



Mountain States
REGIONAL GENETICS NETWORK

Genetic Ambassador April 2019 Call

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Director of Consumer Engagement
Social Media Coordinator
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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
- BS Chemistry Penn State and MS in Chemistry UCLA
- A mom to a child who doctor's suspect has a 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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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



What's New at MSRGN



Join Us... April 24th
Autism Awareness Month
April 24th : 3 Questions and 3 Facebook Lives:
7/8/9pm ET, 6/7/8pm CT, 5/6/7pm MT, 4/5/6pm PT
on the Mountain States Genetics Facebook Page

Dr. Scott
Answers
3 Common
Questions
about
#Genetics
and #Autism
on Facebook Live

Your Questions Answered about...
GENETICS AND AUTISM
Mountain States
REGIONAL GENETICS NETWORK

Dr. Daryl Scott
Associate Professor
Molecular and Human Genetics
Baylor College of Medicine



Your
GENETIC QUESTIONS
Answered

by
Mountain States
REGIONAL GENETICS NETWORK

- ❖ Facebook Live! Your Genetic Questions Answered
- ❖ Autism

Call for Consumer Subject Matter Experts

- ❖ We have hundreds of questions many of which can be answered by you!
- ❖ Our region is filled with subject matter experts, including our consumers!
- ❖ Contact Kristi if interested

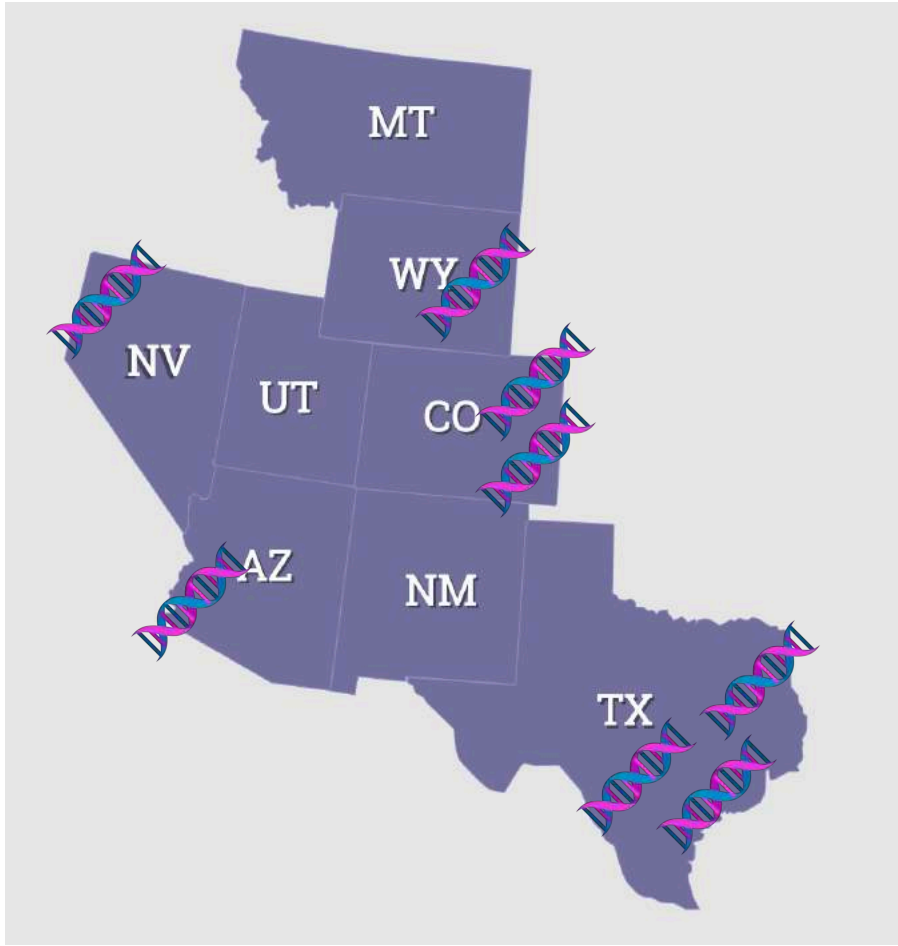


What is a Genetic Pop-Up ?

- ❖ **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!



8 Genetic Pop Ups!



Alysian (Houston, TX)
(date of popup 4/27/19)

Maria (Edgewater, CO)
(date of popup: 5/4/19)

Jamie (Littleton, CO)
(date of popup 5/5/19)

Kathy/Dawn (Yuma, AZ)
(date of popup: week of May
13)

Susan (Dallas Area, TX)
(possibly the week of 5/20)

Mary (Reno, NV)
(date of popup: 5/23/19)

Melissa (Austin, TX)
(date not set yet)

Kenneth (Sheridan, WY)
(date not set yet)

Family Voices Leadership Conference

- ❖ 3 Scholarship Winners + 1 RGN Staff are headed to Washington DC
- ❖ Jenn
- ❖ Jamie
- ❖ Allysa
- ❖ + Kristi
- ❖ **Scholarships from: National Genetics Education and Family Support Center**

National Genetics Education and Family Support Center

- ❖ Scholarships-
- ❖ Adrienne went to AMCHP
- ❖ Melissa went to Kansas City for SOG training

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



- ❖ September 23-25
- ❖ State team meeting:
September 22
- ❖ Albuquerque
- ❖ New Mexico



Resource of the Month!

NIH National Center for Advancing
Translational Sciences

GENETIC AND RARE DISEASES Information Center

GARD: The Genetic and Rare Diseases Information Center (GARD) is a program of the National Center for Advancing Translational Sciences (NCATS) and is funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides the public with access to current, reliable, and easy-to-understand information about rare or genetic diseases in English or Spanish.

Visit our website to access our A-Z library of information:

<https://rarediseases.info.nih.gov/>

Need extra assistance?

Get in touch with a GARD Information Specialist:

Phone: 888-205-2311

Online: <https://rarediseases.info.nih.gov/about-gard/contact-gard>

Mail: Genetic and Rare Diseases Information Center
P.O. Box 8126, Gaithersburg, MD 20898-8126

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



The screenshot shows the Facebook profile page for the Mountain States Regional Genetics Network. The page features a blue header with the name and a search bar. Below the header is a navigation menu with options like 'Page', 'Inbox', 'Notifications', 'Insights', 'Publishing Tools', 'Ad Center', 'Settings', and 'Help'. The main content area includes a profile picture of a DNA double helix, the organization's name 'Mountain States Regional Genetics Network', and a bio. There are also buttons for 'Like', 'Following', and 'Share', along with a 'Learn More' link. The page is divided into sections for 'Home', 'About', 'Photos', 'Events', 'Reviews', 'Videos', 'Posts', 'Community', 'Info and Ads', and 'Promote'.

facebook.com/mountainstatesgenetics.org/



The screenshot shows the Twitter profile page for the Mountain States Regional Genetics Network. The page features a blue header with the name and a search bar. Below the header is a navigation menu with options like 'Home', 'Moments', 'Search Twitter', and 'Have an account? Log in'. The main content area includes a profile picture of three people, the organization's name 'Mountain States Regional Genetics Network', and a bio. There are also buttons for 'Tweets', 'Following', 'Followers', and 'Likes', along with a 'Follow' button. The page is divided into sections for 'Tweets', 'Tweets & replies', 'Media', 'New to Twitter?', and 'Worldwide trends'.

twitter.com/GeneticMtnState



FACEBOOK LIVE!! To see videos

facebook.com/mountainstatesgenetics.org/



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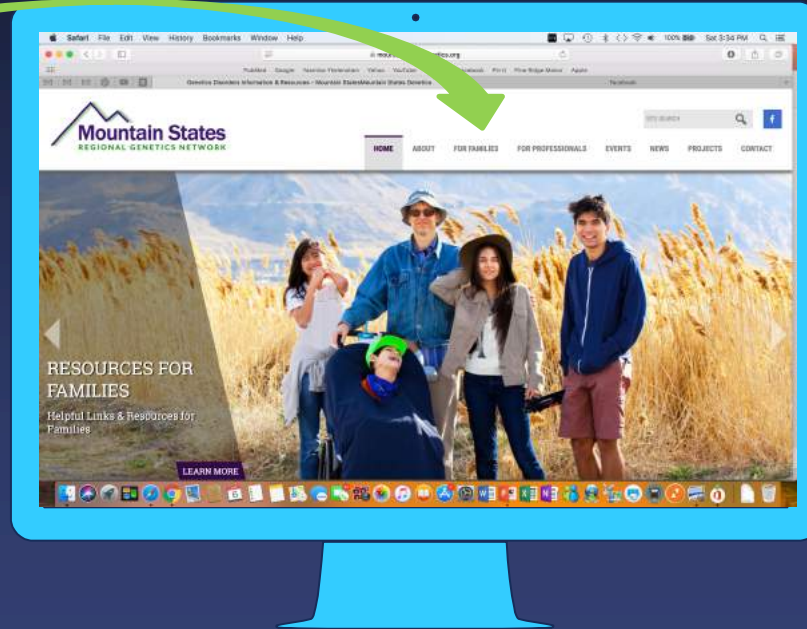
Your Questions Answered about...
GENETICS AND AUTISM
By Mountain States
REGIONAL GENETICS NETWORK

Dr. Daryl Scott
Associate Professor
Molecular and Human Genetics
Baylor College of Medicine

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)

