



Genetic Ambassador June 2019 Call

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Mission:

To ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and information through facilitating a professional network of genetics clinics, key primary care practices, **consumer advocates**, and state health department resources.

Funding: This work is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$600,000.00 with 0 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.



YEAR 3!

June 1, 2019 starts YEAR 3 of our 3 Year Cooperative Agreement award from HRSA. Year 3 will end on May 31, 2020.

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Hello!

I am Kristi Wees

- Social Media Coordinator for MSRGN and MSGRC since 2012
- Consumer Engagement Director for MSRGN in 2018- present
- BS Chemistry Penn State and MS in Chemistry UCLA
- A mom to a child who doctor's suspect had a mitochondrial disease
- My other hat- Patient Advocate for EmpoweredAdvocacy.com



Genetic Ambassador Facebook Group



To Join- Email Kristi (kwees@mountainstatesgenetics.org)
And she will send you an invite to your email (through Facebook).
Please include the email address that you use for Facebook if it is
different from the one you email her from)

Mountain States Regional Genetics Network



Genetic Ambassador Program

www.MountainStatesGenetics.org



What is a Genetic Ambassador?

WHO?

- Consumers of genetic services, and parents, family members, family leaders and individuals with genetic conditions who live in one of the states in our region:

Arizona
Colorado
Montana
Nevada
New Mexico
Texas
Utah
Wyoming



Save the Date: 2019 Genetics Summit

SAVE THE DATE

MOUNTAIN STATES REGIONAL GENETICS NETWORK

**2019
GENETICS
SUMMIT**

SEPTEMBER 23-25

(State Team Meetings tentatively scheduled Sept. 22)

ALBUQUERQUE MARRIOTT
2101 LOUISIANA BOULEVARD NE
ALBUQUERQUE, NM 87110-5401

 Mountain States
REGIONAL GENETICS NETWORK

- ❖ September 23-25
- ❖ State team meeting:
September 22
- ❖ Albuquerque, New
Mexico
- ❖ Scholarship
DEADLINE:
July 1st!

Scholarship Information!

- ❖ MountainStatesGenetics.org
- ❖ See “News” Tab
- ❖ Scholarship DEADLINE:
July 1st!



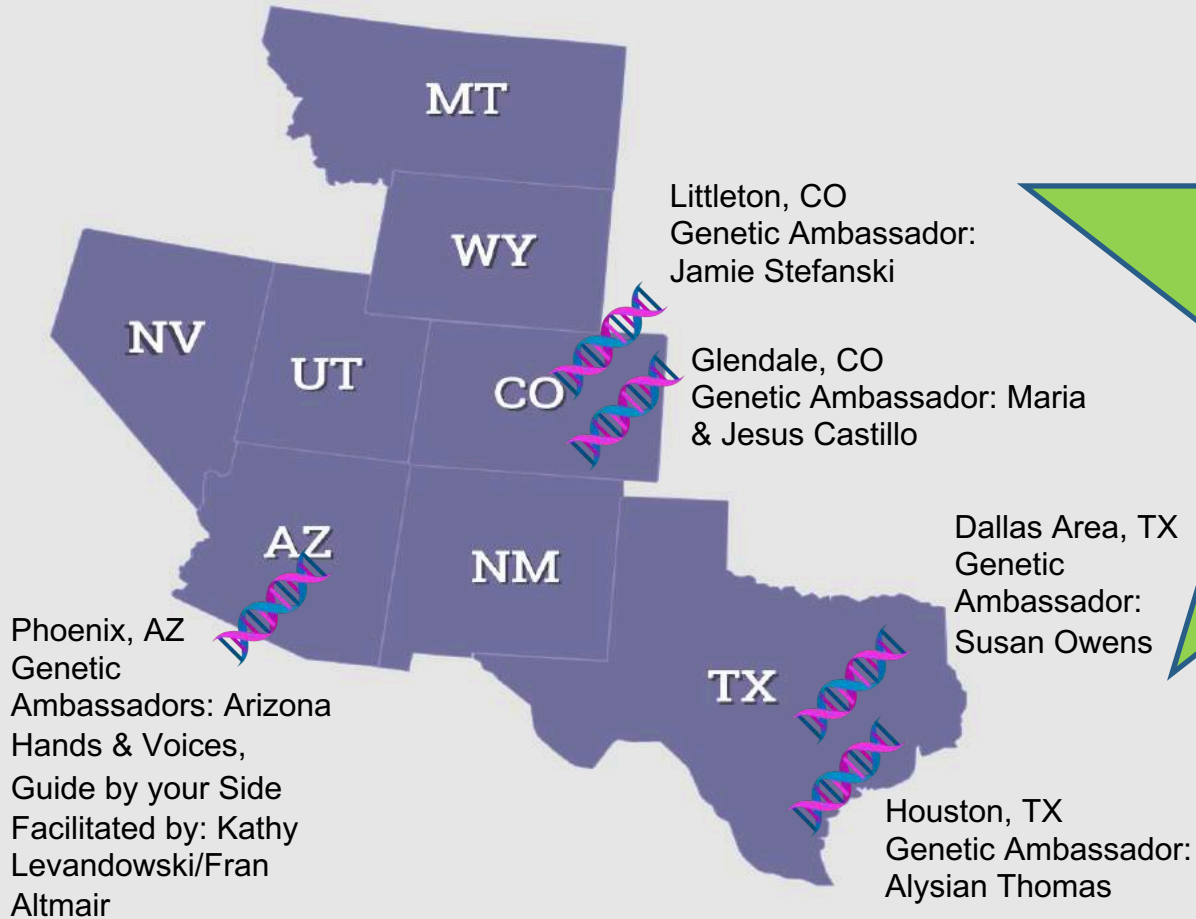
The screenshot shows the website's navigation menu with the 'NEWS' tab highlighted. Below the menu is a large image of an elderly man and a baby. To the right is a map of the Mountain States region with state abbreviations: MT, WY, CO, UT, AZ, NM, TX. Below the map is a 'News' section with a headline: 'Consumer Scholarship Application- Genetics Summit 2019' dated June 28, 2019. There is also a '2019 GENETICS SUMMIT' poster for September 23-25. On the right side of the page, there are 'Archives' and 'Categories' dropdown menus.

What is a Genetic Pop-Up ?

- ❖ **A Genetics Pop-up** is a small (5-8 person) gathering, held in your local community, spearheaded by you, a genetic ambassador, to share genetic resources.
- ❖ MSRGN will send you (Gene in a Box resource + sign in sheet)
- ❖ MSRGN will provide a \$300 budget to cover a \$20 stipend/gift card per attendee, and the remainder of the budget may be used for food/drink (no alcohol!) at the pop-up!



5 Genetic Pop Ups Completed



Thank you
so much!
We
appreciate
you all!

Genetic Acronyms!

A big thank you to Tracy Keller and the Colorado State team and consumers for taking this project on!

We would LOVE your feedback!

What is missing?

What term did you struggle with when you were first on your genetic journey?

Is this helpful?

Discussion- Collaboration!

Call with a few Colorado Consumers this week:

- They suggested adding to Genetic Ambassador calls a time to share upcoming state/regional/national events
- Keep a master Calendar
- Newsletter? Or way to communicate monthly upcoming events. (For Families Around our Region)
- Would everyone be willing to have a slightly longer call to accommodate this? 1.5 hr with last 20-30 min dedicated to GA sharing!
- Serving on Groups Training is ending, what would you all like NEXT? (Leadership training, speakers, Highlight GA each month, a mix?)

MSRGN Facebook Page and Twitter

The screenshot shows the Facebook profile page for the Mountain States Regional Genetics Network. The page header includes the name "Mountain States Regional Genetics Network" and the URL "mountainstatesgenetics.org". The profile picture is a blue and white DNA double helix. The cover photo features a stylized mountain range logo with the text "Mountain States REGIONAL GENETICS NETWORK". The page includes a navigation menu on the left with options like Home, About, Photos, Events, Reviews, Videos, Posts, Community, Info and Ads, and Promote. The main content area shows a "Like" button, a "Following" button, and a "Share" button. Below this is a "Write a post..." section with options for "Create Post", "Live", "Event", "Offer", and "Job". There are also buttons for "Get More Page Likes" and "Get More Learn More". A "Our Story" section is visible at the bottom, describing the network as one of seven regional networks covering the area.

facebook.com/mountainstatesgenetics.org/

The screenshot shows the Twitter profile page for the Mountain States Regional Genetics Network. The profile picture is a circular image of three people. The header includes the name "Mountain States Regional Genetics Network" and the handle "@GeneticMtnState". The page shows 34 tweets, 10 following, 21 followers, and 3 likes. A tweet is visible, mentioning the "APHA Annual Meeting" and "Deborah Nyong'o, Graduate Research Asst working on the MSRGN Evaluation, presents a MSRGN poster: *Expanding Access to Health Care and Achieving Health Equity: Improving Our Understanding of Communities Facilitates Better Intervention Design in the...". There is also a "New to Twitter?" section with a "Sign up" button and a "Worldwide trends" section with various hashtags like #FeltMicrobes, #WesleyWisdom, and #14Nov.

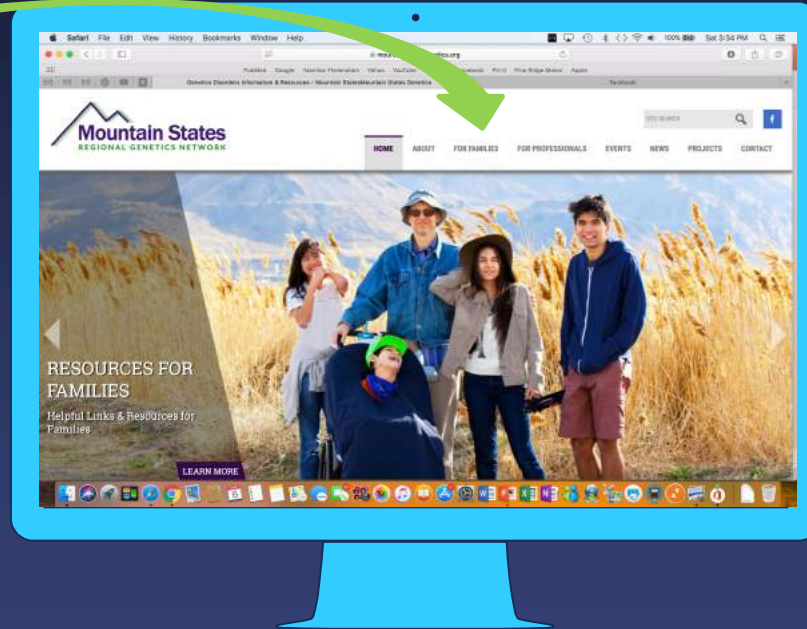
twitter.com/GeneticMtnState



www.MountainStatesGenetics.org

under FOR FAMILIES TAB:

- “Genetic Ambassador” Drop Down
- “Your Genetics Questions Answered” Drop Down



Thanks!

Any questions?

You can find me at

- kwees@MountainStatesGenetics.org
- 281-831-3481 (text or call)

