



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

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June 2014

Greetings,

June is the month when real summer begins, the air gets hot in our southern and southwest mountain regions, and most of us begin to think about at least a short vacation. For Celia, this has been a month for moving back to the Dallas area to be closer to family. Kathy has just returned from a mission trip to Honduras, and Joyce will soon be heading for Nova Scotia for her annual summer retreat. However, all of us will still be working on MSGRC business through the summer months. Our activities will be greatly enhanced by the addition of our newest staff member, Marilyn Brown, who joined us June 3 as MSGRC Project Manager, based at Texas Health Institute in Austin.

Welcome our new Project Manager!

Marilyn completed her B.S. in Biomedical Sciences at Colorado State University and recently received her Master's in Public Health from the Colorado School of Public Health. Having actually grown up in Bay City, Texas, she is delighted to be back in her home state after almost nine years away. While in Colorado, Marilyn began her work in public health as a tobacco inspector for the Food and Drug Administration. She continued her work in public health at the University of Colorado Cancer Center as Program Coordinator for the Generations Project, a program aimed at providing historically underserved patients genetic counseling and testing services for hereditary cancers. Through this experience, Marilyn's interest in public health genetics was fostered. She is excited to continue serving in a role that

advances the availability of genetic and other healthcare services to high-need populations.

Marilyn's favorite activities include running and hiking, and she is currently training for Pikes Peak Marathon, a run up and down a 14,000 foot mountain! While she misses the mountains of Colorado, she already is enjoying running trails around Austin with her dog Cash always at her side. Some of her other activities are perusing antique shops, which are plentiful in Austin, and baking, particularly cheesecakes.



Collaboration with LEND

We completed the month of June with a joint webinar between MSGRC and 3 of the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs. Last November the MSGRC and 5 of the 8 (LEND) programs in our region had a joint meeting at which time we developed a "Collaboration ACTION Plan and Next Steps." The intent of this month's follow-up webinar was to reintroduce ourselves, review the action plans or other related progress made on collaborations, consider projects of interest, and discuss the format and agenda topics for the in-person November meeting.

At the November 2013 meeting, our region and LEND identified two collaboration objectives: to expand the MSGRC Parent Partner project to LEND sites and translation of the Sunkissed video into a learning module by LEND. Although the first objective has not

been met at this time, the second objective has been enhanced and will be completed by September 2014.

The next task, establishing agenda items for the November 2014 meeting, came easily. A number of areas for collaboration were identified. In order to use our time in November efficiently, each LEND program and regional collaborative will complete a brief, factual information form on current activities in Medical Home, Transition, and Telemedicine to be reviewed prior to the November meeting.

We thank the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (NCC) for giving us the opportunity to convene and work with the LEND programs in our region.

Looking Back and Moving Forward

Marilyn and the rest of us spent much of June completing our annual MSSGRC evaluation report for the National Coordinating Center for the Regional Genetic Service Collaboratives (NCC). In looking over the work we have accomplished in the past 12 months, we are impressed again by the tremendous effort put forth by our workgroups and project directors. Thanks to all of you for another productive year.

We have also begun planning for our next full annual meeting, which will be in Phoenix April 22-25, 2015. Please save the date! We still have not finalized plans for possible workgroup meetings this fall.

Redesigned Got Transition Site

We would also like to direct you to Got Transition/Center for Health Care Transition and its redesigned site, www.GotTransition.org. The site is a valuable resource and now includes an interactive section for health care providers corresponding to Six Core Element's practice settings. There is also a set of frequently asked transition questions for youth and their families. Additionally, there is new information for researchers and policy makers as well as a robust listing of transition resources.

Emergency Preparedness Planning Survey

Finally, if you have not yet filled out the survey on disaster planning for our Emergency Preparedness Workgroup, you can do so through this [link](#). There is a version for patients and families as well metabolic providers, and the Emergency Preparedness Workgroup will use the results of the survey to develop tools to enhance the ability of individuals and their families to be ready for emergencies that are likely to happen in our mountain states region.

Closing Thoughts

It's hard to envision emergencies as we contemplate the sunny skies of June, and we hope none of you will experience anything worse than a sunburn from not quite enough sun screen. Whether you're running with Marilyn, gardening with Celia, visiting college sons with Kathy, or enjoying beautiful Canada with Joyce, we hope July is both restful and energizing for you.

Warm regards,



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