



Genetic Ambassadors Call

October 2019

Kristi Wees, MS Chem
Consumer Engagement Director
Mountain States Regional Genetics

Hello! I am Kristi



- 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



Agenda

1. Genetic Summit 2019 Recap
 - Scholarship Perspectives and Others
2. Global Genes 2019 Recap
 - Heather Schichtel (CO)
 - Carrie Ostrea (NV)
3. Genetics Pop-Ups
 - Rare Disease Day 2020
4. GA Calendar
 - Collecting events! Send them to me!
5. Recruiting for Facebook LIVE
 - Email me!

2019 Genetics Summit



DNA artwork © Mallery Quetawki-Zuni-Pueblo, 2007. All Rights Reserved.



PRESENTS:

2019 GENETICS SUMMIT

SEPTEMBER
23-25

ALBUQUERQUE MARRIOTT
2101 LOUISIANA
BOULEVARD NE
ALBUQUERQUE, NM 87110

Register Here:

WWW.MOUNTAINSTATESGENETICS.ORG



Featured Genetic Ambassadors: Heather and Carrie

- Global Genes Conference: RARE Patient Advocacy Summit
- <https://globalgenes.org/>
- Next Year's Conference: 09/21/2020 - 09/23/2020

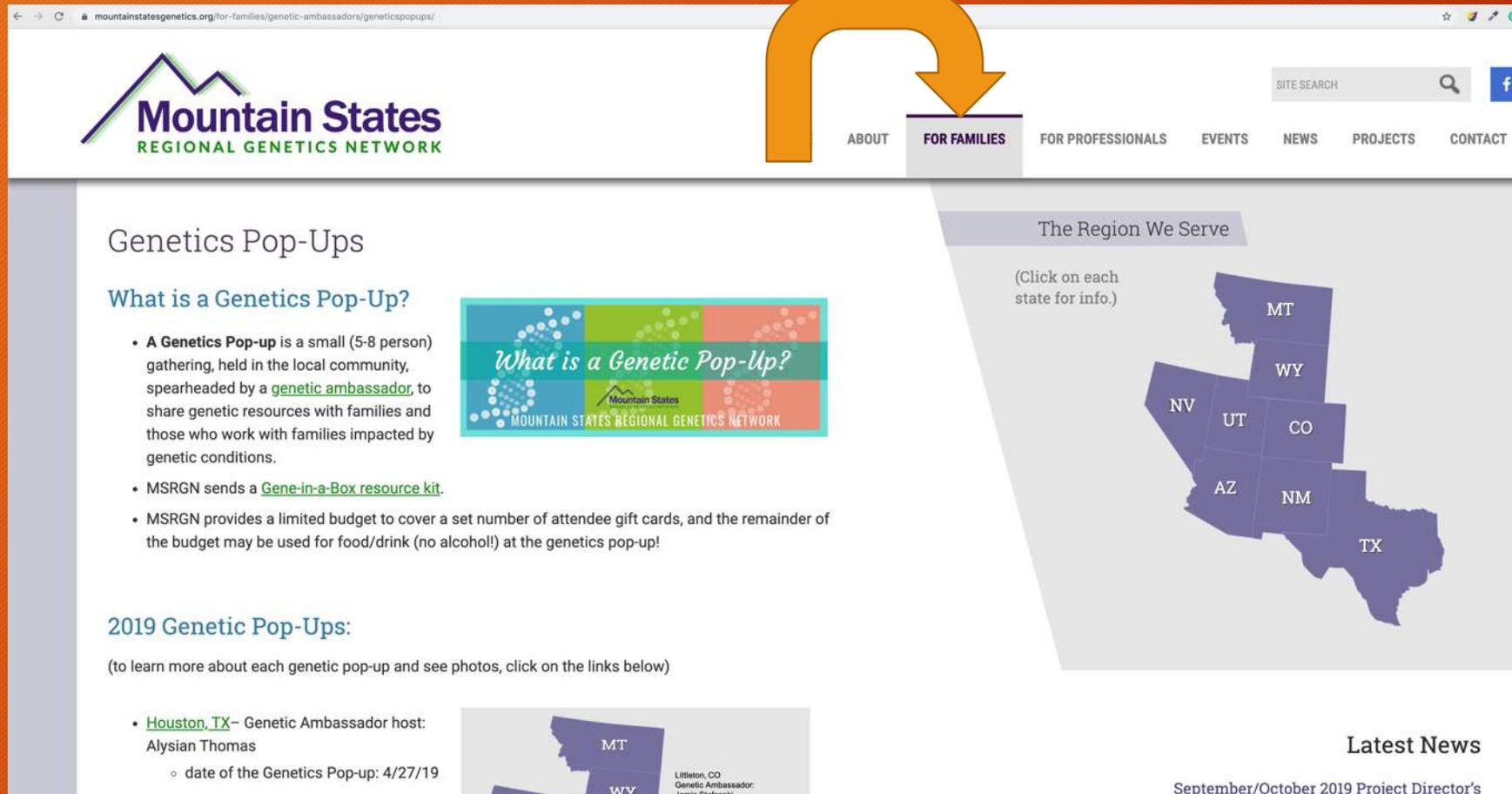


Genetics Pop-Ups: 2020 Rare Disease Theme



- Round 2 of Genetic Pop-Ups
- NEW THEME- Rare Disease Day
- Rare Disease Day: February 29, 2020
- 121 Days Away!
- <https://www.rarediseaseday.org/>
- Application for genetics pop-ups will be out next week!
- Funding available for 8 pop-ups, 1 per state
- Deadline for application: December 1, 2019

Genetic Pop-Ups on the Website



mountainstatesgenetics.org/for-families/genetic-ambassadors/geneticspopups/

Mountain States
REGIONAL GENETICS NETWORK

ABOUT **FOR FAMILIES** FOR PROFESSIONALS EVENTS NEWS PROJECTS CONTACT

SITE SEARCH [magnifying glass icon] [Facebook icon]

Genetics Pop-Ups

What is a Genetics Pop-Up?

- A **Genetics Pop-up** is a small (5-8 person) gathering, held in the local community, spearheaded by a **genetic ambassador**, to share genetic resources with families and those who work with families impacted by genetic conditions.
- MSRGN sends a **Gene-in-a-Box resource kit**.
- MSRGN provides a limited budget to cover a set number of attendee gift cards, and the remainder of the budget may be used for food/drink (no alcohol!) at the genetics pop-up!



2019 Genetic Pop-Ups:

(to learn more about each genetic pop-up and see photos, click on the links below)

- **Houston, TX** – Genetic Ambassador host: Alysian Thomas
 - date of the Genetics Pop-up: 4/27/19
- **Littleton, CO** – Genetic Ambassador: Jamie Stefanski

The Region We Serve

(Click on each state for info.)



Latest News

[September/October 2019 Project Director's](#)

NORD is the USA Affiliate for Rare Disease Day

The screenshot shows the website for Rare Disease Day 2020, specifically the United States page. The header features the Rare Disease Day logo, a navigation menu with links for 'ABOUT THE DAY', 'EVENTS WORLDWIDE', 'GET INVOLVED', 'NEWS', and 'SHOP', and a 'Select Language' dropdown. A prominent banner reads 'RARE DISEASE DAY 2020 29 FEBRUARY' with a '121 DAYS TO GO' counter. Below the banner, a 'DONATE' button and a 'SIGN UP FOR UPDATES' button are visible. The main content area is titled 'UNITED STATES' and includes a 'NATIONAL ALLIANCE' section featuring the logo for NORD (National Organization for Rare Disorders). The central text, 'RARE DISEASE DAY IN UNITED STATES', explains that the USA joined the campaign in 2009 and provides information on past events and how to get involved. A 'Share this' section with social media icons (Facebook, Twitter) is also present. On the right side, there are buttons for 'EVENTS WORLDWIDE', 'DOWNLOAD MATERIALS', and 'FOLLOW US' with social media icons. The bottom section lists '2020 EVENTS IN UNITED STATES' with two featured events: 'RACE FOR RYLAND' in San Antonio and '2020 VEGAS CARES ABOUT RARE KIDS' in Henderson.

rarediseaseday.org/country/US/united-states

Select Language

RARE DISEASE DAY®

RARE DISEASE DAY 2020
29 FEBRUARY

121 DAYS TO GO

ABOUT THE DAY | EVENTS WORLDWIDE | GET INVOLVED | NEWS | SHOP

UNITED STATES

UNITED STATES

NATIONAL ALLIANCE

NORD
NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

RARE DISEASE DAY IN UNITED STATES

The USA joined Rare Disease Day in 2009, making the campaign a truly international affair. Diverse events and campaigns have been organised ever since then, and in 2013 President Barack Obama sent a letter proclaiming his support of the day.

In previous years, a huge variety of events have taken place across America from an inclusive online music campaign to make a compilation of songs to unite a global community, to races both in real time and virtual. High-School students with rare diseases have organised events at their schools and spoken in assemblies to raise awareness and the 'Beyond the Diagnosis' art exhibition also placed patients at the heart of the day.

For events in the US, please submit your information to the US specific website for Rare Disease Day: <https://www.rarediseaseday.org/send-us-your-event>

Find out about RareDisease Day in the US at <https://rarediseases.org/rare-disease-day>

Share this

f t

GET INVOLVED BY POSTING YOUR EVENT!

FRIENDS IN UNITED STATES:
Ryland Grace...

2020 EVENTS IN UNITED STATES

RACE FOR RYLAND
Lace up your shoes and
29 Feb 2020 San Antonio

2020 VEGAS CARES ABOUT RARE KIDS
Registration is open for
29 Feb 2020 Henderson

Arizona

Email sent

Arizona



Melinda Burnworth
Arizona State Ambassador
melinda.burnworth@rareaction.org

Follow Arizona RAN on Facebook

Colorado

Call Scheduled 11/5 at 11am ET

Colorado



Nick Kirchof

Colorado State Ambassador Needed

nick.kirchof@rareaction.org

[Follow Colorado RAN on Facebook](#)

Montana

Montana



Montana State Ambassador Needed
Interested in learning about the State
Ambassador Program and how to apply?
[Click Here](#)

Nevada

Nevada



Nevada State Ambassador Needed
Interested in learning about the State
Ambassador Program and how to apply?
[Click Here](#)

[Follow Nevada RAN on Facebook](#)

New Mexico

New Mexico



New Mexico State Ambassador Needed

Interested in learning about the State
Ambassador Program and how to apply?

[Click Here](#)

Follow New Mexico RAN on Facebook

Texas

Call Scheduled 11/5 at 1pm ET

Texas



Deborah Skolaski
Texas State Ambassador
deborah.skolaski@rareaction.org



Molly Plant
Texas Community Engagement Liaison
molly.plant@rareaction.org

What's Happening Now?



Would you like to volunteer to assist in hosting a local community awareness event? Do you have an opportunity for Texas' Rare Action Network to attend your event? Contact your State Ambassador today and learn more. Please check back regularly for news of upcoming events and activities in Texas.

Utah

Utah



What's Happening Now?



Utah State Ambassador Needed
Interested in learning about the State
Ambassador Program and how to apply?
[Click Here](#)

Follow Utah RAN on Facebook

Wyoming

Wyoming



Wyoming State Ambassador Needed
Interested in learning about the State
Ambassador Program and how to apply?
[Click Here](#)

Follow Wyoming RAN on Facebook

Calendar- November 2019

- SERN Webinar~
- Preparing Teens for Transition
- 11/12/19
- 7:30 pm ET



S E R N
SOUTHEAST REGIONAL
G E N E T I C S
N E T W O R K

CONSUMERS INTERACTIVE SESSIONS



Janet Hess, DrPH
Project Director
Florida Health and Transition
Services (HATS)
University of South Florida

**“Preparing Teens for Transition to
Adult Healthcare:
10 Steps for Successful Healthcare Transition”**

Janet Hess, DrPH
University of South Florida

**Tuesday, November 12, 2019
7:30 pm ET**

Live presentation available via Zoom
Register at the link below by Monday, November 11th:

<https://tinyurl.com/consumertransitioning>

A HRSA SPONSORED EVENT
GRANT #UH7MC30772
PI: Rani H. Singh PhD, RD

Calendar- December 2019

- Any Events?



Calendar- January 2020

- MSRGN Grant Proposal due- 1/14/20



Calendar- February 2020

- Rare Disease Day
- February 29,
2020



Calendar- Future Months March 2020- December 2020

- **May 2020-**

- Living Rare, Living Stronger 2020, Cleveland Ohio
- May 14-16, 2020

- **September 2020**

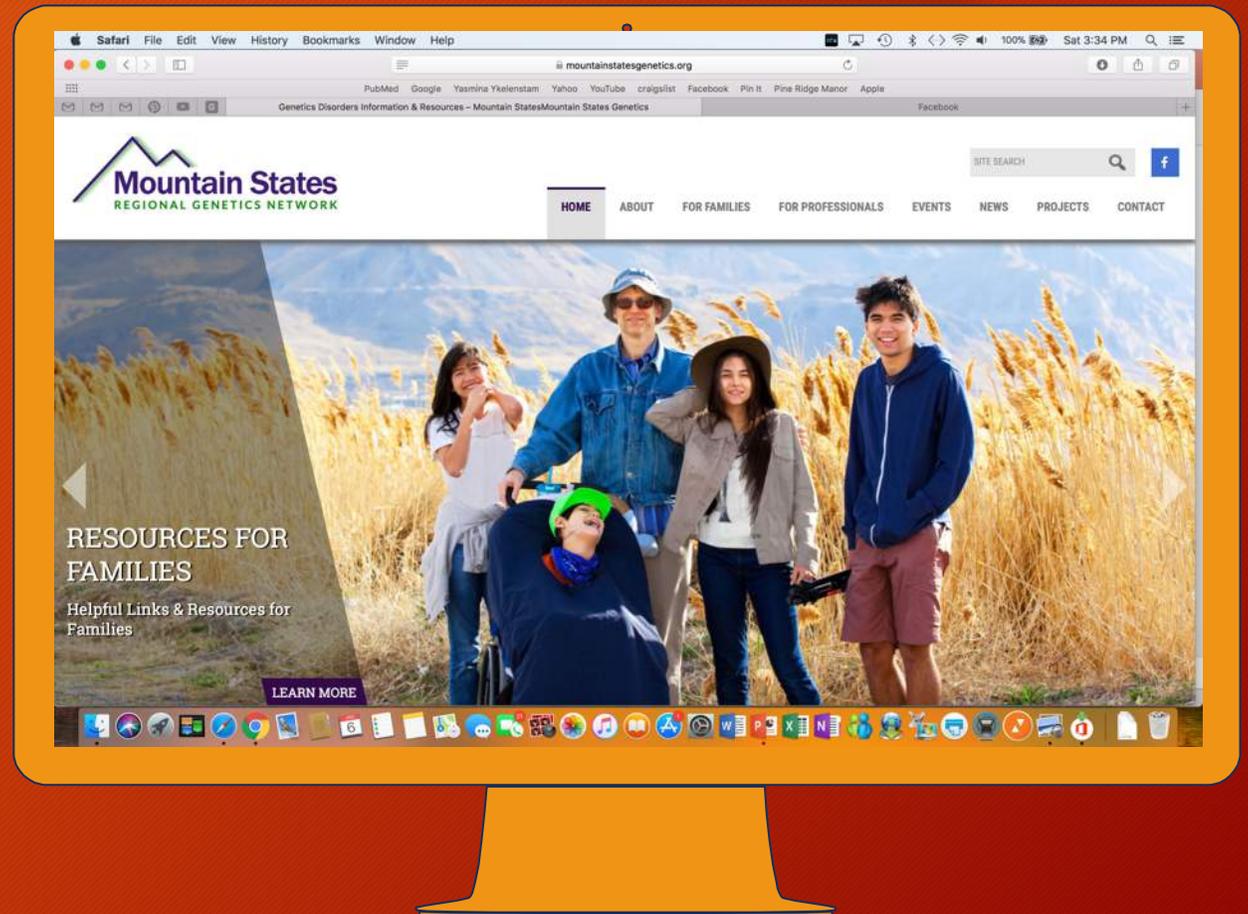
- Global Genes Conference, San Diego, CA
- Sept 21-23, 2020



www.MountainStatesGenetics.org

under FOR FAMILIES TAB:

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



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)

Thanks!

Any questions?

You can find me at

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