



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

June, 2011

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Greetings!

Summer is here at last! Children are out of school, vacations are on the calendar, and we can all plan a few evenings in the park or the backyard to just enjoy the warm weather. Here at MSGRCC we're finishing up the work of last year (which ended May 31) and getting started on our new activities for year five of our cooperative agreement. Here are some of the highlights:

Strategic planning is high on the agenda of the Genetic Services Branch (GSB) at HRSA, our funder. GSB undertook a very intensive and comprehensive strategic planning effort over the past year, including providers, public health officials, and consumers from all of the regions. Numerous important tasks were identified, and once this was done, a process of feasibility testing and priority setting resulted in four broad areas of focus for the future. These are: 1) improve quality and access to genetic services; 2) integrate data collection and assessment systems; 3) integrate genomic information into the medical home; 4) develop best practices that include support services for families. Regional collaboratives will now work with these areas of focus to undertake their own strategic planning, identifying specific priorities that are consistent with the needs of the particular region. MSGRCC has begun this process, with the next step being a strategic planning session with our Advisory Council at the annual meeting in July.

The National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (NCC) held the Project Director/Project Manager (PD/PM) interim meeting in Chicago on June 6th. Attending the meeting on behalf of MSGRCC was Dr. Steve Amato, serving in place of Dr. Celia Kaye. Joyce Hooker and Liza Creel also attended as usual. The meeting, titled *Extending the Reach: Linking Local and RC Activities with HRSA/MCHB National Centers*, had a goal of creating stronger linkages between regional collaboratives and HRSA sponsored national centers. We heard presentations from the National Center for Medical Home, National Coordination and Evaluation Center for Sickle Cell Disease, National Health Care Transition Center, Data Resource Center for Child and Adolescent Health, and National Center for Family/Professional Partnerships. The meeting also included presentations from each region on their medical home, transitioning, evaluation, and consumer engagement activities. The meeting concluded with a discussion on increasing linkages with HRSA's national centers, how the RCs may be able to use a chronic disease mode to further promote care of rare diseases across the lifespan, and how RCs could move from a primary focus on newborn screening to a broader focus on genetics and the medical home. As we hear more from these national centers, we will be sure to share information about their resources and opportunities for collaboration with our region.

If you are interested in learning about activities in other Regional Collaboratives, or with other national partners, we encourage you to read the NCC's quarterly newsletter, the NCC Collaborator. Each issue includes updates from each RC as well as a focused article on interregional or national current events in genetics. You can access the current and all past issues of the NCC Collaborator [here](#). Many thanks to the NCC for supporting this valuable publication!

Finally, if you haven't been to our website lately, we invite you to visit <http://r20.rs6.net/tn.jsp?llr=ofvp6xbab&et=1106321522649&s=9723&e=001txmwdIuKId82eTq30SBxOxxzyiKGh55qxnKnnKorgOtlcWpBmMOYssyxfOEVrIN0fSI4vwSff13chZxAc76KikPt3dwrIUOPW7H3IGAtasbwIdrdhWG-8Xemyrc40mmyh-Cozg2op8=>. With the technical support of the Western States Genetics Collaborative, we've streamlined and updated our website content to make finding information easier for you. We are still developing content for some of the pages and welcome any suggestions you can provide. In July, we will present a demonstration of this new website during the monthly NCC PD/PM conference call.

So now we're looking forward to seeing many of you in Denver July 12-14 to review our projects and programs, set future priorities, and hear from national leaders on health care reform, the work of GSB and the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, and other topics of interest to all of us. Please find me to say hello during the meeting. I'm anxious to hear your news!

Warm regards,

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