



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

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May 2017

Greetings,

April was an exciting month here at MSGRC. We were delighted to have so many of our members in attendance at our Annual Meeting, "Seeds of Sustainability," in Salt Lake City, Utah. While we may be nearing the end of our five-year cycle, the atmosphere of the Annual Meeting was energized and celebratory. MSGRC was pleased to have this final opportunity to showcase our own projects in the region as well as bring in new partners. For our members that were not able to join in-person, this month's message will focus on an overview of the meeting, complete with links to presentations and photos taken throughout.

Highlights from the 2017 Annual Meeting

The general meeting commenced with a presentation from MSGRC's own Project Directors, Kathy and Janet. The presentation oriented attendees to the work of the MSGRC over the last five years, as well as insight on our future cycle as the Mountains States Regional Genetics Network (MSRGN). Janet was able to debut the recent work done by our evaluator, Liza Creel, and her colleagues at the University of Louisville in geo-mapping of genetic services for one of our genetics clinics in the region, Colorado Children's. Our goal is to demonstrate where patients are originating from and what areas might still be underserved. The Colorado Children's map demonstrated exactly how large their catchment area was with the utilization of outreach sites and telegenetics clinics. Ana Herrera Morales and Mary Ann Coffman of the Heartland Genetics Collaborative presented on their Hispanic Access

Project. With a high need to ensure access to genetic services for underserved populations in the MSGRC region, which is home to a large Hispanic population, this project has relevance to the future work of Regional Genetics Networks (RGNs). Heartland and MSGRC continue to work together on strategies to effectively ensure access to services by the underserved populations in future years.



A full room of approximately a hundred attendees

The Parent Partner Project team hosted a panel that discussed different perspectives and experiences with the project. Tarra Thomas, current MT State Coordinator and previous Parent Partner, gave a wonderful overview of the program and also offered a family perspective. Cathy White, pediatrician at a Parent Partners site, gave insight as to how it had transformed her practice to deliver better patient care and increase her effectiveness as a provider. Rachel Donahoe, Director of Montana's CYSHCN, described why the state had funded Parent Partners and how other states could integrate Parent Partners into their own programs.

Chuck Norlin led the rest of the Medical Home Session, describing the Utah Pediatric Improvement Partnership (UPIQ) and other state initiatives in Quality Improvement (QI). With an increasing focus on QI, Chuck's timely presentation provided important resources and information for states interested in developing their own QI programs.

Thursday commenced with a very special Consumer Advocacy Session. Eileen Forlenza has many roles as a consumer leader- parent, President of AMCHP, Director of Family Engagement at Colorado's Health Department, and motivational speaker. She described her journey from

struggling mom with an affected child to the leadership role she has gained today in Consumer Advocacy. Her presentation was followed with a generous Networking Session hosted by Gold Sponsor PerkinElmer. Silver sponsors Oz Systems and Prevention Genetics generously donated items for a door prize drawing after the Networking Session commenced. Progeny Genetics, Recordati Rare Diseases, and Shire were also in attendance as sponsors. Thursday evening, most attendees stayed for Dinner & a Film, to watch "Life According to Sam," a powerful documentary about a young man with Progeria.

Friday morning began with a very special presentation by Hans Andersson of Tulane University in New Orleans. He recounted his experience as a geneticist during Hurricane Katrina, and how the medical campus, city and community, and emergency responders reacted to a large-scale disaster with an extremely long-lasting impact. MSGRC reviewed the state emergency preparedness (EP) resource handout previously created by Arizona. During the session, we were able to find volunteers from all of our other states to create similar EP resource handouts. Sylvia Mann of Western States Collaborative and Janet Major of the Southwest Telehealth Resource Center (SWTRC) led us through a session on their telegenetics program, providing a useful overview of its use and applications for our clinicians in attendance. Dale Alverson and Janet Thomas provided a wrap-up of the session, with Dale giving input on the rapidly changing landscape of telemedicine and regulations and Janet giving her account as Director of Children's Colorado Metabolic Clinic, which has quickly and successfully integrated telegenetics into their practice. Janet Thomas was able to present an encore presentation of the Cook's Case Study Friday afternoon, previously a platform presentation at the ACMG Annual Conference. Cook Children's in Texas has risen as a leading institution in their use of telemedicine in our region and they offer a real-life example of the effectiveness of telemedicine when integrated at an institution-wide level.

Friday commenced with the Newborn Screening (NBS) Workgroup. MSGRC was honored to be joined by Dr. Bocchini, presenting updates on ACHDNC. Discussion following his presentation was lively, with questions from many of the state leaders in NBS from our region. Our state leaders in NBS followed Dr. Bocchini's presentation with a panel, highlighting the advancements made in their states over recent years. The session wrapped-up with discussion on some of the current challenges and issues for NBS programs and how they they might be addressed.

That evening, MSGRC wanted to offer one more networking opportunity for our consumer members. Kristi and Marilyn of MSGRC were delighted to host many of our consumer advocates at an off-site dinner held at Alamexo's. The following Saturday morning MSGRC held the Collaboration Caf  , giving many of our members a final opportunity to network and plan for the future before heading home.

MSGRC has received a high level of positive feedback from the 2017 Annual Meeting. We hope many of you took home your seed cards and expect that some may already have their own herb gardens started. More importantly, we hope everyone was able to take away ideas to further genetic services and other supporting resources in our region. MSGRC is still looking for feedback as we complete our five-year evaluation and strategize how we will successfully serve as a Regional Genetics Network (RGN) in our upcoming cycle, initiating June 1, 2017. For those that did not have the opportunity in-person, please complete the ["Working Together" survey](#).



Remember to "plant your seeds!"

To see presentations, please visit our [Annual Meeting page](#). For a full gallery of the Annual Meeting, visit our [Facebook](#). Thanks to the efforts of our Social Media Coordinator, Kristi, and all of our members we are now above 550 "likes." This exceeds our meeting goals of reaching 500 and makes us the leading region in "likes!"

Clinical Practice

As mentioned above, our colleagues from Heartland Genetics Collaborative have made much progress on their Hispanic Access Project, focused on identifying barriers to care and increasing cultural competence among providers. They would like to invite everyone from the MSGRC region to participate. For providers seeing Hispanic patients, this webinar is intended to provide information that will improve genetics clinics visits. The webinar is scheduled for **May 25 at 11-12 pm MT/ 12-1 pm CT**. We hope many of our clinicians will be able to join. Please follow the [link to register](#).

ACHDNC & NBSTRN Meetings

The next ACHDNC meeting will be held in-person in Rockville, MD and via webcast on May 11-12. If interested in attending in-person or webcast, please register at <http://www.achdncmeetings.org/registration/>.

The Newborn Screening Translational Research Network (NBSTRN) will be meeting in-person in Washington, DC, June 1-2. The meeting agenda can be accessed [here](#). While the meeting will not be webcast, MSGRC staff will be in attendance and we will offer a recap in a future PD message.

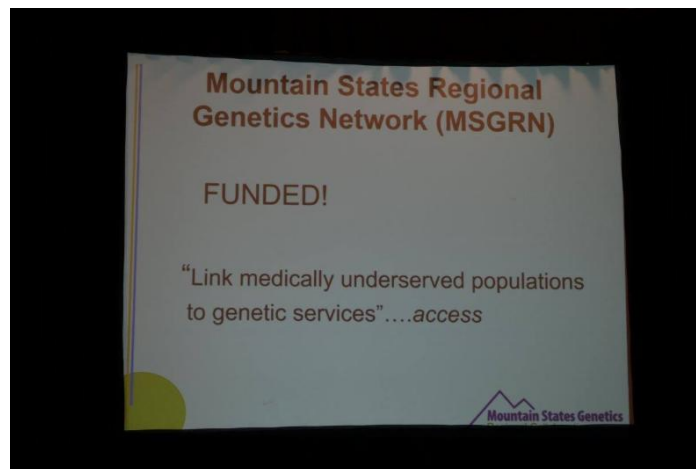
Working Together Survey

Again, your feedback counts! As we move into a new cycle, input and suggestions on our work over the last five years will be crucial. If you did not already follow the link above, please find the ["Working Together" survey here](#). Please note this survey was distributed at the Annual Meeting. If you already completed it, there is no need to submit an electronic response. We would like to thank everyone that is able to complete the survey!

Planting Seeds for the Future

Again, a sincere thank you from MSGRC to all that traveled from across (and beyond) our region to come to our Annual Meeting. We know that many of our members are still anticipating the new focuses and work planned for our future cycle, as the Mountain State Regional Genetics Network (MSRGN). We plan to offer more information in our June PD message on our future activities. In the meantime, the MSGRC would like to give a final thank you

to all of the hard work given by our members over the past five years!



Warm regards,



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