



Mountain States

REGIONAL GENETICS NETWORK

Genetic Ambassadors Call

Kristi Wees, MS Chem

Consumer Engagement Director

Mountain States Regional Genetics Network

April 2020

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

**INTRODUCTIONS:
WHAT HAS BEEN YOUR OR
THE FAMILIES YOU SERVE,
BIGGEST CHALLENGE
DURING COVID-19?**



**GUEST SPEAKER:
DR. EMILY SHELKOWITZ
TOPIC:
PARENT-FRIENDLY ACT
SHEETS FOR NBS CONDITIONS**



***COVID19 RESOURCES
*PUBLIC HEALTH GENETICS
WEEK – VOLUNTEER NEEDED
*VIRTUAL POP-UPS
*CALENDAR UPDATES**



GUEST SPEAKER:

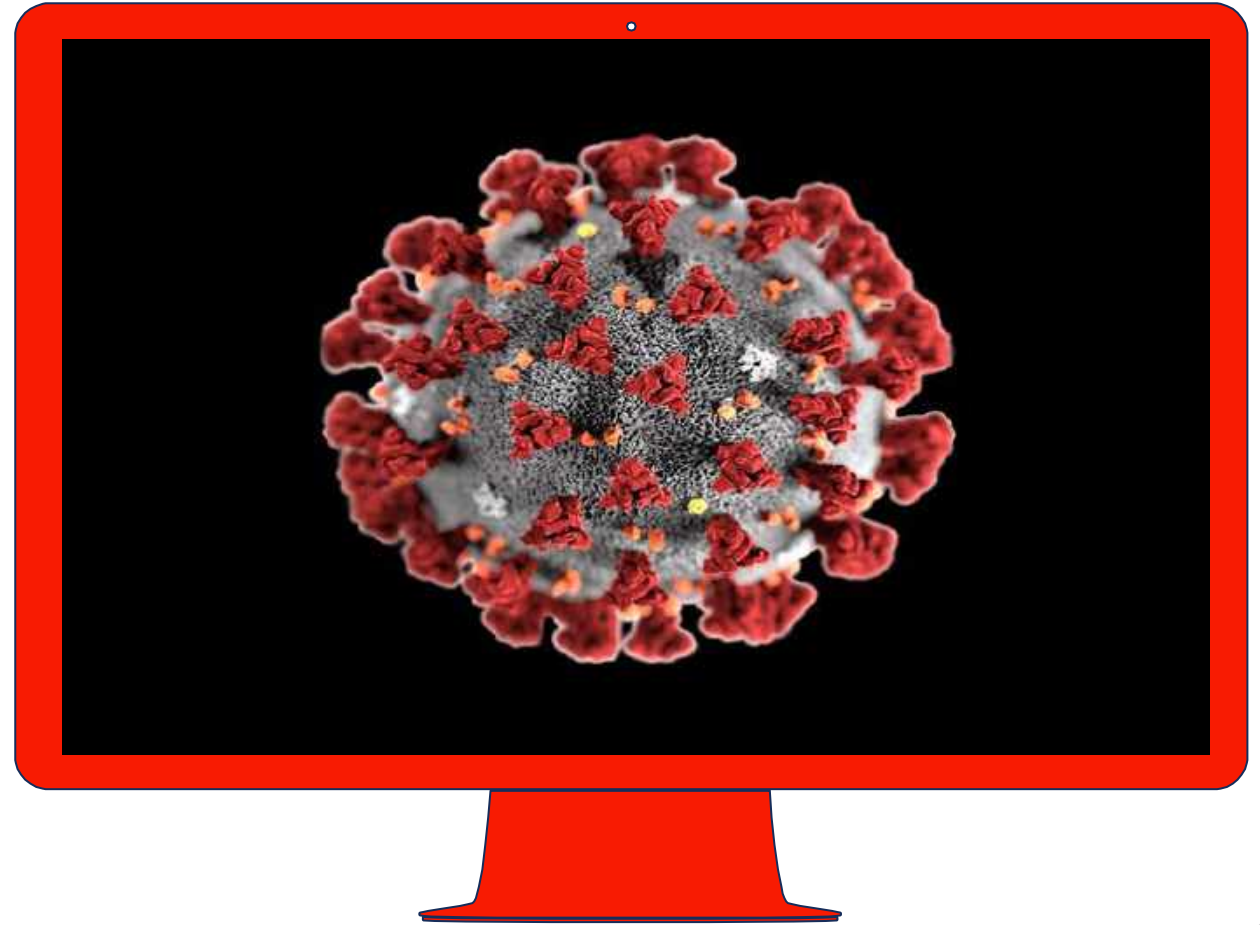
DR. EMILY SHELKOWITZ

TOPIC:

**PARENT-FRIENDLY
ACT SHEETS FOR
NBS CONDITIONS**

COVID 19 Resources for Individuals and Families with Genetic Conditions

State specific
COVID 19
resource sheets
Are Completed!



www.MountainStatesGenetics.org

Mountain States
REGIONAL GENETICS NETWORK
COVID 19
COLORADO RESOURCES
for Those Impacted by Genetic Conditions

KNOW THE FACTS ✓
To find the latest COVID19 facts, statistics and guidance from a:

- [Colorado/Local](#)
- [Colorado Pediatric Specific](#)
- [USA/ Federal](#)
- [World perspective](#)

 Please visit these websites linked above.

EMERGENCY PLANS 📄
The best time to plan for an emergency is before it happens. Take time now with your loved ones to prepare an emergency plan for their specific health needs.

- [Emergency Information Form \(ACEP\)](#)
- [Emergency Preparedness for those with Metabolic Disorders](#)
- [Emergency Cards for Genetic and Metabolic Conditions](#)

CONDITION SPECIFIC 📄
If you or your loved one has been diagnosed with a specific genetic condition please reach out to your healthcare provider or to the patient support organization for that condition, for specific information or advice. This [webinar from NORD](#) addresses COVID concerns for those with a rare disease. The [MSRGN website](#) has some other useful links for those with genetic conditions.

FOOD, MEDS & INSURANCE 📄
Having an extra 30-60 day supply of food, medication, metabolic food or formula is advisable for any emergency situation.

- [Uninsured: Special Enrollment](#)
- [Food Access: Bumper-Free CO](#)
- [Medical Foods Access](#)
- [Medication Access: Colorado Temporary Insurance Changes for one-time early refills](#)

SUPPORT 📄
Having a support system in place can really enhance mental health during times of crisis. Below are some organizations that are available for support in times of need:
Colorado Crisis Services:

- 1-844-493-8255
- or
- Text the word: "TALK" to 38255

TELEHEALTH 📄
Many primary care clinics and specialty clinics are changing their in-person follow up appointments to [telehealth visits](#). Please watch [this video](#) to learn more about telemedicine, telehealth and telogenetics. Ask your provider if telehealth is available to you, in an effort to minimize your exposure to the virus.

This document 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 a period of performance from 08/01/2020 to 07/31/2022. The contents are those of the author(s) and do not necessarily represent the official views of HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

For More Information:
www.MountainStatesGenetics.org

Colorado

Mountain States
REGIONAL GENETICS NETWORK
COVID 19
TEXAS RESOURCES
for Those Impacted by Genetic Conditions

KNOW THE FACTS ✓
To find the latest COVID19 facts, statistics and guidance from a:

- [Texas/Local](#)
- [USA/ Federal](#)
- [World perspective](#)

 Please visit these websites linked above.

EMERGENCY PLANS 📄
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FOOD & MEDICATION 📄
Having an extra 30-60 day supply of food, medication, metabolic food or formula is advisable for any emergency situation.

- [Food Access: ZIL.org](#)
- [Medical Foods Access](#)
- [Medication Access:](#) Talk with your pharmacist, specialist and insurance company to obtain.

SUPPORT 📄
Having a support system in place can really enhance mental health during times of crisis. Below are some organizations that are available for support in times of need:

- [Texas Parent to Parent](#)
- [Crisis Line Resources \(Texas\)](#)
- [Navigate Life Texas](#)

TELEHEALTH 📄
Many primary care clinics and specialty clinics are changing their in-person follow up appointments to [telehealth visits](#). Please watch [this video](#) to learn more about telemedicine, telehealth and telogenetics. Ask your provider if telehealth is available to you, in an effort to minimize your exposure to the virus.

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For More Information:
www.MountainStatesGenetics.org

Texas

Mountain States
REGIONAL GENETICS NETWORK
COVID 19
NEW MEXICO RESOURCES
for Those Impacted by Genetic Conditions

KNOW THE FACTS ✓
To find the latest COVID19 facts, statistics and guidance from a:

- [New Mexico/ Español](#)
- [Pediatric Specific \(NM/CMS\)](#)
- [USA/ Federal](#)
- [World perspective](#)

 Please visit these websites linked above.

EMERGENCY PLANS 📄
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- [Emergency Preparedness for those with Metabolic Disorders](#)
- [Emergency Cards for Genetic and Metabolic Conditions](#)

CONDITION SPECIFIC 📄
If you or your loved one has been diagnosed with a specific genetic condition please reach out to your healthcare provider or to the patient support organization for that condition, for specific information or advice. This [webinar from NORD](#) addresses COVID concerns for those with a rare disease. The [MSRGN website](#) has some other useful links for those with genetic conditions. The [NM Medical Home Portal](#) is also a great resource.

FOOD, MEDS & INSURANCE 📄
Having an extra 30-60 day supply of food, medication, metabolic food or formula is advisable for any emergency situation.

- [Insurance: COVID19 Testing Costs](#)
- [Food Access: Road Runner Food Bank](#)
- [Medical Foods Access](#)
- [Medication Access: NM Emergency Dispensing Declaration #1 \(30 day supply\) #2 \(controlled substance\)](#)

SUPPORT 📄
Having a support system in place can really enhance mental health during times of crisis. Below are some organizations that are available for support in times of need:

- [New Mexico Crisis Services: 855-662-7474 or \[www.nmcrisisline.com\]\(http://www.nmcrisisline.com\)](#)
- [Parents Reaching Out \(PRO\)](#)
- [Navajo Family Voices](#)

TELEHEALTH 📄
Many primary care clinics and specialty clinics are changing their in-person follow up appointments to [telehealth visits](#). Please watch [this video](#) to learn more about telemedicine, telehealth and telogenetics. Ask your provider if telehealth is available to you, in an effort to minimize your exposure to the virus.

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For More Information:
www.MountainStatesGenetics.org

New Mexico

COVID 19

ARIZONA RESOURCES

for Those Impacted by Genetic Conditions



KNOW THE FACTS

To find the latest COVID-19 facts, statistics and guidance from a:

- **Arizona/Local & Español**
- **Pediatric: Phoenix Children's Hospital-COVID19 Resource Center**
- **USA/ Federal**
- **World perspective**

Please visit these websites linked above.

EMERGENCY PLANS

The best time to plan for an emergency is before it happens. Take time now with your loved ones to prepare an emergency plan for their specific health needs.

- **Emergency Information Form (ACEP)**
- **Emergency Preparedness for those with Metabolic Disorders**
- **Emergency Cards for Genetic and Metabolic Conditions**



CONDITION SPECIFIC

If you or your loved one has been diagnosed with a specific genetic condition please reach out to your healthcare provider or to the patient support organization for that condition. For specific information or advice.

This [webinar from NORD](#) addresses COVID concerns for those with a rare disease. The [MSRGN website](#) has some other useful links for those with genetic conditions. AZ Developmental Disability info is found [here](#) and AZ Early Intervention info [here](#).

FOOD, MEDS & INSURANCE

Having an extra 30-60 day supply of food, medication, metabolic food or formula is advisable for any emergency situation.

- **Uninsured: Special Enrollment**
- **Food Access: Arizona 211**
- **Medical Foods Access**
- **Medication Access: Arizona Department of Pharmacy COVID-19 FAQs: emergency refills of maintenance medications for 90-day supply.**

TELEHEALTH

Many primary care clinics and specialty clinics are changing their in-person follow up appointments to telehealth visits.

Please watch [this video](#) to learn more about telemedicine, telehealth and telegenetics. Ask your provider if telehealth is available to you, in an effort to minimize your exposure to the virus.

SUPPORT

Having a support system in place can really enhance mental health during times of crisis. Below are some organizations that are available for support in times of need.

- **Arizona Crisis Response Network:**
- **1-800-631-1314**
- **Behavioral Crisis Resources**
- **Raising Special Kids (AZ)**
- **Navajo Family Voices (AZ/NM)**

For More Information:
www.MountainStatesGenetics.org

Arizona

COVID 19

NEVADA RESOURCES

for Those Impacted by Genetic Conditions



KNOW THE FACTS

To find the latest COVID-19 facts, statistics and guidance from a:

- **Nevada/ Español**
- **Pediatric Specific (Medical Home Portal)**
- **USA/ Federal**
- **World perspective**

Please visit these websites linked above.

EMERGENCY PLANS

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CONDITION SPECIFIC

If you or your loved one has been diagnosed with a specific genetic condition please reach out to your healthcare provider or to the patient support organization for that condition. For specific information or advice.

This [webinar from NORD](#) addresses COVID concerns for those with a rare disease. The [MSRGN website](#) has some other useful links for those with genetic conditions.

FOOD, MEDS & INSURANCE

Having an extra 30-60 day supply of food, medication, metabolic food or formula is advisable for any emergency situation.

- **Insurance: Special Enrollment COVID-19**
- **Food Access: TIEAF**
- **Medical Foods Access**
- **Medication Access: NV COVID-19 Prescription Refills Guidance**

SUPPORT

Having a support system in place can really enhance mental health during times of crisis. Below are some organizations that are available for support in times of need.

- **Crisis Support Services of Nevada:**
- **1-800-273-8255; text CARE to 839863**
- **Family Ties of Nevada**
- **Nevada 211 Mental Health Services**

For More Information:
www.MountainStatesGenetics.org

Nevada

COVID 19

UTAH RESOURCES

for Those Impacted by Genetic Conditions



KNOW THE FACTS

To find the latest COVID-19 facts, statistics and guidance from a:

- **Utah / Español**
- **Pediatric Specific & UT Medical Home**
- **USA/ Federal**
- **World perspective**

Please visit these websites linked above.

EMERGENCY PLANS

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- **Emergency Information Form (ACEP)**
- **Emergency Preparedness for those with Metabolic Disorders**
- **Emergency Cards for Genetic and Metabolic Conditions**



CONDITION SPECIFIC

If you or your loved one has been diagnosed with a specific genetic condition please reach out to your healthcare provider or to the patient support organization for that condition. For specific information or advice.

This [webinar from NORD](#) addresses COVID concerns for those with a rare disease. The [MSRGN website](#) has some other useful links for those with genetic conditions.

FOOD, MEDS & INSURANCE

Having an extra 30-60 day supply of food, medication, metabolic food or formula is advisable for any emergency situation.

- **Insurance: Medicaid***
- **Food Access: UT Against Hunger and UT Food Bank**
- **Medical Foods Access**
- **Medication Access: UT Insurance Department**

SUPPORT

Having a support system in place can really enhance mental health during times of crisis. Below are some organizations that are available for support in times of need.

- **Need Immediate Help Crisis Line:**
- **801-587-3000**
- **Utah DOH Crisis Line: 888-222-2542**
- **UT Parent Center** (including sign language resources)

For More Information:
www.MountainStatesGenetics.org

Utah



Mountain States
REGIONAL GENETICS NETWORK

COVID 19
WYOMING RESOURCES
for Those Impacted by Genetic Conditions

KNOW THE FACTS
To find the latest COVID19 facts, statistics and guidance from a:

- Wyoming/Local
- USA/ Federal
- World perspective

Please visit these websites linked above.

EMERGENCY PLANS
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- **Emergency Cards for Genetic and Metabolic Conditions**

CONDITION SPECIFIC
If you or your loved one has been diagnosed with a specific genetic condition please reach out to your healthcare provider or to the patient support organization for that condition, for specific information or advice. This [webinar from NBDQ](#) addresses COVID concerns for those with a rare disease. The [MSRGN website](#) has some other useful [links](#) for those with genetic conditions.

FOOD & MEDICATIONS
Having an extra 30-60 day supply of food, medication, metabolic food or formula is advisable for any emergency situation.

- **Food Access: WY TEFAP**
- **Medical Foods Access**
- **Medication Access:** Talk with your pharmacist, specialist or insurance company to obtain.

TELEHEALTH
Many primary care clinics and specialty clinics are changing their in-person follow up appointments to [telehealth visits](#). Please watch [this video](#) to learn more about telemedicine, telehealth and telegenetics. Ask your provider if telehealth is available to you, in an effort to minimize your exposure to the virus.

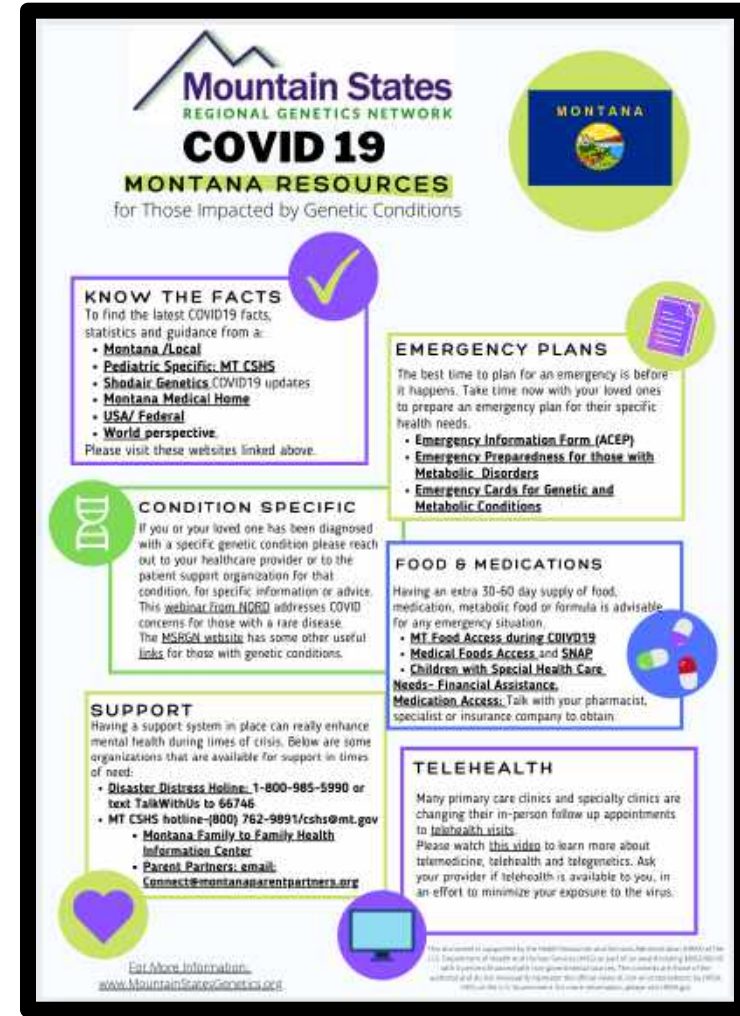
SUPPORT
Having a support system in place can really enhance mental health during times of crisis. Below are some organizations that are available for support in times of need.

- **U.S. National Suicide Prevention Lifeline**
- **1-800-273-TALK (8255)**
- **Text "WYO" to 741-741**
- **WY Institute for Disability (WIND)**
- **Uelift- Wyoming**

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For More Information:
www.MountainStatesGenetics.org

Wyoming



Mountain States
REGIONAL GENETICS NETWORK

COVID 19
MONTANA RESOURCES
for Those Impacted by Genetic Conditions

KNOW THE FACTS
To find the latest COVID19 facts, statistics and guidance from a:

- Montana /Local
- Pediatric Specific: MT CSHS
- Shodor's Genetics COVID19 updates
- Montana Medical Home
- USA/ Federal
- World perspective

Please visit these websites linked above.

EMERGENCY PLANS
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- **Emergency Preparedness for those with Metabolic Disorders**
- **Emergency Cards for Genetic and Metabolic Conditions**

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FOOD & MEDICATIONS
Having an extra 30-60 day supply of food, medication, metabolic food or formula is advisable for any emergency situation.

- **MT Food Access during COVID19**
- **Medical Foods Access and SNAP**
- **Children with Special Health Care Needs- Financial Assistance, Medication Access.** Talk with your pharmacist, specialist or insurance company to obtain.

TELEHEALTH
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SUPPORT
Having a support system in place can really enhance mental health during times of crisis. Below are some organizations that are available for support in times of need:

- **Disaster Distress Hotline: 1-800-985-5990 or text TalkWithUs to 66746**
- **MT CSHS hotline: (800) 762-9891/cshs@mt.gov**
- **Montana Family to Family Health Information Center**
- **Parent Partners: email: Connect@montanaparentpartners.org**

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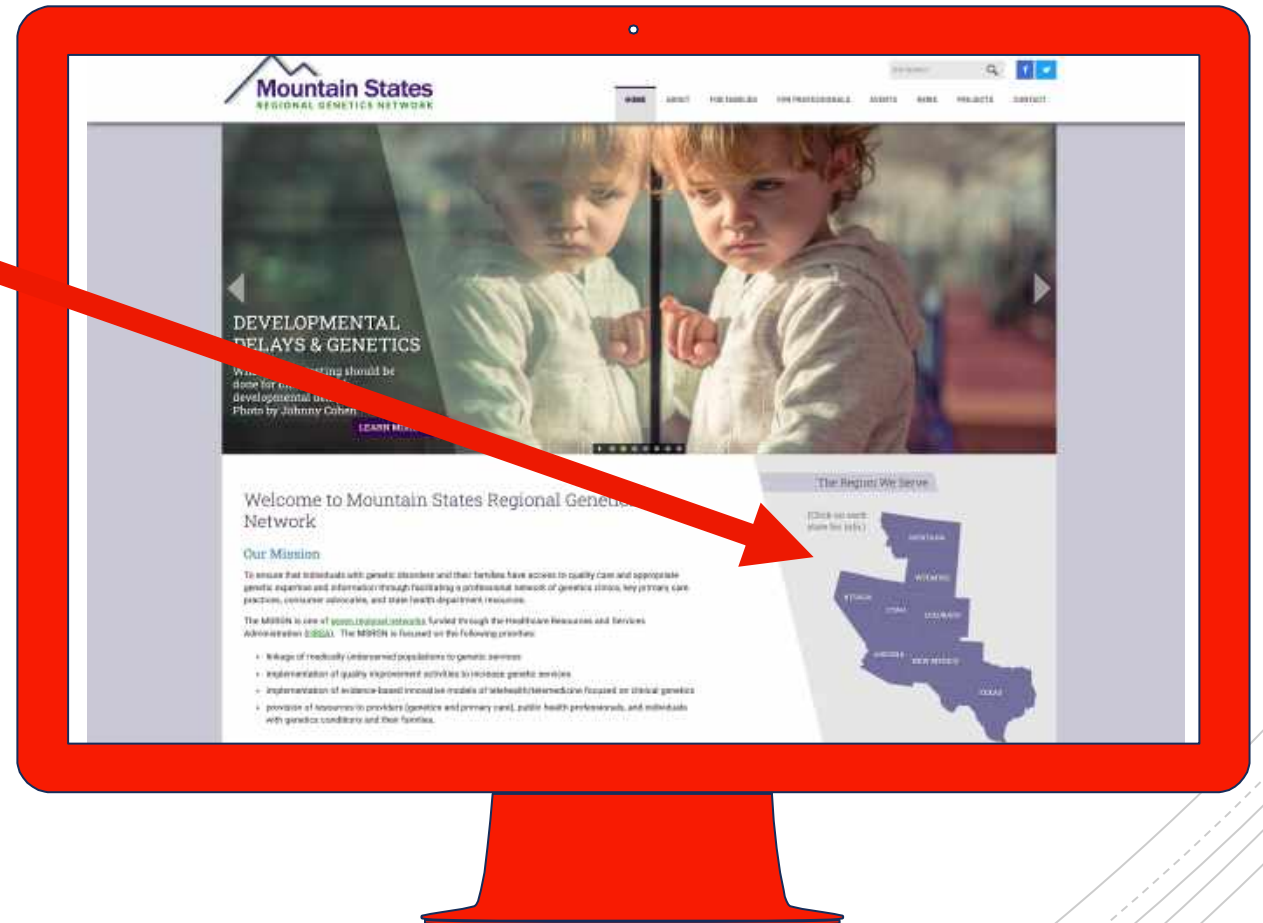
For More Information:
www.MountainStatesGenetics.org

Montana

www.MountainStatesGenetics.org

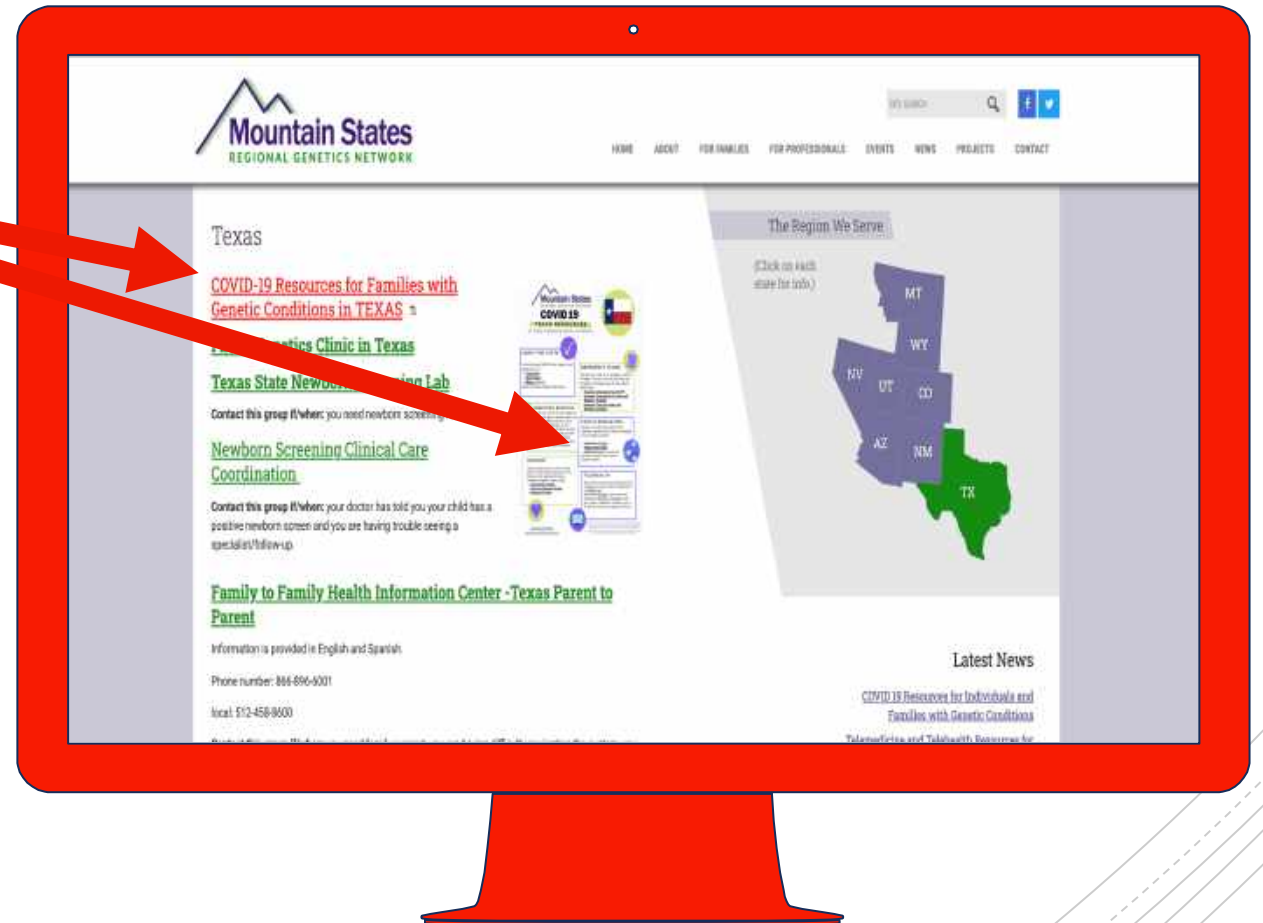
Click on **CLICKABLE MAP**

COVID19 Resource at the
TOP of each State Team
Page



www.MountainStatesGenetics.org

COVID19 Resource at the
TOP of each State Team
Page



Public Health Genetics Week- Family Input/Interview Requested

Request for Consumer Volunteer

**Let Kristi know if you
are interested.**

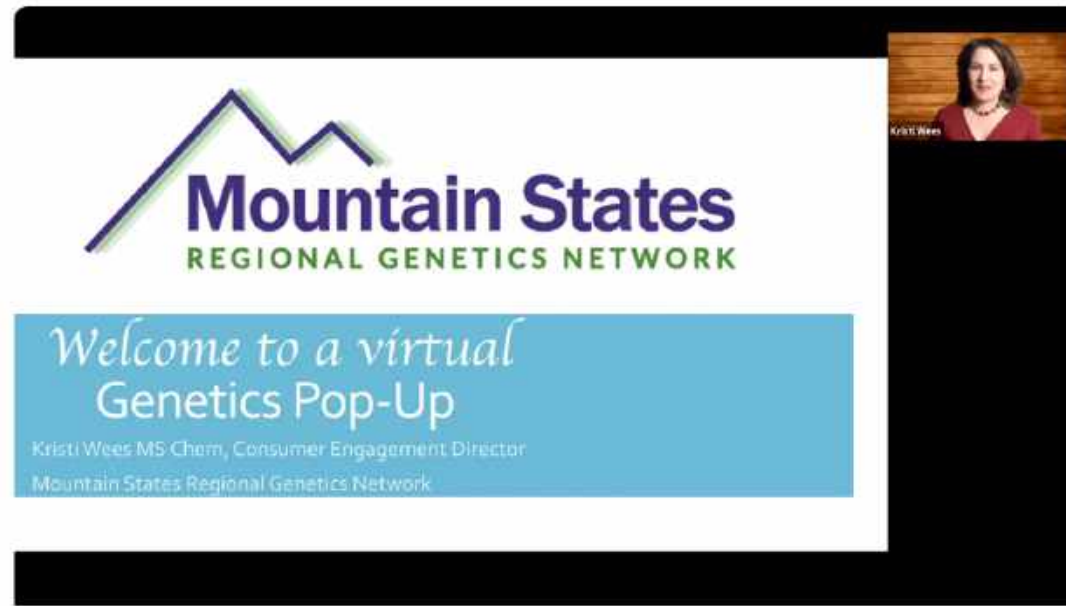
- **May 26-29, 2020**
- <https://phgw.org/>
- National Coordinating Center
- How did you learn about public health genetics?
- How has public health genetics impacted your/your child's life?
- Why is public health genetics important?
- How would you describe public health genetics to a family or individual who was unfamiliar?
- **Recording interview late next week**



Virtual Genetics Pop-Ups!

BIG THANKS TO...

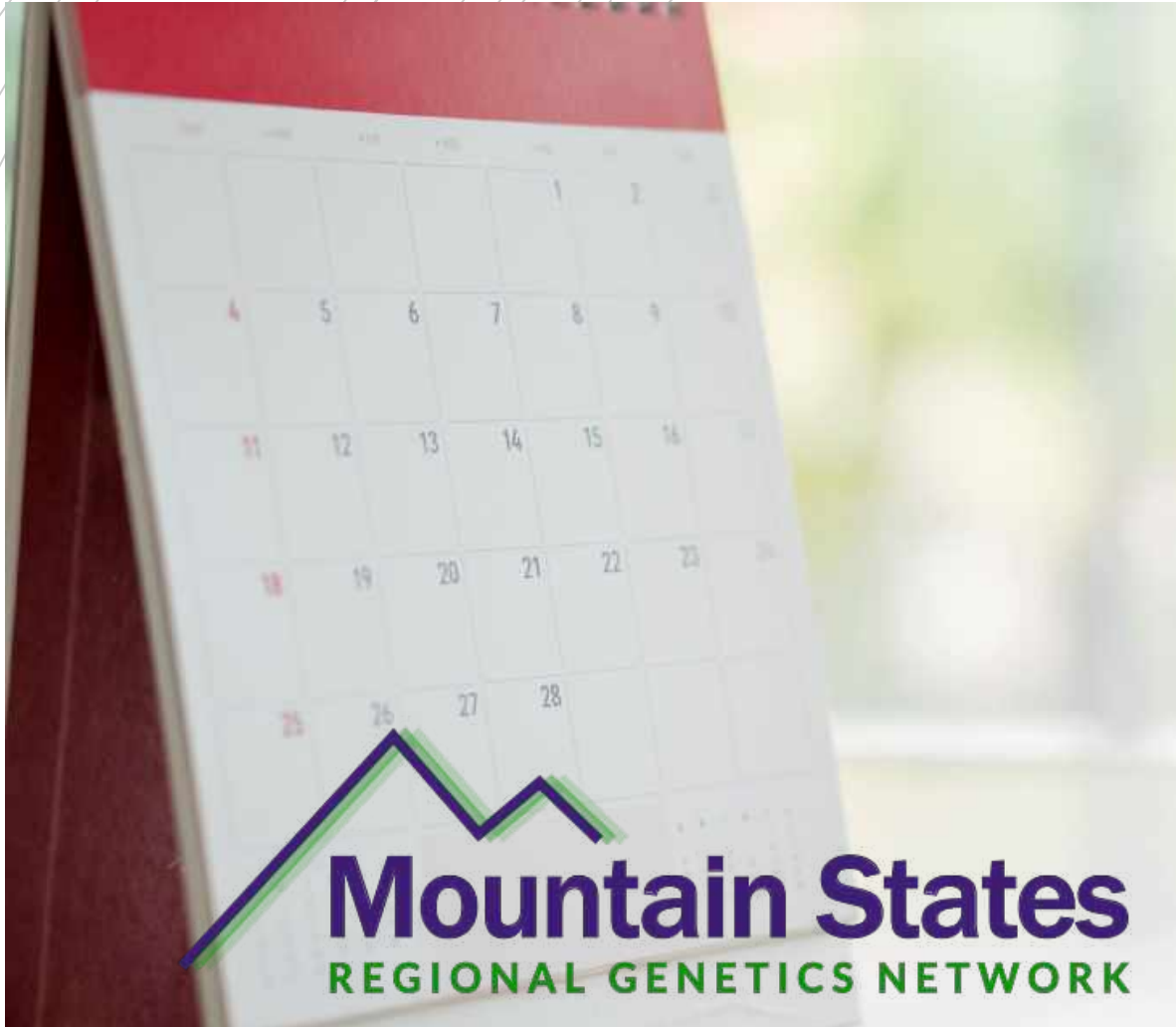
**Jamie S. (CO)
and
Alysian T. (TX)**



- May 2 & 3
- GOING ONLINE with the Genetics Pop-ups!
- We now have a 17 minute video that can be used for VIRTUAL Genetics Pop-Ups! Reviews TOP 5 Resources



MSRGN Calendar- April 2020



- April 2020
 - ~~CO Genetics Pop-Up: Heather~~
~~April 2020 Postponed~~
 - ~~Grand Rounds Miracles for Mito~~
~~CO 4/15/20 Cancelled~~



LIVE WEBINAR
 Highlighting Support Offerings
 from Parent to Parent USA
 and its Members

REGISTER NOW



Wednesday, May 13, 2020
 3 P.M. ET / 2 P.M. CT / 1 P.M. MT / 12 P.M. PT

On behalf of the National Genetics Education and Family Support Center (Family Center), please join Parent to Parent USA (P2P USA) for a 1-hour webinar to discuss P2P USA services and family engagement. Together, we will explore P2P USA support offerings and best practices, share testimonials that illustrate the importance of peer support, and learn about opportunities for collaboration.

REGISTER NOW

This webinar will be recorded and made available for viewing after the live presentation.

Presented by:



National Genetics Education
 and Family Support Center



This webinar 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 \$400,000 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.



Calendar- Future Months-May 2020

- **May 2020**
 - **TX Virtual Genetics Pop-Up: Alysian ONLINE THIS SATURDAY- 5/2/20**
 - **CO Virtual Genetics Pop-Up: Jamie 5/3/20 ONLINE THIS SUNDAY- 5/3/20**
 - **5/13/20 1pm MT Parent to Parent- Support Webinar**
 - **Living Rare, Living Stronger 2020, Cleveland Ohio**
 - ~~May 14-16, 2020~~ **tentatively rescheduled for July 18-20**
 - ~~National Down Syndrome Society Adult Summit in Phoenix, AZ~~
 - ~~May 7-9, 2020~~
 - ~~<https://www.ndss.org/engage/ndss-syndrome-adult-summit-2020/>~~
 - **CANCELLED**
 - **Last day of MSRGN Current grant cycle: May 31, 2020**

Calendar- Future Months June 2020- December 2020



- June 2020
 - **National Down Syndrome Congress**
Conference in New Orleans
 - June 25-28, 2020
 - <https://www.ndscenter.org/annual-convention/>
- September 2020
 - **Global Genes Conference, San Diego, CA**
 - Sept 21-23, 2020
- November 2020
 - **MT Transition Conference**
 - Nov. 16-18, 2020

www.MountainStatesGenetics.org

under FOR FAMILIES TAB:

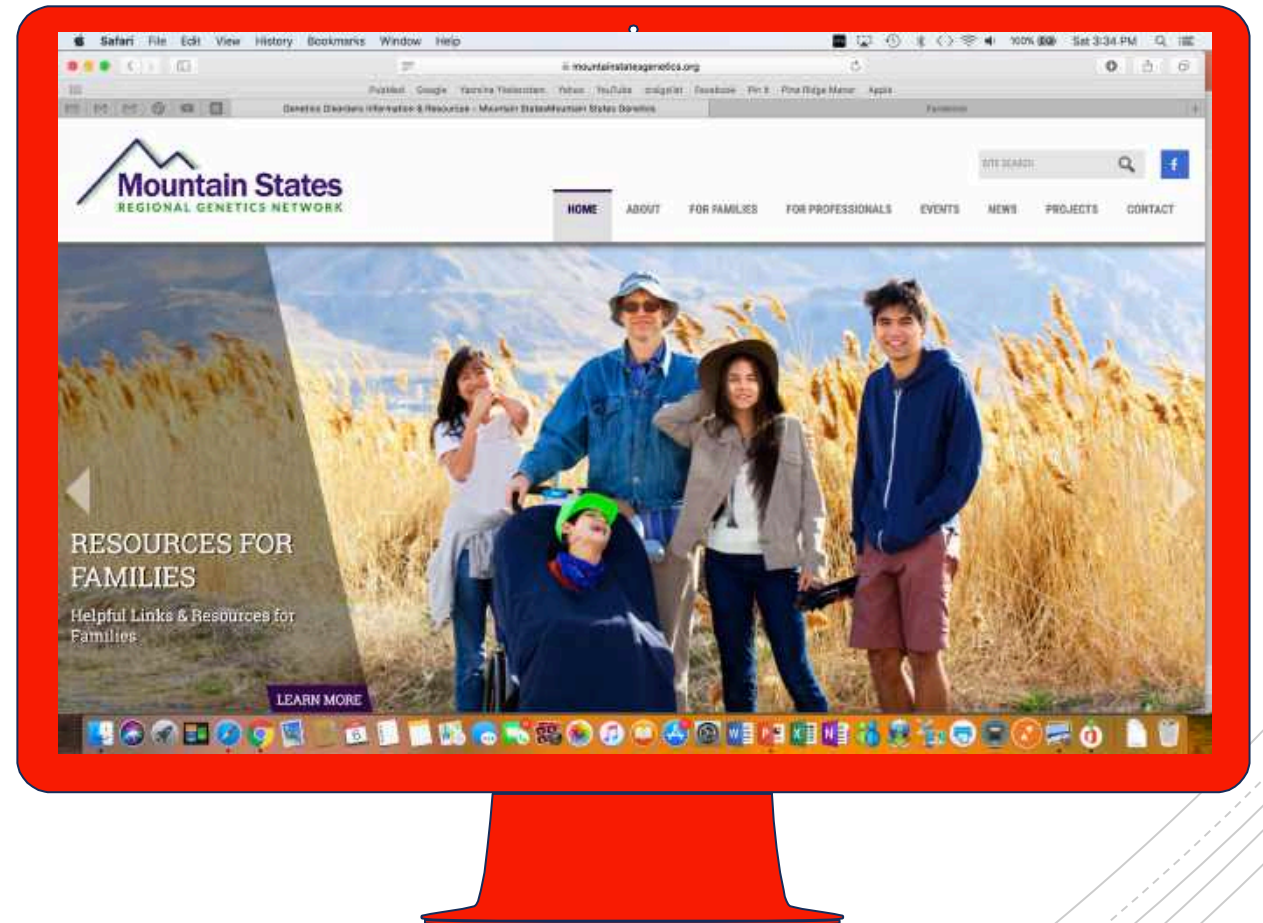
- “Genetic Ambassador” Drop Down
- “Your Genetics Questions Answered” Drop Down
- “Genetics Pop-Ups”



May's 2020 Genetic Ambassador Call

Save the Date

May 26 at 2pm



Facebook Page-
We reached over
1000!
Thank You for
your help!

Mountain States Regional Genetics Network
@mountainstatesgenetics.org

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Mountain States
REGIONAL GENETICS NETWORK

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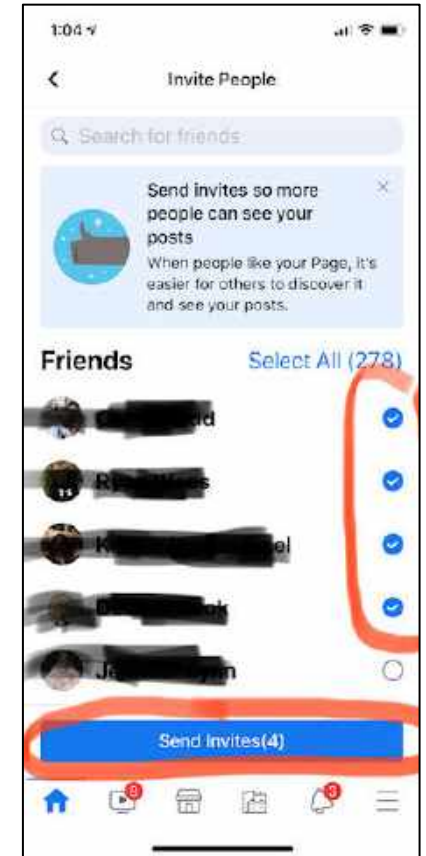
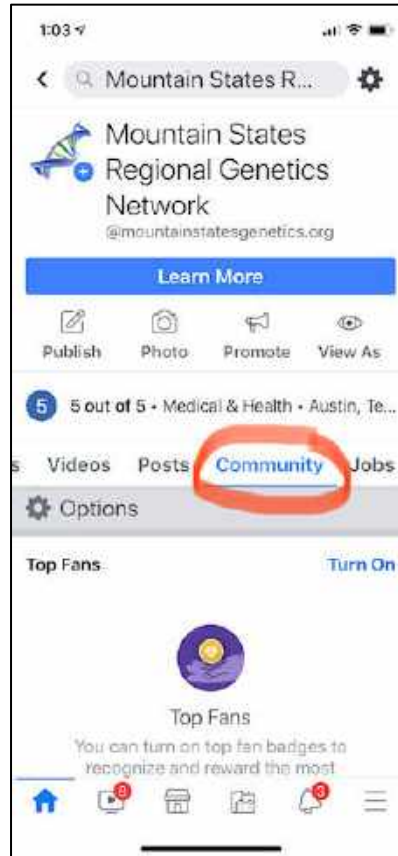
Learn More

Top Fans

1,003
Total Likes

1,074
Total Follows

How to Invite 5 Friends



Genetic Ambassador Facebook Group

Are you in the group?
If not please send an
Email/text to Kristi and
ask her to add you.



A red speech bubble graphic with a white outline, containing the text "Thanks!".

Thanks!

Any questions?

You can find me at

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