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
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.
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
  • State you live in

• 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.
Past Grant Cycles
Have been around since 1985 in one form or another

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

MSRGN
3-year cycle Regional Genetics Networks

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

We are Here!
PRIORITIES OF THIS GRANT CYCLE

Regional Infrastructure

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.

Education

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

Telegenetics

This is an ongoing focus in our region and nationwide. Our plans have been impacted by COVID19 and thus this is an ongoing area for discussion.
PROJECT UPDATES
Genetic Navigators

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

https://www.mountainstatesgenetics.org/msrgn-genetic-navigators-announced/
PROJECT UPDATES
Genetic Ambassadors Red Flags Survey

- 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

- 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
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

Genetic Pop-Ups
8 Virtual Pop-Ups held in February & March 2021
NEW INITIATIVE LAUNCHING
Time 4 Genetics

40 Clinic Initiative

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

- 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!

Video: https://youtu.be/baLf2435Hz4
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](https://rarediseases.org/living-rare-event-details/) 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/](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/](https://navajofamilies.org/)
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.
Email Kristi to be added if you are not already receiving the Newsletter

LINKS TO SHARE & Latest News on Projects
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)