



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

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### September 2015

September was a productive month both regionally and nationally with many projects and activities coming to completion. These activities will lay much of the groundwork for the future of the regional collaboratives. We encourage all of our members and stakeholders to read on and please share with colleagues!

### ACA Policy Brief

In December 2013, New England Genetics Collaborative (NEGC) produced a regional policy brief to better understand the gaps in coverage that may exist using the Essential Health Benefits (EHBs) outlined in the Affordable Care Act (ACA). MSGRC decided in December 2014 to produce an adaption of the NEGC Policy Brief for the states in our region (AZ, CO, MT, NV, NM, TX, UT, and WY). This effort was primarily assumed by University of North Texas PhD candidate, Christine Cardinal, JD, MPH. Both Celia Kaye, MD, PhD and Sharon Homan, PhD, of MSGRC and Meg Comeau of The Catalyst Center also had an extensive role in bringing the brief to completion. As MSGRC continues their needs assessments for genetic resources for both patients and providers the policy brief will have an important role in guiding discussion. Please share the brief with any colleagues that may be interested. The MSGRC ACA Policy Brief can be accessed [here!](#)

### NCC Provider Survey

The National Coordinating Center (NCC), administered by the American College of Medical Genetics (ACMG), is collecting

information on existing genetic services and resources. Information collected will be used to inform the Health Resources and Services Administration (HRSA) on the development of models of centers that can effectively support genetic and genomic services at the regional level.

MSGRC asks all genetic providers to participate in this survey. This survey will guide us as we envision future regional genetic resources that will aid providers in better serving their patients and families. Please share the link below with partners and colleagues!

Survey link:

<https://www.surveymonkey.com/r/ACMGAPHList2015>

### **Genetic Alliance Consumer Survey**

Genetic Alliance, in their role as National Genetics Education and Consumer Network (NGECN) have created a survey to better understand the healthcare experiences of individuals with genetic disorders. The information gathered from affected individuals and families will also be an important keystone in the development of genetic service models.

The survey will explore areas in which families report barriers, including: 1) identification of the condition; 2) finding services, information, and support; 3) accessing care; 4) telemedicine; 5) adult care; and 6) care beyond the clinician's office. Genetic Alliance and MSGRC encourages partners to share the link below with everyone that may be interested in completing this survey.

Survey link:

<https://www.surveymonkey.com/r/ImprovingGeneticServices>

### **Final Thoughts**

As MSGRC, NCC, and the other regional collaboratives continue to develop future visions in the realm of genetic services, we hope to continue receiving feedback from all of our partners. We hope everyone's Fall is off to a lively start and also wish everyone a fun and safe Halloween with plenty of tasty treats!

Warm regards,



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