



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

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November/December 2017



Dear friends and colleagues,

We hope this note finds you all well after the Thanksgiving holiday and as you prepare for the winter holidays, and ringing in 2018.

We could not be MORE THANKFUL for all of YOU, our friends, colleagues, consumers, practitioners, public health professionals, and family organization representatives! Without you, MSRGN would not be the thriving genetics network, it is today.

We have just completed the first 6 months of the new grant cycle and wanted to update you all on what is new in the Mountain States.

Saying Goodbye to Marilyn

First the sad news. After 3 years as project manager, Marilyn Brown has stepped down and is pursuing a new position in sunny Miami, Florida. We will surely miss her, and we thank her for her service to MSGRC and MSRGN over the past years. We ask that you join us in wishing Marilyn well! Recruitment is underway for a new project manager, and interviews are complete. Our hope is we will have the position filled and have that new individual in place by early 2018.

New Texas Health Institute Executive Director

Next the good news, a new Executive Director for Texas Health Institute has been named. THI serves as the fiduciary agent for MSRGN. Ankit Sanghavi will be taking over the role that was formally held by Camille Miller up until her retirement earlier this fall. We welcome Ankit and his leadership to THI and the MSRGN. You can read more about his background [here](#).

State Teams Meeting and Steering Committee January 2018 Meeting

Now the busy news. Planning is underway for a small State Teams & Steering Committee meeting in Austin, TX at the beginning of January. During this meeting, we will be convening a few members from each state team to continue the work of the new grant cycle, including expanding access to genetic services for underserved populations.

If you have a strong desire to be part of the state team structure for your state and want to volunteer to be a part of one of these state teams, please [contact us](#) so we can help facilitate your role in this new structure.

ACHDNC November Meeting

Last month was also the in-person meeting of the Advisory Committee on Heritable Disorders in Newborns and Children, which took place November 8 & 9. MSRGN was represented by Kathy Hassell and Joyce Hooker at the meeting. The major takeaways from the meeting included:

- Joshua Miller from NewSTEP's provided a current assessment of strategies states are taking as they work toward meeting newborn screening goals. It was good to hear most states are meeting the goals of 24

hours ideal, but 48 hours reality. The data and specific information via his slides will be available on the ACHDNC web site.

- The session on Implications of Detecting Carriers Through Newborn Screening identified a number of issues both pro and con on detecting carriers. Two points that flowed through the presentations were carrier screening should be disease specific and the best interest of the child is paramount.
- Dr. Alex Kemper presented an update on the SMA Evidence Review. The final report will be presented at the next meeting where a decision will be made by the Committee regarding addition of SMA to the Recommended Uniform Newborn Screening Panel.
- The 3 Workgroups Education and Training, Laboratory Standards and Procedures and Follow-up and Treatment continue to pursue tasks approved by the ACHDNC. Details will be available in the minutes on the ACHDNC web site.
- The archive of the meeting can be found [here](#).

Other News

Our Underserved Patient Populations Project is moving full steam ahead with implementation ideas being presented to our collaborators at the phase 1 sites including: San Antonio, Tuba City, Durango, and Grand Junction.

We have a number of telehealth and telegenetics programs underway in our region, and a few others that are just getting started in Wyoming, Arizona, Utah and Colorado.

In our consumer outreach, three of our members, Kristi Wees, Yolanda Sandoval-Nez and Susan Owens, attended the [Family Voices Conference](#) in Washington, DC in November. This year marked the 25th anniversary celebration of Family Voices, whose mission is: "to achieve family-centered care for all children and youth with special health care needs and/or disabilities."

Stay tuned to our [website's "News" tab](#) for more from our consumers who attended!

We wish all of you a Happy Holiday Season and a Happy New Year! We look forward to the accomplishments we will achieve together in 2018 for genetics in our Mountain States Region.

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

Vacant, Project Manager

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

Kristi Wees, Interim Project Manager/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:

Ankit Sanghavi, Project Administrator
asanghavi@texashealthinstitute.org

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

Stephanie Sondrias, Events Manager
sondrias@texashealthinstitute.org

**HAVE YOU VISITED OUR NEW
Website:**

www.MountainStatesGenetics.org

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