



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

Join Our List.

[Join Our Mailing List!](#)

August 2017

Greetings,

The MSRGN prides itself on its diverse and engaged membership. This month, we would like to celebrate the wonderful contributions that have been made by our partners. This help has been crucial as we quickly begin progress on the substantial projects and activities we planned for Year 1 of the new cycle.

Welcome to a New Website !

To start off, MSRGN is proud to announce the release of the new website, which can be accessed at mountainstatesgenetics.org. Kristi Wees, both our Social Media Coordinator and an active consumer advocate, led much of its design, especially envisioning what resources are needed by families. Project Co-Director Janet Thomas gave important insight on the needs of clinician stakeholders. Sondi Aponte, with the Arizona Department of Health Services, was extremely helpful in her review of our resources for public health professionals. In addition, many of our members were very willing to give feedback on our site before its launch. We truly appreciate the work of all of those that have been involved. The new website is intended to be interactive and "live," meaning we will be updating it often and using it as a way to connect across our region.

MSRGN is still interested in receiving feedback on the newly launched site so we can continue to refine its layout and content. Please take a look around. Under our news, you can find a post titled [Come and Take a Look Around](#). This is a wonderful place to start and is intended to help re-orient our members to the new site.

Underserved Populations Project (UPP)

As you may recall, the goal of the UPP is to identify barriers in access to care at four initial sites (San Antonio, TX; Tuba City, AZ; Durango, CO, Grand Junction, CO), focusing on their unique underserved populations. Celia, Marilyn, Kristi, and our intern Grace have spent the last month analyzing demographic data at sites, finalizing both a family and provider questionnaire, and beginning interviews with families and providers. For those interested in reading a more comprehensive overview of the UPP, Grace developed a [wonderful presentation](#) with the MSRGN team.

This work though has not been accomplished without notable contribution from our membership. On July 27, we were joined by many long-time as well as new consumer advocates to discuss the UPP, getting feedback on overall design as well as the draft family questionnaire. This feedback allowed us to make several improvements to the questionnaire before its use. The clinics and providers in our regions have been immensely helpful as well. We've been fortunate enough to interview with Scott McLean and his colleagues (Children's Hospital of San Antonio), Steve Holve (Tuba City/HIS), and Janet Thomas and Austin Larson (Children's Colorado). We also have future interviews scheduled with some of our existing consumer members as well as families that have been identified through the work of the UPP.

State Team Progress

The MSRGN held its first webinar conference with our state team contacts on August 2, 2017. We were pleased to have at least one representative from each of our eight states. The meeting gave us the opportunity to present the goals for this funding cycle and discuss the role state teams would serve in accomplishing our proposal. Our initial work with our state teams will involve completing a unique "State Team Template" for each state. This template will help us understand the layout of each state (state programs, clinics, and family resource groups) with the goal of increasing their communication so they can effectively identify and help fulfill the needs of their states. The meeting presentation can be accessed [here](#). Again, our state teams will be comprised of members from all sectors. Please do not hesitate to reach out to MSRGN if you may be interested in serving on a state team.

Closing Thoughts

We would like to give our thanks to our members that have given their input and volunteered for current MSRGN activities. As always, we pride ourselves on being an open forum where all members have equal voice. Do not hesitate to reach out if you would like to lend your voice as we set the foundation for our region's future!

Warm regards,



Kathryn Hassell, M.D.
Project Director



Janet Thomas, M.D.
Project Director

MSGRC staff contact information:

Kathryn Hassell, Project Director
Kathryn.Hassell@ucdenver.edu

Janet Thomas, Associate Project Director
Janet.Thomas@ucdenver.edu

Marilyn Brown, Project Manager -303-477-1976
mbrown@mountainstatesgenetics.org

Joyce Hooker, Director of Social Outreach
jhooker@mountainstatesgenetics.org

Kristi Wees, Social Media Coordinator
kwees@mountainstatesgenetics.org

Liza Creel, Evaluator Liza.Creel@louisville.edu

Celia Kaye, MSGRC Consultant
Celia.Kaye@ucdenver.edu

THI staff contact information:

Camille Miller, Project Administrator
cmiller@texashealthinstitute.org

Sherry Wilkie-Conway, Project Oversight
swilkie@texashealthinstitute.org

Stephanie Sondrias, Events Manager
sondrias@texashealthinstitute.org

Website: www.MountainStatesGenetics.org

Acknowledgement

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under [Grant UH7MC30776](#), The Mountain States Regional Genetics Network.

This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.