



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

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March 2015

Greetings,

Long awaited Spring temperatures are finally here in the Mountain Region. With the arrival of Spring, we are gearing up for many important activities in our region.

ACMG 2015 Annual Conference

The MSGRC team was pleased to attend the 2015 American College of Medical Genetics (ACMG) Annual Conference hosted in the beautiful Salt Lake City, Utah, from March 24-28. ACMG gave us the opportunity to meet with many partners and colleagues and we were able to participate in many events of notable importance during our time in Salt Lake City.

The National Coordinating Center (NCC) had in-person meetings for both the Transition and Medical Home Workgroups. The workgroup meetings were attended by NCC and RC representatives, as well as other colleagues critical to the work of the RCs. Celia presented at the Public Health Special Interest Group (SIG) on "Addressing Regional Challenges in Access to Genetic Services." MSGRC has recently begun a Genetic Services Mapping Project to assess shortages of genetic services throughout the region and the forum provided an excellent opportunity for us to share our initial findings. Kristi, MSGRC's Social Media Coordinator, presented as part of a special satellite event. A clip of the documentary "Undiagnosed" shared the story of individuals and the families of children living with unknown genetic conditions. The Utah Population Database

(UPD) was also presented. The UPD is an extensive database of diagnostic records and demographic information of Utah families. The UPD has great potential to provide answers for many unidentified genetic disorders. Kristi participated as a member of the parent panel and shared her experience as a parent of a child with an undiagnosed disorder. Marilyn presented a poster on initial data extracted from MSGRC's Emergency Preparedness Survey. The information collected through both the Genetic Services Mapping Project and Emergency Preparedness Survey will be integral as MSGRC focuses on needs assessment and gaps in services in the upcoming grant year.

MSGRC Annual Meeting: Call for Posters

We are looking forward to seeing many of our members and partners this month at the MSGRC Annual Meeting, April 23-25, 2015. MSGRC will host a sponsor and poster session on April 24 from 1-1:30 PM. We would like to invite all attendees to use this session for encore poster presentations. If you have a poster you would like to exhibit, please contact [Marilyn](#) for more details.

Closing Thoughts

We are very eager to see many of you this month in Phoenix, Arizona. We expect the next few weeks to pass very quickly as we put together final plans for our Annual Meeting. These endeavors though are well worth the important work and connections we expect at our 2015 Annual Meeting.

Warm regards,



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