



Message from the Project Directors Kathryn Hassell, MD & Janet Thomas, MD

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June 2015

While the summer days may be longer, days here at MSGRC feel brief with the many activities accompanying our new grant year. Kathy, Celia, and Marilyn all attended the discussion in Washington D.C. on access and payment for genetic services hosted by the National Coordinating Center (NCC). Kathy also recently returned from a mission trip to Honduras, and Joyce is excited to be planning her annual summer trip to Nova Scotia. In between our travels, we also were busy completing our annual MSGRC evaluation report for the NCC.

NCC Meeting: Addressing & Paying for Genetic Services

The discussion attended by the MSGRC team focused on many of the critical issues that have been widely recognized by our MSGRC members and colleagues. Some of the issues addressed were inadequate access to genetic services, limited knowledge of genetics in primary care, limited availability of information on genetic testing and services for consumers, and inadequate public health infrastructure for integration of genetics in disease prevention. The [briefing book](#) and [recorded webinar](#) for this meeting are both linked.

Kathy shared her experience with Hemoglobinopathies patients in her presentation, "Using Clinical Knowledge to Identify Services and Payment Issues." While there is much focus on the shortage of genetic professionals, Kathy noted that for many genetic conditions, for example Sickle Cell Disease and Cystic Fibrosis, patients are primarily served by the providers that have expertise in managing

the condition. Kathy used a condition specific approach (Sickle Cell Disease) to demonstrate the services and essential health benefit coverage needed and how this approach can support service and payment considerations.

Celia led the panel "Approaches to Addressing Genetics/Genomics in Integrated Systems." Medical geneticists from Geisinger, Kaiser, and Westchester Medical Center had diverse perspectives and experience in providing genetic services within their systems. The discussion addressed education of providers on obtaining coverage of genetic services for patients and how to work with payers to expedite the process. The panel members also discussed the importance of measuring what is currently happening in practice. A large issue is obtaining data so that changes in coverage and delivery of genetic services can be addressed. Many rare conditions currently do not have US Preventative Services Task Force (USPSTF) guidelines which are currently driving determinations for coverage under the Affordable Care Act (ACA).

Upcoming Events

Session: Genomic Technology in NBS

Aaron Goldenberg from Case Western Reserve University, Beth Tarini from the University of Michigan, and Amy Gaviglio from Minnesota have a new project funded by HRSA to assess the viewpoints of State Newborn Screening Officials regarding the integration of genomic technology into their programs. They are working collaboratively with each of the Regional Collaboratives to set up a series of phone focus groups to hear from program and laboratory officials. These sessions are approximately 1 hour long and are meant to give the States a chance to have their voices heard about the potential uses of genomics in their programs. Individuals and their States will not be identifiable in the data. Regions may be identified to show regional differences. We have set up a poll below to determine a time best for our members. We have also [attached an information sheet](#) about the project. Thank you so much in advance! We look forward to hearing from you on these important issues.

Poll Link: <http://doodle.com/yw4kn8732eymgc66> (listed in Mountain Time Zone)

Webinar: Navigating the Affordable Care Act

The Catalyst Center and National Center for Medical Home Implementation will be hosting a webinar, *Navigating the Affordable Care Act (ACA)- Help for families of children with special health care needs*, will be held on **July 20th at 1:00 PM ET**. Please see below for more information on the webinar (provided by Meg Comeau).

Date: July 20, 2015

Time: 1:00 to 2:00 pm ET (12:00- 1:00 pm CT; 11:00 am - 12:00 pm MT; 10:00 - 11:00 PT)

Join us for a free webinar where experts from the Catalyst Center and the National Center for Medical Home Implementation will share information, based on recently developed fact sheets on how the following ACA provisions can help families raising children with special health care needs:

- Medicaid "wrap-around" coverage for privately insured children with special health care needs
- Concurrent care for children with life-limiting diagnoses
- Habilitative benefits in the State Health Insurance Marketplace plans
- Section 2703 Health Homes for funding care coordination

Register [here!](#)

Closing Thoughts

Much of the focus for the regional collaboratives in the remaining grant cycle will be assessing the needs for effective delivery of genetic services and the barriers existing in our current healthcare system. As we completed our NCC Evaluation Report, we were once again reminded of how much work and advancement has been realized with the immense support from our members and colleagues. We are currently developing workplans that will serve as a guide for our activities over the next two years. The continued support of our members will continue to be a vital component in realizing our objectives. Next month, we will be sharing many of our proposals. In the meantime, please have a wonderful and safe Fourth of July!

Warm regards,



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