

GENETIC AMBASSADORS

Mountain States Regional Genetics Network

October 2020



AGENDA

Welcome and Introductions by All

Intro:

- *Tell us your Name*
- *Group you represent or if you represent yourself*
 - *State you live in*
- *Question: What are you most grateful for?*

Grant Updates-Kristi

- EDS Algorithm
- 40 Clinic Initiative
- Genetic Pop-Ups

Genetic Ambassador Project: Red Flags Survey- All

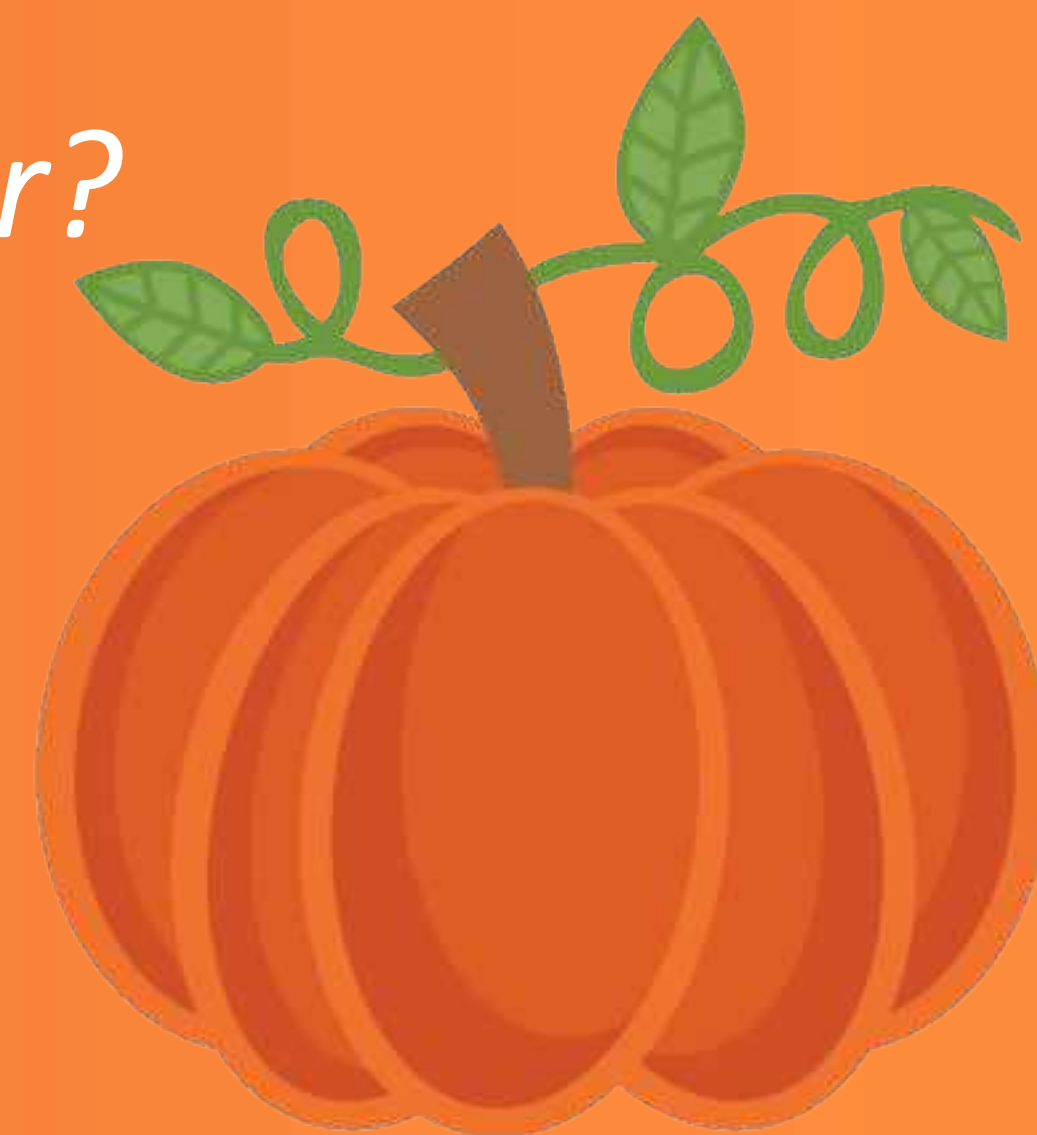
What's coming up/Final Thoughts –Kristi

- MSRGN Virtual Winter Meeting



Introductions & Question

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A WARM WELCOME

to our new 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.

MEET OUR MANAGEMENT TEAM

For MSRGN



Ankit
CEO at Texas Health
Institute
Texas



Kathy
Hematologist
Colorado



Janet
Metabolic Geneticist
Colorado



Joyce
State Teams
Colorado

MEET OUR MANAGEMENT TEAM

For MSRGN



Cody
Administrative Assistant
THI, TX



Stephanie
Meetings and
Convenings
THI, TX



Katie
Assistant with Meetings
and Convenings
THI, TX



Liza
Evaluation
KY



Sherry
Financial and
Operations
THI, TX

THE MOUNTAIN STATES REGION

8 States



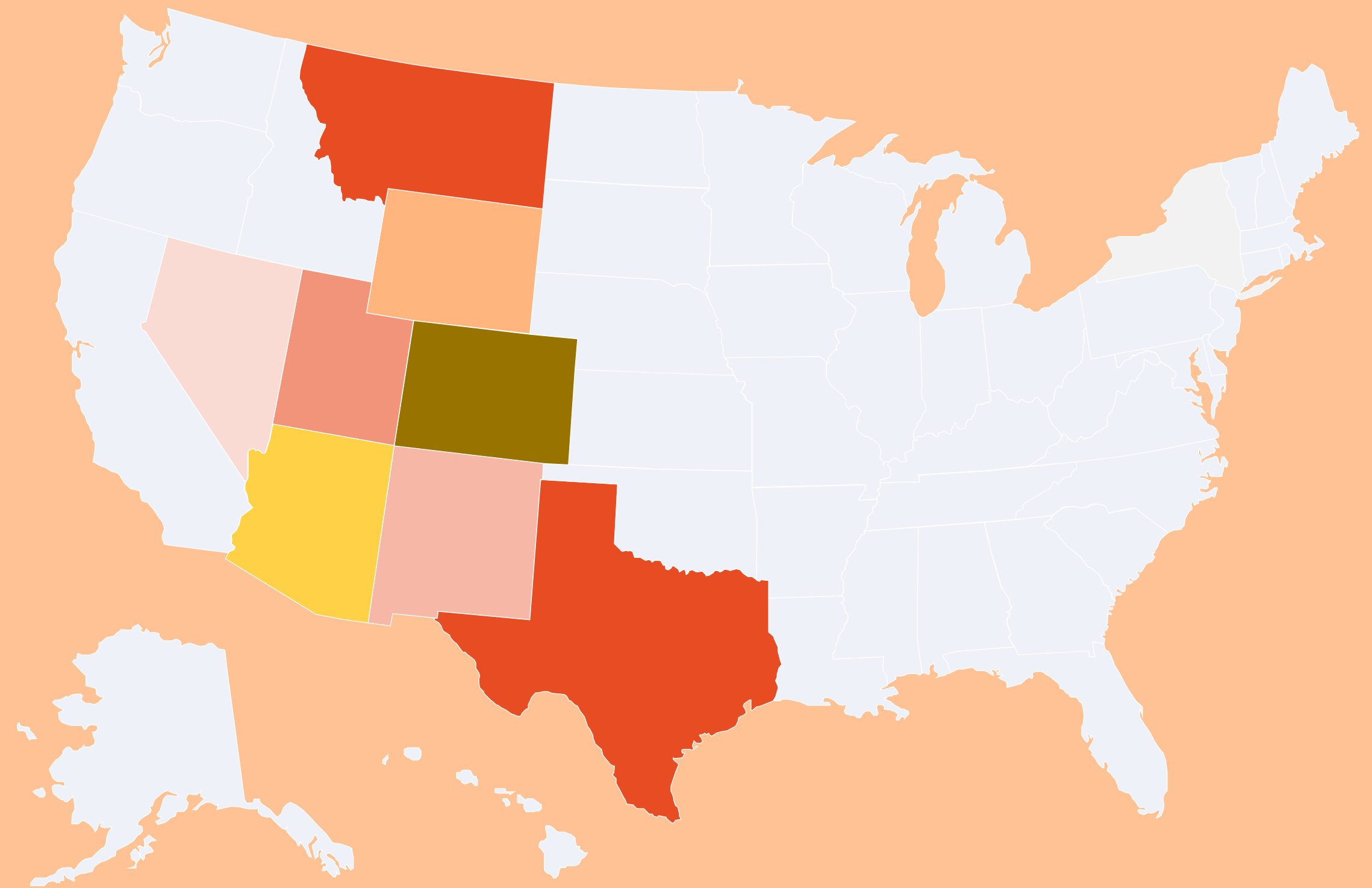
Geography

Our 8 states represent 1 million Square Miles!



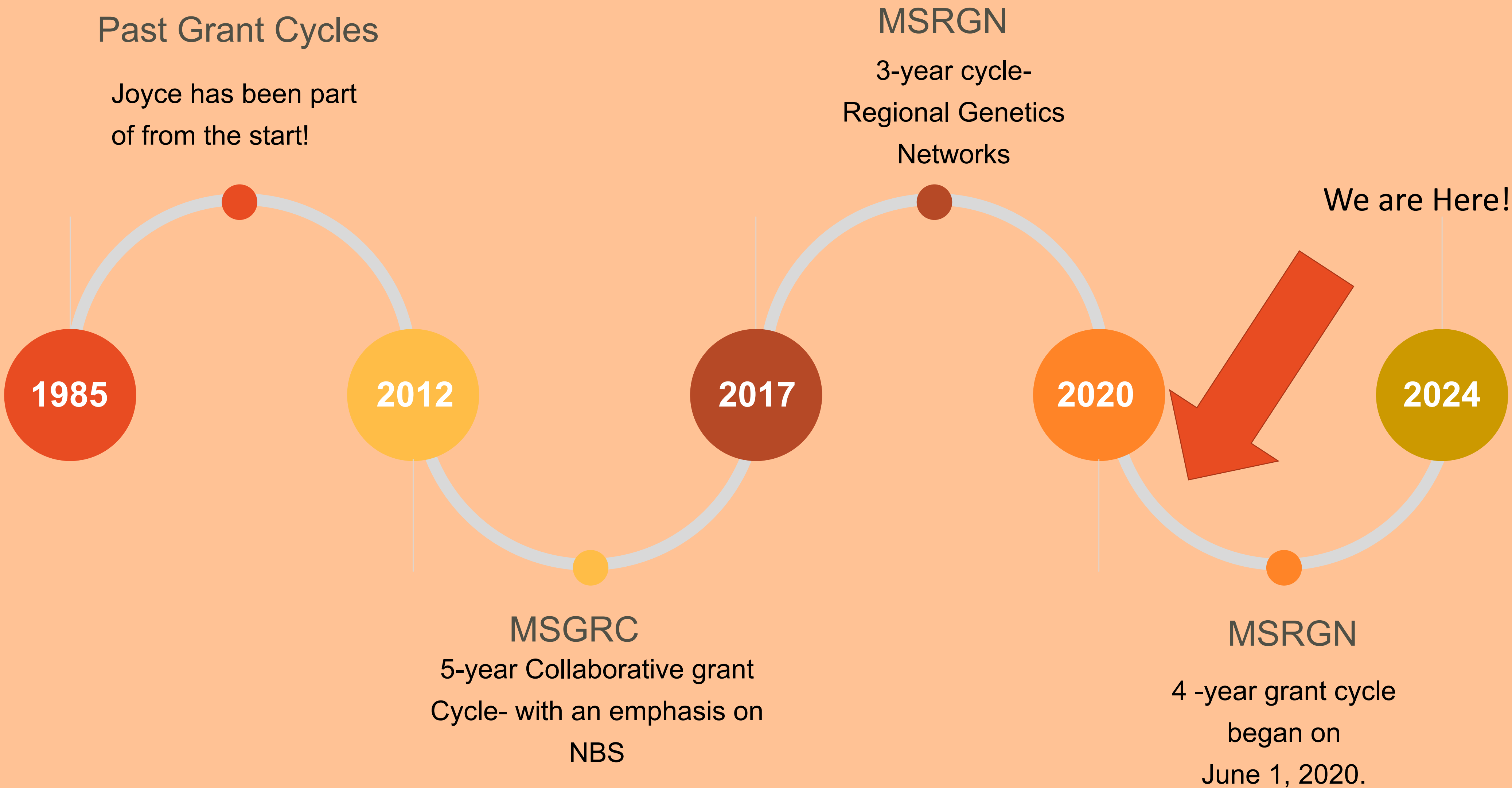
Genetics

Most states only have 1 genetics center.



MOUNTAIN STATES TIMELINE

Through The Years



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

EDS Algorithm

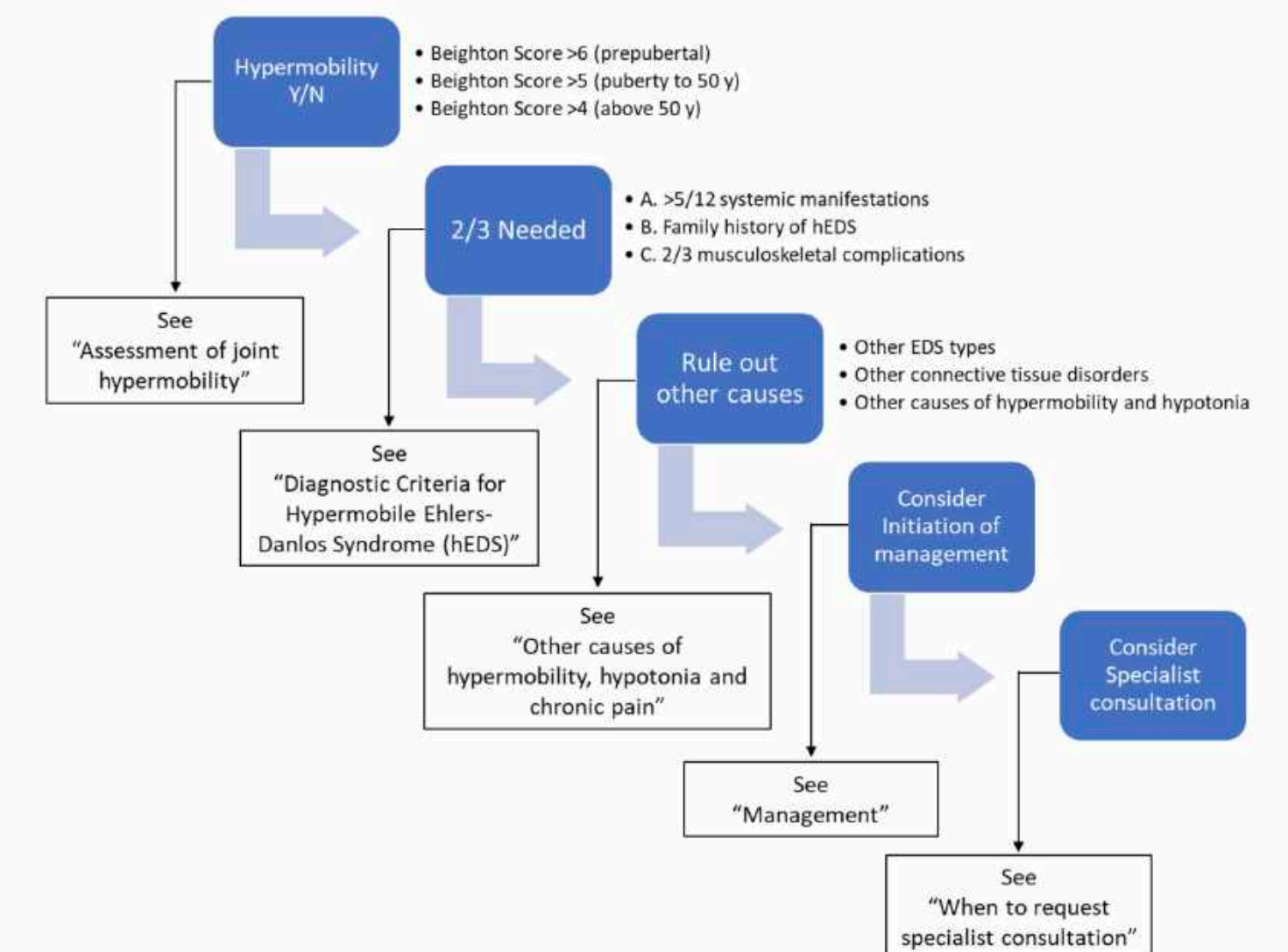


EDS Algorithm
Launched July 2020

- EDS stands for Ehlers Danlos Syndrome
- This algorithm is for primary care and pediatric providers
- Genetic Ambassadors can help to distribute it!
- Colorado VES Webinar on November 10th on EDS

Algorithm for diagnosis, management, and referral

This algorithm serves as a quick reference on how to approach JHS/hEDS. Each step (blue boxes) links to a more detailed description in this guide (rectangles). It is based on the 2017 diagnostic criteria for JHS/hEDS (Malfait et al. 2017).



<https://www.mountainstatesgenetics.org/projects/eds-algorithm/>

NEW INITIATIVE LAUNCHING

40 Clinic Initiative



40 Clinic Initiative

Coming
December 2020

- The 40 Clinic initiative will strive to build relationships with, equip and provide technical assistance for 40 primary care/pediatric clinics in our region with 5 per each state ($5 \times 8 = 40$).
- MSRGN staff will outreach and equip these “genetic champion” primary care/pediatric clinics with developed tools to assist them with genetics in their clinic.
- State team choosing 1 for year 1
 - How GA can help

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

PROJECT UPDATE

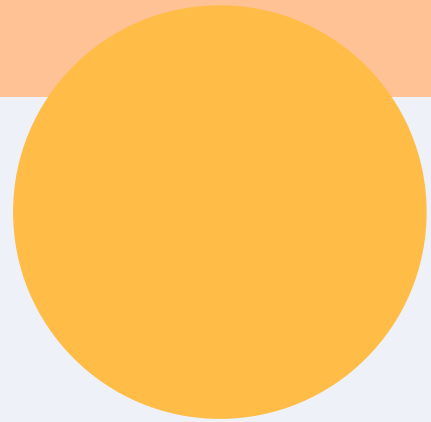
Genetics Pop-Ups



Genetic Pop-Ups
Going Virtual in
February 2021

- This year the Genetics Pop-Ups will be Virtual!
- There will be 8 funded spots available, 1 in each of our 8 states
 - Applications coming early December
 - Begin brainstorming now!

Questions- RED FLAG SURVEY



Any Questions Need Added



Re-wording of Questions



Ideas for distribution- GA or more widely?



Final Product- what could it look like

RED FLAGS

As reported BY FAMILIES FOR FAMILIES
Some examples...



Developmental Regression



Floppy Baby or LOW
Tone



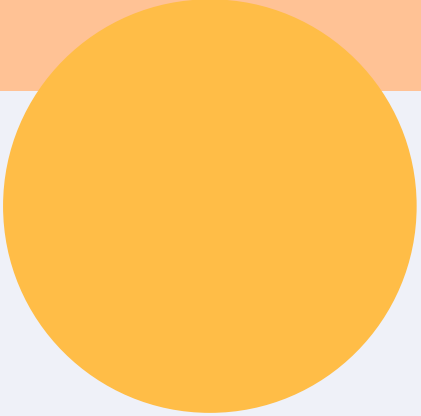
Crying ALL the time or
NEVER Cried (quiet
baby)



Feeding Issues

Link to Survey: <https://www.surveymonkey.com/r/MSRGNRedFlagSurvey>


Events and Final Thoughts




Family Advisory Council for the National Genetics Education and Support Center
Email Kristi if you would like more details



Scholarships available for AUCD (Association of University Centers on Disability) virtual conference (Dec. 7-9): Deadline NOVEMBER 2nd:
<https://www.aucd.org/conference/index.cfm/scholarships2020>



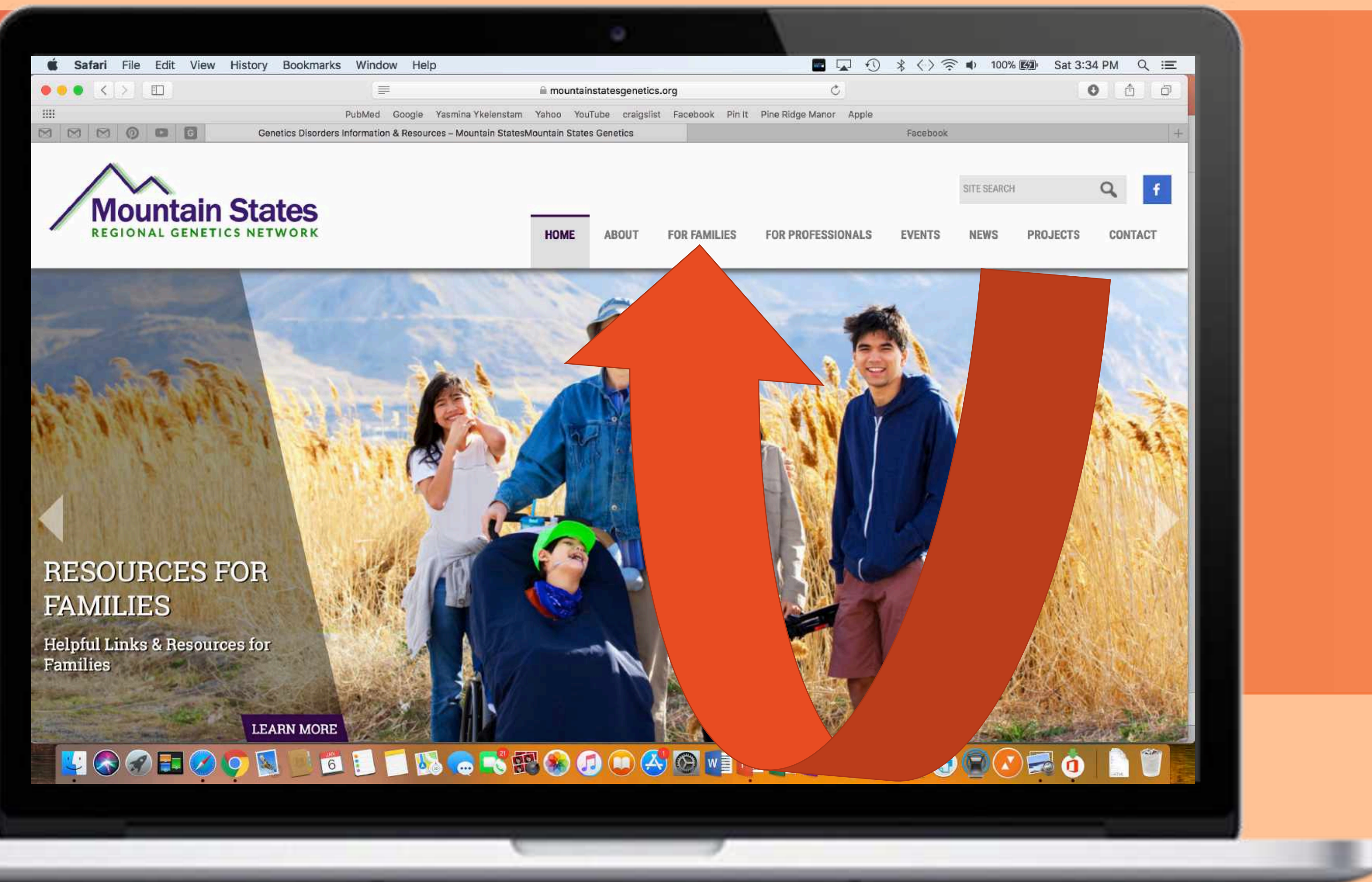
MSRGN Virtual Winter Meeting – January 28, 2020
You should have received a calendar invite, but if you haven't please email Kristi.



Next Genetic Ambassador Meeting will be last week in April (date TBD), since we will all be coming together for the MSRGN meeting in January

MSRGN WEBSITE

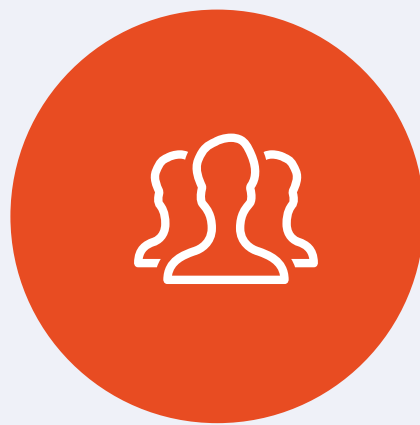
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WWW.MOUNTAINSTATESGENETICS.ORG

The Place for all things
Genetics in our Network!

GENETIC AMBASSADOR FACEBOOK GROUP



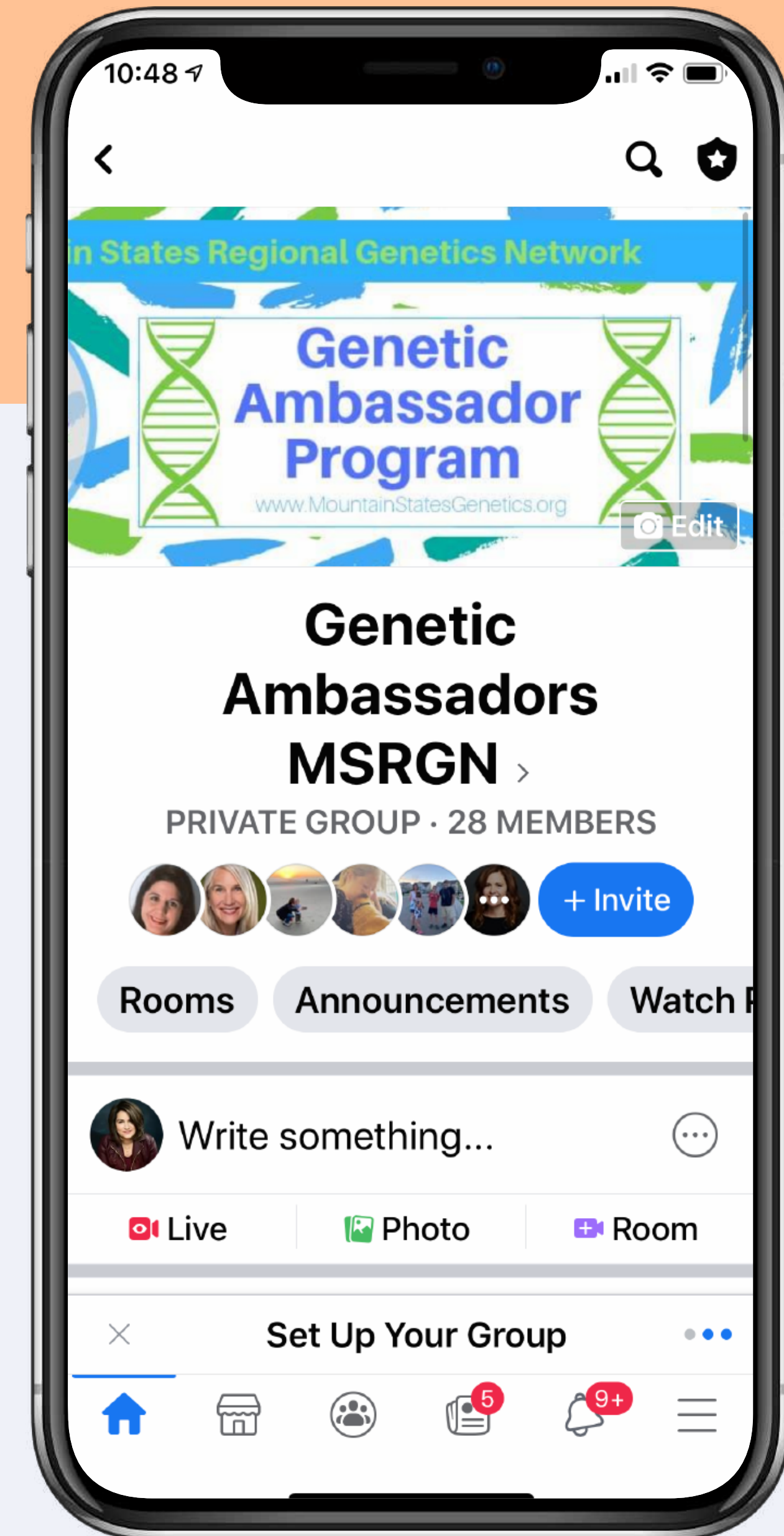
SEND KRISTI AN EMAIL TO BE ADDED

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



Fill out this form to be added

<https://www.surveymonkey.com/r/GETINVIVED>



LINKS TO SHARE & Latest News on Projects

Mountain States
REGIONAL GENETICS NETWORK

October 2020
MSRGN Project Directors' Message

Time 4 Genetics
MSRGN'S 40 CLINIC INITIATIVE

Dedicate 1 hour a month to improving your clinic's ability to serve those impacted by pediatric genetic conditions.

Mountain States
REGIONAL GENETICS NETWORK

Time 4 Genetics
We are excited to announce "Time 4 Genetics", MSRGN's 40-clinic initiative to educate, equip, and empower

Wyoming Genetics Services RFP

Wyoming has released a request for proposals for their outreach genetics clinics for the 2021 calendar year. The RFP can be found at publicpurchase.com by creating an account and searching for "0075-F". All questions regarding the content of the RFP can be asked via the public purchase website through October 15, 2020 and it will **close for bids on October 30, 2020.**



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.