

September 2022 **MSRGN** Project Directors' Message



Dannah Raz, MD, MPH Phoenix Children's



Matt Fickie, MD, FACMGG **Highmark**, Inc.



Andrea Shipley, MPA

Wyoming Telehealth

Network

Don Bailey, Ph.D. **RTI International**

MSRGN GENETICS SUMMIT 2022

MOMENTUM IN THE MOUNTAINS

Register Now



Iountain States

Register Now for the Genetics Summit 2022

The MSRGN Genetics Summit is a virtual summit to educate, engage, and connect families, providers, and public health professionals around contemporary topics in genetics.

Featured Speakers:

Momentum in the...

M - Dannah Raz, MD, MPH, Phoenix Children's Hospital

Down Syndrome: Birth and Beyond O - Matt Fickie, MD, FACMGG, Highmark, Inc. Insurance Coverage of Genetic Testing U - Andrea Shipley, MPA, Wyoming Telehealth Network What the Public Health Emergency Has Taught Us About Sustaining Telehealth

NT - Don Bailey, Ph.D., RTI International Early Intervention and Newborn Screening

> The theme of this year's Genetics Summit: Momentum in the MOUNTains will feature 4 topic areas:

> > Medical Diagnosis and Research

Outreach and Resources

Underserved Populations

N&T

Newborn Screening and Transitions to Adult Medical Services

MSRGN is pleased to present the <u>agenda</u> for the 2022 Genetics Summit and <u>registration</u> is OPEN.

Register Now for the Genetics Summit 2022

MSRGN Launches <u>Genetic</u> <u>Connections:</u>



Autism: What Can Genetics Tell Us? Guest presenter: Naomi Meeks, MD September 22, 2022

Did you miss our Autism & Genetics Webinar last week?

No worries, you can watch the recording <u>here</u> (and still claim CME/CEU for watching the recording!) Please help us share this valuable resource by forwarding this newsletter to 3 of your colleagues!

A big thanks to Dr. Meeks for presenting this webinar in such an easy to understand format!

"The information was so well presented and easy to follow and understand. I have been apart of other genetic webinars on similar/ same topics and this was by far the best." --- Participant at the MSRGN Time 4 Genetics Autism Webinar 9/22/22

Watch the Webinar Recording Here

Have you missed any of our other Time 4 Genetics Webinars? The recordings can all be found at the links below:

Time 4 Genetics Webinar Archive

Red Flags 4 Genetics

<u>A Workshop for</u> Early Intervention <u>Providers</u>



A Workshop for Early Intervention Providers



Mountain States Regional Genetics Network is pleased to offer a new workshop for Early Intervention Professionals called <u>Genetic Connections.</u> This workshop can be delivered in-person or on Zoom as a two hour training, two 60-minute trainings, or four 30-minute trainings.

The four modules are:

Module 1: The Who and Why of Genetics? Module 2: The Vocabulary of Genetics Module 3: Four Family Case Studies Module 4: Red Flags and Next Steps

We are excited to offer this training free of charge to early intervention rofessionals in a group setting in our 8 state region.

This training will be conducted by our Project Manager, Kristi Wees, and 5 of our Genetic Navigators who have been trained to deliver this workshop.

If you are an early intervention professional in the states of Arizona, Colorado, Montana, Nevada, New Mexico, Texas or



(May 2021)

Developmental Delays (September 2021)

<u>Ehlers Danlos Syndrome</u> (EDS) (January 2022)

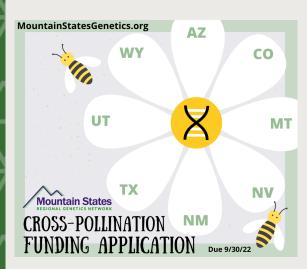
Genetic Testing (May 2022)

<u>Autism</u> (September 2022) Utah and are interested in hosting a training for your group of 10 or more individuals, please <u>fill out this</u> <u>form</u> and we will be in contact with you to get more details on your group.

To download a flyer about this training click <u>here</u>.

Fill out this form to request a Free Training for Early Intervention Professionals

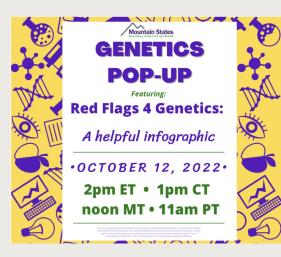
Cross-Pollination Application Deadline DUE 10/31/22



DEADLINE is FAST APPROACHING....

For year 6 of the grant cycle, this NEW funding opportunity is available for ANYONE in the mountain states region (AZ, CO, MT, NV, NM, TX, UT, WY) who has an idea they would like to submit which improves access to genetics services.

This funding opportunity will



Genetics Pop-Up: Red Flags 4 Genetics October 12, 2022

Calling all families and individuals interested in learning more about genetics.

Join us to learn more about genetics! Experience a safe arena to ask questions, learn about resources such as the <u>Red Flags 4</u> <u>Genetics Handout</u> for families and connect with others who have explored genetics for their own loved ones.

At this virtual event on October

prioritize submissions where individuals from 2 or more of the states in our region are collaborating together on a project... since the focus is cross-pollination in our region!

The deadline to submit the application HAS BEEN EXTENDED UNTIL October 31, 2022

> Cross Pollination Funding Application

12, 2022 MSRGN will be sharing our <u>Red Flags 4 Genetics</u> <u>Handout</u> for families and providers! You won't want to miss learning about this valuable resource about some of the red flags that may be associated with a genetic diagnosis.

Wednesday, October 12, 2022 2pm ET • 1pm CT • noon MT • 11am PT Register to join us <u>here</u>. PDF Flyer to share <u>here</u>. Graphic to share on social media <u>here</u>.

> Register for Genetics Pop-Up Here

State Team Accomplishments & Momentum



Each month we will be highlighting the projects and accomplishments of our state teams. This month we are highlighting:

WYOMING

Click <u>here</u> (or on the image above) to take a closer look at the Wyoming State Team's accomplishments

infographic.

This is a graphical summary of some highlights from Years 4 & 5 of this grant cycle and also what momentum the team is building on for year 6! To learn more about the Wyoming State Team check out their updated team page <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 state teams in the "Why are you interested in connecting with MSRGN?" box.

SERN SERN GENETICS NETWORK

From our sister region: Please join the Southeast Regional Genetics Network (SERN) for their next Lunch and Learn, via Zoom

> THIS Friday September 30, at 12 pm ET. Speaker: Christine Matus Founding Attorney The Matus Law Firm Topic: Long-term Care Planning for Children with Complex Healthcare Needs



Long-term Care Planning for Children with Complex Healthcare Needs

> Register HERE

Acknowledgement of Funding

Christine Matus

Founding Atrorney

The Matus Law Grour

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Aountain States Regional Genetics

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