



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

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**March 2014**

Greetings,

Yesterday I found a little daffodil sprout peaking up from my garden. I hope those of you in the cooler parts of our region are also beginning to see signs of spring. For those of you in warmer sections, I'm sure you're enjoying this mild weather before the hot days of summer arrive. This talk of weather reminds me of beautiful Phoenix, of course, where so many of us enjoyed the sunshine and flowers at our MSGRC Annual Meeting February 6-8. This message will review the events of the annual meeting to remind those who were there and inform those who weren't able to attend. The theme of the meeting, "Home is Where the Heart Is," allowed us to focus much of our attention on medical home and enjoy an early Valentine's Day celebration.

### Highlights of February Annual Meeting

All attendees enjoyed a plenary session on February 7, including a keynote panel on medical home moderated by Chuck Norlin. We were very pleased to welcome Michelle Esquivel, Director of the National Center for Medical Home Implementation, and Sharon Romelczyk, from the National Genetics Education and Consumer Network, as members of the panel. Other panel members were MSGRC favorites Joe Martinec and Brad Thompson. The plenary session also included updates from important national and regional partners. Attendees were particularly interested to hear from Joe Bocchini, Chair of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children, on activities of the committee in reviewing conditions for possible inclusion in the recommended panel for newborn screening. Joe joined us by phone because of

stormy weather, and there was little opportunity for discussion of issues related to implementation of new recommendations in the mountain states. To fill that gap, our Newborn Screening Workgroup will be sponsoring a conference call with Joe in the near future.

In addition to the keynote panel, a consumer panel discussed the consumer's perspective on medical home. Our thanks go to Joe Martinec for moderating the panel and to Lori Wise, Bill Morris and Yolanda Sandoval-Nez for their insightful comments. Later in the meeting, Mary Kohn from the University of Colorado Hospital presented information on CCHD implementation in Colorado. The impact of high altitude on CCHD screening is of particular concern in our region, and Dr. Kohn provided data on this issue.

All six MSGRC workgroups also met in Phoenix. Sharon Homan, MSGRC evaluator, reviewed workgroup logic models with each workgroup. The purpose of these logic models is to have a succinct, five year plan for each workgroup, so that we can focus our activities and chart the progress of these hard-working volunteers. Newsworthy items from the workgroup meetings include a focus on timing of specimen arrival and reporting and Pompe disease nbs implementation in the Newborn Screening Workgroup; coordination of MSGRC projects with NCC national projects in the Medical Home Workgroup; focus on public health informatics and personal health records in the HIT Workgroup; focus on a possible learning collaborative with other RC consumer groups in the Consumer Advocacy Workgroup; continued work on the family and provider emergency preparedness surveys in the Emergency Preparedness Workgroup; and identification of access issues and telemedicine tools to address them in the Telegenetics Workgroup.

The Metabolic Consortium and Hemoglobinopathies Interest Group had their regular meetings in Phoenix, but this year both took on a new project. Both groups are working on the Patient Protection and Affordable Care Act (ACA) supplement received by NCC earlier this year. Our task at MSGRC is to produce current care plans for PKU and Sickle Cell Disease; using those care plans, we are to develop templates to be used in a future project to allow reviewers to determine if Essential Health Benefit benchmark plans and Medicaid plans in various states are likely to cover the services in the care plans. The overall goal of the NCC supplement is to provide information to policy makers that will improve coverage of essential

services through ACA for individuals with heritable disorders.

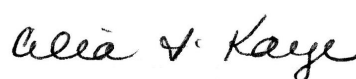
### Next Steps

As March comes to a close, MSGRC staff are pleased to have successfully submitted the non-competitive renewal of our MSGRC grant from the Genetic Services Branch at HRSA. We are currently attending the American College of Medical Genetics and Genomics Annual Meeting which began on March 24 in Nashville, and are looking forward to sharing meeting updates and lessons learned in our next message.

### Closing Thoughts

It was so much fun to see old friends and meet new ones as well. We look forward to our next time together. Please be sure to check out the photos that were captured at the Annual Meeting that have been uploaded to our facebook page. You can find them here: [MSGRC Meeting - Phoenix 2014](#). Please leave us a comment, a "Like" or feel free to "Tag" yourself in a photo if you choose!"

Warm regards,



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