MSGRCC. She also gave an update on her CDC-funded project on second-tier testing, and provided some recent data demonstrating the cost-benefit of second-tier testing.

After starting off the first full day of the meeting with an update on the State of the Region, I was delighted to welcome our keynote speaker, Meg Comeau, MHA, who is the Project Director for the Catalyst Center at Boston University. Meg offered participants an in depth review of insurance and finance needs of children with special healthcare needs, and the impact of the Affordable Care Act (ACA) on the same population. Take a moment to review Meg's [presentation](#) and learn about provisions in ACA that will impact children with special healthcare needs and, therefore, those genetics patients we all serve. We also heard from Ann Chou, PhD who leads the Heartland Region Genetic Systems Assessment Project, which is developing a system to assess genetic services in consultation with regional and national colleagues. Ann's review of the Heartland project provided many in the audience with ideas about quality improvement activities in genetics and how the lessons learned could be used in the Mountain States Region.

Much of our first session was spent listening to updates from MSGRCC's national partners. We heard from Sara Copeland, MD, the Acting Branch Chief for the Genetic Services Branch (GSB), about current and planned activities at HRSA. As you know from my previous messages, HRSA and the GSB have been undergoing extensive strategic planning and we were excited to hear Sara speak at our meeting about the outcomes of that planning. HRSA and the GSB have developed a specific vision for their future that includes the Regional Collaboratives. During her presentation, Sara mentioned her appreciation for all the work in our region, and she specifically mentioned the telemedicine projects and consumer participation as exceptional. Other national presentations included an

update on activities of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) from Dr. Rod Howell, MD, Chair of the SACHDNC; the National Coordinating Center for the Regional Genetic and Newborn Screening Collaboratives (NCC) from Dr. Barry Thompson, MD, FACMG, Medical Director at ACMG/NCC; the National Newborn Screening and Genetics Resource Center (NNSGRC) from Colleen Buechner Wu, MS, CGC, Research Study Coordinator at NNSGRC; and the Genetic Alliance from Liz Horn, PhD, PBI, Director of the Genetic Alliance Registry and BioBank. You can visit the annual meeting [webpage](#) to find presentations from each of the national partners.

The lunch session on July 13 included a presentation from Dr. Chuck Norlin on The Medical Home Portal and his progress expanding the Portal within the Mountain States Region. As you may recall, Dr. Norlin served as our Medical Home Visiting Professor during a workshop in February, and at that meeting garnered significant interest in the portal from several states in our region. Since then, Dr. Norlin and his team have been working on expansion with Arizona, Colorado, and Montana.

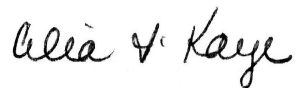
The final day included another plenary session beginning with a presentation from Kelly Leight, JD, the Coalition Coordinator for Preserving the Future of Newborn Screening, who discussed recent advocacy efforts at a state and national level. Her presentation led to a lively conversation in the audience, which highlighted the need for collaboration inside and outside the newborn screening community. Other presentations included a report from Dr. Laura Pickler on her project, Improving Medical Homes and Transition Outcomes for Youth Served in IMD; and updates from two other regional projects, The Texas Newborn Screening Performance Measures Project, presented by Susan Tanksley, PhD, and Promoting Public Dialogue on the Use of Residual Newborn Screening Samples, presented by Rebecca Anderson, RN, BS, and Erin Rothwell, PhD, CTRS.

To close the Annual Meeting, we hosted a panel discussion on Dine' for our Children, which was a HRSA-funded project aimed at improving access to integrated services for Navajo children with special health care needs and their families. Jenny Rodgers, MPH, who was the project Director for the grant, gave background on the project and discussed some of their successes and lessons learned, including challenges with linking families to large, interdisciplinary health systems within a medical home. Her presentation was followed by a panel discussion with myself and Trish Thomas, the Partnership Coordinator for the National Center for Family and Professional Partnerships, and excellent conversation with the audience. All MSGRCC Workgroups met during the Annual Meeting, and we'll be updating you on their specific activities in the coming months.

In the near future, we may be asking for your input on the outcomes of a strategic planning process that the MSGRCC Advisory Council initiated during their July meeting. During that meeting, and building upon the planning activities from HRSA as well as our regional successes, our Advisory Council has determined strategic priorities for this region. We are currently completing a report of the meeting and identifying a method by which we can gather your input, so stay tuned!

Next week-end brings us to Labor Day and the beginning of the fall season. All of us at MSGRCC are looking forward to working with you on our on-going activities and planning the work of the next several years as we develop our competitive grant renewal. Be sure and take some time to enjoy the fall colors and the cooler days!

Warm regards,



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