

February 2023

MSRGN Project Directors' Message

MSRGN ♥'s Genetic Caregivers!



February is the month where LOVE is in the air!
This year we wanted to share a special shout out to all the
GENETIC CAREGIVERS

in our region.

Those caregivers come from all walks of life and wear all sorts of hats. Some are parents, foster parents, grandparents, aunts, uncles, and even those who may not share any DNA but are connected by the heart. Often they wear the hats of medical assistant, head dietician/nutritionist, transportation coordinator, appointment scheduler, insurance coverage guru, and #1 advocate for those they care for, with love.

Sometimes caregiving can seem like an invisible role.

At MSRGN, we want to say 'we see you' and commend you for your

commitment to Genetics Caregiving.

Take a peek at <u>this news story</u> from one of our Genetic Ambassadors in Colorado, Mariah, who shares the joys and her family's daily routine of genetic caregiving for her 2 sweet girls.

To learn more about genetic caregiving, please explore this 2017 study and resources here.

To listen to Mariah's presentation at our 2021 Genetics Summit click here.

And to learn more about Family Voices Colorado (mentioned in the clip) click <u>here</u> or to find the Family Voices group in your state, click <u>here</u>.

Sending our 💙

to all caregivers in our regionfrom the MSRGN Management team

Good-Bye to Mekayla and a Job Opening

Mekayla Longoria, our projects coordinator for MSRGN, has moved onto another job opportunity and her last day was 2/10/23. We wish her well and thank her for her contributions to MSRGN and THI.

Due to her departure, we now have an open role for a part-time virtually based (but with Texas residency) projects coordinator. We encourage you to share <u>this link</u> with any colleagues you may know in Texas who might be interested in this role or who might be able to share it on job boards in Texas.

Thank you for your help in finding our next projects coordinator for MSRGN. To apply, click the <u>link here</u> or button below and follow the instructions on the projects coordinator job description.

Projects Coordinator Job Description (TX residents only)



Genetic Connections Update

In January and February, MSRGN Genetic Navigators who were trained facilitators, held 6 <u>Genetic Connections Workshops</u> for over 150 Early Intervention Professionals in Colorado, Nevada, and Utah. More workshops are scheduled for CO, NM, UT, and NV in the coming months as we complete this year 6 pilot of this training. If you are in the states of Arizona, Texas, Montana or Wyoming and would like to schedule a workshop, please fill out the form below for more info.

To request more info or schedule a workshop

Did you miss our Rare Disease Day Genetics Pop-Up?

If you missed our Genetics Pop-Up for Rare Disease day last week, you can catch the replay on Facebook Live below.

Rare Disease Day Genetics Pop-Up
Recording

Our next Genetics Pop-Up will be for DNA Day and will be held on April 24, 2023.

Registration is OPEN here.

Register for the DNA Day Genetics Pop-Up



2023 Genetics Workforce Survey is Now Live!

Partnering with:









Check your inbox from your membership/certification organization to complete this important survey today!

Genetic Workforce Survey

Are you a geneticist, metabolic dietitian, genetic nurse, or genetic PA in the U.S.?

The <u>National Coordinating Center</u> has released its 2023 Genetics Workforce Survey in partnership with the ABMGG, GMDI, ISONG, and SPAGG. This survey provides vital information about the capacity of the genetics workforce.

Make sure your voice is heard by checking your inbox from one of the partner organizations to complete the survey today!

State Team Accomplishments & Momentum



All about the New Mexico State Team

2020-2022



Year 4: 2020-2021

The New Mexico team in partnership with Hero's Path Palliative Care, planned 2 respite events for families in Farmington and Taos to be held in Year 6 utilizing the year 4 state team funds of \$1200.





Year 5: 2021-2022

The New Mexico team decided to print and distribute the MSRGN Ehlers Danlos algorithm (EDS) and checklist to PCP clinics in New Mexico. Their state team Year 5 funds went to the printing of the materials.

Diverse Representations and Partnerships

The New Mexico team is proud to highlight their state team members from various backgrounds, both personally and professionally. They are thankful for the partnerships which have allowed them to have a state team project focused on families in underserved communities such as Taos and on the Navajo Reservation and look forward to continuing and growing these partnerships in the future years.







www.MountainStatesGenetics.org/NewMexico

State Team Webpage

The New Mexico team updated their website in 2022 to feature the EDS Algorithm that they are distributing state wide to PCP /NewMexico clinics as their team project.

Momentum...stay tuned

The New Mexico team in conjunction with Hero's Path, will be holding a rescheduled respite event for families in Taos in year 6. Due to family emergencies, the original date had to be cancelled for the event and rescheduled.



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

This month we are highlighting:

NEW MEXICO

Click <u>here</u> (or on the image above) to take a closer look at the New Mexico's 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 New Mexico 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, Jamie Stefanski or fill out this form here and note your interest in the state teams in the "Why are you interested in connecting with MSRGN?" box.

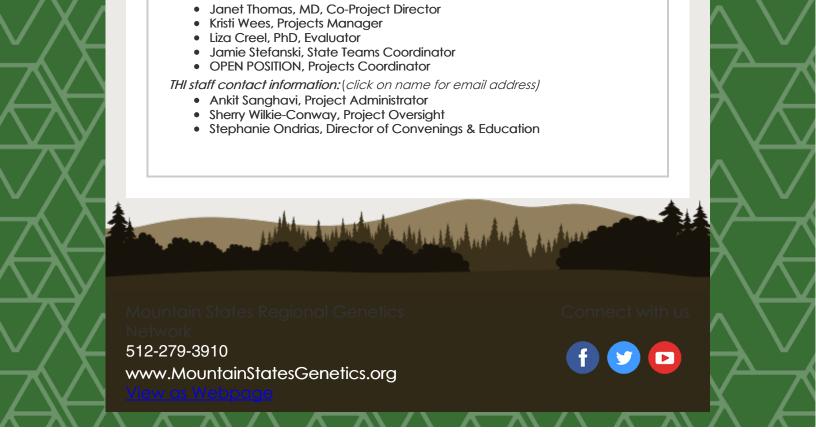
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