



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

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**September 2012**

### Greetings!

Fall has arrived in our beautiful mountain states, with golden color blanketing the high Rockies and dark reds and burnt orange covering the underbrush. What a glorious time of year! We have some updates for you as you look to the rest of this year and the start of the next, plus our continuing description of some of our projects.

### MSGRC Meetings

We have rescheduled the MSGRC Annual Meeting for March 17-19, 2013 in Phoenix, Arizona just prior to the American College of Medical Genetics and Genomics Clinical Genetics Meeting. The meeting will be a cross between our usual annual and mid-year meeting schedules, focusing on kicking off our new grant with a few plenary sessions and more time for the workgroups to meet. Be on the lookout for a draft agenda and registration details soon!

### New MSGRC Staff

We have some other exciting news to share with you! Our friend and colleague Donna Williams has joined the MSGRC team as the new MSGRC Project Coordinator. Donna comes to MSGRC from the Texas Department of State Health Services where she served as Newborn Screening Program Specialist. She brings previous experience working with newborn screening and genetics stakeholders, including her work coordinating activities for a CDC grant to develop pre- and post-analytical performance measures for the Texas NBS System, and serving as Project Coordinator for the National Newborn Screening and Genetics Resource Center (NNSGRC) for five

years. Please join us in welcoming Donna to the team! Her email is [dwilliams@texashealthinstitute.org](mailto:dwilliams@texashealthinstitute.org) and her phone number is 512-279-3919.

### Mountain States Medical Home and Family Partnership Project

Similar to the last message, we'd like to share some information about a new project MSGRC will support in the new grant cycle. One of our goals for the new cycle is to increase the number of primary care providers creating formal partnerships with family members within the medical home. To meet this goal, MSGRC will support a new mini-project: the Mountain States Medical Home and Family Partnership Project.

The MSGRC envisions that all individuals affected by or at risk for genetic disorders have access to a medical home. While many of the essential components of the medical home require services by a clinician, there are others that can be provided by non-clinical participants in the medical home. For example, families of children with special health care needs often need access to community-based emotional and social supports that are not typically provided by physicians or nurses.

The MSGRC has been engaged with Brad Thompson, Director of the HALI Project, since 2008. Mr. Thompson, who is the parent of a child with special health care needs, has developed and piloted an innovative program that incorporates parent partners into the primary care setting. The parent partners provide the non-medical supports essential to promoting health and providing a complete medical home. As the first parent partner, Mr. Thompson provides these services in a pediatric practice in Amarillo, Texas, where he interacts directly with other families of children with special needs to provide emotional and social support services. Since 2010, Mr. Thompson has been engaged in a pilot project supported by the Boys Town Clinic in Omaha, Nebraska, where he trains parents to serve in similar roles in primary care practices.

The Mountain States Medical Home and Family Partnership Project, which is set to begin in January 2013, will expand this model of care to Wyoming over the next two years. The Wyoming Department of Health, Children's Special Health Program, has committed to helping recruit physician practices to participate. The project will engage three parents of children with special health care needs to serve as parent partners with pediatricians in their communities.

With the help of the Wyoming Department of Health, the project team is identifying pediatric practices that are willing to participate in the project. The next step will be to work with the practices to identify parent partners that have a child with special health care needs and are interested in helping other families. Each parent partner will be selected because of their experiences in managing care for their own child with special health care needs.

In January 2013, the project will begin with the first parent training session after which the parent partners will return to their community pediatric practice to begin working within the pediatrician's office to help families of children with genetic disorders and other special health care needs navigate their community's available resources. The parent partners will convene monthly via conference call with Mr. Thompson to share their experiences, ask for guidance, and reflect on their progress. Each parent partner will also have a monthly one-on-one call with Mr. Thompson. Other in-person, one-day training events will be held in late summer 2013 and in 2014. This project presents an opportunity for MSGRC to pilot a new model of care within the Mountain States and we are excited to build, develop, and implement an evaluation of this innovative work.

### Closing Thoughts

Last month we asked you to send along photos or stories about your activities outside of work. Our Project Manager Liza offered to be the guinea pig for this experiment so here's some insight into her summer fun!



*Here are some pictures of me on the banks of the Gallatin River (Montana) after a day of fly fishing with my dad this month. Fly fishing is a favorite pastime in the Creel Family and something we all enjoy doing together. Although I am a native Texan, half of my heart lies in Montana where my grandfather studied for his PhD (in genetics!) and where my dad, my brother, and I all learned to fish. I have many fond memories of Big Sky Country and most of them involve me wearing these waders or sitting on the front porch of an old log cabin. Not a bad place for the weary to rest and for the busy to relax! ~ Liza*

We'd love to feature you in our next monthly message, so please send along a picture that shows the real you, beyond the professional you. Meanwhile, enjoy those fall colors and cooler days!

Warm regards,

*Alia & Kaye*

A handwritten signature in black ink, appearing to read "Rob Hill".

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