



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

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September 2017

Dear friends and colleagues,

We would like to start off this message by extending our thoughts towards those that were affected by Hurricane Harvey. The devastation to Texas was severe, although MSRGN was relieved to hear from both our genetics clinics and the Texas State Health Department Newborn Screening Program that they were able to continue operations. In the wake of Harvey, we will continue to keep Texas in our thoughts. We also would like our colleagues, families, and partners to know that MSRGN is eager to help in any way we can.

Resources from FEMA

Although extensive efforts are in place in the recovery from Hurricane Harvey, the Federal Emergency Management Agency (FEMA) has published [recommendations](#) for keeping children safe through the cleanup. The fact sheets can also be accessed directly on [FEMA's website](#) and are available in Spanish, Chinese, and Arabic as well as other languages.

National Coordinating Center (NCC) Annual Meeting

The MSRGN team recently traveled to DC for the Annual Meeting for the NCC and Regional Genetics Networks (RGNs). The meeting highlighted the goals of this funding cycle, creating regional networks that would increase access for rural and medically underserved populations.

As this was the first meeting of the new cycle, the beginning of the meeting was formatted as a learning collaborative, in which RGNs all presented on how they had defined and identified underserved populations in their region and by what methods regions would reach these populations. After

RGN presentations, discussion developed around the performance measures that will be submitted to HRSA and the common evaluation measures that will be coordinated across RGNs by NCC.

MSRGN is enthused with the early progress we have made through our partners. Many of the clinics in our region are already utilizing outreach and telemedicine clinics to increase access to genetic services in our region. As we have detailed in previous newsletters, Cook Children's Ft. Worth has multiple outreach and telemedicine sites throughout north and west Texas. Children's Colorado has been able to add services in Grand Junction and Durango and is also working with Indian Health Services (IHS) in Tuba City. Much of this progress is due to the efforts of Dr. Steve Holve in Tuba City. In addition, many genetics clinics in our region have been willing to share details on their clinic structure and size, patient demographics and catchment, and outreach. The ultimate goal of MSRGN is to interface and work with all clinics in our region to increase access for their underserved patient populations.

Camille Miller's Retirement

As many of you know, the MSRGN is administered by Texas Health Institute (THI), a public health institute and think tank led by President Camille Miller, MSSW. After many years of service, Camille has recently announced her retirement. MSRGN has appreciated her tremendous input and leadership on our activities over our previous cycles. While we will miss her, we all know her retirement is well deserved. The MSRGN will continue to be administered by THI, and we anticipate continued success with them.

Regional and National Updates

- A big thank you to Patricia Carroll, of the Utah Telehealth Network (UTN), for her years of service with our region. Patricia recently announced her retirement...while MSRGN will miss her, we are happy to see her enjoy retirement!
- NCC will be hosting returning and new workgroups in this cycle (telemedicine, data collection/evaluation, quality improvement, healthcare access/financing, and genomic education). As these workgroups develop, MSRGN will be working to pool resources from NCC with regional activities).
- If you haven't already, please check out the new MSRGN website at <https://www.mountainstatesgenetics.org/>.

Closing Thoughts

While trying to increase access throughout the region will be a challenge, it is exciting for an opportunity to have high impact in an area of high need. The early input and efforts already being made by clinics in our region makes us optimistic that our region is up for the challenge.

Warm regards,



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