



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

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**May 2015**

Summer days are near as the days get longer and warmer. As we head into summer, changes are about at MSGRC. We welcome new leadership as well as the new directions this grant year will bring.

### Message from Celia

As most of you know, this will be my last message to you as MSGRC Project Director. Kathy Hassell will take over this role on June 1, assisted by Janet Thomas as Associate Project Director. Since I expect to see all of you again at various MSGRC and NCC activities, I'm not saying good-bye. But it does feel like a time for reflection.

I suspect all of you are familiar with Robert Frost's poem, "The Road Not Taken", which ends with the idea that taking the road less traveled made all the difference. All of us in genetics have taken the road less traveled, and those of us in the regional collaboratives and public health genetics have taken a road that many clinicians and policy makers barely know. Looking forward to the next two years, we'll be working hard on re-setting our path on this road, with an eye toward making access to genetic services for all patients and families more accessible. This is a critical time for the regional collaboratives -- and a tremendous opportunity. Instead of just noticing that some populations, including people we've gotten to know and love in MSGRC, struggle to receive genetic services, we are asked to envision a system that actually starts to serve these individuals. As I take off my Project Director hat for MSGRC, I'll be working with NCC for the next year

to look at what such a system might actually do, how it might be organized, and how it would show its effectiveness. I hope that this idea will catch fire in you as it has in me, and that you'll be willing to help with your ideas and insights. Those of you who participated at the listening session led by David Flannery at our annual meeting have already been part of the process of re-setting our path.

Now for the "reflection" part: change is inevitable. As I change my status with MSGRC from Project Director to consultant, I want to rejoice in the opportunity to grow my service and maybe even my skills. One thing I don't want to change is my opportunity to know you and work with you toward our common purpose. It has been an honor to be your project director, and I hope you'll continue to call me and email me whenever I can be of help to you, or just to check in. I plan to do the same.

### **Welcome Dr. Janet Thomas**

While many of you are already acquainted with Dr. Janet Thomas, June 1st marked her first day as Associate Project Director for MSGRC. Dr. Thomas is the Director of the Inherited Metabolic Diseases Clinic at Children's Hospital Colorado. She has been on the faculty of the University of Colorado School of Medicine since 1996 and devotes her time to caring for individuals of all ages with inborn errors of metabolism in the Rocky Mountain region. She has a particular interest in lysosomal storage disorders and newborn screening. Teaching medical students, pediatric and genetic residents, and graduate genetic counseling students is also a part of her duties. Dr. Thomas is a faculty member of the UCDHSC Human Medical Genetics Program, a member of the State of Colorado Newborn Screening Program Advisory Committee, and Director of the University of Colorado Medical Genetics Residency Program. She also developed and co-directs the Colorado Lysosomal Disorders Program. She is actively involved in industry sponsored therapeutic research for PKU and several lysosomal storage disorders. Dr. Thomas has been active with MSGRC for several years as Project Lead for the Metabolic Consortium. We are very pleased that she is taking on an expanded leadership role with MSGRC.

### **ACHDNC Updates**

The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) met May 11-12 via webinar. Day 1 opened with a presentation on ACA

mandated coverage of NBS and models for payment. The rest of the day focused on the Newborn Screening Saves Lives Reauthorization Act of 2014- Informed Consent Amendment. Use of dried blood spots (DBS) for research use remains under debate and consent from parents is currently required in Texas and Minnesota. Policies regarding secondary use of DBS varies widely throughout states. Susan Tanksley (TX) presented on the "opt-in" required in Texas for use of DBS.

Day 2 of the ACHDNC webinar meeting centered on the work by ACMG's National Coordinating Center (NCC) and Newborn Screening Translation Research Network (NBSTRN) on long-term follow-up tools. The meeting concluded with updates from the Condition Review Workgroup on X-Linked Adrenoleukodystrophy (X-ALD). The workgroup is currently focused on both better establishment of the evidence around X-ALD diagnosis and treatment as well as the Public Health System Impact Assessment Survey currently in distribution to all 50 states, DC, and Puerto Rico. The report for this survey will be completed by July or August.

If you were unable to attend the webinar, the archived presentations can be accessed through this [link](#). The next ACHDNC meeting is planned in-person for August 27-28.


### Reminder: NCC Meeting and Webinar

We would also like to invite our colleagues to join the NCC meeting and webinar for a national dialogue to address access and payment for genetic and genomic healthcare in integrated delivery systems. The meeting will be **June 15th, 6 AM to 3 PM MT**. Please follow this [link](#) to register.

### Closing Thoughts

While we expect this new grant year to bring new direction here at MSGRC, the involvement of our friends and colleagues will continue to be integral to our success. As the regional collaboratives evolve, we are excited to continue engaging with leaders in the field both regionally and nationally.

Warm regards,



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