



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

**June/July 2018**

**Join Our List.**

[Join Our Mailing List!](#)

Dear Friends and Colleagues,

Happy Summer! We have many activities going on in our region and we are looking forward to the second grant year, which started June 1, 2018. MSRGN is finishing up the final arrangements for our Genetics Summit. We are busy completing our annual MSRGN evaluation report, thanks to the assistance from our evaluator, Dr. Liza Creel.

**2018 Genetics Summit Registration Now Open!**

**Mountain States**  
REGIONAL GENETICS NETWORK

PRESENTS THE:

# 2018 GENETICS SUMMIT

ACCESSING GENETICS CARE  
IN OUR REGION

**OCTOBER 1-3, 2018**

COURTYARD  
SAN ANTONIO RIVERWALK  
207 N ST MARY STREET  
SAN ANTONIO, TX 78205

TO REGISTER & FOR MORE INFORMATION:  
[WWW.MOUNTAINSTATESGENETICS.ORG/EVENTS/GENETICS-SUMMIT/](http://WWW.MOUNTAINSTATESGENETICS.ORG/EVENTS/GENETICS-SUMMIT/)

**When:** Oct 2-3, 2018

**Where:** [Courtyard San Antonio Riverwalk](#)

**Registration fees: \$75 for CE's (CME, CNE, SW, or Genetic Counselors)  
\$50 non CE's**

**Registration:** Online [here](#)

**Agenda:** [here](#)

The **2018 Genetics Summit** will 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.

Listed below are two sessions that will be offered at the **Summit:**

**Underserved Population Project (UPP)**- Speaker: Janet Thomas, MD

First year activities to improve access to genetic services in four communities will be described. We will discuss the tools developed for needs assessment and genetics education in primary care practices. Early outcomes will be reviewed.

**Changes and opportunities: the role of medical genetics in the era of genomic testing**- Speaker: Austin Larson, MD

This session will discuss recent improvements in technology and implementation that have reduced the cost and turnaround time of genetic testing and increased the likelihood of finding a definitive diagnosis with testing. With these improvements have come changing roles for genetic counselors and medical geneticists in the care of patients with suspected genetic conditions and new approaches to the clinical application of genetic testing.

## State Team Spotlight: Colorado

Colorado had their first ECHO Lite on June 20th. For those of you not familiar with the ECHO program you can learn more [here](#). This activity introduced participants to the Mountain States Regional Genetics Network with the goal of making genetic services more accessible to patients, families and clinicians through online learning and consultation. This session covered some new developments in genetic diagnosis and treatment, and participants had the opportunity to shape the content of future sessions in terms of topics and presentation of case scenarios.

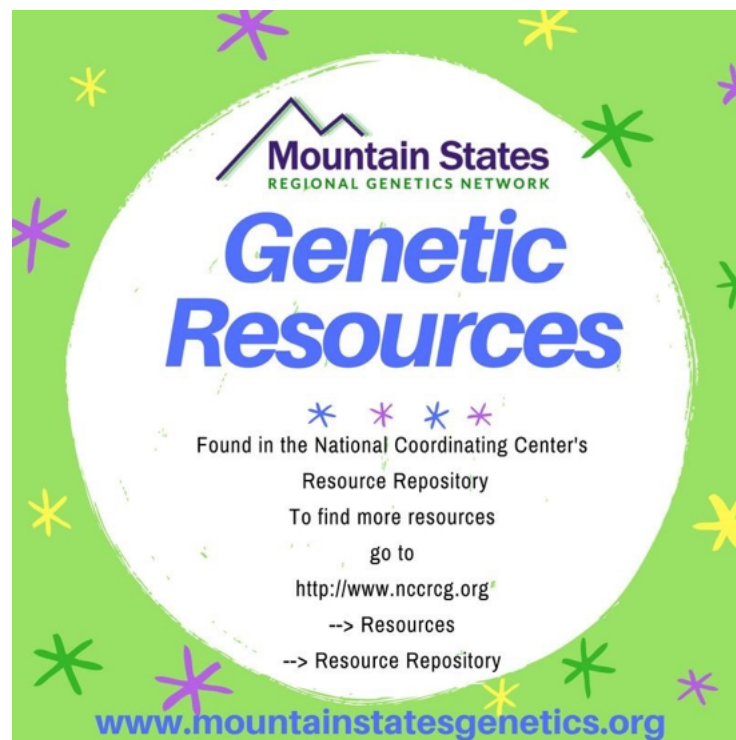
Upcoming ECHO session's will be on the MSRGN website.

The Colorado team also chose to purchase MSRGN magnets in both English and Spanish with their state team year 1 funding. They plan to distribute these to families and providers in Colorado. They may even share one with you if you ask one of the state team members really nicely at the Genetics Summit!

# Colorado State Team Magnets



## Facebook Post of the Month



This is a great resource for #newbornscreening! We found it in the [NCC's Resource Repository-](#)

The goal of the Newborn Screening Coding and Terminology Guide is to promote and facilitate the use of electronic health data standards in recording and transmitting newborn screening test results.

<https://newbornscreeningcodes.nlm.nih.gov>

## MSRGN Participates in Advisory Committee on Heritable Disorders in Newborn and Children (ACHDNC)

Joyce Hooker, MSRGN's Community and Public Health Outreach Coordinator, attended the Advisory Committee on Heritable Disorders in Newborns and Children meeting in Rockville Maryland at HRSA Headquarters May 9th and 10th. One focus of the meeting was two educational tools developed by the Education and Training Workgroup: a Communication Aid and an Educational Planning Guide. The Communication Aid will assist medical staff in talking to parents about a positive newborn screen. It is designed



to accompany the ACT sheets and has information on how to communicate the information to parents rather than what to communicate. The Educational Planning Guide will help with content for brochures and other educational materials. Other agenda items focused on cutoffs and risk assessment in newborn screening, and lessons learned in working on timeliness in newborn screening. Son-di Aponte presented on Arizona's experience, and an overview on assessing the public health system impact of adding conditions to the Recommended Uniform Screening Panel (RUSP). All the sessions contained practical and thoughtful information.

## Funding Opportunity for Newborn Screening State Evaluation Program

We are pleased to announce Health Resources and Services Administration's (HRSA's) recent release of their newest funding opportunity for the Newborn Screening State Evaluation Program. [The full announcement can be found on Grants.gov: \(HRSA-18-125\).](#)

This notice solicits applications for the Newborn Screening State Evaluation Program. The goal of the program is to reduce the morbidity and mortality associated with heritable disorders screened at birth. The purpose of this program is to evaluate the effectiveness of newborn screening programs by evaluating and assessing the effectiveness of screening, follow up, and referral to counseling or health care services. This will be accomplished by supporting state newborn screening programs in the implementation of a demonstration program to use quality indicator information, as determined by the HRSA-funded Newborn Screening Data Repository and Technical Assistance program (HRSA-18-080), to evaluate the effectiveness of their state newborn screening system. Quality indicators were created to provide longitudinal comparisons within newborn screening programs and to aggregate data at a national level. Quality indicators cover actions within the newborn screening system including assessing borderline results, eligible newborns, specimen collection, improper transport, and time of medical intervention. It is expected that the Newborn Screening Data Repository Technical Assistance program will be able to accept data into their data repository by September 2019.

## Submission Requested



**Mountain States**  
REGIONAL GENETICS NETWORK

**WANTED:**  
NEWS FROM YOU!

*We would love your  
submissions for this  
Newsletter!*

Events, Webinars, Grant Opportunities or Awards,  
Publications, Presentations, Posters, Promotions,  
Articles, Reports back from regional or national  
meetings, state team updates or any other news  
about #genetics in our Region!

Submit to:  
MSRGN Project  
Manager:  
alara@mountainstatesgenetics.org  
by the 10th of the  
month

We are always looking for NEWS from our members! That is you! If you have an event, webinar, state team update, recent publication, promotion or other "genetics" news you think that our Mountain States region would benefit from knowing about, please send it to us! Our newsletter deadline is the 10th of each month, so please send submissions to our: Project Manager, Annette Lara [alara@mountainstatesgenetics.org](mailto:alara@mountainstatesgenetics.org)

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 Events & Education

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

**HAVE YOU VISITED OUR NEW  
Website:**  
[www.MountainStatesGenetics.org](http://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.*