



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

**February 2019**

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Dear Friends and Colleagues,

The MSRGN team would like to thank all the team members that attended the in-person State Team meetings in Austin on February 14-15, 2019. We love your willingness to spend your Valentine's Day with us! We appreciate all the hard work the State Teams are putting into their projects to help the underserved populations in their state.



(Janet Thomas, MD, Co-Project Director)

## State Team In-Person Meeting

Day one, February 14th, Co-Project Director, Janet Thomas, MD, discussed the MSRGN program priorities and goals. State Teams were able to work individually on their projects, in addition to pairing with other States to share ideas and current project challenges. We enjoyed crafting and networking over dinner as they all competed for the best decorated cut out of their state.



*(Texas State Team, Colorado State Team and Nevada State Team)*



*(Wyoming State Team, New Mexico State Team, Arizona State Team)*

Alisha Keehen, MPA, National Coordinating Center (NCC), presented, "Cross-Country Tour: Highlighting Exciting Projects from Across the NCC/NGEFSC/RGN System." Liza Creel, Ph.D., MPH, MSRGN Evaluator, gave an overview of the data that MSRGN has reported to NCC which was followed up by a discussion on regional QI Initiatives from Co-Project Director, Kathryn Hassell, MD. Kristi Wees shared information on Facebook live series "Your Genetic Questions Answered."

If you were not there in person and would like to listen to these presentations and State

Team report-outs, they are recorded and archived [here](#).

Photos from the event can be found [here](#).

Each State Team reported out on their Strategic Plan at the end of the second day.

#### Wyoming State Team

Wyoming currently offers both in-person and telehealth visits with the University of Utah Genetics Team, led by Nicola Longo, M.D. During a recent evaluation, the Wyoming team received feedback from patients, health department nurses and clinical staff about the need for, as well as acceptability and utility of, telehealth clinics in Cheyenne and Casper. In 2019, the team will add a clinic in Fremont County, a Central Wyoming county that is also the home of Wind River Reservation. They will continue to look at the data on patient satisfaction for one more year. The team will be working to expand outreach to local providers and public health nurses, as well as developing a system to connect genetic patients with resources in their community.

#### New Mexico State Team

The team would like to implement telegenetics clinics to extend access to genetic services for patients and families in rural, remote areas of New Mexico, including the tribal communities. The team applied for the "Healthy Tomorrows Partnerships for Children" grant for funding of telegenetics. Dr. Heidenreich, a genetics provider in New Mexico, will be attending the telegenetics training in Arkansas in April. The team will be working on building trust with the tribal and community leaders and address their needs for genetic services in their communities.

#### Arizona State Team

The team is aiming to work with the underserved in the Navajo reservation to provide more services in the area. Phil James, MD, has agreed to offer educational trainings to primary care providers in the Navajo area. The family home visiting program will be holding a training in Fall 2019, and the team is looking to provide information on resources available to them at this meeting. They will also be looking at ways to use interpreters on the reservation. With the assistance of the Early Intervention Program, the team will be working on updating its resources for families.

#### Colorado State Team

The team will provide education and resources to providers and families caring for individuals with genetic diseases through their ECHO Project at Children's Hospital and their consumer advocacy group. The ECHO Project series will address newborn screening and common diagnosis that are being seen by primary care providers throughout the state. Colorado will be working with Family Voices to create a "Fast FACT" sheet related to genetics in English and Spanish. They would like to develop a road map for families to navigate through the state team website and develop an acronym dictionary. The team has also developed a consumer workgroup.

#### Texas State Team

Texas will be looking to do outreach to school nurses, community clinics and nurse practitioners to provide resources on starting the genetic testing before a patient's first visit with a geneticist. The team is also using Facebook advertisement to draw more attention to the [Texas State Team page](#) on the MSRGN website.

#### Nevada State Team

Nevada had an in-person meeting in Reno in January to discuss their projects. Nevada is looking into the logistics and funding of a Project ECHO. The team will create and distribute a survey to families through Family Ties and Little Miss Hannah Foundation (LMHF) to get their experience on access to genetic testing in Nevada. The team will develop a postcard to promote the Project ECHO, list genetic testing laboratories, links and phone numbers for Medicare/Medicaid along with contact numbers for the geneticist in the state.

(note: Utah and Montana joined via zoom, so they have not gotten a chance yet to decorate their state cutout!)

### Utah State Team

Utah is looking to increase genetics services to the developmentally delayed population by providing guidance to primary care providers who can intervene more quickly during the time families are waiting to see a geneticist. The team has adapted and customized MSRGN's developmental delay algorithm for Utah and is collaborating with two Utah pediatric office to pilot its implementation.

### Montana State Team

Montana will have an in-state team meeting in February where they will be working on the plans for their project. The team's next project is to focus on consumers, providers and other interested parties to attend a conference using scholarships and incentives in exchange for the recipient to return to their communities and spread the word about genetics in Montana.

We hope everyone was able to take away ideas to further genetic services and other supporting resources in our region. We are thrilled and proud to support all the work being done in our region.

## Vote For The People's Choice Awards

At the meeting in Austin, a team building activity was completed by the teams in attendance. The teams decorated their state team cut-outs. Please vote for your favorite team's decorated state by Feb 28<sup>th</sup>. The Winner of the People's Choice Award for best-decorated state will be announced on March 1<sup>st</sup>.

Click [here](#) to vote (by "liking" your favorite photo on Facebook).

## GENETICS/GENOMICS ECHO Sessions

Heartland Regional Genetics Network is partnering with Missouri Telehealth Network and Show-Me-ECHO, to provide a series on genetic service delivery in primary care settings. For more information on these sessions and registration click [here](#).

### **May 9, 2019, 12-1 p.m.: "Caring for the child with multiple congenital anomalies (MCA): the lens of a medical geneticist."**

- Identify children with minor (and major) anomalies that warrant a genetics evaluation \* Initiate appropriate first-tier genetic testing on selected patients with minor and major anomalies.
- Explain first-tier testing to the patient's family.

### **May 23, 2019, 12-1 p.m.: "Newborn and infant hearing screening: when to act."**

- Explain the principle of 1-3-6 as promoted by the state's early hearing detection and intervention program.
- Identify local resources for evaluation of a child with suspected hearing loss.
- Trouble-shoot barriers to successful implementation of "1-3-6."
- Identify at least one change to incorporate into their practice.

## Funding Opportunity

CDC recent release of their newest funding opportunity for the Disability Research and Dissemination Center (DRDC). [The full announcement can be found on Disability Research Center \(RFA-2019-01\)](#). The closing date is March 4, 2019.

Project Title: Impact of Early Hearing Detection and Intervention (EHDI) on the Educational Costs and Placements of Hearing Impaired Children.

The research goals and objectives is intended to explore the academic placements, educational services and the cost of educating D/HH children before and after the widespread adoption of EHDI in the United States. The collection and analysis of data regarding the usage of varying types of educational plans and approaches (e.g., Individualized Educational Plans (IEP), 504 Plans, mainstream approach to placement, special individualized services provided to D/HH students) will be helpful in understanding the educational landscape. Similarly, the estimated costs associated with the various approaches, as well as best estimates of the overall costs of educating D/HH children before and after EHDI programs were established, should be compared and adjusted for inflation.

The second funding opportunity from the Disability Research and Dissemination Center (RFA-2019-02) full announcement can be found [here](#). The closing date is March 4, 2019.

Project Title: Impact of congenital CMV infection on neurodevelopmental and language outcomes of children with sensorineural hearing loss.

The research goals and objectives are intended to study the developmental and language outcomes of children with congenital CMV infection.

## MSRGN's First Facebook Live



The Facebook live event went live on January 23, 2019, featuring "Your genetic questions

answered about consumer advocacy."

Click [here](#) to listen to Heidi Wallis from the Association for Creatine Deficiencies for answering our first question: "How do you go about getting a researcher interested in studying a rare genetic disorder?"

## FOLLOW MSRGN ON TWITTER

MSRGN is now on Twitter. Please follow us [@GeneticMtnState](#)

## Email Communications from MSRGN

MSRGN is in the process of updating our contact list. If you would like to update your email preference or do not wish to receive communications from MSRGN, please email [Annette Lara](#).

Warm regards,



Kathryn Hassell, MD  
Co-Project Director



Janet Thomas, MD  
Co-Project Director

### **MSGRC staff contact information:**

Kathryn Hassell, MD, Co-Project Director

[Kathryn.Hassell@ucdenver.edu](mailto:Kathryn.Hassell@ucdenver.edu)

Janet Thomas, MD, Co-Project Director

[Janet.Thomas@ucdenver.edu](mailto:Janet.Thomas@ucdenver.edu)

Annette Lara, Project Manager

[alara@mountainstatesgenetics.org](mailto:alara@mountainstatesgenetics.org)

Joyce Hooker, Community and Public Health Outreach Coordinator

[dnjhooker@msn.com](mailto:dnjhooker@msn.com)

Kristi Wees, Consumer Engagement Director & Social Media Coordinator

[kwees@mountainstatesgenetics.org](mailto:kwees@mountainstatesgenetics.org)

Liza Creel, PhD, Evaluator

[Liza.Creel@louisville.edu](mailto:Liza.Creel@louisville.edu)

Celia Kaye, MD, PhD, Genetics Services & Systems Consultant

[Celia.Kaye@ucdenver.edu](mailto:Celia.Kaye@ucdenver.edu)

**THI staff contact information:**

Ankit Sanghavi, Project Administrator

[asanghavi@texashealthinstitute.org](mailto:asanghavi@texashealthinstitute.org)

Sherry Wilkie-Conway, Project Oversight

[swilkie@texashealthinstitute.org](mailto:swilkie@texashealthinstitute.org)

Stephanie Ondrias, Director of Convenings & Education

[sondrias@texashealthinstitute.org](mailto:sondrias@texashealthinstitute.org)

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Website:***

[www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)

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