



November 2019

Genetic Ambassadors Call

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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

Genetics Pop-Ups

Rare Disease Day 2020

GA Calendar

New Grant Application

2020 Genetics Pop-Ups


- APPLICATION IS OPEN
- <https://www.mountainstatesgenetics.org/genetics-pop-up-application-is-open-for-2020/>
- DUE DECEMBER 1, 2019

practices, consumer advocates, and state health department resources.

The MSRGN is one of [seven regional networks](#) funded through the Healthcare Resources and Services Administration ([HRSA](#)). The MSRGN is focused on the following priorities:

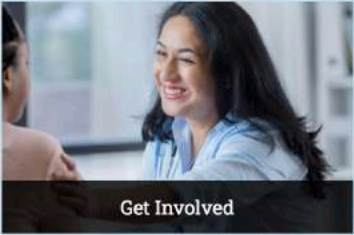
- linkage of medically underserved populations to genetic services
- implementation of quality improvement activities to increase genetic services
- implementation of evidence-based innovative models of telehealth/telemedicine focused on clinical genetics
- provision of resources to providers (genetics and primary care), public health professionals, and individuals with genetics conditions and their families.

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Latest News

- [Genetics Pop-Up Application is OPEN for 2020](#)
- [Texas DSHS Hosts Newborn Screening Grand Rounds: Spinal Muscular Atrophy \(SMA\)](#)
- [Utah State Team Developmental Delay Algorithm](#)
- [September/October 2019 Project Director's Message](#)
- [Virtual Education Series: Newborn Screening: Colorado, Past Webinars](#)



Get Involved



Find A Clinic

Genetics Pop-Ups: 2020 Rare Disease Theme



- Round 2 of Genetic Pop-Ups
- NEW THEME- Rare Disease Day
- Rare Disease Day: February 29, 2020
- <https://www.rarediseaseday.org/>
- Funding available for 8 pop-ups, 1 per state
- Deadline for application: December 1, 2019

Genetic Pop-Ups on the Website



Mountain States
REGIONAL GENETICS NETWORK

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

GENE SEARCH

Genetics Pop-Ups

Application open NOW for Genetic Pop-Ups 2020: [Click Here](#)

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
- [Glendale, CO](#) - Genetic Ambassador hosts: [unclear]

The Region We Serve

(Click on each state for info.)



Latest News

- [Genetics Pop-Up Application is OPEN for 2020](#)
- [Texas DSHS Hosts Newborn Screening Grand Rounds: Spinal Muscular Atrophy \(SMA\)](#)
- [Utah State Team Developmental Delay](#)

Rare Disease Day
2020

www.rarediseaseday.org

100 Days from TODAY!

The screenshot shows the homepage of the Rare Disease Day 2020 website. At the top right, there is a "Select Language" dropdown menu. The main header features the Rare Disease Day logo (a stylized eye with colorful rays) and the text "RARE DISEASE DAY 2020 29 FEBRUARY". Below the header is a navigation menu with links for "ABOUT THE DAY", "EVENTS WORLDWIDE", "GET INVOLVED", "NEWS", and "SHOP". A "100 DAYS TO GO" counter is also present. The main content area includes a large image of colorful hands, a "WHAT IS A RARE DISEASE?" section with a "FIND OUT MORE" button, and a "DONATE" button. Below this is a "2020 EVENTS" section with a "Country" dropdown menu, featuring an event titled "BRAZILIAN RARE DISEASE SCENARIO" by Casa Hunter, scheduled for 05 Mar 2020 - 06 Mar 2020 in São Paulo, Brazil. A "NEWS" section is also visible, with a headline "100 DAYS UNTIL RARE DISEASE DAY 2020!". On the right side, there are buttons for "SIGN UP FOR UPDATES", "EVENTS WORLDWIDE", "DOWNLOAD MATERIALS", and "FOLLOW US".

Rare Disease Day
2020

ON THE MAP



GET INVOLVED BY
POSTING YOUR EVENT!

Colorado

Colorado



Nick Kirchhof
Colorado State Ambassador Needed
nick.kirchhof@rareaction.org

Follow Colorado RAN on Facebook



Colorado Rare is moving ahead with plans for Rare Disease Day at the Capitol on Thursday, February 27



Texas



RARE DISEASE DAY

JOIN US TO RAISE AWARENESS

Saturday, February 29, 2020

10:30 a.m. – 2 p.m.

Sugar Land Town Square
Located at Highway 6 and U.S. 59
Sugar Land, TX 77479

Family Friendly Event with Live Music, Games & More

According to the National Institutes of Health (NIH), a disease is rare if it affects fewer than 200,000 Americans. One in 10 Americans live with a rare disease—affecting 30 million people—and nearly half of these patients are children. There are more than 7,000 rare diseases, 95 percent of which have no treatment. Often, research gets funded by the families and friends of patients or by patient organizations

Rare Disease Day is an annual awareness day celebrated around the world dedicated to elevating public understanding of rare diseases and calling attention to the special challenges people face. Rare Disease Day takes place every year on the last day of February (February 28 or February 29 in a leap year)—the rarest date on the calendar—to underscore the nature of rare diseases and what patients face.

RARE DISEASE DAY

RareTX.org



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



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

Nevada

Little Miss Hannah Foundation- Vegas Cares about Rare 5k



FEBRUARY 29, 2020

CORNERSTONE PARK,
HENDERSON



Our federal funds for our MSRCN grant cannot be used to LOBBY.



Bottom line: As a 501(c)(3), you can advocate for your



organization or mission, but you can't directly engage



in political lobbying efforts.

Advocacy
vs.
Lobbying

Advocacy vs. Lobbying

As a nonprofit organization, a big part of your work has to do with advocating for your mission or cause. However, there's a difference between advocacy and lobbying — and deciding between them can make all the difference in your [tax-exempt status](#) with the Internal Revenue Service.

<https://www.thebalancesmb.com/nonprofit-advocacy-vs-lobbying-which-is-the-best-strategy-4177308>

What is Advocacy?

Advocacy makes your voice heard regarding the issues most closely related to your organization's purpose or [mission](#).

Advocating for your mission may include:

- Contacting your city, state, and federal representatives to explain your mission and share information about the work that you're doing.
- Inviting representatives or members of the community to visit your site or to engage in informational sessions about your organization.
- Creating an email or social media campaign to share information and to promote events, projects, or initiatives.

What is Lobbying?

Lobbying supports or opposes a specific piece of legislation, regulation, or candidate or official.

Staff or volunteers may work to influence legislation or legislators on behalf of the organization, or an organization may ask for public support on a specific issue.

Types of legislation that nonprofit organizations frequently lobby for or against include:

- Laws
- Resolutions
- Nominations
- Initiatives
- Proposals
- Referendums

Calendar- November 2019

- **Happy Thanksgiving!**





Calendar- December 2019

- **Due Date for Genetic Pop-Up Applications: 12/1/19**
- **Miracles for Mito Holiday Party: 12/7/19**

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
 - May 7-9, 2020 National Down Syndrome Society Adult Summit in Phoenix, AZ
 - <https://www.ndss.org/engage/ndss-syndrome-adult-summit-2020/>
- June 2020-
 - June 25-28, 2020 National Down Syndrome Congress Conference in New Orleans
 - <https://www.ndsccenter.org/annual-convention/>
- 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”



The background features several sets of concentric, curved lines in shades of gray, some solid and some dashed, creating a sense of motion and depth. A blue speech bubble shape is positioned on the left side of the slide.

New Grant Cycle 2020-2024

- **We Want Your Input!**
- <https://www.surveymonkey.com/r/inputongrant>

Genetic Ambassador Facebook Group

The image shows a screenshot of a Facebook group page for "Genetic Ambassadors MSRGN". The page is partially obscured by blue rectangular redaction boxes on the left and top. The main content area features a banner for the "Genetic Ambassador Program" with a DNA double helix graphic and the website "www.MountainStatesGenetics.org". The left sidebar contains navigation options: "Genetic Ambassadors MSRGN", "Secret Group", "About", "Discussion", "Chats", "Members", "Events", "Photos", and "Moderate Group". Below these are "Shortcuts" for "Documenting Hope", "SUPER moms", "Empowered Medica...", and "Mountain States R...". The main post area includes a "Write Post" button, a "Write something..." text box, and options for "Add Photo/Video", "Live Video", "Photo/Video", "Get Together", and "Poll". On the right, there is an "ADD MEMBERS" section with a search input and a "MEMBERS" list showing "2 Members".



Thanks!

Any questions?

You can find me at

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