



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

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**November 2013**

Greetings!

There's snow on the ground in Colorado, but it's mild and sunny in Phoenix and rainy and cool in Las Vegas. How lucky we are to live in this beautiful region, where you can ski or sun-bathe, depending on your preference. Our great geographic diversity is matched by the cultural diversity we also enjoy.

The size of our region and diversity of our population was brought home to the MSGRC Management Team and our national partners when we attended the National Coordinating Center (NCC) sponsored meeting of the project directors and project managers of the seven regional collaboratives (RCs) November 13-16 in Washington DC. We'll use this monthly message to highlight the general meeting and the various workgroup meetings that took place over four work- and fun-filled days.

### **NCC Evaluation Workgroup**

The NCC Evaluation Workgroup met on November 13 to review the evaluation report for the first year of this 5-year grant cycle (June 1, 2012 - May 31, 2013). MSGRC and the other RCs demonstrated a wide range of service and technical assistance activities, with significant efforts to improve care coordination and medical home services for individuals with or at risk for heritable disorders and their families. We were able to demonstrate the value of the regional system by showing shared projects across regions and use of products developed in one

region by multiple other regions. One component of the evaluation was a survey of MSGRC workgroups, which showed a high level of satisfaction with the activities of the workgroups. The NCC Evaluation Workgroup also talked about new evaluation measures which may be added next year, as well as adding a question on genetic disorders to current national surveys. There will be more on these initiatives as decisions are made by the Evaluation Workgroup and the RC leadership.

### **Affordable Care Act (ACA)**

Implementation of the Affordable Care Act (ACA) was a major topic for discussion at the general meeting of the project directors and project managers with NCC and HRSA leadership. While not a component of our original grant work plans, ACA implementation has become a major HRSA priority. RCs have been asked to focus some of our resources on providing information to consumers and their families on Essential Health Benefits (EHBs) in our states, as well as on national and state information resources about the ACA. All regions have improved their website information on the ACA, using tools developed by national organizations and the Catalyst Center, a national center funded by HRSA and dedicated to improving health care coverage and financing for children and youth with special healthcare needs. Please take a look at the ACA section of the MSGRC Website to see what we have, and let us know what additional information would be helpful to you. Following the general meeting, the ACA Implementation Workgroup met to plan future activities through which the RCs can assist families to benefit from the ACA. There will be more materials developed to be posted on RC websites. In addition, through a new grant from HRSA, the NCC and the RCs will be working on a brief for state policy makers regarding the ACA. This new grant will also provide funds for the NCC and the RCs to do a cost of care analysis of two or three model conditions, with the goal of developing state by state information on what is present in the EHBs.

### **Updates from National Partners**

Another useful component of the general meeting was the report of the [National Genetics Education and Consumer Network \(NGECN\)](#), an NCC project led by the Genetic Alliance. NGECN has produced numerous educational materials, including [Baby's First Test](#) and other web-based resources for the general public and for families of individuals with heritable disorders. NGECN has also produced tools to assist families with obtaining and sharing

their family health histories. These tools are available electronically through their website.

The extensive resources of the [National Center for Medical Home Implementation](#) were also highlighted. This is a cooperative agreement between the Maternal and Child Health Bureau and the American Academy of Pediatrics. The National Center will soon have state pages on its website containing information on Accountable Care Organizations (ACOs) within states.

There are also extensive resources developed by the [Genetics in Primary Care Institute \(GPCI\)](#) to assist primary care providers and geneticists to enhance collaboration in the provision of medical homes for individuals with heritable disorders and their families.

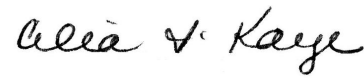
Finally, on the last day of this marathon set of meetings, the RCs met with the [LEND Programs](#) throughout the United States (Leadership Education in Neurodevelopmental Disabilities) to identify common goals and consider projects that we might do together. LEND has a focus on workforce development to serve individuals with developmental disabilities, and there is clear overlap with the goals of the RC regarding access to care for individuals with heritable disorders. For our region, there was great interest in collaborating with the LEND programs on training of consumers to work in medical home environments to provide comprehensive and family centered care for individuals with special healthcare needs. We are very hopeful that one or more projects will emerge from this energizing meeting.

### **Closing Thoughts**

The MSGRC management team came home from these meetings with long lists of "things to do", many of which relate to new opportunities to provide you with resources to help those in need of care. The educational and training tools available now or under development are extensive and impressive, and we'll be working to improve our ability to provide you with easy links to these resources. Please feel free to let us know what delivery methods are most useful to you.

Now as the days grow ever shorter and cooler, we hope you have plans to enjoy the holidays ahead with your friends and family. We do, and we will take a break from these monthly messages for the month of December. But we'll be thinking of you as we enjoy these special times. May your travels be safe, your meals nutritious as well as delicious, and your memories warm and sweet.

Warm regards,



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