



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

May 2018

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Dear Friends and Colleagues,

As we near the end of May and we reflect on the end of our first grant year as MSRGN: a new name, a new logo, a new website, four pilot sites through our Underserved Population Project (UPP) and eight new state teams with an in-person meeting conducted in Austin in January. We pause to thank all of our stakeholders who have been involved with the new focus of this grant cycle: improving access to genetic services for underserved populations in our region. We look forward to two more years to accomplish those goals that have been formulated this year with your help!

**Mark your calendar for the 2018 Genetics Summit
October 2nd and 3rd, 2018**



The Mountain States Regional Genetics Network (MSRGN) is calling all those interested in genetics to come together for the first Genetics Summit in October 2018. This first-ever gathering will provide CEUs accredited learning sessions of interest to healthcare providers, public health officials, community organizations, individuals and their families impacted by genetic conditions.

The **2018 Genetics Summit** will be held in San Antonio, Texas October 2-3, 2018. There will be a focus on the potential impact of state-of-the-art genetics services, barriers to and possible solutions for access to these services. The Summit will bring together genetics specialists and primary care providers, public health professionals, community-based resources and consumers from across the region to share, learn, and network to influence positive change in access to genetic services. Please plan on attending and register early!

Consumer Scholarships for Genetics Summit

At MSRGN we appreciate our consumers! We have developed a scholarship program for our consumers to assist them in traveling to the Genetics Summit. The scholarship will cover registration fees, air travel (or mileage based on location), hotel and daily per diem for meals. Scholarships will be awarded based on availability of funds and will be reviewed by the MSRGN management team. Scholarship recipients will be notified by email. Scholarship submission deadline is July 1, 2018. Applications will be reviewed on a rolling basis as they are received. To apply for the scholarship please click [here](#).

Educational Activities

If you were unable to attend Dr. Austin Larson's webinar: Genetic Tools 2018, on May 3, 2018 the archived webinar, presented as part of the Indian Health Services Clinical Rounds, can be accessed [here](#).

The webinar discussed the recent advances in genetic testing and their implications for diagnostic testing strategies for children with suspected genetic conditions.

MSRGN Participates in National Coordinating Center's Quality Improvement Meeting

Liza Creel, MSRGN Evaluator, and Annette Lara, MSRGN Project Manager, attended the [National Coordinating Center \(NCC\)](#) Quality Improvement meeting in Washington, DC on April 26th and 27th. The meeting offered training in key processes within quality improvement (QI), including process mapping, root cause analysis, and measurement of small changes. The NCC's QI efforts include providing the regional genetics networks with QI Coaches as QI projects develop. MSRGN is currently working to initiate one or more QI projects in our region. If you are interested in doing QI within your state team project or in your genetics clinic, please contact our project manager, Annette Lara, at: alara@mountainstatesgenetics.org.

State Team Spotlight: Arizona

The Arizona Team: Fran Altmaier, Sondi Aponte, and Kathy Levandowsky from The Department of Health Services as well as Dawn Bailey, a mom and parent advocate that works with the Department of Health Services, headed North to the Navajo Nation to visit Tuba City Regional Healthcare Corp. They learned more about how Navajo families access care to genetic services. As part of the visit, Dr. Steve Holve, and his wife Dr. Diana Hu hosted a dinner reception for the state team where they were introduced to other pediatricians who work for IHS. The visit also included a tour of the hospital where they met nurses from the OB and postpartum units, as well as laboratory staff. Meetings were also coordinated with a Public Health Nurse Manager and a Community Health Representative (CHR), each of whom helped the group gain a better understanding of where disparities in care exist. Together everyone brainstormed about opportunities to provide services for families and patients affected with genetic conditions and the team hopes to pursue several avenues for improvement that arose from the discussions.



Left to Right- Dawn Bailey, Dr. Steve Holve, Kathy Levandowsky, and Fran Altmaier in Tuba City, AZ



Left to right-Dawn Bailey, Kathy Levandowsky, Bobbie Yazzi, and Sondi Aponte, at Tuba City Regional Medical Center.

State Team Project Update

Montana State Team developing a needs assessment survey to identify underserved areas in genetics.

Texas State Team organizing a booth at the Texas Pediatric Society fall meeting and using their remaining funds on Facebook outreach marketing.

New Mexico State Team developing a consumer outreach survey and resource list to handout to families.

Colorado State Team developing first ECHO Lite to be held on June 20 and having MSRGN magnets printed.

Wyoming State Team implementing new telegenetics clinics with evaluation process in place.

Arizona State Team exploring access to genetic services: needs and barriers for American Indian populations through collaborations with Indian Health Services (IHS) and primary care clinics.

Nevada State Team reviewing previous state needs assessment documents.

Utah State Team is considering two projects: 1) using consumer input to improve understanding of information for PCP's and patients with rare disorders 2) exploring how to improve access to care and understand the difficulties from the perspective of a specialist.

Funding Opportunity for Family-to-Family Health Information Centers (F2F HIC)

We are pleased to announce Health Resources and Services Administration's (HRSA's) recent release of their newest funding opportunity for the Family-to-Family Health Information Centers (F2F HICs) Program. [The full announcement can be found on](#)

The purpose of this program is to provide information, education, technical assistance, and peer support to families of children and youth with special health care needs and the professionals who serve them. Through this announcement, HRSA will fund one F2F HIC in each of the following five United States Territories - American Samoa, Guam, Puerto Rico, the Northern Mariana Islands and the U.S. Virgin Islands; and up to three F2F HICs to serve American Indians/Alaska Natives.

Warm regards,



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**HAVE YOU VISITED OUR NEW
Website:**
www.MountainStatesGenetics.org

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