



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

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**January 2014**

We hope all of you had a safe, restful and joyous holiday season. Here in Colorado, we've seen plenty of cold and snow. As the seed catalogues begin to arrive in the mail, tempting us to think of the spring garden, we're starting to dream of warmer days and those first spring flowers.

Before spring arrives, we're looking forward to seeing many of you in Phoenix for the MSGRC annual meeting, February 6-8. The theme of the meeting is "Home is Where the Heart Is," in celebration of Valentine's Day and our many activities in support of the medical home.

MSGRC received a supplemental award from NCC, the National Coordinating Center for the Regional Genetics Collaboratives, and we will be doing much of the work for that supplement at our annual meeting. The purpose of the supplemental award is to develop a template that will allow all of the Regional Collaboratives (RCs) to begin looking at Essential Health Benefits (EHBs), as specified by the Affordable Care Act (ACA), and some insurance plans in their states to determine if essential services for certain genetic disorders are likely to be covered. In collaboration with the New England Genetics Collaborative (NEGC), our Metabolic Consortium (MC) and Hemoglobinopathies Interest Group (HIG) will convene in Phoenix with billing experts from University Physicians, Inc (UPI), which manages the faculty physicians' practice for the University of Colorado School of Medicine. The purpose of this initial meeting is to develop templates that identify care plans throughout the lifespan for PKU and Sickle Cell Disease as well as billing codes for these components of the care plans. NEGC will be focusing on templates for fragile X syndrome. Once these templates have been approved by the NCC ACA Implementation Workgroup and the RCs, they will be used to review EHBs and certain insurance

plans throughout the U.S. Our providers in the Mountain States are excited about the opportunity to work on this project with NCC and NEGC, and we are very appreciative of the support provided by NCC, HRSA and UPI.

Also at our annual meeting, all MSGRC workgroups will see logic models to define their work for this grant cycle (2012-2017), based on the work they all did at our MSGRC workgroup meetings in July, 2013. Sharon Homan, MSGRC Evaluator, has been working with the MSGRC Management Team and workgroup co-chairs to develop these logic models. All of the logic models are related directly to the overall MSGRC mission, which is to improve access to high quality services for individuals with and at risk for heritable disorders within the medical home. Each workgroup has a critical role to play if MSGRC is to fulfill its mission, and these logic models are meant to focus our attention on the purpose of our many activities, every time we meet or work on workgroup projects or review the mini-projects that MSGRC funds. Most of you will have the opportunity to talk about these logic models when you meet with your workgroups in February. As you reflect on them, remember that they are living documents, meant to evolve and change as we identify our successes and challenges in the work we do. We've included the logic models [here](#), for you to get an idea of what we'll be working on in February and in the future.

In addition to preparing for the annual meeting in February, members of MSGRC participated in a two-day webinar of the Discretionary Advisory Committee on Heritable Disorders in Newborn and Children (DACHDNC), as well as in the DACHDNC subcommittee meetings. The February Message from the PDs will provide a summary of the webinar and the subcommittee meetings, and some of the things we learned through the webinar and these meetings will be presented at the meeting in Phoenix.

Early registration for the MSGRC meeting encourages us to think that we will see many of you in Phoenix, as well as representatives of some of our most important national partners. If you have any questions about registration or logistics, please contact Stephanie Ondrias at [sondrias@texashealthinstitute.org](mailto:sondrias@texashealthinstitute.org). It will be nice to enjoy the beautiful weather and surroundings in Phoenix as we catch up on our professional and personal lives together, and as we move the work of MSGRC forward. Thanks to all of you who are attending. For those of you who are unable to come, we'll be providing you with news from the meeting through these messages.

Warm regards,

*Celia I. Kaye*

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