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

• Tell us your Name
• Group you represent or if you represent yourself
  • State you live in
• Question: What are you most grateful for?
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
Administrative Assistant
THI, TX

Cody
Administrative Assistant
THI, TX

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!

1985

2012

2017

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

MSRGN
3-year cycle- Regional Genetics Networks

2020

2024

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

We are Here!
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 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

https://www.mountainstatesgenetics.org/projects/eds-algorithm/
NEW INITIATIVE LAUNCHING

40 Clinic Initiative

• 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).
• 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

- 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!

Genetic Pop-Ups Going Virtual in February 2021
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
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.
MSRGN NEWSLETTER

Fill out this form to be added
https://www.surveymonkey.com/r/GETINVIVED

LINKS TO SHARE & Latest News on Projects

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

NANCY WYNNE NEWHALL
Any questions?
You can find me at
kwees@MountainStatesGenetics.org
281-831-3481 (text or call)