



# Summer Meeting 2022

Moving Mountains:  
One Boulder at a Time



# A statement from our funders

**This meeting 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](https://www.hrsa.gov).**







MSRGN Virtual Summer 2022 Meeting

# **Moving Mountains: One Boulder At A Time**



**June 14, 2022**

9am-1pm PT    11am-3pm CT  
10am-2pm MT    noon-4pm ET

**June 15, 2022**

12:30-3:30 pm PT    2:30-5:30 pm CT  
1:30-4:30 pm MT    3:30-6:30 pm ET

1

We are asking everyone to stay on MUTE during the presentation portion of the meeting. We will be "Raising Hands" virtually for interactive and discussion portions.

3

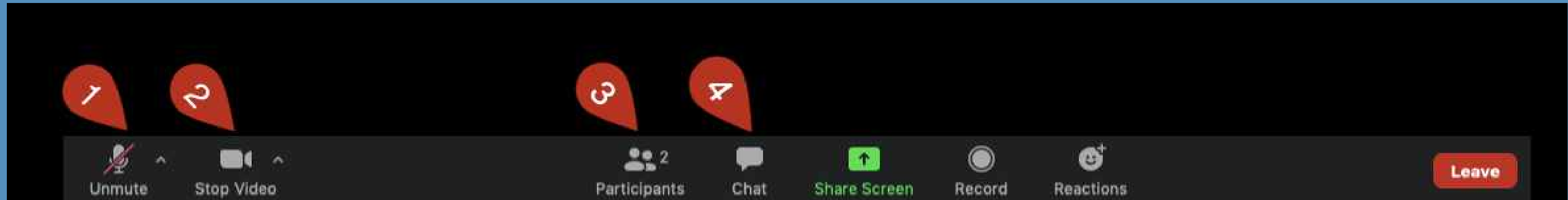
This is the active online participants list.

2

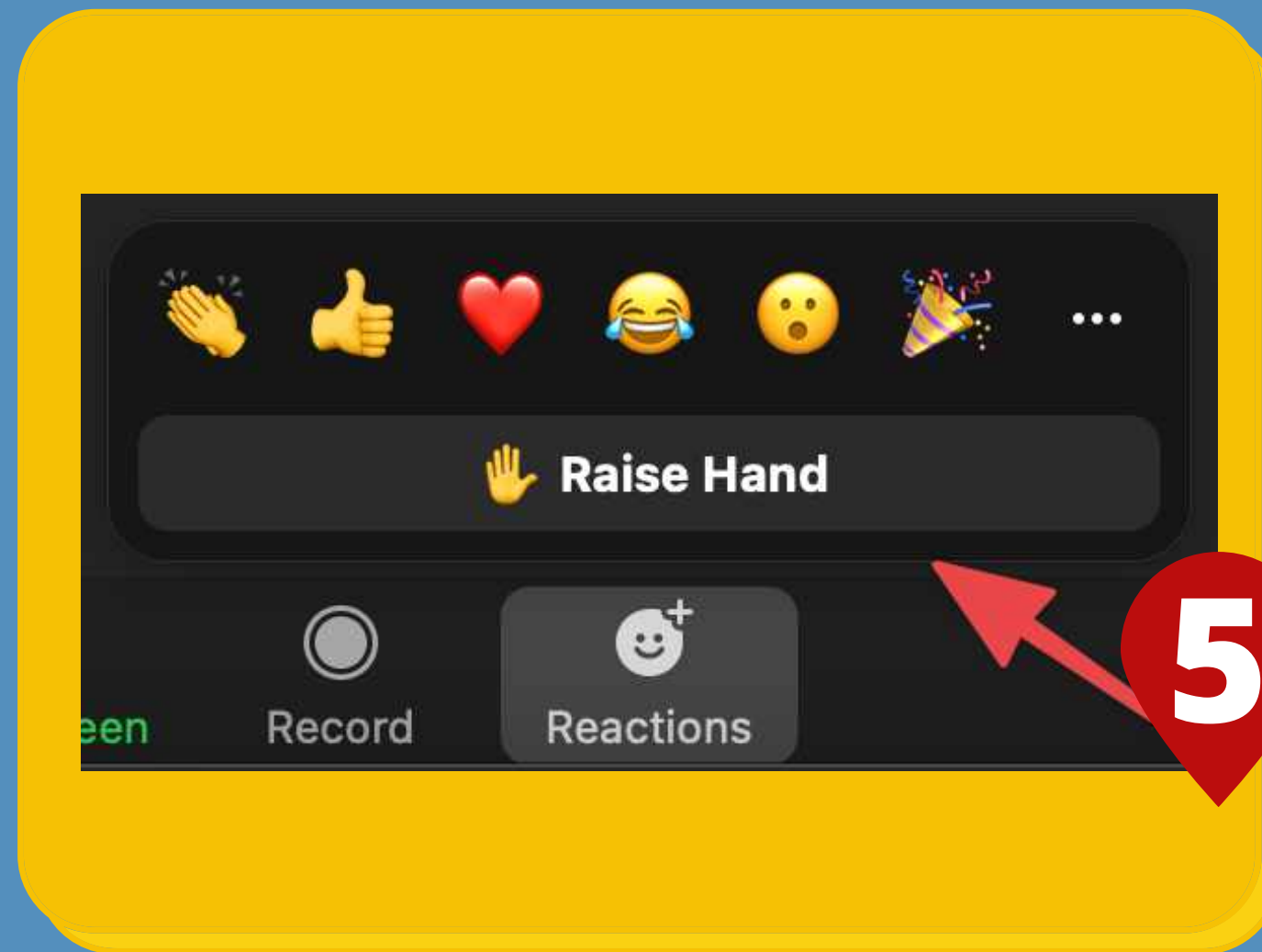
Feel free to turn your camera on if you feel comfortable.

4

Please use the chat feature for Q&A or tech issues (to: Katie Bradley or Stephanie Ondrias)

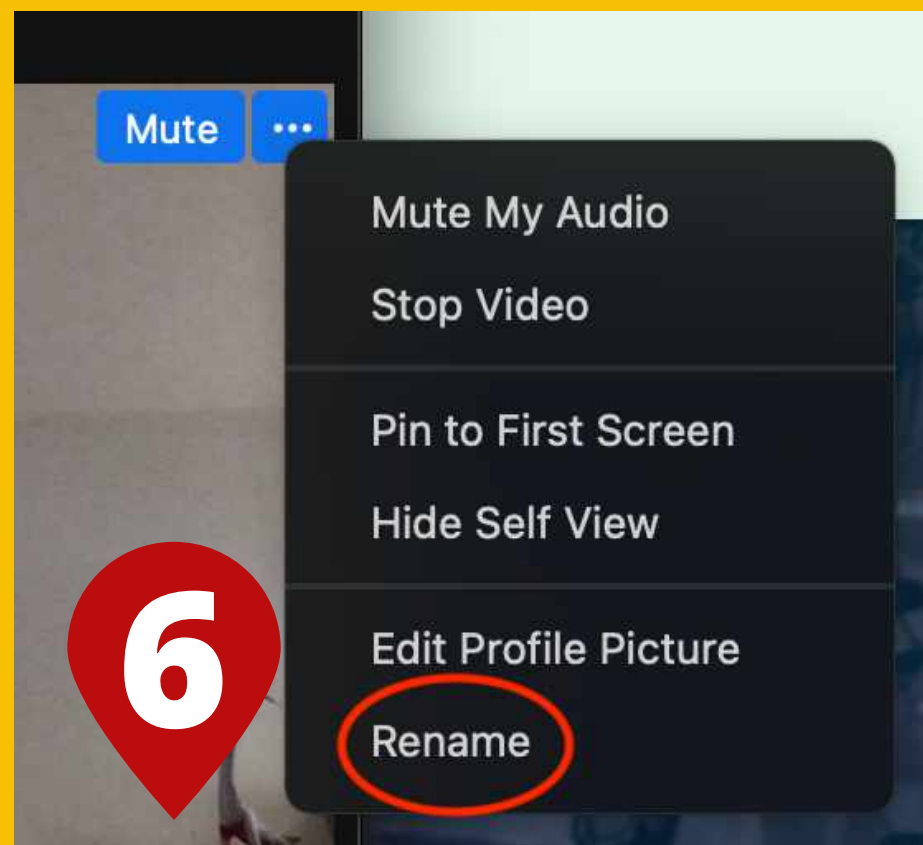






5

When asking a question, please raise your hand and wait to be called on, then state your name when you begin to talk



6

A screenshot of a 'Rename' dialog box. It has a title bar with a camera icon and the word 'Rename'. Below the title bar, it says 'Enter a new screen name:'. There is a text input field containing 'John Doe (TX)'. Below the input field, it says 'Your Name Here (2 letter state code)'. At the bottom right, there are two buttons: 'OK' (blue) and 'Cancel' (white with a grey border). A red location pin icon with the number '6' is positioned to the left of the dialog box.

6

Look for the 3 dots (...) in the top right corner of your video. Click on that and then click Rename with your First and Last Name and State Code

## How to Rename Yourself and Add Your State

Day 1: June 14



# Introduction: Moving Mountains, One Boulder at a Time

11:00 AM-11:15 AM CT

Kathy, Janet





Kathy



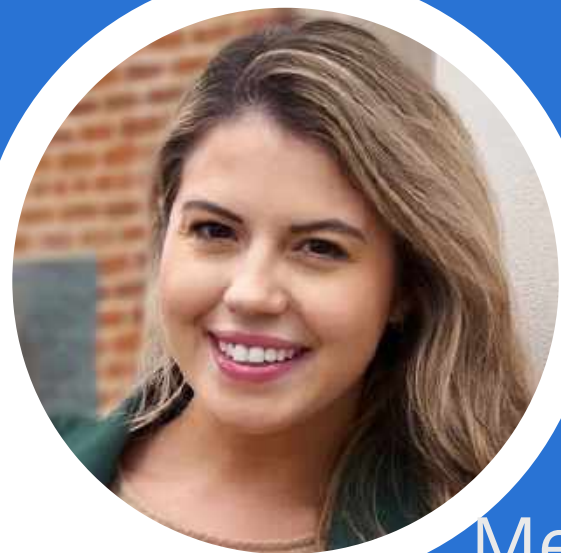
Janet



Kristi



Liza



Mekayla



Jamie

# MSRGN TEAM

*Welcome to our 2 newest members,  
Mekayla and Jamie!*





Ankit



Sherry

# MSRGN TEXAS HEALTH INSTITUTE TEAM

Stephanie



Katie





# WELCOME

To our new HRSA Grant Officer

**Mabatemije Otubu**

FIRST: Mah-bah-teh-me-jeh      LAST: Oh-too-boo





# Day 1 Agenda

Introduction: Moving Mountains, One Boulder at a Time  
11:00 AM-11:15 AM CT

It's in Your DNA: What Improvisational Principles Teach  
Us About Working Collaboratively  
11:15 AM-1:15 PM CT

Break  
1:15 PM-1:45 PM CT

State Team Case Study  
1:45 PM-2:00 PM CT

Looking Back: The Last 2 Years  
2:00 PM-2:45 PM CT

Day 1 Wrap-Up  
2:45 PM-3:00 PM CT

Day 1: June 14

See Chat for Zoom Link or  
check your reminder email for  
Zoom Link



# It's in Your DNA: What Improvisational Principles Teach Us About Working Collaboratively

11:15 AM-1:15 PM CT

Erica Marx



# Zoom Link:

<https://us02web.zoom.us/j/89427427911?pwd=bnVEV3duYno3a2p3dkJVYjczdVBudz09>

In this highly-interactive session you will learn from research the key factor that predicts team success under conditions of uncertainty and how principles and practical skills from the improvisational arts can support your ability to form and maintain collaborative partnerships. Come with your video on and ready to participate.



11:15 AM-1:15 PM CT

Erica Marx

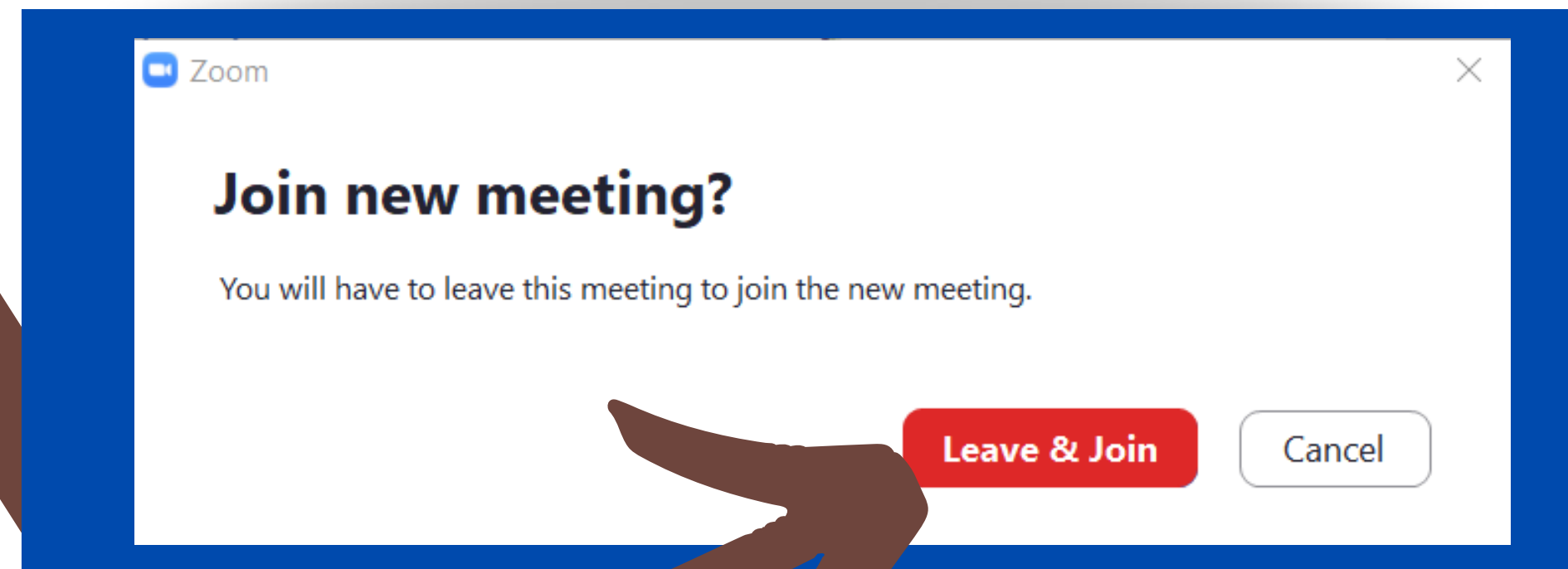


# Day 1: June 14

See Chat for Zoom Link  
or check your reminder  
email for Zoom Link



## Leaving this Zoom Meeting to Join the next one...





Day 1: June 14



# LUNCH BREAK

1:15 PM-1:45 PM CT

Up next:

**State Team Case Study**

**1:45 PM-2:00 PM CT**

Zoom link (same as now!)



Day 1: June 14



# State Team Case Study

1:45 PM-2:00 PM CT

Liza



Day 1: June 14



Stop share and  
switch to Liza





Day 1: June 14



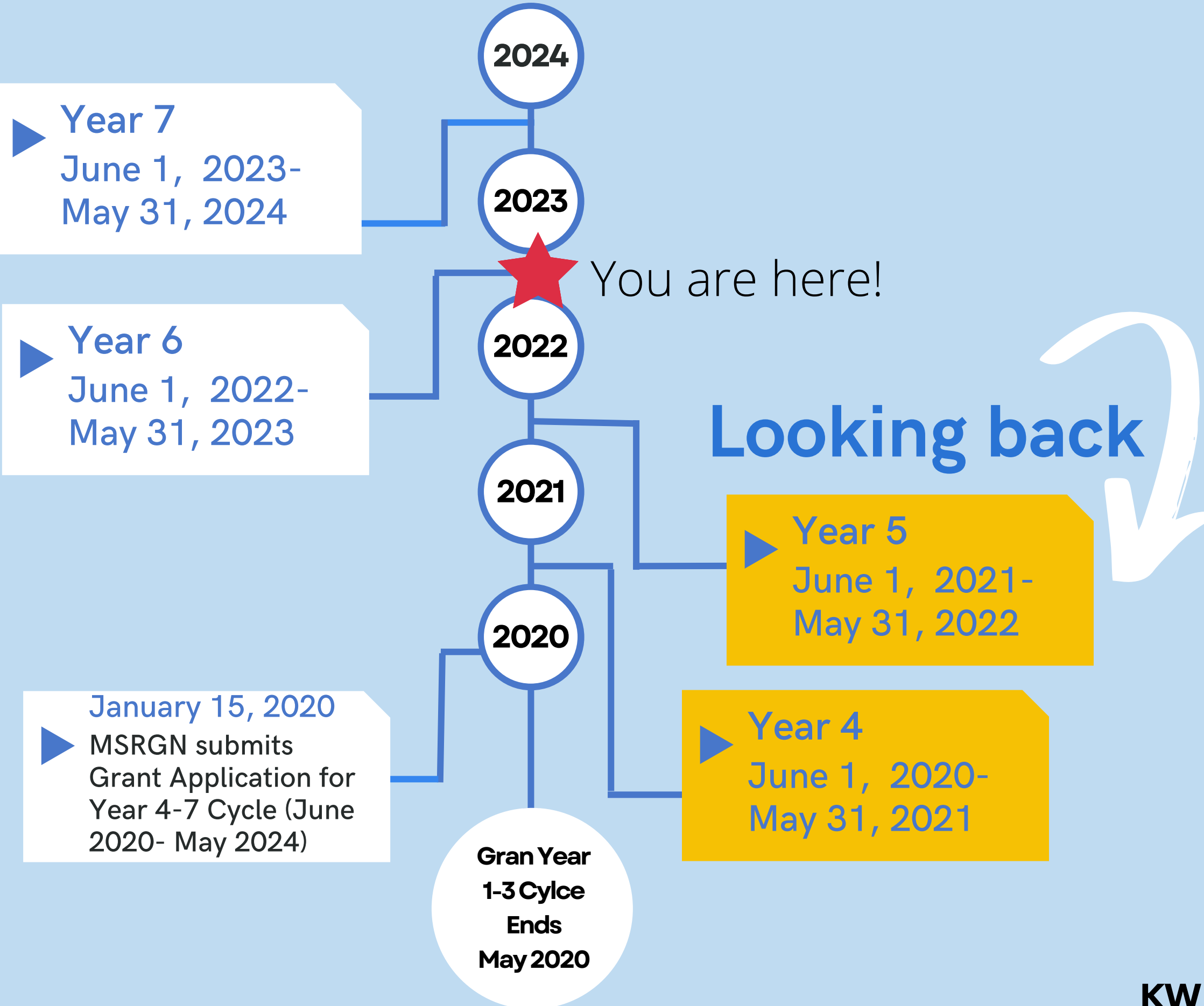
# Looking Back: The Last 2 Years

2:00 PM-2:45 PM CT

Kathy, Janet, Jamie, Kristi



# Looking Back: 2020- 2022





# Some MSRGN Accomplishments: Year 4 & 5

## Virtual Genetics Summit 2021

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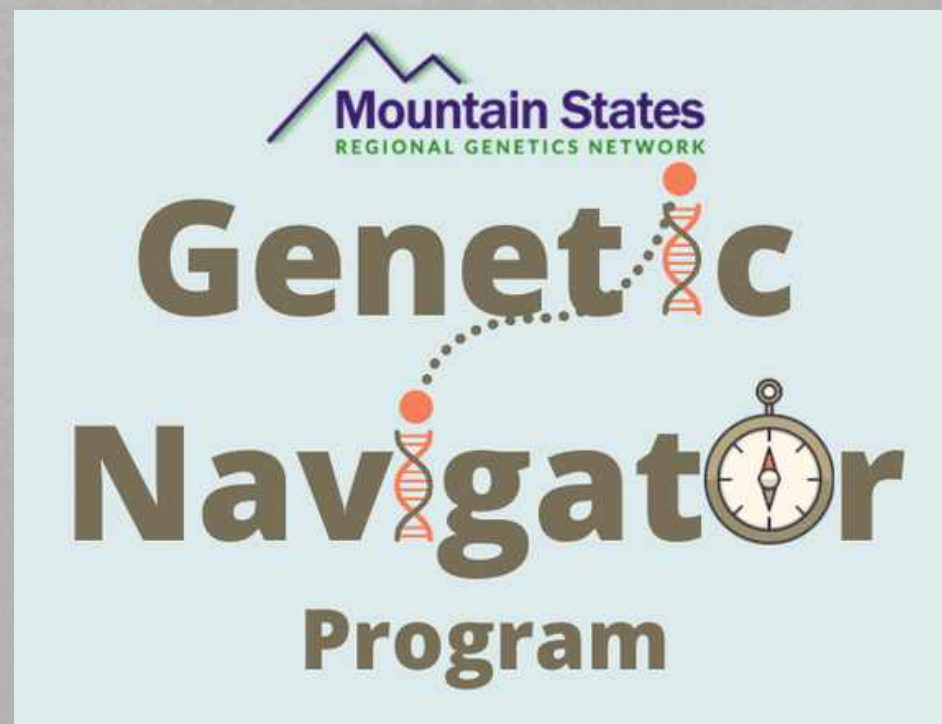
## Launched Time 4 Genetics Initiative

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## Launched: Genetic Navigator Program

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# MSRGN State Teams: Year 5

**16**

team members



Arizona



**13**

team members



Colorado



**13**

team members



Montana



**18**

team members



Nevada





# MSRGN State Teams: Year 5

**22**

team members



New Mexico

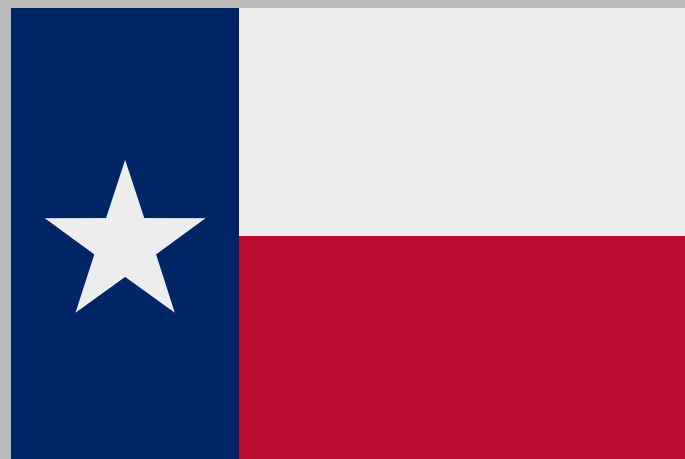


**13**

team members



Texas



**13**

team members



Utah



**3**

team members



Wyoming





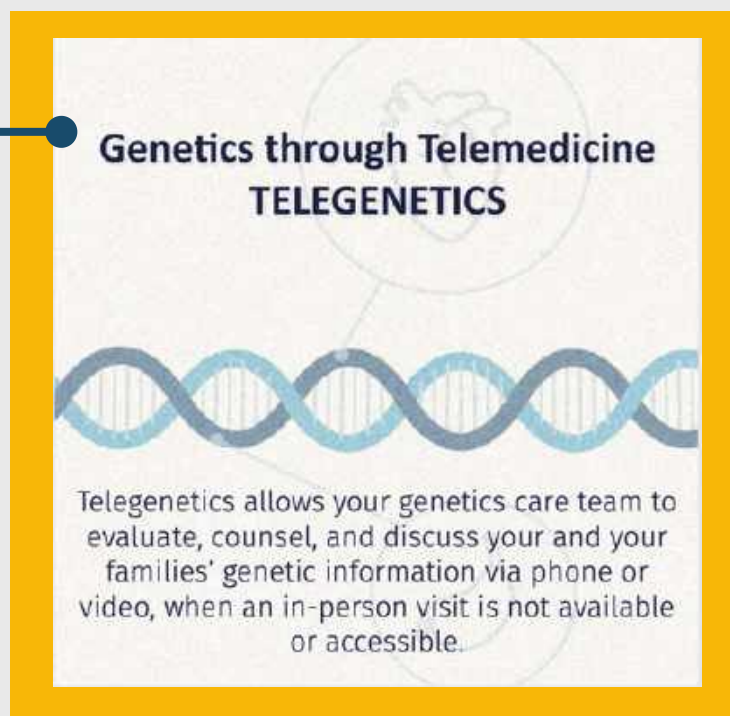
# All about the Arizona State Team



2020-2022

## Year 4: 2020-2021

The Arizona team created, designed and printed 1100 Telegenetics Brochures for distribution with partners: Raising Special Kids and Phoenix Children's Hospital.



1,100

## Year 5: 2021-2022

In year 5, the Arizona team hit the ground running with their project to translate their "Telegenetics Brochure" into Spanish. Then they also formed 2 project subgroups.

## Telegenetics Brochure in Spanish

Through a partnership with Phoenix Children's Hospital translation department and utilizing MSRGN's Spanish medical translation contract, the Arizona team was able to finish their Telegenetics brochure in Spanish and add it to their new/updates state team webpage.



## Momentum...stay tuned

The Arizona team has been convening 2 sub-workgroups. These workgroups meet outside of the monthly state team call. Both workgroups are designing resources around their topic areas which will hopefully be ready to share far and wide in Year 6.

KW



## State Team Webpage

The Arizona team updated their website in 2022 to feature their Telegenetics Brochure that they created in 2021.

Clinical  
Trials  
sub-group

Late Onset  
Conditions  
sub-group





Presents this Award:

# The Boulder Blazer Award

to the

## Arizona State Team

*For their intentionality of removing communication barriers  
and boulders by being inclusive to the deaf and hard of  
hearing community as well as translating their telegenetics  
brochure into Spanish to reach the Hispanic population in  
Arizona and beyond.*

*This award is presented on  
the June 14, 2022*

*This award is presented by the  
MSRGN Management Team*





## 2020-2024 Co-Leads

Jamie Stefanski (2020-2021)

Erica Wright (2020-present)

Brittany Parke (2021-present)

# All about the Colorado State Team



2020-2022

## Year 4: 2020-2021

2000 Where is Bear? books  
purchased:

1000 English and 1000 Spanish

Where is Bear? is a book from the  
CDC's Learn the Signs Act Early  
program, about developmental  
milestones for 2 year olds.



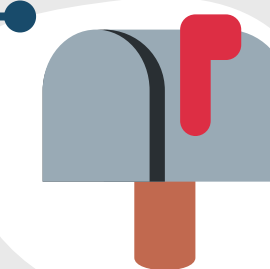
 **2,500**

## Genetic Counseling Student Intern... 2022

The Colorado team paid a genetic counseling student  
intern to work on compiling a list of addresses and  
contacting 50 pediatric offices in CO and placing **21**  
**large flat rate FedEx boxes** of books and red flags in  
the mail to those 21 pediatric offices.

## Year 5: 2021-2022

2,500 **Red Flags 4 Genetics** (E&S) handouts  
were purchased for distribution with the  
Where is Bear? Books.



## The boxes of resources were mailed all across CO..

The GC student intern and the team used the map  
of the Community Center Board Regions to make  
sure the entire state was covered in their  
distribution plan.

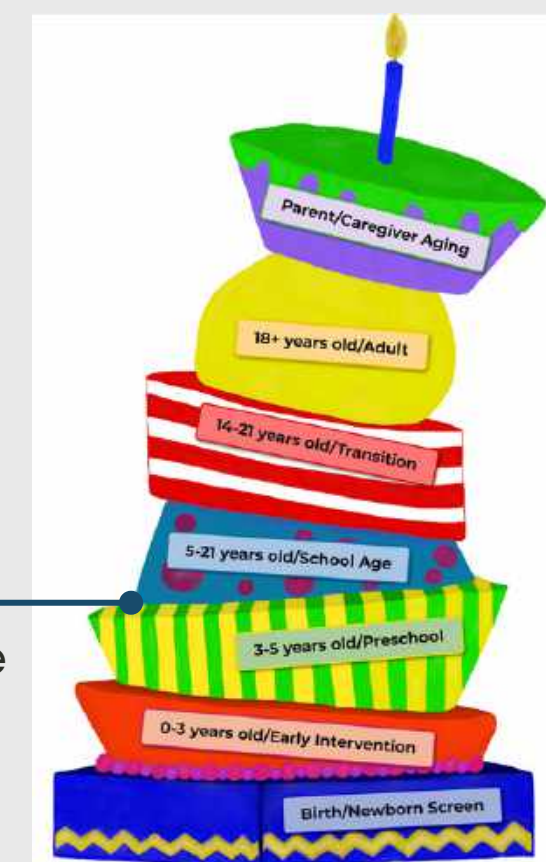


## State Team Webpage

The Colorado team updated  
their website in 2022 to feature  
the Where is Bear? Book.

## Momentum...stay tuned

The Colorado team is converting the  
resources they have gathered for  
their Birthday Cake Transition  
Guide to the MSRGN website.







Presents this Award:

# The Exploration Award

to the

# Colorado State Team

*For their exploration of their entire state through the distribution of the "Where is Bear?" Books and Red Flags 4 Genetics Handouts. The creative use of the Community Center Board map and regions ensured that every corner of Colorado received these valuable resources, and the personal phone call by the CO State Team Genetics Counselor Student intern increased the likelihood of these materials being welcomed at Pediatric Practices across the state!*



*This award is presented on  
the June 14, 2022*

by the MSRGN Management Team



# All about the Montana State Team

2020-2022

MONTANA



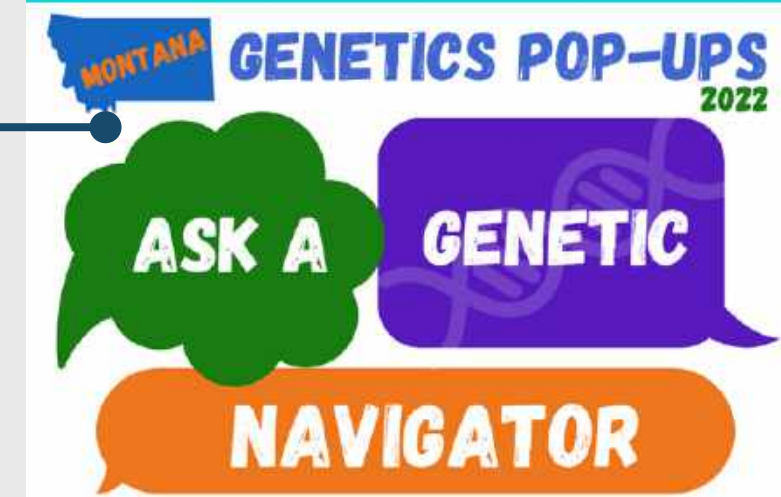
## Year 4: 2020-2021

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 visits.



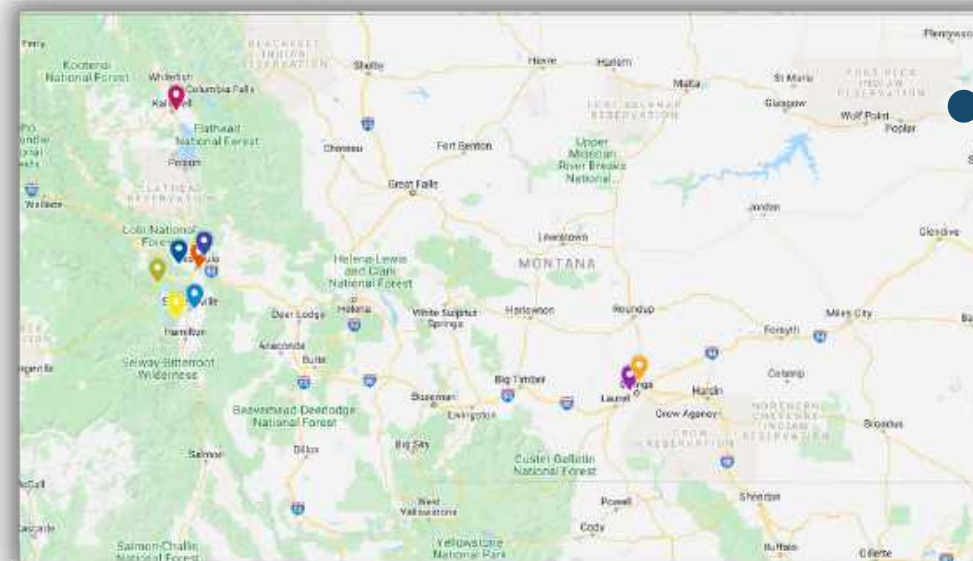
## Year 5: 2021-2022

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 31 attendees.



## 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.



## State Team Webpage

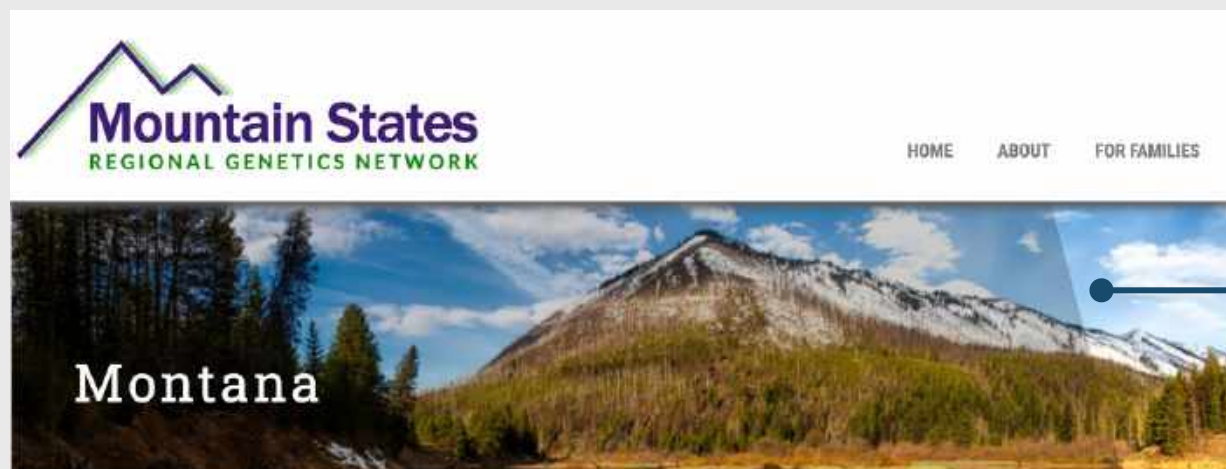
The Montana state team updated their website in 2022 to feature their partnership with Montech and equipment purchase in 2021.

## Momentum...stay tuned

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



KH







Presents this Award:

# The Excavator Award

to the

# Montana State Team

*For their excavation and mining of bright gems in the world of Early Intervention Professionals and Family Support specialist across the state of Montana through 4 Montana Genetics Pop-Ups and for their partnership with MONTECH to provide equipment to help families “excavate” telehealth access in Montana.*

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the June 14, 2022*

*This award is presented by the  
MSRGN Management Team*





# All about the Nevada State Team



2020-2022

## Year 4: 2020-2021

The Nevada team had a virtual booth at the NV AAP Meeting in October of 2020. As part of their attendance at this meeting they received a participant list which would form the basis of their outreach in Year 5.

### Nevada Chapter

American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN®

### MOU with Intern... 2021

The Nevada team paid an intern to expand on the AAP list and add additional pediatric and PCP clinics to the list.



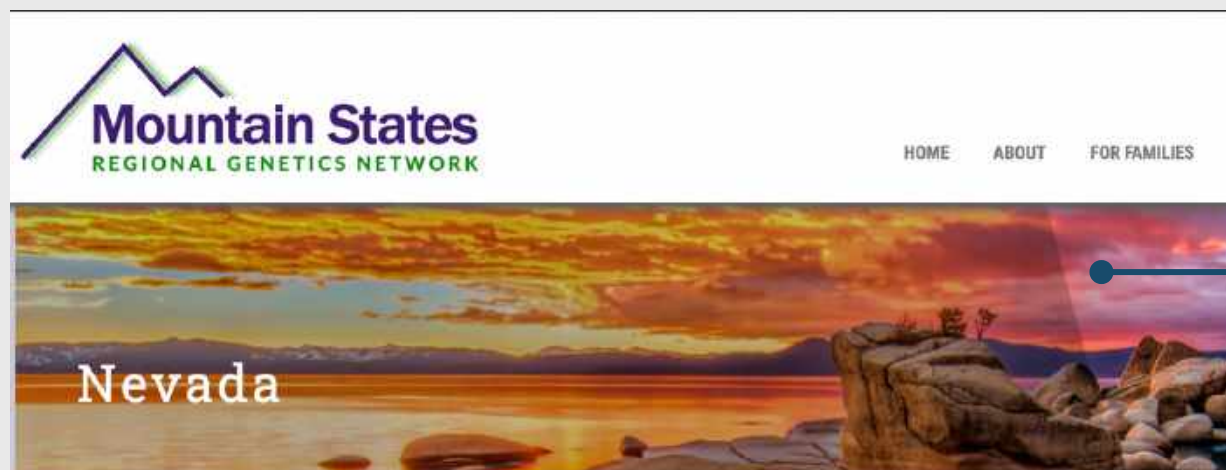
## Nevada Genetic Resource Magnet

The Nevada team paid an intern to expand on the AAP list and add additional pediatric and PCP clinics to the list.



### State Team Webpage

The Nevada team updated their website in 2022 to feature their Genetic Navigator: Hannah.



[www.MountainStatesGenetics.org/Nevada](http://www.MountainStatesGenetics.org/Nevada)

**1,000**

### MOU with Intern... 2021

The Nevada team paid the same intern they had in 2021 to return in 2022 to expand the list of providers in NV to include more from the Reno area and around the state.

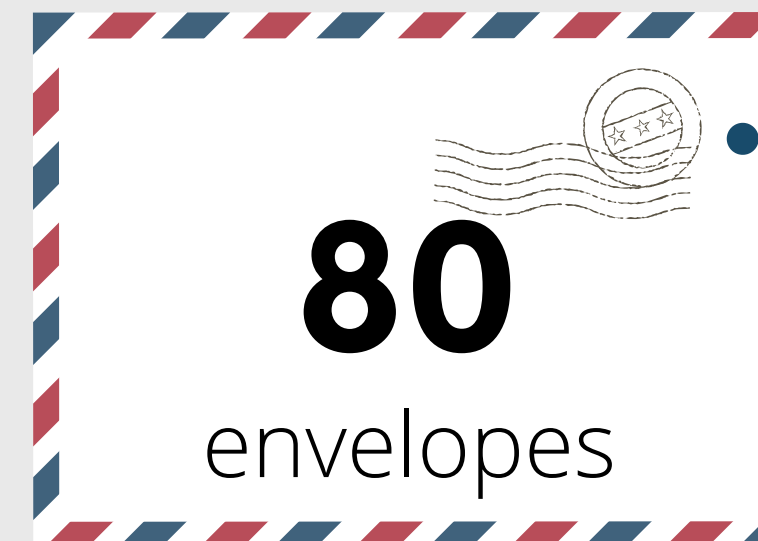


## Year 5: 2021-2022

1,000 **Red Flags 4 Genetics** handouts were purchased by the Nevada team for distribution with the magnets.

### Nevada Mailing

The Nevada team with an MOU with their Genetic Navigator, Hannah, created a cover letter with a QR code survey, compiled genetic & partner resources and mailed these to 80 PCP in Nevada via flat rate envelopes.



### Momentum...stay tuned

The Nevada team also purchased with some of their extra funds some booth supplies so they can attend in-person community events in the coming year.





Presents this Award:

# The Avalanche Award

to the

## Nevada State Team

*For their avalanche and landslide mailing of 80 envelopes to Primary Care Clinics in Nevada. This effort started as a tiny snowball rolling down a mountain with a virtual booth at the Nevada AAP conference in 2020 which provided the team with an initial list of providers who attended the meeting. With the help of a Nevada State Team intern over the last 2 years the list grew and grew and is still growing for future mailings.*

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the June 14, 2022*

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MSRGN Management Team*





# 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.

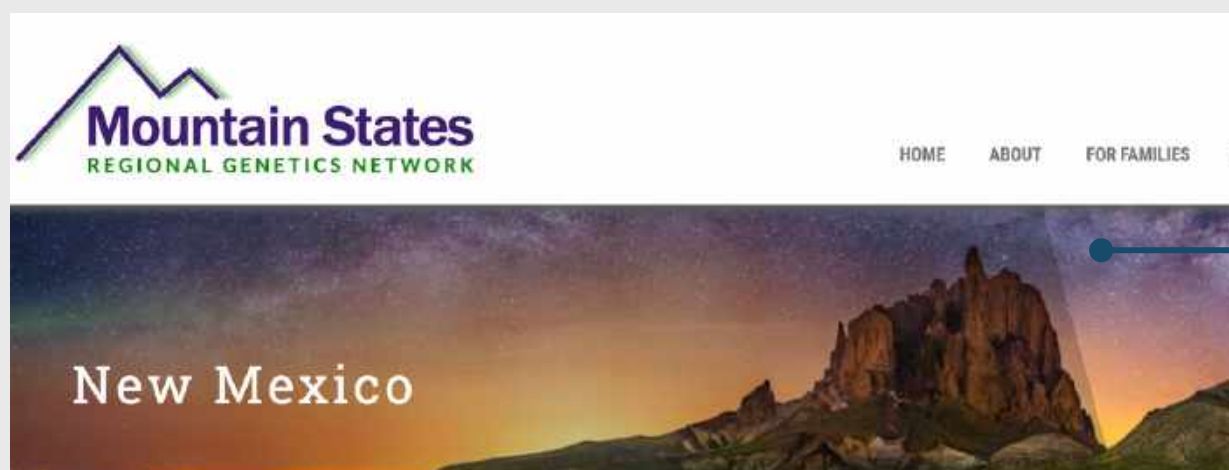
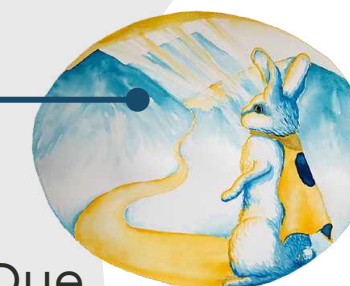


## State Team Webpage

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





Presents this Award:

# The Redwood Tree Award

to the

# New Mexico State Team

*For the team's resiliency during COVID to carry on with their project plans to serve families with genetic conditions in Taos and Farmington with a respite day. Redwood trees grow in clusters, are strengthened and outlive many natural disasters and have shallow but intertwining root systems.*

*Just like the Redwoods, the New Mexico state team has shown their strength in clusters by forming vast intertwining partnerships across the state to sustain them and strengthen them in challenging times.*

*This award is presented on  
the June 14, 2022*

*by the MSRGN Management  
Team*





**2020-2024 Co-Leads**

Melissa Fox (2020-present)

KC Singletary (2020-2021)

Daphne Fulton (2021-present)

# All about the Texas State Team

2020-2022



## Year 4: 2020-2021

The Texas team purchased \$200 in postcard stamp postage to mail the postcards they planned to design in year 5.



## Year 5: 2021-2022

In year 5, a subgroup formed out of the Texas state team of individuals who were interested in exploring the manner in which a genetic diagnosis is delivered to a family. The group has become known as the HOPE group for families and this group went on to advocate for a speaker on this topic (Laila Andoni) at the 2021 Genetics Summit. Their work now continues with Laila and a few new members from Utah who have joined the conversation.

## MOU with Intern... 2021

The Texas team paid a public health student intern to work on compiling an Excel spreadsheet of addresses for primary care offices in Texas.



## Facebook Advertising

The Texas team had plans for a large Facebook advertising campaign in Year 5, which they are still working on and will perhaps pick back up in year 6.



## State Team Webpage

The Texas team updated their website in 2022 and hope to feature their postcard design (once it is finished in Year 6).



[www.MountainStatesGenetics.org/Texas](http://www.MountainStatesGenetics.org/Texas)

## Momentum...stay tuned

The Texas Team has a postcard design in process for a mailing to primary care professionals in Year 6.







Presents this Award:

# The Cautious Camper Award

to the

## Texas State Team

*For their careful planning, packing, and preparing for their state team project journey. Over the last 2 years, built on a history of finding inexpensive or free opportunities to share their message frugally, the Texas team has utilized the help of students, interns and the next generation of “not quite yet parents” to move their project forward. While this approach has had its challenges along the way, it has undoubtably shared wisdom, insights, and lessons learned to many generations to come.*

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MSRGN Management Team*





# All about the Utah State Team

2020-2022



## Year 4: 2020-2021

The Utah team led the way in the MSRGN region in customizing the Where is Bear? book with a QR code and printing 2000 English and 2000 Spanish books.



## Year 5: 2021-2022

The Utah team devised and implemented a creative, sustainable delivery model for the Where is Bear? books they had printed in Year 4. They are utilizing the NBS department and the shipping in place for second screen NBS cards to distribute all items created by the team,

## Table Tents (E&S) and Magnets for Pediatric Clinics

The Utah team created magnets and table tents in English and Spanish for distribution through the UT NBS department to pediatric clinics across the state.



## State Team Webpage

The Utah team updated their website in 2022 to feature the Where is Bear? book.

[www.MountainStatesGenetics.org/Utah](http://www.MountainStatesGenetics.org/Utah)

## Momentum...stay tuned

The Utah team is looking forward to Year 6 to expand it's membership and explore new ideas on reaching underserved families in Utah.





Presents this Award:

# The Sustainability Award

to the

## Utah State Team

*For the team's creative distribution method of "Where is Bear?" books and table tents/magnets throughout the state of Utah utilizing the already well-established "extra" 2<sup>nd</sup> screen NBS card distribution system at the UT Department of Health to pediatrician and family practice clinics across the state. This distribution illustrates a sustainable method with just a bit of support and funding for more materials, by the Utah State team.*

*This award is presented on  
the June 14, 2022*

*by the MSRGN Management  
Team*





# All about the Wyoming State Team

2020-2022



## Year 4: 2020-2021

The Wyoming team purchased and mailed 500 DNA Squishes to Pediatricians across the state of Wyoming. The squishes contained contact information for the Wyoming genetics program as well as the MSRGN website for resources.



## Year 5: 2021-2022

1500 (English) & 1000 (Spanish) Where is Bear? books were purchased for distribution throughout the state.



## Distribution of Where is Bear? books

Carleigh, the Wyoming state team co-lead, compiled a list of nurses, nurse practitioners and pediatric clinics in Wyoming and mailed the books to them.

## State Team Webpage

The Wyoming state team updated their webpage on the MSRGN website in 2022 to feature the Where is Bear? book.

## Momentum...stay tuned

The Wyoming team is poised to expand their reach across the state as well as their team size as new staff are hired and new programs roll out to reach early intervention providers.







Presents this Award:

# The Diamond Award

to the

# Wyoming State Team

*For their small but precious and brilliantly shining genetics outreach throughout the state of Wyoming. Over the last 2 years the team distributed DNA squisheys and "Where is Bear?" books to pediatric, family practice and nurses across the state to raise awareness about Wyoming genetics clinics. Diamonds start out as rocks in the rough and with immense pressure become brilliant sparkling gems. Similarly, the Wyoming team has weathered their own staffing pressures, health challenges and stressors that they continued to overcome to shine brightly!*



*This award is presented on  
the June 14, 2022*

*by the MSRGN Management  
Team*



Day 1: June 14



# Day 1 Wrap-Up

2:45 PM-3:00 PM CT

Kathy, Janet



# Recap Day 1: Top 3 takeaways

## YEAR 4 & 5

Lots has been accomplished by so many members of MSRGN.

"Many hands make for light work"- even when you are moving mountains!

## STATE TEAMS

MSRGN is incredibly proud of the 8 state teams and the national precedent that this model is setting. Stay tuned for a state team case study publication.

"Don't follow the path, blaze the trail."

## MOMENTUM

Looking forward to the next 2 years and continuing the MOMENTUM that has been building from the work done in the first 2 years of this cycle.

"For any movement to gain momentum, one must start with a small action."



## Moving Mountains: One Boulder at a Time



Thank You For Joining Us Today!



# Join us Tomorrow for Day 2: Looking Forward to the Next 2 Years!

Please see your email  
reminder for the

**DAY 2: Zoom Link.**

Stick around for one more slide!

Turn your camera on please!





**SMILE!**  
**Your on**  
**MSRGN CANDID CAMERA!!**  
**Turn Your Camera ON Please!**

**Group Photo!**

