

GENETIC AMBASSADORS

Mountain States Regional Genetics Network

July 2020



AGENDA

Welcome and Introductions by All

Intro:

*Tell us your Name
group you represent
state you live in*

Question: Would you rather live where it only snows or the temperature never falls below 100 degrees?

New Grant Overview and New Initiatives- Kristi

Genetic Ambassador Topics Brainstorming- All

- red flags

What's coming up (Calendar, Announcements)- Kristi



A WARM WELCOME

to our new Ambassadors

Kristi Wees

New Position: 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



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



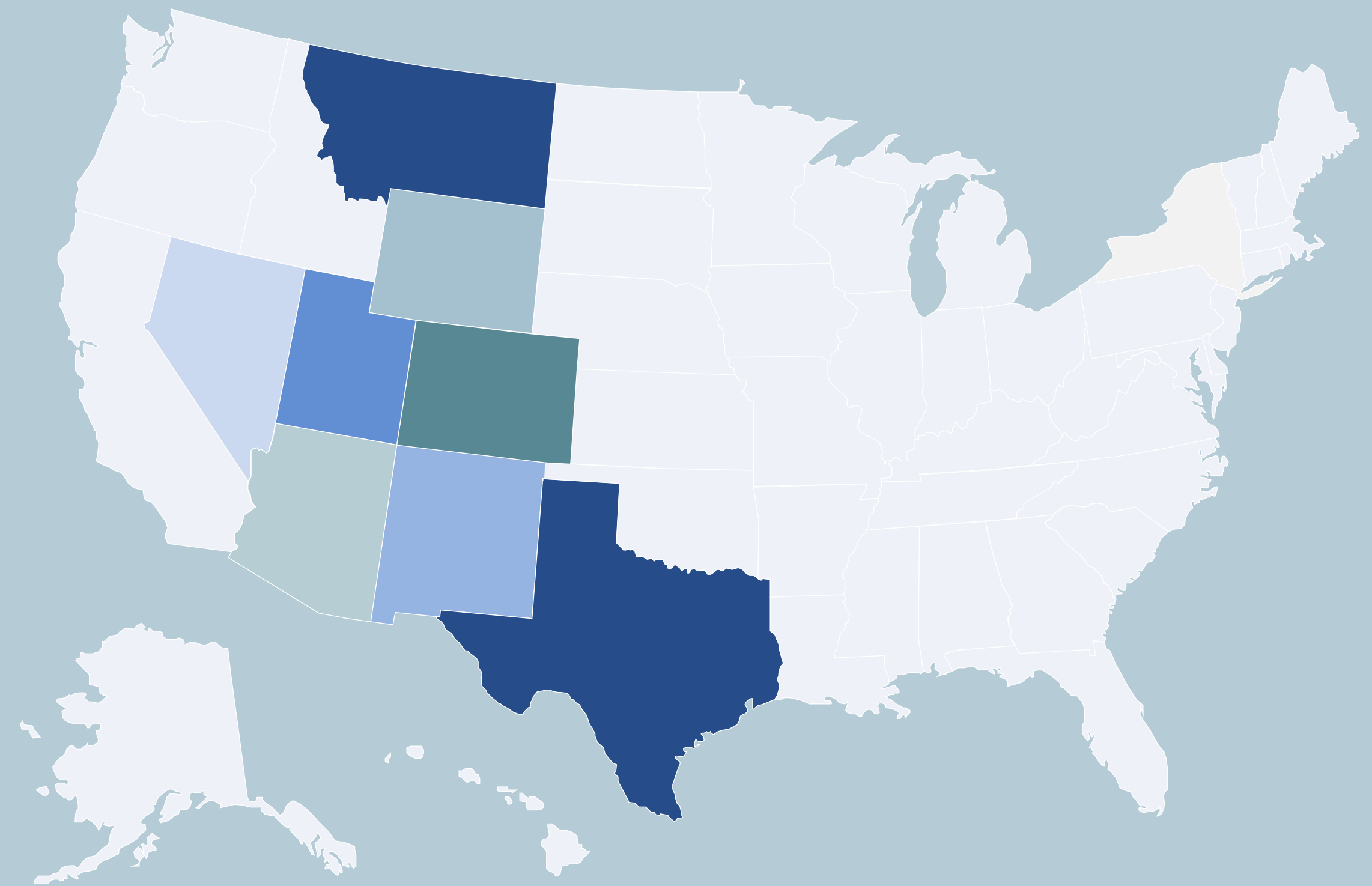
Geography

Our 8 states represent 1 million Square Miles!



Genetics

Most states only have 1 genetics center.



MOUNTAIN STATES TIMELINE

Through The Years

Past Grant Cycles

Joyce has been part
of from the start!

MSRGN

3 year cycle-
Regional Genetics
Networks

We are Here!



OUR CULTURE

Equal & Integral



Everyone is an equal and integral member of the Network.

Family First



Family comes FIRST, always!

First Name



We are all on a FIRST name basis. No need for title or letter.

All Genetic Conditions



Our organization is not disease specific. We do not represent individuals impacted by one genetic condition, but all individuals impacted by all genetic conditions

NANCY WYNNE NEWHALL

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

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



Genetic Ambassador Program

Going to a QUARTERLY Meeting

Guest Speakers

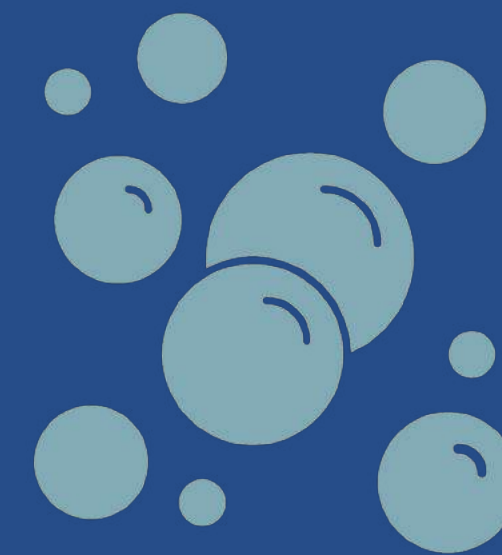
Other Topics

Genetic Pop-Ups

Funding for 8 Pop-Ups per Year

Next Round- Rare Disease Day 2021

Applications in December





State Teams

8 state teams led by 2 co-leads and consisting of a multidisciplinary team of genetics providers, public health individuals, consumers, families, primary care docs, etc.

Genetics Summit

An annual educational event held in our region.
Consumer Scholarships available.



GENETIC NAVIGATORS

NEW!

40 CLINIC INITIATIVE

NEW!

NEW INITIATIVES

Genetic Navigators

A new program will be developed to train and equip state genetic navigators, one per state in our region. This program will be stipend funded and will include individuals and families who have experience navigating the genetics system in their state. These individuals will also serve on the state team and work closely with them.



Genetic Navigator Program

Coming December 2020

NEW INITIATIVES

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 ($5 \times 8 = 40$). These clinics will be identified by our state teams and MSRGN staff will outreach and equip these “genetic champion” primary care/pediatric clinics with developed tools to assist them with genetics in their clinic.

BRAINSTORMING- 3 MIN

GENETIC AMBASSADORS

TOPICS

REPLY IN CHAT BOX:

What GENETIC related topics are you wanting to learn more about?

SPEAKERS

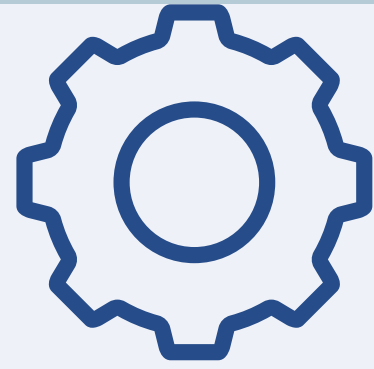
REPLY IN CHAT BOX:

WHO would you like to hear talk to our group?

TRAINING

REPLY IN CHAT BOX:

Is there a skill you are missing or some type of training you would like to attend that relates to GENETICS?



how to get testing
into newborn
screenings

Advocacy, Genomics education and
Newborn Screening or
developing genetic tests.

Disease areas:
Isolated Congenital Asplenia,
primary immunodeficiencies
and genetic birth defects

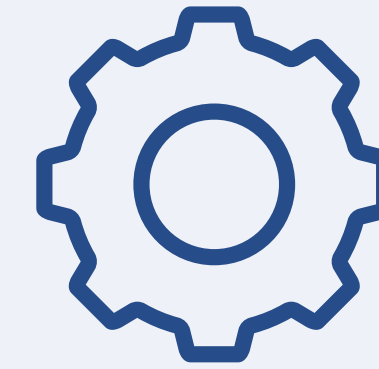
how can families continue to be
connected and partners with the
provider community in helping
families navigate
their genetic journey and accessing
resources.

SOME IDEAS

medical home, telemedicine,
and emergency preparedness
and telemedicine.

How to get
involved in
National Advocacy

Leadership
Training for
leading a Family
Support
organizations



EDS, rare disease,
invisible conditions, and
patient advocacy within
the navigation of medical
services

Undiagnosed
Conditions and
Individuals

how they were able to cultivate
doctor's interest and to go even
further with it how were done
able to get enough interest in
research beyond just case studies
for classification and diagnosis.

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

ANNOUNCEMENTS



Genetic Discrimination



The Cost of Rare Disease Survey



Global Genes Rare on the Road and
NORD Living Rare Forum just took place.



Calendar Continuation?

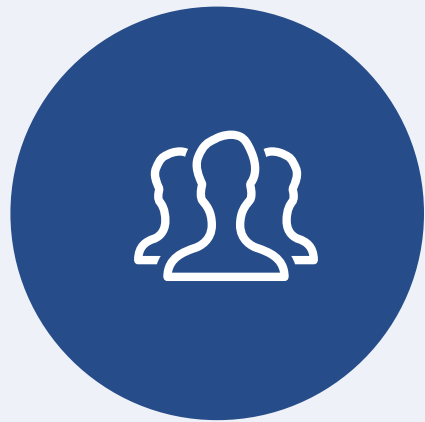
MSRGN WEBSITE

WWW.MOUNTAINSTATESGENETICS.ORG

The Place for all things
Genetics in our Network!



GENETIC AMBASSADOR FACEBOOK GROUP



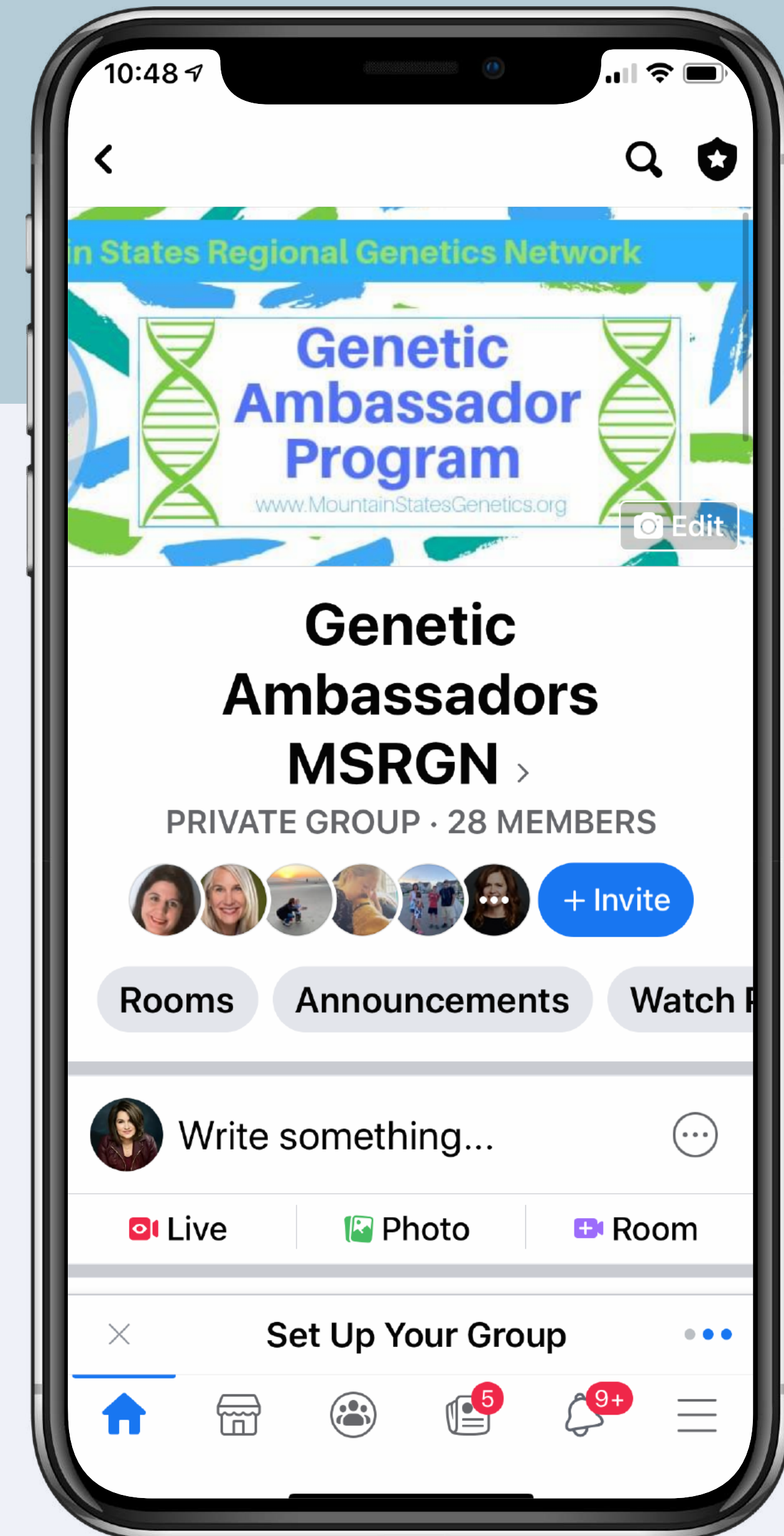
SEND KRISTI AN EMAIL TO BE ADDED

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.



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.