

August 2023

MSRGN Project Directors' Message

Back to School: Genetics & Education



Hello Mountain States members-

In August, Janet Thomas, our co-project director, attended the NCC Project Managers and Directors Annual meeting in Washington DC, while Kathy Hassell (co-project director), Kristi Wees and Liza Creel attended via zoom.

At that meeting the RGN system learned about some updates that we would like to pass along to our members, collaborators and long time partners:

It has been communicated to the regional genetics networks, NCC and Family Center that the HRSA funded RGNs (including MSRGN) as we know them to exist today, will not exist in the same format/system beyond 5/31/24. Other grant opportunities may be available to continue pieces or parts of our work. We welcome input from MSRGN members about other opportunities for funding or partnerships for our various programs.

In the meantime, we currently have funding through 5/31/24 and program objectives from HRSA that MSRGN is committed to complete. Hence, we appreciate your continued commitment to MSRGN and our important work. We remain committed to completion of the projects started by the state teams, and to the other programs and activities such at Time 4 Genetics, the Genetic Navigator Program and the 2023 Genetics Summit, that are in place for the 2023-2024 grant year. In addition, we will facilitate conversations about sustainability beyond MSRGN.

If you have further questions, please contact Kristi Wees (kwees@mountainstatesgenetics.org) and she will take your questions back to the MSRGN Management Team for a response.

Thank you for your understanding and grace as we work through next steps and answers to your "what's next?" questions and ours.

the MSRGN Management team

Speaker Spotlight



Genetic Summit 2023 Registration

Genetics Summit 2023

October 11th & 12th

This Year's Theme...

PEAK Performance

Register now for our October 11-12th, 2023 MSRGN Genetics Summit: **PEAK Performance**:

P- Primary Care and Genetics:

Lauren Treat, MD

Promoting Personhood and Perspective

E- Emotional Perspectives of Genetics:

Amy Gaviglio, MS, CGC Kelsey Sala-Hamrick, PhD Jessica Scott Schwoerer, MD Trauma Informed Care in the Genetics Clinic

A- Access to Genetics Care for Underserved Populations:

Emily Magness, MS, CGC Lauren Westerfield, MS, CGC Creative Strategies to Access Genetic Care Across Genetic Counseling Disciplines

K- Karyotypes to Knockouts (Genetic Testing /Research):

Melissa Haendel, PhD Data Driven Approaches to Define Rare Disease Genetic Summit 2023 Registration





REGISTER TODAY for the upcoming Webinar: Seizures and Genetics





JOIN US FOR THE TIME 4 GENETICS WEBINAR:

THE GENETICS OF PEDIATRIC SEIZURES AND EPILEPSY



September 26, 2023
(at 11am PT, noon MT, 1pm CT, and 2pm ET)



Guest Presenter:
Amanda G. Sandoval Karamian, MD
Assistant Professor of Pediatric
Neurology & Epilepsy
University of Utah | Primary
Children's Hospital

MSRGN's <u>Time 4 Genetics</u> Initiative is a primary care provider genetics education program focusing on pediatric genetic topics.

Register Here

this initiative 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 \$600,000.00 with 0 percent financed with non-governmental 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.



In support of improving patient care, this activity has been planned and implemented by Mountain States Regional Genetics Network and Projects In Knowledge®. Projects In Knowledge is jointly accredited by the Accreditation Council for Continuing Medical Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

MSRGN is inviting you to our Time 4 Genetics Webinar:

The Genetics of Pediatric Seizures and Epilepsy

September 26, 2023 at 11am PT, noon MT, 1pm CT, and 2pm ET

featuring Guest Presenter:

Amanda G. Sandoval Karamian, MD
Assistant Professor of Pediatric Neurology & Epilepsy

University of Utah | Primary Children's Hospital

To register please click: here and to download a pdf flyer to share click here

Register for Webinar

Back to School Resource:

Genetic Education Materials for School Success from our sister-region <u>NERGN</u>:

GEMMS

GEMMS Website Here

Roundtable on GENOMICS and PRECISION HEALTH

from the National Academies of Science
Next-Generation Screening —
The Promise and Perils of
DNA Sequencing of Newborns at Birth:
A Workshop

held on June 7, 2023

Watch Recording here

Back to School...

time to brush up on your

Genetics Education

and earn free Continuing Education Credits

Click on the links below to access free Continuing Education Credit (CME and CEUs):

Past Genetic Summit:
Genetics Summit 2021
Genetics Summit 2022

Time 4 Genetics Webinars:

Developmental Delays

Ehlers Danlos Syndrome (EDS)

Genetic Testing

Autism

Cerebral Palsy

Newborn Screening

Our <u>Projects Coordinator</u> position is still open.

Texas Health Institute is seeking a projects coordinator to provide administrative support for the Mountain States Regional Genetics Network project.

The projects coordinator must have strong business acumen and organizational skills, website management skills, excellent verbal and written communication skills, and social media experience is helpful.

If you know anyone in our region who might be interested please have them reach out to **Kristi Wees** or apply below.

Apply Here



Family Survey from the Family Center

The National Genetics Education and Family Support Center (**Family Center**) at **Expecting Health** is conducting a survey to gather feedback

from Family Leaders about your journey in this role, understanding the responsibilities you have, opportunities this work has provided (for you/your family, your local community, and the larger genetics healthcare delivery system), and what matters to you as a Family Leader to be meaningfully engaged; how is it going and are you getting what you need.

Who should respond to the survey? Any and All Family Leaders! Family Leaders are individuals who participate actively in their own health care and the care of others, raise awareness in the community, share their story with others, and advocate for a cause, OR are interested in learning more for themselves and their family members and sharing that information.

Your response is important to help the Family Center further understand what family leaders need along their journey to support your participation in advancing the system of care. This information will also inform the Family Center's decision-making by helping them plan future initiatives.

Please access the survey here (https://www.surveymonkey.com/r/39PM2YS).

The survey may take 10-15 minutes to complete

At the end of the survey, you can choose to be entered into a drawing for one of twenty \$50 Amazon gift cards that will be given away. If you have any questions or need special accommodations to participate, please contact Vicki Hunting at vhunting@expectinghealth.org.

Take Family Survey here

State Team Corner What's ROCK'n in Arizona?



Each month we will be highlighting a project or resource created by one of our state teams that is ROCK'n the MSRGN Region.
This month we are highlighting:

ARIZONA

The Arizona team's Year 6 State Team project included printing Red Flags 4 Genetics, the MSRGN Developmental Delay Algorithm and other materials to share with pediatricians in Arizona at the AZAAP's Pediatrics in the Red Rocks conference.

State team co-lead, Fran Altmaier (pictured above), attended in July 2023 and answered questions and shared <u>Arizona State Team Web Page</u> resources while also encouraging attendees to attend the <u>Genetics Summit 2023</u>.

Go Team Arizona!

To learn more <u>here</u>.

If you live in the mountain states and are interested in getting involved in the state team in the state where you live, please reach out to our state teams coordinator, <u>Jamie Stefanski</u> or fill out this form <u>here</u> and note your interest in the <u>state teams</u> in the

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The MSRGN Management Team

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- Kristi Wees, Projects Manager
- Liza Creel, PhD, Evaluator
- Jamie Stefanski, State Teams Coordinator
- Open Position Projects Coordinator

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