



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

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July/August 2013

Greetings!

It's hard to believe our work-groups met face to face less than a month ago! Time seems to be flying by as we enjoy beautiful weather and summer vacations.

We are still working on selecting a new MSGRC Project Manager, and although Liza will be a hard act to follow we have a wonderful selection of applicants to choose from. Be on the lookout for updates!

MSGRC 2012-2013 Annual Meeting

Eighty active MSGRC members came together July 10-12 in Denver for MSGRC workgroup meetings and time to catch up with each other. We enjoyed the away time at the hotel and the good food, but most important was our time together to share our personal stories, catch up on work events in our various states, and unwind over dinner.

Every MSGRC workgroup met to discuss on-going activities and continue development of their evaluation plans. The Telemedicine, Emergency Preparedness, and Newborn Screening workgroups continued to share information on projects in their various states and made plans to continue work on their grant funded activities. The MSGRC Advisory Council met to review progress on the first year of this grant cycle and discuss evaluation activities for MSGRC and the National Coordinating Center for the Regional Collaboratives (NCC).

The Medical Home workgroup held its second face-to-face meeting. They reviewed progress on the newly funded

Parent Partner project, which is training parents of children with special healthcare needs to work in primary care offices to support children and families with special needs. **Brad Thompson** is the director of this exciting new project. **Laura Pickler** reported on her project, Improving Medical Homes and Transition Outcomes for Youth Served in IMD Clinics. In this final year of funding, **Dr. Pickler** will complete data collection and analysis of patients with genetic disorders or inborn errors of metabolism who are transitioning to an adult model of care. At their request, work-group members participated in a webinar on aspects of the Affordable Care Act, presented by **Meg Comeau** of the Catalyst Center.

The Health Information Technology Workgroup held its first meeting, an open forum for all interested MSGRC members to discuss priorities in health information technology for MSGRC. The purpose and mission of this workgroup were discussed, and then the group engaged in a discussion, facilitated by **Donna Williams**, of potential benefits and risks of information technology for children and adults with special healthcare needs. From among numerous ideas shared by the group, MSGRC staff will propose three goals for this workgroup, and then workgroup members will describe a scope of work for each goal. At a future meeting, workgroup members will prioritize these goals and identify timelines for work in the current year.

The Hemoglobinopathy Interest Group discussed the highly anticipated release of the National Heart Lung and Blood Institute's (NHLBI's) [Expert Panel Report on the Management of Sickle Cell Disease](#) and possible strategies for dissemination throughout the region. In addition to discussion on the new guidelines, work is underway to identify the primary and specialty providers known to State newborn screening programs who care for children with sickle cell disease. These pediatric providers can in turn contribute information about where youth receive care as they enter adulthood, so that contact can be made with those adult practices. One goal of this process is to facilitate dissemination of the NHLBI guidelines for the management of children and adults with sickle cell disease. Successful transition from the pediatric to adult-oriented care will be critical to sustain implementation of the new guidelines across the lifespan and can drive collaboration around recommended health care goals.

Next Steps for the Project Team

Now that this wonderful meeting is behind us, the MSGRC Management Team will focus on recruiting a new project

manager. We'll also continue to monitor our projects, and **Sharon Homan**, our evaluator, will complete logic models and evaluation plans for each work-group and project. This should keep us busy for the rest of the summer!

Closing Thoughts

We hope you all find some time to enjoy these warm days. Please spend some precious moments with family and friends, and don't forget to send us a picture of yourself enjoying some time away from work.

MSGRC Project Coordinator, **Donna Williams**, has a new found love for orchids and unusual plants. Here are some pictures of beautiful plants she nurtured from cuttings to adults. The plants were gifts from her colleague and friend, MSGRC NBS Co-Chair **Susan Tanksley**.



Warm regards,

Alia & Kaye *Roby Hill*

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