

October 2022

MSRGN Project Directors' Message

Featured Speakers



David H. Viskochil, MD, PhD University of Utah Health



Vence L. Bonham, JD National Human Genome Research Institute, National Institutes of Health



Sikha Singh, MS, PMP Association of Public Health Laboratories



Jenn Banna, Mom Montana Family to Family Health Information Center



Jamie Stefanski, PT Mountain States Regional Genetics Network



Elizabeth Reynolds, PhD RTI International

MSRGN GENETICS SUMMIT 2022

MOMENTUM IN THE MOUNTAINS

Register Now

NOVEMBER 9-10, 2022

Mountain States

Register Now for the Genetics Summit 2022

The Genetics Summit is 2 Weeks Away!

Please forward this newsletter to 3 individuals and personally invite them to the MSRGN 2022 Genetics Summit!

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 - David H. Viskochil, MD, PhD, University of Utah Health Implementation of Sponsored Clinical Trials by Genetics Providers

O - Jamie Stefanski, PT & Jenn Banna, MSRGN Genetic Navigators While You Are Waiting for a Genetics Appointment

U - Vence L. Bonham, JD, National Human Genome Research Institute

Advancing Health Equity Requires Examining the History of Genetics

N&T - Sikha Singh, MS, PMP, Association of Public Health Laboratories

State of Newborn Screening in the Mountain States: A NewSTEPs Summary

& Elizabeth Reynolds, PhD, RTI International Early Intervention and Newborn Screening

The theme of this year's Genetics Summit:

Momentum in the MOUNTains

will feature 4 topic areas:

M

Medical Diagnosis and Research

C

Outreach and Resources

U

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



Please join me in welcoming our 2 newest Genetic Navigators:
Kristina Hone (Utah) and Desirée Maddux (New Mexico) and saying goodbye and thank you to Melody Rupple our Wyoming Genetic Navigator who has moved with her family to Ohio and this had to step down from her WY role.

The application is **OPEN** for our Wyoming Genetic Navigator position with a due date of 11/15/22. Please click the button below to apply and please share with any families or individuals who might like to apply in WYOMING!

Apply for Wyoming Genetic Navigator Role Here

Time 4 Genetics Webinar: Cerebral Palsy



January 2023
Time 4 Genetics Webinar:

New discoveries in the evolving world of genetics: diagnosis and treatment of cerebral palsy

January 10, 2023 (at 11am PT, noon MT, 1pm CT, and 2pm ET)

Guest Presenter: Michael C. Kruer, MD

Associate Professor of Child Health, Genetics, Neurology and Cellular & Molecular Medicine at the University of Arizona College of Medicine–Phoenix





MEET THE NEW MSRGN
NEW MEXICO & UTAH GENETIC NAVIGATORS:
DESIRÉE & KRISTINA

www.MountainStatesGenetics.org

Welcome Kristina and Desirée!

Kristina can be reached at <u>utahgenetic@gmail.com</u> and Desirée can be reached at <u>newmexicogenetic@gmail.com</u>

They both have completed their 5 hours of Genetic Navigator training and are all set up on email and ready to connect with families in their state. In the next few months they will be joining their state team's call to meet you all. Drop them a quick email and welcome them to the MSRGN team!

Email Desirée

Email Kristina

Director of the Pediatric Movement Disorders Program at the Barrow Neurological Institute, Phoenix Children's Hospital

Register for Cerebral Palsy Webinar Here



Did you miss it?

Red Flags 4 Genetics Genetic Pop-Up Watch here on <u>Facebook Live</u>

Please <u>listen</u> to Colorado Co-Lead: Brittany Parke and Montana Genetic Navigator: Jennifer Banna's powerful stories and how the <u>Red Flags 4 Genetics</u> handout has impacted them.

New MSRGN
Early Intervention
Workshop
Available!



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

Fill out this form for more information on this workshop



Did you miss it?

Watch the GENETICS EXPLAINED: Variants of Uncertain Significance (VUS) video <u>here!</u>



It's TIME 4 GENETICS...

Applications for Cohort #3 are due 1/15/23

Our goal is to reach 40 clinics in our 8 state region with our Time 4 Genetics Primary Care Genetics Education Initiative. We need all of your HELP to reach this goal!

Clinic Commitment- one hour each month from someone at the primary care clinic (nurse, care coordinator, PA, doctor, office manager) to take <u>Time 4 Genetics</u> (to learn about genetics) with MSRGN.

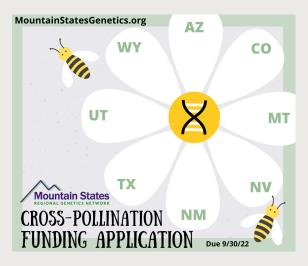
We are now accepting applications for our final cohort (#3) of this funding cycle. We have 20 openings for 20 primary care clinics across our region to apply and join us for Time 4 Genetics (beginning in March 2023 with the application due on January 15, 2023).

Please share this <u>short video</u> overview of Time 4 Genetics and <u>the application</u> with any clinics in

our region who would like to take part in this initiative! <u>Kristi</u> is available to speak with any clinics who are interested and would like more info.

Apply here for Time 4
Genetics

Cross-Pollination Application Deadline DUE 10/31/22



DEADLINE is just a few days away...

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 with priority to 2 or more state working together on an application.

More information about this opportunity can be found here.

The deadline to submit the application is

October 31, 2022

Cross Pollination Funding
Application

State Team Accomplishments & Momentum



All about the

Montana State Team



2020-2022

Year 4: 2020-2021

The Montana team purchased 2 computers and one tablet for Montech to lend out as part of their MT -wide lending library, for families to utilize for telehealth and telegenetics





Year 5: 2021-2022

Genetics Pop-Ups in Montana in collaboration with Early Intervention Providers across the state in each region. The three 2022 MT Genetics Pop-Ups had







Montech Year 5 Lending of Telehealth Equipment

With items purchased with Montana state team funds in year 4, MONTECH lent out the ipad and laptop computers to 10 families in 10 zip codes across Montana in year 5



The Montana state team updated their website in 2022 to feature their partnership with Montech

Momentum...stay tuned

The Montana team used a few state team dollars they had extra in their budget to purchase 96 MSRGN plastic tubmlers to be distributed at the MT AAP meeting in the fall.



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

MONTANA

Click here (or on the image above) to take a closer look at the Montana 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 Montana State Team check out their updated team page here.

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.

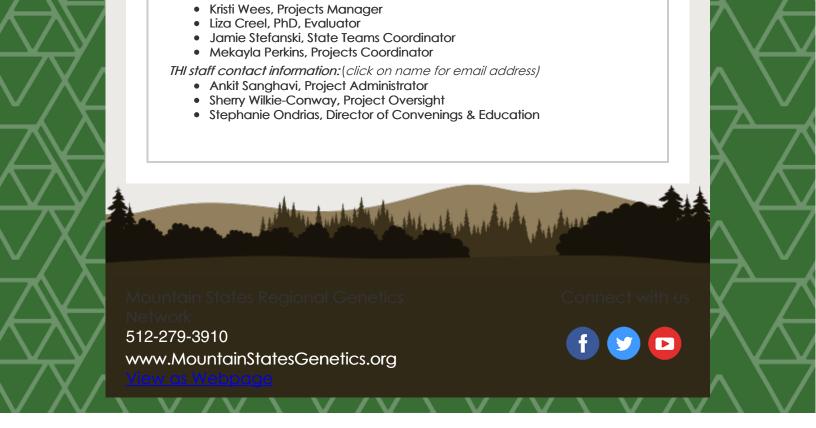
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The MSRGN Management Team

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