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 form 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.
Past Grant Cycles

Joyce has been part of from the start!

1985

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

2012

MSRGN
3 year cycle-Regional Genetics Networks

2017

2020

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

2024

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.
The (genetics) wilderness holds answers to questions we have not yet learned to ask.
There will be an added focus this grant cycle to increase education to primary care and pediatricians, in addition to individuals and families.

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.

Regional Infrastructure

Education

Telegenetics

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.
Funding for 8 Pop-Ups per Year

Genetic Pop-Ups
Funding for 8 Pop-Ups per Year
Next Round- Rare Disease Day 2021
Applications in December

Genetic Ambassador Program
Going to a QUARTERLY Meeting
Guest Speakers
Other Topics
An annual educational event held in our region.

Genetics Summit

Consumer Scholarships available.

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.
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
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 (5x8=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

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

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.

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
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!
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)