

GENETIC AMBASSADORS

Mountain States Regional Genetics Network

Quarterly Call:
April 2021



Guest Speaker: Molly Martzke
The National Genetics Education and Family Support Center

Welcome and Introductions by All

- *Tell us your Name*
- *Group you represent or if you represent yourself*
 - *State you live in*
- *Question: If you could immediately gain one skill, what would it be?*

Genetic Navigators: Welcome to our 8 navigators

Genetic Ambassador Project: Red Flags Survey- Update &

Discussion of Wording for Infographic

Genetic Pop-Ups: 2021 Update

Time 4 Genetics Project: Family Perspective on Red Flags

What's coming up/Final Thoughts –Kristi

- MSRGN Genetics Summit- November 9-10, 2021
- NGEFSC Family Engagement: Family Interviews
 - Navajo Family Voices
 - NORD

AGENDA

A WARM WELCOME

To all of our
Genetic Ambassadors

Kristi Wees
Projects Manager for MSRGN



Kristi came to MSRGN through her own family's journey with genetics for her daughter. Kristi has a degree in Chemistry from Penn State and a graduate degree from UCLA. Her passion is empowering families to make the best informed decisions for their children's health.

A WARM WELCOME

to our Guest Speaker

Molly Martzke
Senior Program Manager for
NGEFSC: “The Family Center”
Expecting Health



Molly has extensive experience working with diverse groups from local to international in providing family leadership training.

Molly Martzke brings passion and real-life experience to her role with the National Genetics Education and Family Support Center. She has dedicated her life's work to improving the experiences and outcomes of all families with children with special healthcare needs. Molly is committed to actively engaging families as equal partners in their child's health care and ensuring that the family voice is represented throughout the family's journey and within their system of care. She believes that this change happens at the system level when there is diverse representation and honest dialogue amongst all parties.

Introductions & A Question

- *Tell us your Name*
- *Group you represent or if you represent yourself*
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- *Question: If you could immediately gain one skill, what would it be?*



THE MOUNTAIN STATES REGION

8 States



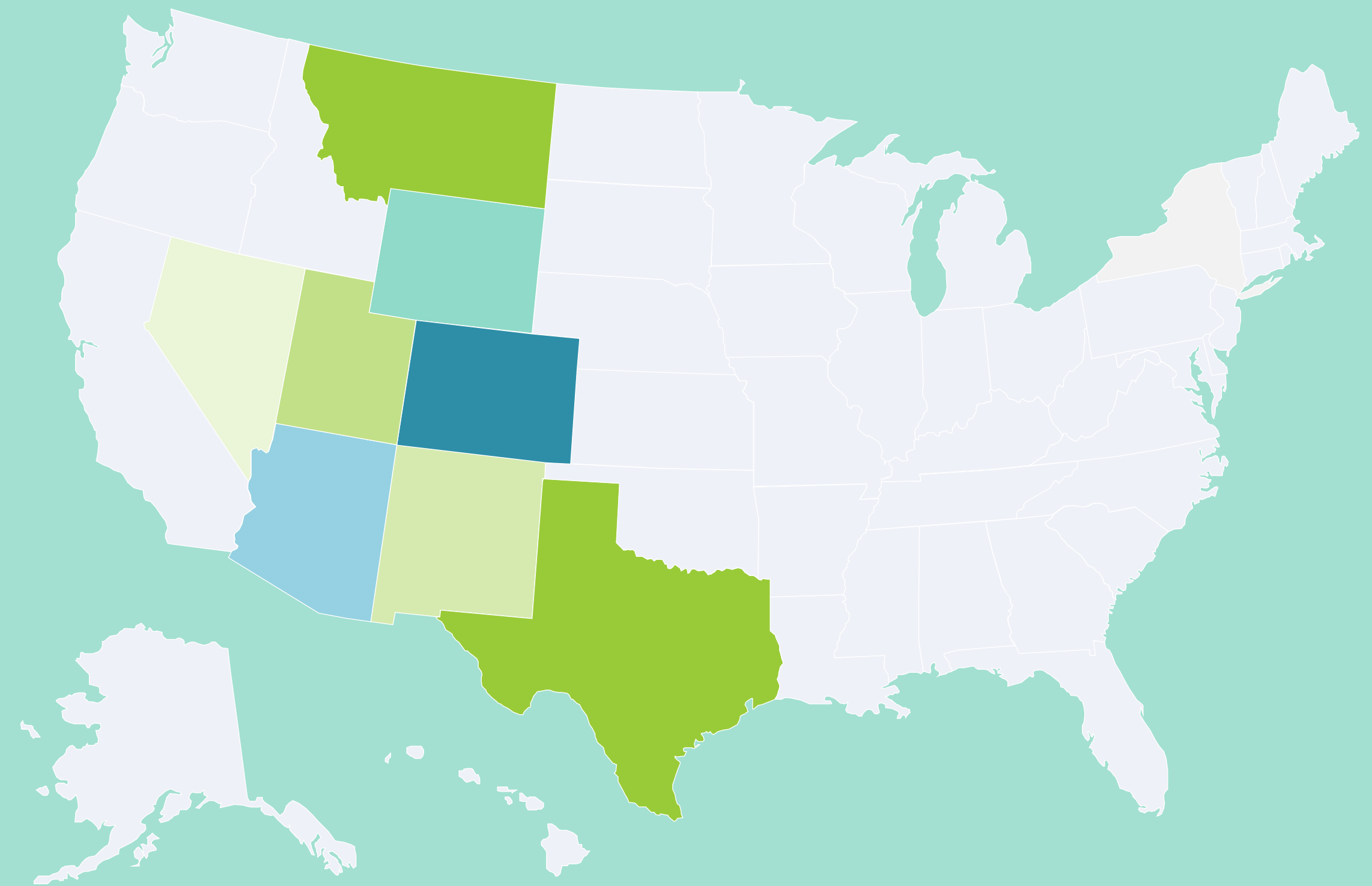
Geography

Our 8 states represent 1 million Square Miles!



Genetics

Most states only have 1 genetics center.

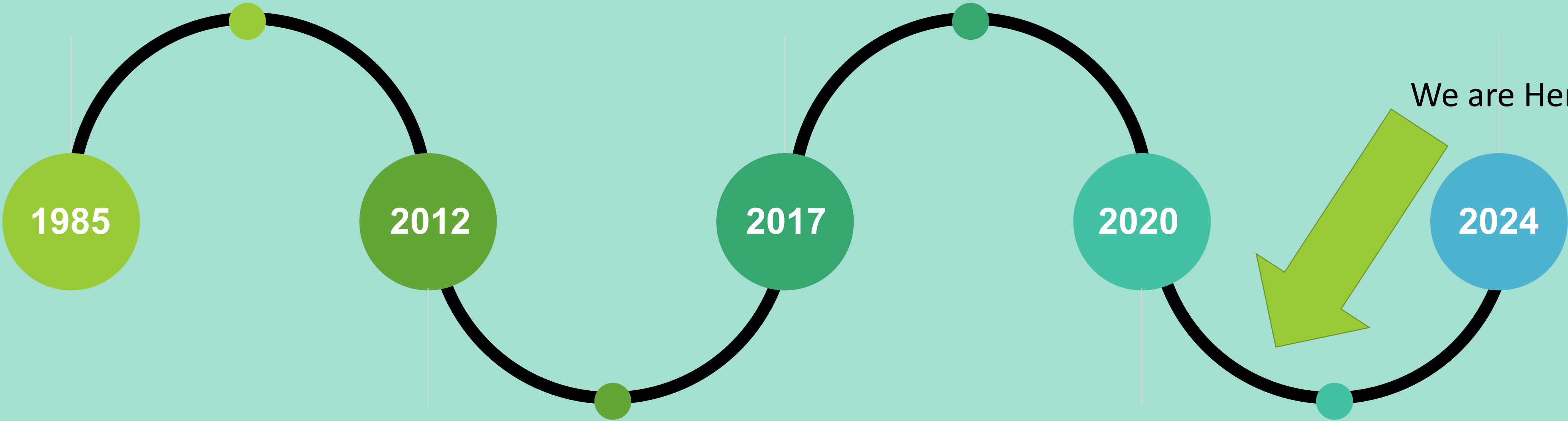


MOUNTAIN STATES TIMELINE

Through The Years

Past Grant Cycles

Have been around since
1985 in one form or another

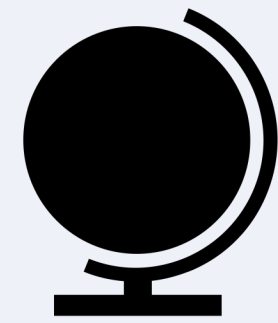


MSRGN
3-year cycle-
Regional Genetics
Networks

MSGRC
5-year Collaborative grant
Cycle- with an emphasis on
NBS

MSRGN
4 -year grant cycle
began on
June 1, 2020.

PRIORITIES OF THIS GRANT CYCLE



The regional infrastructure that MSRGN has chosen to continue in this grant cycle is the State Team Model.

2 other regions are implementing this model.

Regional
Infrastructure



There will be an added focus this grant cycle to increase education to primary care and pediatricians, in addition to individuals and families.

Education



This is an ongoing focus in our region and nation wide.

Our plans have been impacted by COVID19 and thus this is an ongoing area for discussion.

Telegenetics

PROJECT UPDATES

Genetic Navigators



Genetic Navigators

Announced March 2021
Training April & May 2021
Navigation begins
in June 2021



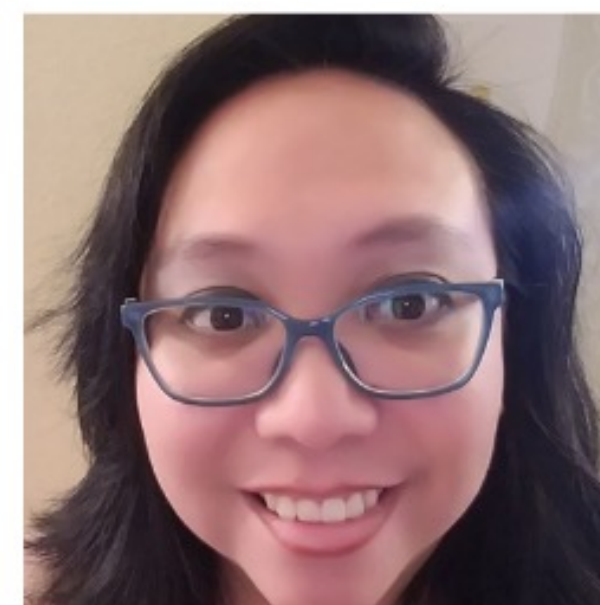
Arizona: Noan



Colorado: Jamie



Montana: Jennifer



Nevada: Hannah



New Mexico: Jennifer



Texas: Lourdes



**GENETIC
NAVIGATORS**



Utah: Tristin



Wyoming: Melody

PROJECT UPDATES

Genetic Ambassadors Red Flags Survey



Red Flags Survey
Closed March 20, 2021

- English Responses: 113
- Spanish Responses: 20
- Genetic Ambassadors: THANK YOU to all of you for your help in sharing this survey!
 - A special Thanks to
 - Hannah B.- initial questions
 - Lourdes T.- translation
 - Brittany P.- infographic
- Coming in June: Red Flags Infographic (English)
 - Spanish to follow in later summer

RED FLAGS- TOP 6 BUCKETS/Categories (pull up excel)

11



Developmental Delays



Failure to Thrive



LOW Muscle Tone



Feeding Issues



Sleep issues



Physical Features

RED FLAGS

As reported BY FAMILIES FOR FAMILIES
Other BUCKETS 1



Skin Irregularities



Immune Issues



Bruising



GI issues

RED FLAGS

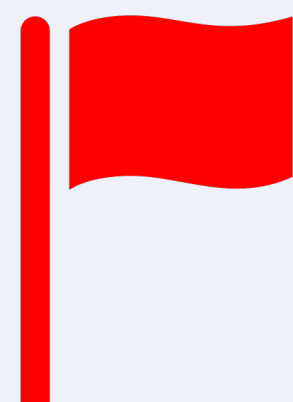
As reported BY FAMILIES FOR FAMILIES
Other BUCKETS 2



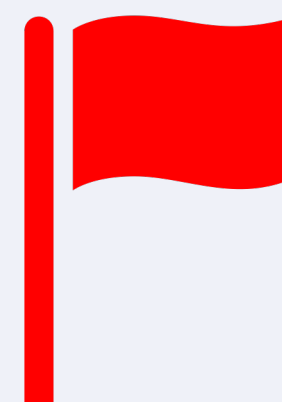
Behavior



Autism Spectrum



Opthomological (Eye)
Issues



Seizures

RED FLAGS

As reported BY FAMILIES FOR FAMILIES
Other BUCKETS 3



Loss Of Milestones/
Regression



OTHER

OPEN DISCUSSION of WORDING for Infographic:



Developmental Delays



Failure to Thrive



LOW Muscle Tone



Feeding Issues



Sleep issues



Physical Features

PROJECT UPDATE

Genetics Pop-Ups



Genetic Pop-Ups

8 Virtual Pop-Ups held
in February & March
2021



This year the Genetics
Pop-Ups were 100%
Virtual!

Big thanks to our pop-up
host and hostesses:

- Maria & Jesus Castillo
- Jamie Stefanski
- Jennifer Bana
- Becki Coleman
- Heidi Klomhaus
- Emma Burt
- Hannah Barnhart
- Lourdes & Gabriel Torres

NEW INITIATIVE LAUNCHING

Time 4 Genetics



40 Clinic Initiative

First Month of Topic #1:
Red Flags 4 Genetics
April 2021

Video: <https://youtu.be/baLf2435Hz4>

- 7 Clinics were recruited
- First topic: Red Flags 4 Genetics
 - April: Newsletter
 - May: Webinar
 - June: Mailer (Infographic)
- July: Family Centered Perspectives
- If anyone has a personal experience with a RED FLAG and Genetic diagnosis and would like to participate in the Family Centered perspectives, contact Kristi!

Events and Final Thoughts



Family INTERVIEWS on Family Engagement for the National Genetics Education and Support Center

Email Kristi if you would like to participate on May 10 from 2-4pm ET/ 1-3pm CT/ noon-2pm MT/ 11am-1pm PT



MSRGN 2021 Genetics Summit– Save the Dates! November 9-10, 2021


SAVE THE DATE: Genetic Summit 2021 (Virtual Event) November 9-10, 2021 We have a date for the 2021 Genetics Summit! Please hold November 9-10 on your calendar for this 2-day VIRTUAL event.

Our plan is to start at: 8:30 PT, 9:30 MT, 10:30 CT, 11:30 ET and end at: 1:30 PT, 2:30 MT, 3:30 CT, 4:30 ET.



Next Genetic Ambassador Meeting will be in July.

More Events



The Advisory Committee on Heritable Disorders in Newborns and Children May 13-14, 2021 Webcast

Registration: This meeting will be open to the public but advance registration is required. Please register [online](#) by 12:00 p.m. ET on May 12, 2021. For technical support accessing the registration website, please email achdncmeetings@lrginc.com.

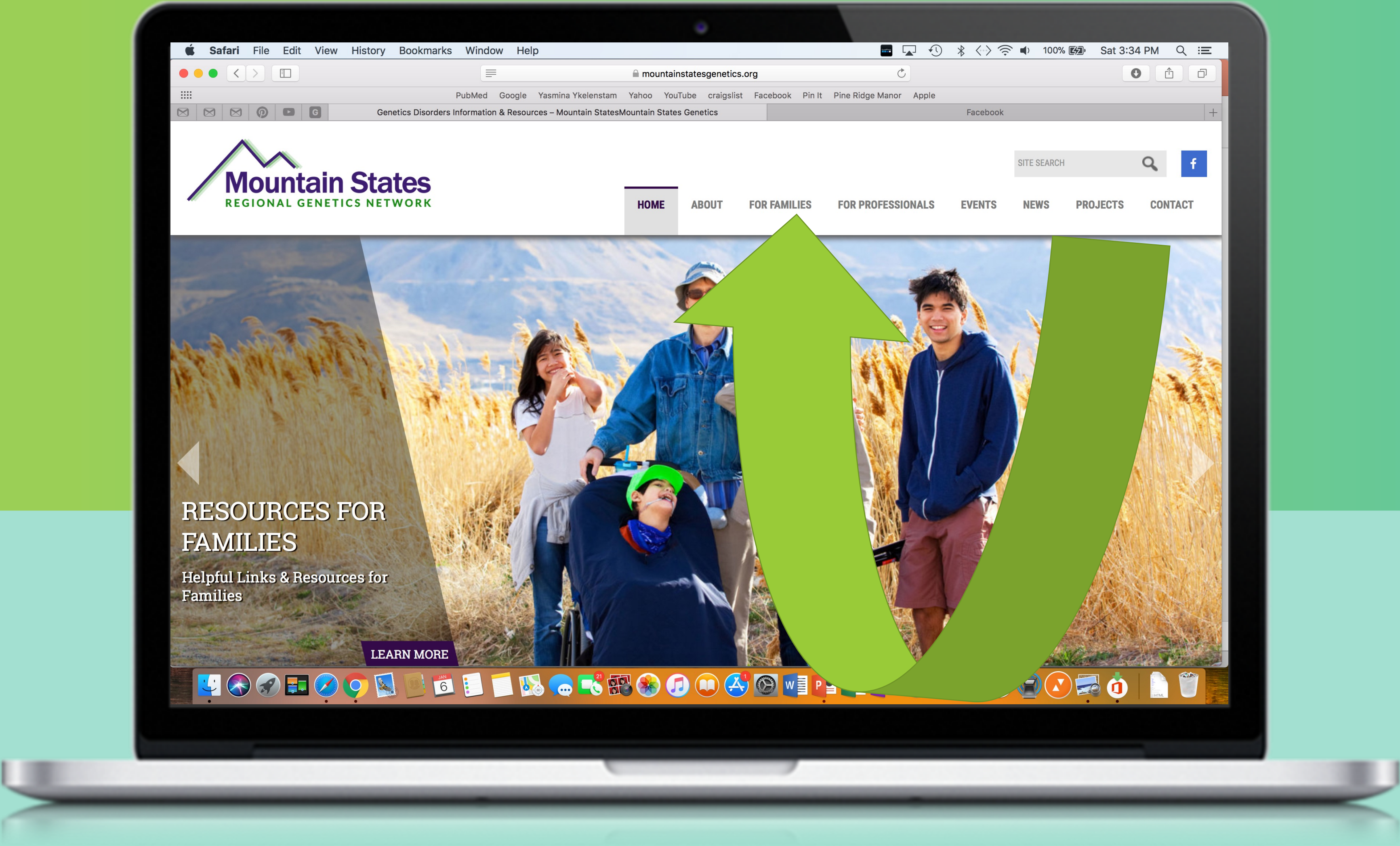


Scholarships available: Patient and Student Scholarships: June 26-27 (virtual)
NORD <https://rarediseases.org/living-rare-event-details/>



Stipends Available: Navajo Family Voices: \$300 kinship team vision stipend and kinship advice from families for Dine families in NM on or near the Navajo Nation. Submissions available: May 10-May 30 <https://navajofamilies.org/>

MSRGN WEBSITE



WWW.MOUNTAINSTATESGENETICS.ORG

The Place for all things
Genetics in our Network!

GENETIC AMBASSADOR FACEBOOK GROUP



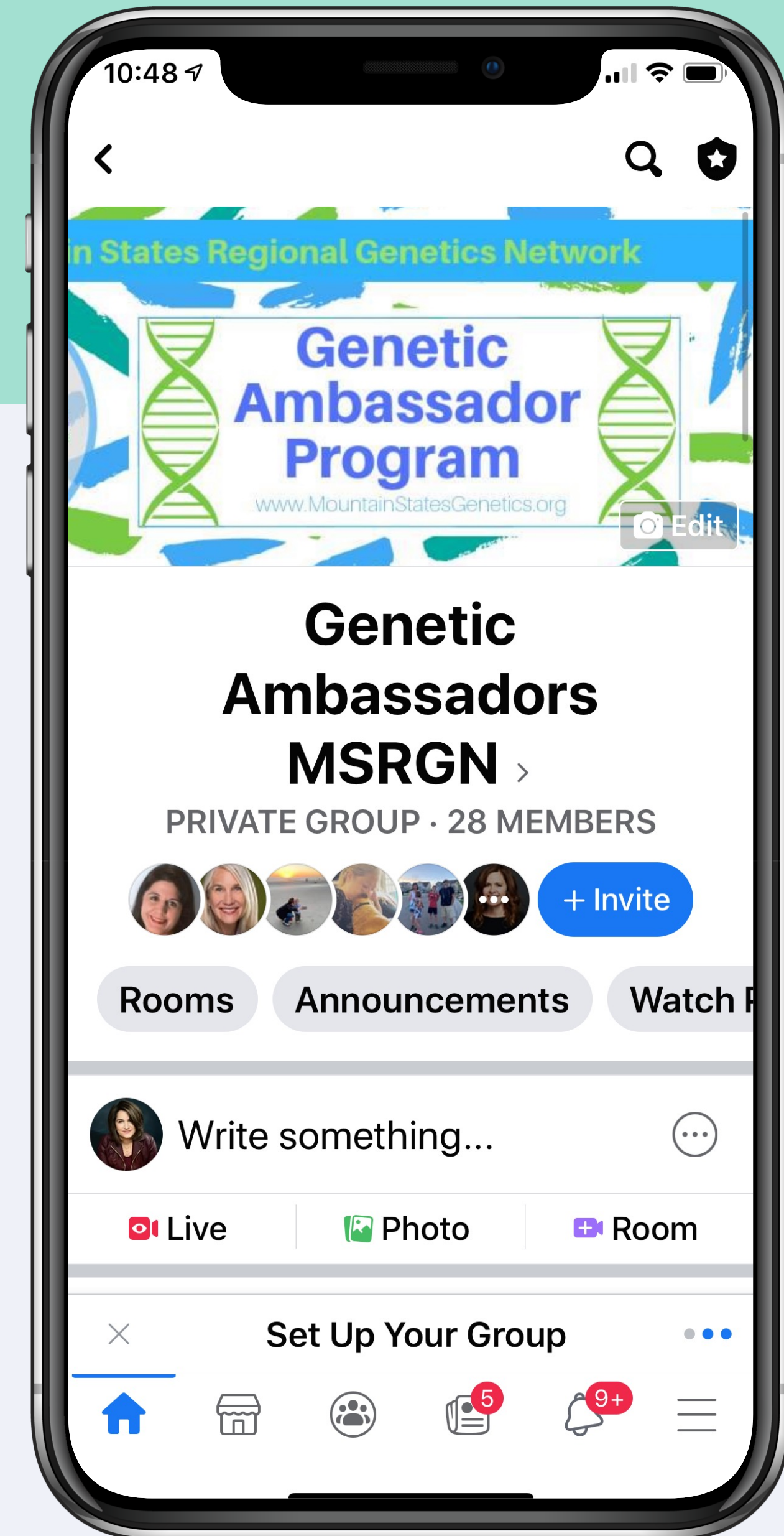
SEND KRISTI AN EMAIL TO BE ADDED

She will need your EMAIL you log into Facebook with to send invite



LINKS TO SHARE

I Post items here that you may want to share with your networks.



MSRGN NEWSLETTER



Email Kristi to be added if you are not already receiving the Newsletter



LINKS TO SHARE & Latest News on Projects



March 2021

MSRGN Project Directors' Message



Bloom where you are planted! Spring has sprung in the MSRGN region with the first signs of blooming trees, daffodils, and tulips poking their heads up to see if the coast is clear! Much of our region is thawing from a strange winter, except maybe in AZ where this week it is in the 90's!

MSRGN March Highlights:

- This month we **LAUNCHED** our **Time 4 Genetics Initiative**! Thank you to all our state teams who have helped in identifying the 7 primary care clinics participating in the program.
- We have decided on a **DATE** for the **Genetics Summit 2021**! Please

Joyce Hooker is Retiring!

join us in wishing her well



Joyce has been a cornerstone of MSRGN with all its various names, iterations, and formats since 1985, and now after over 36 years of being involved in the genetics services system in the Mountain States Region, she will be 'officially' retiring on 5/31/21. She is looking forward to not keeping track of which time zone she is in when she travels! If Joyce has touched your life, your work or your connection with the network in some way, and you would like to send her some well wishes for the next part of her journey, please send them [here](#). (We will be collecting them and sharing them with her soon!)



NANCY WYNNE NEWHALL

The (genetics) wilderness holds answers
to questions we have not yet learned to ask.

Any questions?

You can find me at

kwees@MountainStatesGenetics.org

281-831-3481 (text or call)



GET IN TOUCH WITH ME

OFFICE HOURS- Monday- Thursday

Keep in Touch.