



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

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**July/August 2014**

Greetings,

These are the long and lazy days of summer - at least they used to be, when we were all in grammar school and had real summer vacations. Even though most of us don't have two months to play outside anymore, summer is still a good time to reflect on a successful year. To that end, this summer message highlights MSGRC activities for the fiscal year that ended May 31. This is your work, and I hope you feel good about all you accomplished!

### Summary of Last Year's Activities

Since June 2013, MSGRC provided training to 1265 consumers via 43 educational sessions including in-person meetings, webinars, and teleconferences. Areas of focus included medical home, newborn screening capacity building, collaboration, ACA implementation, newborn long-term follow-up, and transition from pediatric to adult care. All six of our workgroups (Consumer Advocacy, Newborn Screening, Telegenetics, Emergency Preparedness, Medical Home, and Health Information Technology) conducted monthly calls and an annual conference focused on strategic initiatives, and projects and deliverables assigned to each workgroup.

Through six projects, MSGRC tested innovative medical home-centered approaches to improve access to quality genetic services and coordinated care for families with genetic disorders. These projects have directly benefited the lives of

families affected by genetic disorders, as well as improving clinical practices to better serve individuals and families into the future.

All projects have directly contributed to improving the lives of persons with genetic disorders. For example, one project resulted in the diagnosis of 72 patients through newborn screening, with nine of these patients now tracked via a data system used to determine best treatment practices for these rare disorders. Through this project, diagnosed children received full-scale neuropsychological evaluations, useful in planning educational and other services. In another project, families of children with special health care needs received technology to assist in coordinating comprehensive care with their providers. In a third project, clinical staff assisted adolescents and young adults with transitions from pediatric to adult models of care.

One project highlight includes the Medical Home and Family Partnership Project which operates in partnership with the HALI project, a non-profit in Amarillo, Texas. This program identifies, trains, and offers support to parent partners to help guide parents of children with genetic disorders in accessing the "non-medical care" pieces of the medical home. MSGRC supported the placement of two parent partners in both Montana and Wyoming. The HALI project also received an Impact Award from Genetic Alliance to expand the program to two more practices in Wyoming. In addition, this project was selected by the state of Montana as a recipient of their D-70 grant funds to expand the project to two additional practices in Montana. MSGRC's role is to support this project as a pilot program to demonstrate the effectiveness of the model. We hope our evaluation in this new grant year will demonstrate cost-effectiveness so that parent partners will be supported by more pediatric practices in the future.

Innovation, collaboration and technology are essential ingredients to meeting the challenges of providing access to coordinated genetic services across the lifespan to persons living in the culturally diverse region of the Mountain States, with many remote regions and low population density areas. The MSGRC projects serve as models for innovative approaches to providing access to comprehensive services in a medical home model. As a result, this work will benefit numerous other individuals and their families as these approaches are disseminated and adopted widely.

## Current Priorities

Now that we are well into a new fiscal year, we need your input on some of our current activities. For individuals with metabolic disorders and their families, and for those who provide medical services to them, please complete a survey on disaster planning ([link](#)) prepared by our Emergency Preparedness Workgroup, if you haven't done so already. This survey will help us develop tools for families and providers to be sure these families are prepared for disasters, big and small, that may befall them. This survey will close October 1.

For our workgroup members, please complete the (very short) **Working Together** survey. Just click this [link](#)!

Finally, for families of individuals with PKU or Maple Syrup Urine Disease, there is an opportunity to join the Newborn Screening Registry. Please open a flyer attachment [here](#) for more information and registration can be completed at [nbsconnect.org](http://nbsconnect.org).

## Closing Thoughts

In honor of the shorter vacations that some of us are able to schedule, we won't have a Project Directors' message in August. If you are traveling, please be safe. If you are in the sun, please apply sunscreen. If you are taking some quiet days at home with family and friends, enjoy!

Warm regards,



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