



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

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November, 2011

### Greetings!

Most of the leaves are off the trees in Colorado, and cold nights remind us that the year is coming to an end. We at MSGRCC divide our time between finishing up the work of 2011 and preparing to celebrate the winter holidays.

The first piece of news I want to share is a happy one for all of us at MSGRCC. Kathy Hassell, M.D., Professor of Medicine at the University of Colorado School of Medicine, has accepted the position of MSGRCC Associate Project Director, effective December 1, 2011. Kathy hails from Minnesota originally but has been in Colorado since 1989. She has played a major role in the development of systems of care for individuals with sickle cell disease in Colorado, and she has been very active in newborn screening for hemoglobinopathies for over a decade. Kathy has supervised the Colorado hemoglobinopathy newborn screening follow-up program since 2000, and she has been Director of the Colorado Sickle Cell Treatment and Research Center since 2003. Kathy is project director of a MSGRCC small grant for standardization of hemoglobinopathies newborn screening follow-up in the mountain states region. We are excited to welcome Kathy to this new leadership position within MSGRCC; she will add tremendous knowledge and expertise to our management team.

Liza, Joyce and I attended the annual meeting of the National Coordinating Center for the Regional Collaboratives (NCC) with project directors and project managers in Washington, DC on November 17-18. We heard updates from the Newborn Screening Translational Research Network (NBSTRN), which is working to finalize a data collection system for newborn screening follow-up data. Regional projects focusing on quality improvement

were also presented, and Liza provided information on telemedicine projects in the mountain states region. Meg Comeau, Ellen Riker, and Carolyn Mullen reviewed provisions of the healthcare reform legislation and provided insights on likely scenarios as additional components of the legislation go into effect. We were all impressed with the number and quality of the projects in the various regions, as well as the national activities in newborn screening follow-up led by the NCC. As always, it was a pleasure to spend time with our colleagues from around the country.

We are excited to announce that the MSGRCC has recently funded a new telemedicine project focused on delivering genetic services in Texas. The new project, based at Cook Children's Genetics Clinic in Fort Worth, Texas, will build upon the existing telemedicine program at Cook Children's and will expand access to clinical genetic services and other ancillary services such as nutrition and genetic counseling. The MSGRCC funding will help the clinic purchase a mobile telemedicine unit, and will support other infrastructure needs, with a goal of increasing the availability of genetic services delivered by telemedicine. Cook Children's Genetics Clinic started their telemedicine program in the early 2000's with a grant from the Office for the Advancement of Telemedicine at HRSA. They currently offer services in Abilene, Denton, Midland, San Angelo, and Waco, Texas.

We'd like to remind you to complete the Newborn Screening Workforce Survey that was developed with the University of New Hampshire Survey Center with funding from the NCC. The survey seeks to understand national and regional newborn screening workforce needs and it would be great to have the Mountain States Region well represented. You can access the survey [here](#).

Remember to mark your calendars for our mid-year workgroup meetings. They will be held February 24-26 in Phoenix, Arizona, and details will be available soon.

With the holidays around the corner, we at MSGRCC are looking forward to spending time with family and friends. I imagine myself warming up by the fireplace, listening to seasonal music, and watching children enjoy the excitement of the season. In anticipation of this wonderful time of year, we will take a month off from these regular messages and communicate with you next in January. In the meantime, travel safely if you will be on the road or in the sky.

Warm regards,

*Celia I. Kaye*

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