



Message from the Project Directors Celia I. Kaye, MD, PhD & Kathryn Hassell, MD

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September/October 2013

Greetings!

Summer is over, and we hope you enjoyed some time with family and friends before getting back to work in the fall. At MSGRC, we are awaiting the arrival of our new Project Manager next month. Meanwhile, **Donna Williams** and **Joyce Hooker** have continued to coordinate the work of our Regional Collaborative, and we are deeply appreciative of the extra time and effort they have devoted to our many projects and activities.

By now, our stakeholders and partners are familiar with the MSGRC model of facilitating regional collaboration, information sharing, and support of quality services. In the recent months, we have also been busy working with our wonderful Project Evaluator, **Sharon Homan**, to identify specific indicators to gauge overall impact of our efforts. The following sections provide a brief overview of her assessment.

How much did we do?

Our workgroups focused attention on increasing consumer involvement, improving newborn screening lab protocols, data exchange, identifying unique needs of mountain and frontier communities in emergency preparedness related to medical foods and access to telemedicine in the context of a medical home in medically underserved areas.

MSGRC strengthened partnerships with new stakeholders, including governmental and community-based organizations and other HRSA MCHB-funded programs including:

- Baylor Health Care System, Texas Children's Hospital (Texas)
- Billings Children's Clinic (Montana)
- Cheyenne Regional Medical Center (Wyoming)
- Colorado Sickle Cell Network, a HRSA Sickle Cell Disease Treatment Demonstration Project
- Fremont County Pediatrics (Wyoming)
- Grey's Gift Memorial Foundation (Texas)
- Missoula Valley Pediatrics (Montana)
- Leadership Education in Neurodevelopmental (LEND) programs in Nevada, Utah, Idaho, Montana Wyoming and North Dakota
- Parents Let's Unite for Kids, Inc. (Montana)
- Texas Pulse Oximetry Project (Texas)
- Wyoming Medicaid Program (Wyoming)

Members of the MSGRC team continue to have national leadership roles with the:

- Discretionary Advisory Committee on Heritable Disorders in Newborns and Children National Coordinating Center Workgroups
- Newborn Screening Translational Research Network
- Genetics in Primary Care Institute
- Surveillance Design Committee of the Registries and Surveillance for Hemoglobinopathies
- Hemoglobinopathies Workgroup for the National Library of Medicine Standardized Reporting of NBS Results Initiative
- Sickle Cell Disease Primary Care Guidelines Panel at NIH
- Centers for Disease Control (CDC) Sickle Cell Trait Workgroups
- Texas Pulse Oximetry Project

How well did we do it?

Because the region has large concentrations of Hispanic, Latino and Native American groups, it is essential that they participate as equals in addressing relevant genetic services and issues. MSGRC successfully recruited and engaged multi-racial/cultural consumers in each Workgroup and mini-project, and is supporting a new innovative approach to patient navigation. The project, Parent Partners, is actively training parents who have successfully navigated the healthcare system for their children with special needs, to work within medical homes

in order to support and assist families with infants newly diagnosed with a genetic disorder.

Based on the NCC Working Together survey findings, MSGRC workgroup members report high levels of understanding the critical issues that face genetics and newborn screening, are willing to devote necessary effort to achieve the goals, and are working toward developing concrete and measurable goals.

Was anyone better off?

MSGRC supported six mini-projects that tested innovative approaches and piloted new initiatives to improve access to quality genetic services and information. Each of these projects has uniquely contributed to improving the lives of persons with genetic disorders.

Data on 72 patients diagnosed through newborn screening and nine diagnosed clinically were entered into a long-term follow-up database. The information will help to develop best treatment practices, and many of these children received full-scale neuropsychological evaluations through the project.

Another project provided technology to families of children with special health care needs to assist them in coordinating comprehensive care with their providers.

Additionally, more than 10 adolescents and young adults participated in a program that guided their transitions from pediatric to adult models of care. Data and protocols resulting from the project will provide tools to help ensure young adults continue to receive the level of care necessary for continued health during a vulnerable and stressful time in their life.

All of these projects assist individuals and their families to receive access to genetic services in a medical home, and serve as models for innovative approaches to providing access to comprehensive services in a medical home. Additional families will benefit as the protocols are adopted on a larger scale.

Funding available for projects in support of the Affordable Care Act (ACA)

The NCC announced additional regional funding for projects in support of the Affordable Care Act (ACA). Tentative topics include developing a Model Condition Cost of Care Analyses and State Coverage Issues both focusing

on PKU and Sickle Cell Anemia. A third potential project may include working with an Accountable Care Organization (ACO) to define and standardize genetic components within their practice. ACO's are networks of doctors and hospitals providing coordinated care to patients with a goal of limiting unnecessary spending.

Annual Meeting Planning

We have begun early planning for our annual meeting in late winter or early spring of 2014, and we will be contacting you soon to get your views on possible dates and locations. In the meantime, enjoy those fall colors and cool days. Don't forget to send photos of yourselves enjoying some non-work time!

Warm regards,



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