

Genetic Ambassador Program

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Hello!

I am Kristi Wees

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





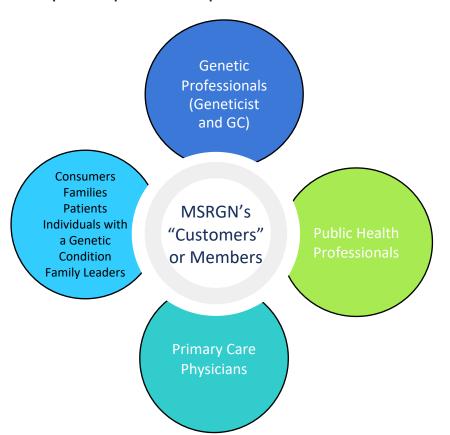


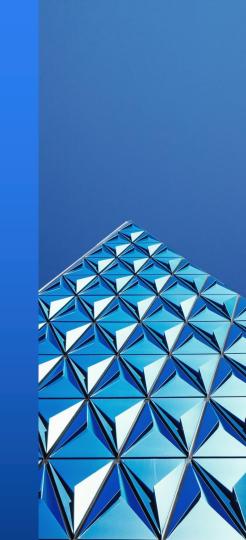
Mission:

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.

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MSRGN's Members: Consumer Advocates and genetics professionals participate as equals







Some History

- The Mountain States Region has always had strong consumer involvement in previous grant cycles.
- In the last grant cycle- MSGRC (Regional Collaboratives), consumers were members on all WORKGROUPS and many were co-leads of the WORKGROUPS.
- In the Regional Collaborative structure, a Consumer Advocacy
 Workgroup was one of the WORKGROUPS.
- In this grant cycle (6/2017-5/2020)- MSRGN (Regional Genetics Networks), there are no longer WORKGROUPS but instead we now have STATE TEAMS.
- The Genetic Ambassador Program was created to provide another avenue for consumers to get involved with Mountain States.



Mountain States Regional Genetics Network



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





#1

A program within MSRGN to help promote genetic awareness and access to genetics care. Participation can include any or all activities:

1. Serve on the state team for your state

AND/OR

All of our State Teams have consumer members, some are looking for more and some are not at this moment.



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- 2. Assist with projects including (but not limited to):
- UPP (Underserved Population Project sites: Tuba City, San Antonio, Grand Junction & Durango).
- Developmental Delay Algorithm
- Medicaid Waivers Navigation
- Genetic Testing & Training Manual
- Navajo Genetic Literacy Social Media Graphics
- Telegenetics Outreach and Training
- Project ECHO
- Primary Care Genetics Webinars (IHS)

#2

Many of these projects are in various stages. If any of them are of interest to you, please contact Kristi for more info.





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3. Assistance with awareness, outreach and dissemination of information about genetics, MSRGN, MSRGN products, website, and social media links to the ambassador's local community.

AND/OR

#3

Are you someone who loves to be ON-LINE and would like to help share #genetic resources?



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4. Spearhead a **Genetics Pop-up** in your local community (more details coming in January/February 2019)



WHEN?

- Once a month conference call for the genetic ambassador program calls.
- For the first few months of the program these calls will be covering the serving on groups curriculum that will be kicked off at the Genetics Summit October 2018.
- If the ambassador participates on their state team, a once a month call is expected.
- Other projects calls may occur 1-2x per quarter.
- Another in-person meeting at Genetics Summit is being planned for fall 2019. Stay Tuned for scholarship opportunities, if available.



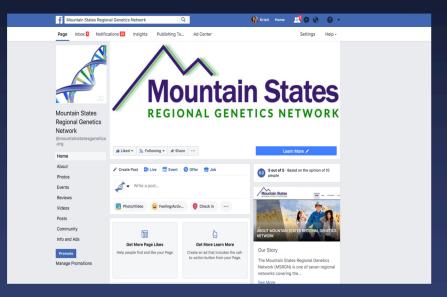
Genetic Ambassador Facebook Group



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)



MSRGN Facebook Page and Twitter





facebook.com/mountainstatesgenetics.org/

twitter.com/GeneticMtnState



www.MountainStatesGenetics.org

Genetic Ambassador information is not listed here yet! But much more information about MSRGN can be found here.





Thanks!

Any questions?

You can find me at

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

