



Mountain States

REGIONAL GENETICS NETWORK

February 2022

MSRGN Project Directors' Message



Love is in the air!



Mountain States
REGIONAL GENETICS NETWORK

Love is in the Air
at MSRGN...

We Love our Advisory Committee
We Love our State Teams
We Love our Genetic Navigators
We Love our Genetic Ambassadors
We Love our Time 4 Genetic Clinics
We Love our Genetic Pop-Up Promoters
We Love our fellow Regional Genetics
Networks
We Love our MSRGN Event Attendees
We Love our National Partners
We Love our Funder: HRSA...
We Love each and every one of YOU
who reads this newsletter each and every
month!

If you would like to get more involved in some of the programs above, contact us for more info.

Sending our **LOVE**
and appreciation to you,
from all of us at
Mountain States Regional Genetics Network



HRSA/RTI GENETICS SYSTEM LISTENING SESSIONS

On behalf of the Health Resources & Services Administration (HRSA), RTI International invites you to participate in a [virtual listening session](#) to identify unmet needs in accessing the [genetics system](#) of care and current strategies being used to address those needs, especially for underserved populations. The results of the listening session will be used to develop innovative ideas and solutions to meeting the needs of the genetics system of care and to inform future HRSA-funded program activities.

Each session will last approximately 90 minutes and will include opportunities for both discussion and anonymous feedback. Please come prepared to participate and share! Participants will receive a \$50 Amazon gift card as a thank you.

Please click on the links below to register in advance for the session that aligns with your role in the genetics system of care.

We encourage you to register early, as the number of attendees is limited for each session. Once you have registered, you will receive a confirmation email including a link to the Zoom meeting.

Geneticists and genetic counselors:
February 17th 2:30pm-4:00pm ET (already over)

Non-genetics specialists and primary care providers:
February 22nd 11:30am-1:00pm ET
[REGISTER HERE](#)

Families, patient advocacy groups, and other family representatives:
February 23rd 12:00pm-1:30pm ET
[REGISTER HERE](#)

Public health genetics professionals:
February 24th 3:30pm-5:00pm ET
[REGISTER HERE](#)

Topics we will cover include:
Unmet needs of the genetic system of care
Barriers that exist in meeting those needs
Current strategies being used to meet those needs
Additional new innovative solutions to meeting unmet needs

If you have any questions, you may reach out to Becca Wright at rwright@rti.org. Thank you in advance for your participation.

**Join our sister region:
Midwest Genetics Network
for a new, no fee**



Meet our Utah MSRGN Genetic Navigator Tristin West

Before Tristin West was the mother of Jayson (9) and Cozette (4), she was focused on big career dreams and collecting college degrees (2 master's in Language and Teaching). Her dreams changed when her son Jayson was born (2011), but her acquired determination, persistence and research skills were helpful when navigating Jayson's rare, complex health conditions, several brain and cranial surgeries, medications and many therapies. Jayson's genetic diagnosis was labeled "unknown" for years due to the many barriers that keep patients from getting answers; but with the help of Tristin's research, connections, resources, determination and a whole lot of patience, Jayson got a diagnosis-- MCTT Syndrome (MN1 C-terminal Truncation). Tristin loves to help families tell their stories, overcome barriers, know their resources, make connections and recognize what is in their control as they navigate their own diagnostic journey.

Check our Tristin's Introduction Flyer
[HERE](#)

You can email Tristin here:
utahgenetic@gmail.com

Continuing Education Learning Activity

Patient-Centered Newborn Screening Communication

This activity is a multi-state virtual learning collaborative to connect clinicians and their clinic staff interested in improving documentation of Newborn Screening (NBS) test results, communication with parents, and making appropriate referrals.

The project can be completed in 4 months (March 2022-July 2022).

This activity has been approved for 25-Pediatric MOC4 points, 20-Family Medicine Performance Improvement points, 3 - Pediatric MOC2 credits and has been approved for *3.00 AMA PRA Category 1 Credit™*.

All activity must be completed by July 1, 2022. There is **no charge** for participation in this HRSA-funded project.

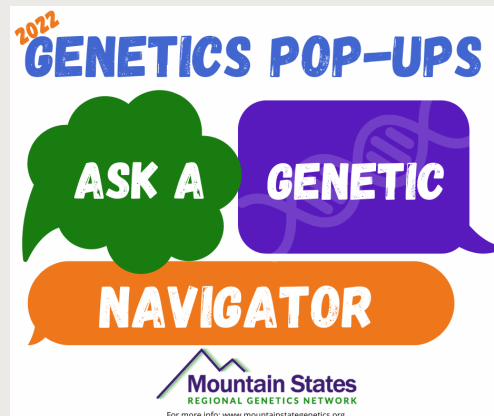
[More Information
Here](#)

COLORADO SURVEY!

Help out our friends at the Center for Public Health Innovation (CPHI) at CI International, in collaboration with the Colorado Sickle Cell Treatment and Research Center who received CDC funding to better understand the epidemiology and health care utilization patterns of sickle cell disease through a statewide surveillance system for individuals of all ages with sickle cell disease. As part of this effort, the grant team is gathering baseline sickle cell knowledge data from the community. All are invited to complete this short [online assessment](#). Respondents will be entered into a drawing for a \$25 gift card. For questions, contact [Yvonne Kellar-Guenther](#).

[Take Sickle Cell Assessment
HERE](#)

HELP US SPREAD THE WORD:
Genetic Pop-Ups are
Next Week
(March 3rd, 4th, 5th)



2022 Genetics Pop-Ups

join us for
3 Region-Wide VIRTUAL Genetics Pop-Ups
Topic: Ask A Genetic Navigator!

Evening

Thursday, March 3, 2022

6:30pm PT/ 7:30pm MT/ 8:30pm CT/ 9:30pm ET

[Register HERE](#)

Daytime

Friday, March 4, 2022

Interpretación en español disponible

9:30am PT/ 10:30am MT/ 11:30am CT/ 12:30pm ET

[Register HERE](#)

Weekend

*ASL Interpreting and Live Transcript available
(in partnership with Arizona Hands & Voices)*

Saturday, March 5, 2022

9:30am PT/ 10:30am MT/ 11:30am CT/ 12:30pm ET

[Register Here](#)

Download ENGLISH Pop-Up flyer to share

Download SPANISH Pop-Up flyer to share

Genetics Pop-Up Registration Page
(English)

Genetics Pop-Up Registration Page
(Spanish)

Acknowledgement of Funding

This publication is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$600,000 with 0 percentage financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

The MSRGN Management Team

MSRGN staff contact information: (click on name for email address)

- Kathryn Hassell, MD, Co-Project Director
- Janet Thomas, MD, Co-Project Director
- Kristi Wees, Projects Manager
- Liza Creel, PhD, Evaluator
- Cody Price, State Teams Coordinator

THI staff contact information: (click on name for email address)

- Ankit Sanghavi, Project Administrator
- Sherry Wilkie-Conway, Project Oversight
- Stephanie Ondrias, Director of Convenings & Education



Mountain States Regional Genetics Network
512-279-3910

www.MountainStatesGenetics.org

[View as Webpage](#)

Connect with us



