



# Genetic Resources for Families

Kristi Wees MS Chem, Consumer Engagement Director

Mountain States Regional Genetics Network



This resource 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 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](https://www.hrsa.gov).

# Who is MSRGN?

Mountain States Regional  
Genetics Network



# Mountain States Regional Genetics Network

- 8 State Region

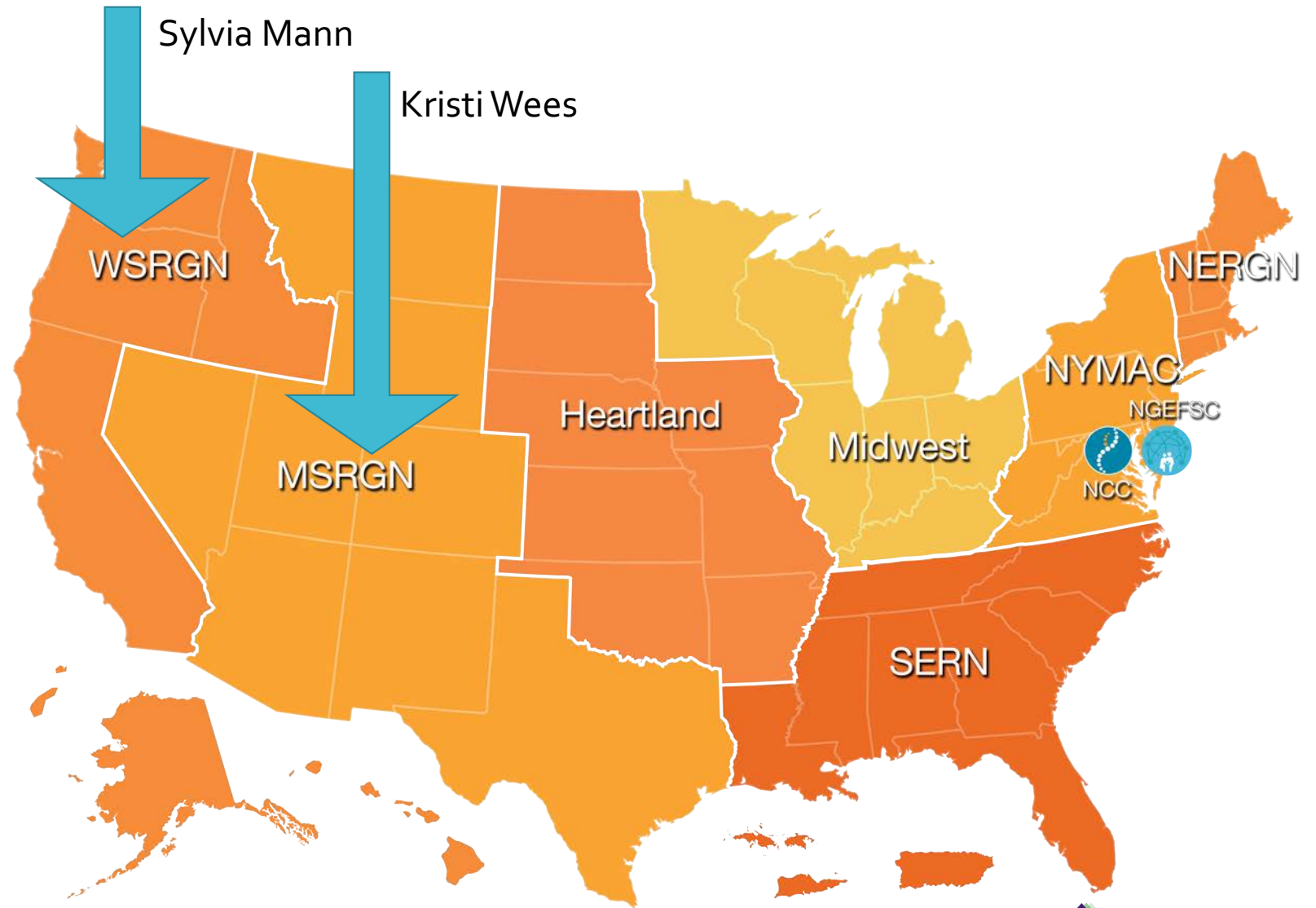
MSRGN's mission is to ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and information through facilitating a professional network of :

- genetics clinics,
- key primary care practices,
- consumer advocates,
- and state health department resources.



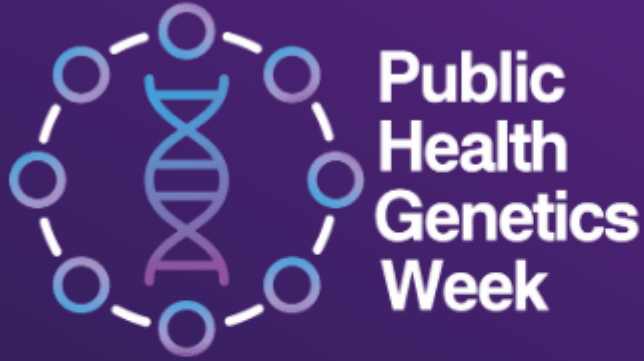
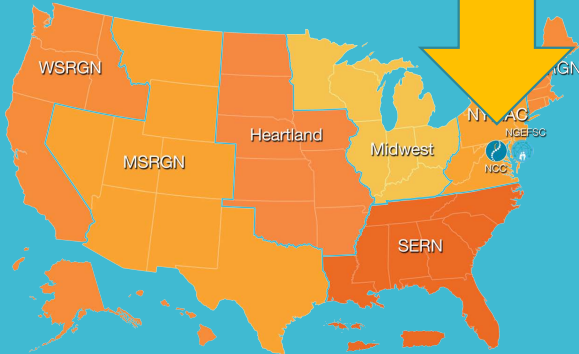
# MSRGN and WSRGN are 2 of the 7 Regional Genetics Networks

## Regional Genetics Networks



# NCC and Public Health Genetics Week

National  
Coordinating  
Center



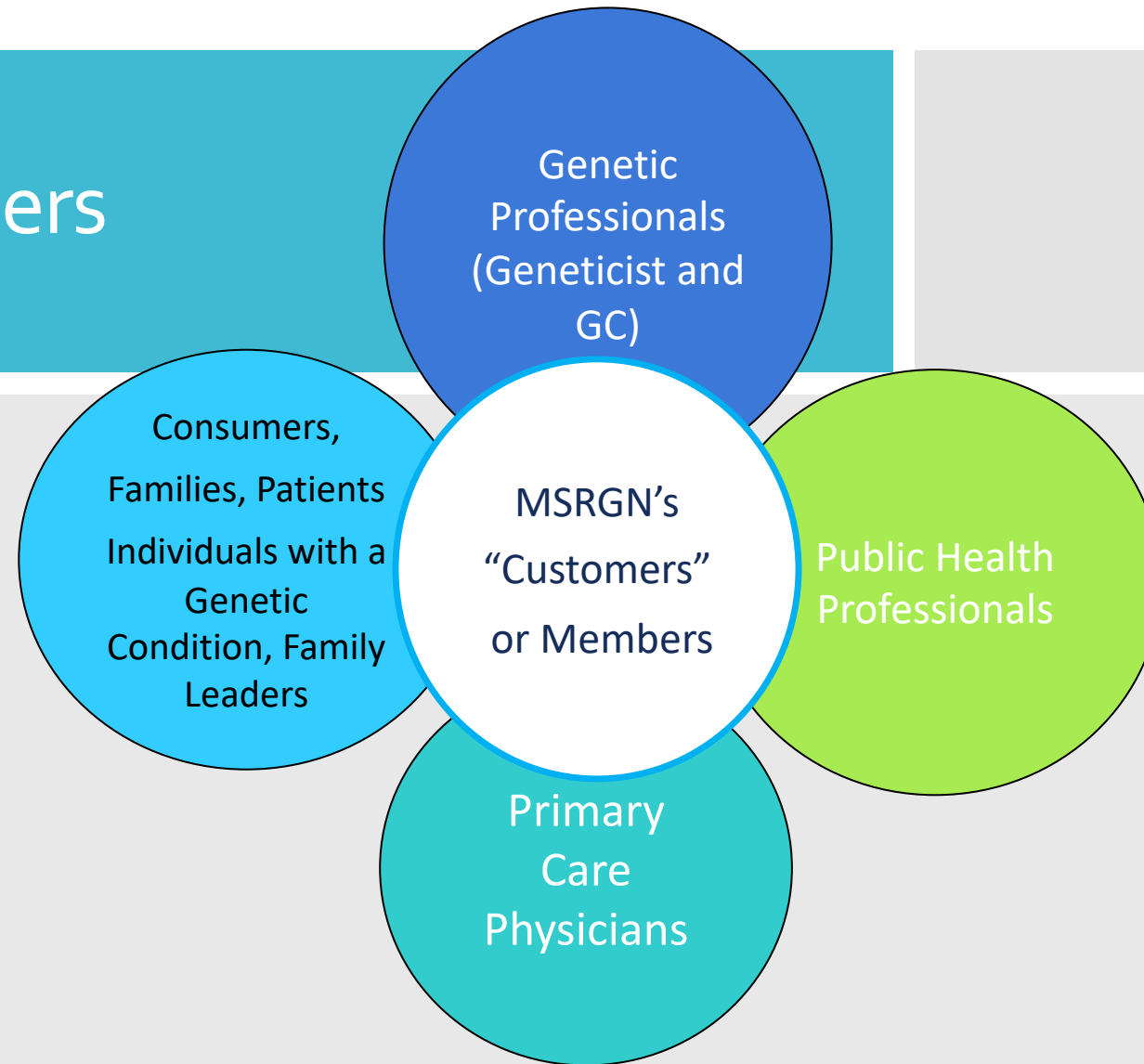
**MAY 26- MAY 29**  
**#PHGW #PUBLICHEALTHGENETICS**  
**PHGW.ORG**

Public health genetics applies genetic and genomic information to improve public health and prevent disease.

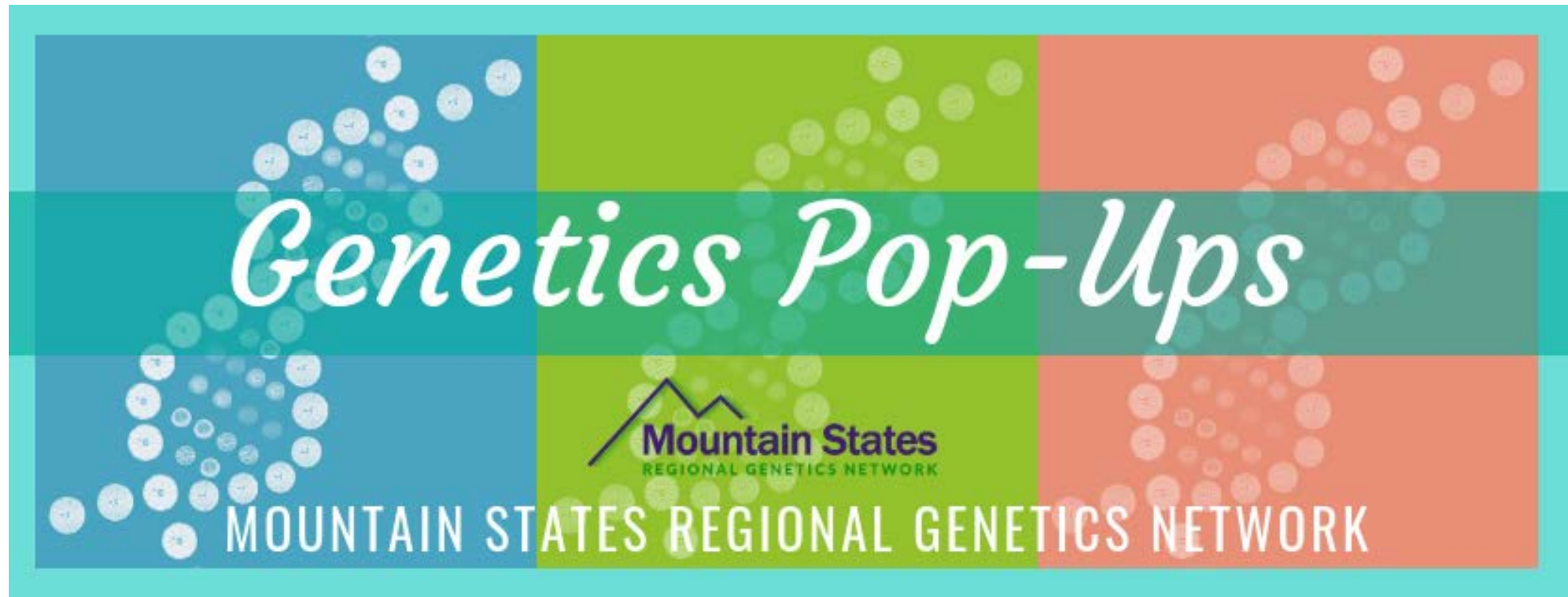
- "What is Public Health Genetics?" *May 26*
- "Who is Involved in Public Health Genetics" *May 27*
- "Public Health Screening" *May 28*
- "Public Health Genetics Resources" *May 29*
- *TWITTER CHAT- May 29<sup>th</sup> 2pm ET*

# MSRGN'S Structure and Members

- State Teams- 8 of them
- Genetic Ambassadors
- Advisory Committee
- Management Team







## What is a Genetics Pop-Up?

Resources, educational materials and information about genetic services for individuals, families and their communities



# A Gene in a Box

When we have an in-person Genetics Pop-Up this box of resources is mailed to the Genetic Ambassador who is hosting the Pop-Up!

For today we will be sharing resources ELECTRONICALLY!



# www.MountainStatesGenetics.org



# Top 10 Genetic Resources

To access electronic versions of the resources we will be sharing: scan this code or use your camera on your smart phone and focus it on this code to open the website.



# 10

## TeleWhat?

Infographic from National Genetic Education Support Center

Partnership with Genetic Alliance, Family Voices, & Expecting Health

Webinar:

[https://www.youtube.com/watch?v=eYHfPq\\_Q3X4&feature=youtu.be](https://www.youtube.com/watch?v=eYHfPq_Q3X4&feature=youtu.be)

**Expecting Health** **FAMILY VOICES**® National Genetics Education and Family Support Center

### TELEWHAT?

An introduction to Telegenetics

**WHAT IS IT?** A Telegenetics visit is similar to an in-person genetics clinic visit. The genetics provider will ask you questions about medical history and family history. The specific things that happen during a Telegenetics visit depend on why you or your family member were referred for genetic services, and whether this is your first time seeing a genetics provider or a follow-up appointment. Sometimes a physical exam might be needed, in which case a local healthcare provider may help. Your genetics provider may also suggest some genetic testing.

**WHY IS IT IMPORTANT?** Telegenetics improves access to genetics services and helps reduce the effects of common barriers to care such as distance, time, childcare, mobility challenges, and transportation.

**Did you know?** In many parts of the United States, families have to drive over 50 miles to see a genetic specialist for their child.

**HOW DOES IT WORK?** A Telegenetics visit is usually 30 – 60 minutes and involves using videoconferencing with a computer, phone, or tablet, either from a provider's office near you or your own home to connect with a genetics specialist located somewhere else for a clinic visit. The four main types of Telegenetics appointments are:

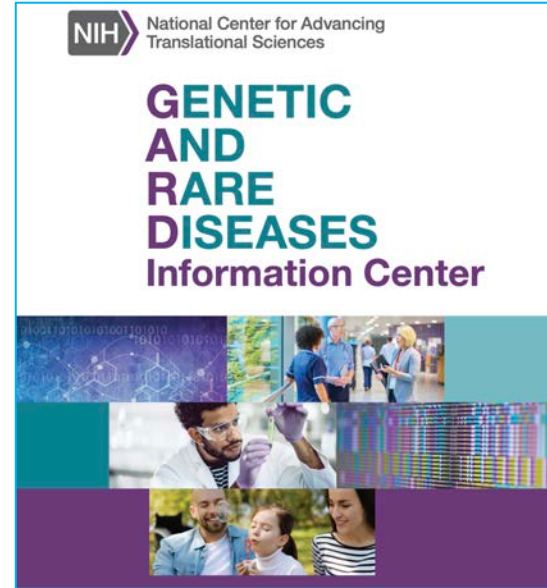
- VIDEO CONFERENCING** Live, two-way interaction between a person and a provider using an electronic platform similar to Skype or Facetime.
- STORE AND FORWARD** Receive an evaluation and treatment recommendations from a genetic specialist based on pre-recorded health history that you've prepared with your child's primary provider.
- REMOTE MONITORING** A local provider monitors your child's health status and behaviors and transfers information to a genetic specialist to assist in providing care to your child.
- MOBILE HEALTH** Exchange text messages or video conferencing with a genetic provider through a secure application on your mobile device.

**POTENTIAL BENEFITS**

- ↓ Less travel time
- ↓ Less cost
- ↓ Less wait time
- ↓ Less distance
- ↑ Increased # of Available Providers
- ↑ More Access to Early Detection
- ↑ Increased Patient Satisfaction

For further information please contact the National Genetics Education and Family Support Center at [jlopez@geneticalliance.org](mailto:jlopez@geneticalliance.org) or [anware@familyvoices.org](mailto:anware@familyvoices.org).

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# Top Genetic Resource:

GARD Information Center and Hotline: Genetic and Rare Disease

 1-888-205-2311

## GARD Hotline

Available in English and Spanish

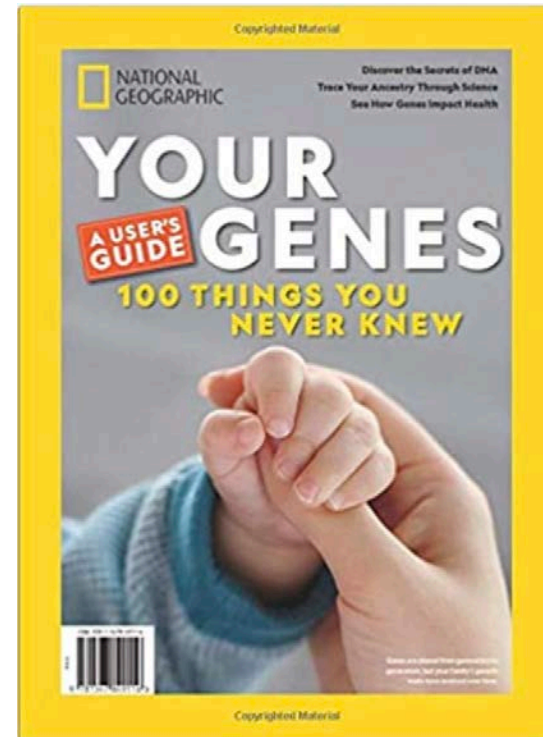
Available Monday - Friday, 12 noon-6 p.m. Eastern Time

Speak with a Genetic Counselor about a Genetic Condition

No Medical Advice can be given



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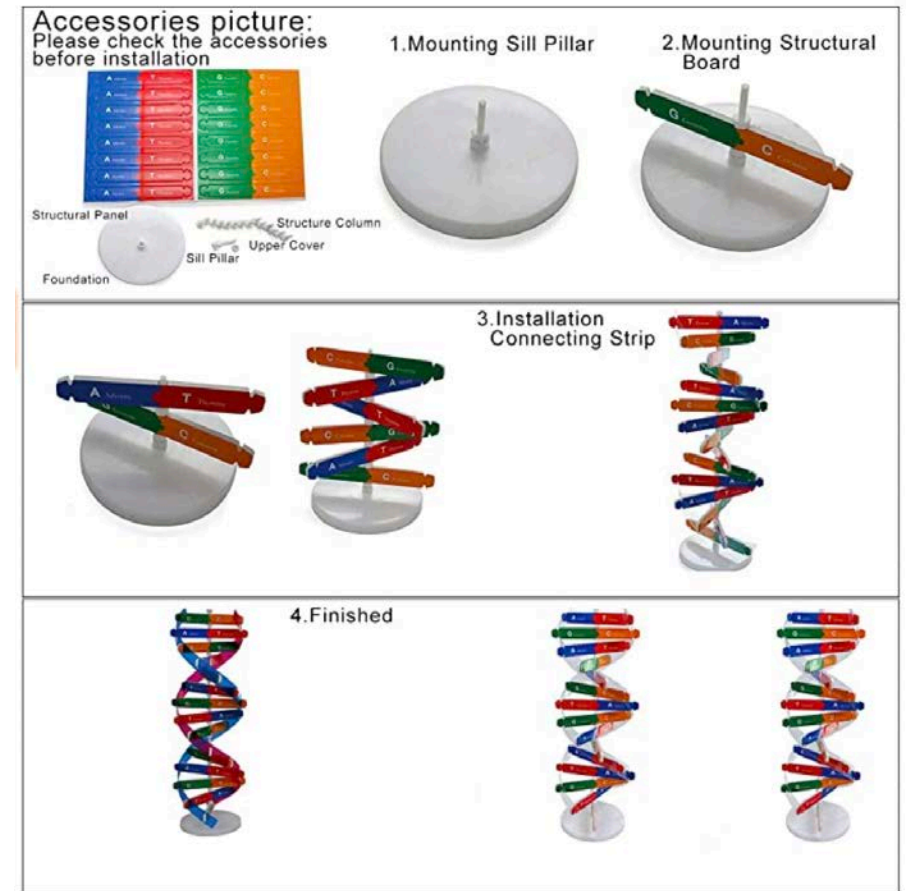


# Top Genetic Resource:

National Geographic: Your Genes- 100 things you never knew!



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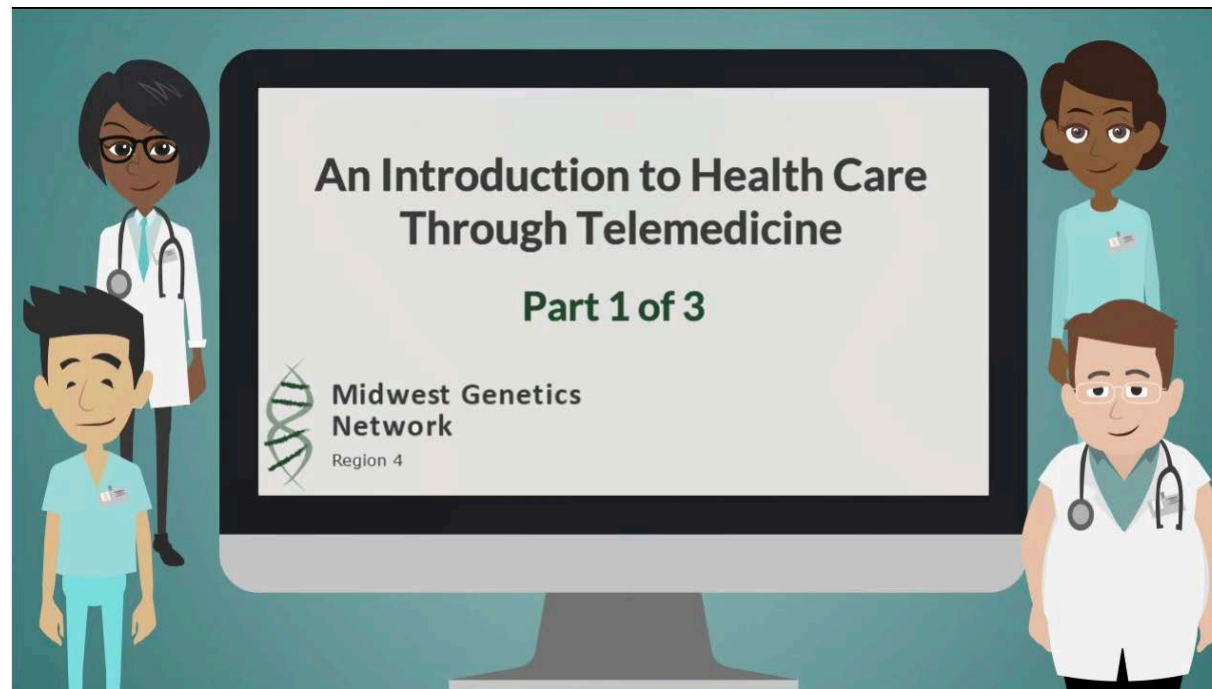


# Top Genetic Resource:

DNA Double Helix model Kit & Giant Microbes Stuffed DNA

Available for \$10-15 each,online

# 6



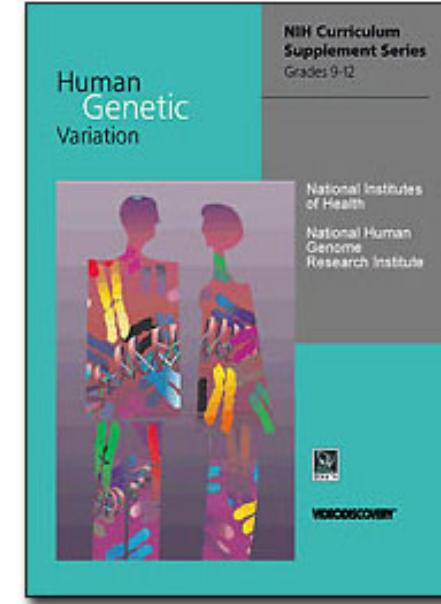
## Top Genetic Resource:

From our Colleague's at Midwest Genetics Network

Introduction to Healthcare Through Telemedicine parts 1-3

Also includes a Family Video about their Telegenetics experience

# 5



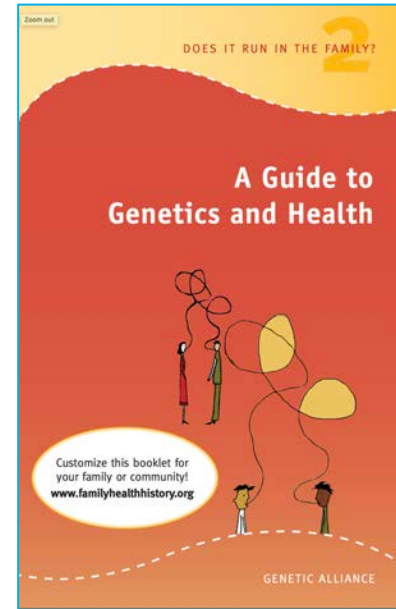
## Top Genetic Resource:

NIH Genetics Curriculum:

Rare Diseases and Scientific Inquiry [Grades 6-8](#)

Human Genetic Variation [Grades 9-12](#)

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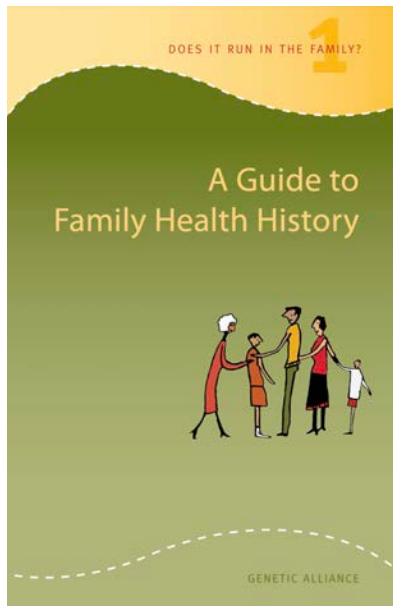


## Top Genetic Resource:

Genetic Alliance Books:

A Guide to Family Health History

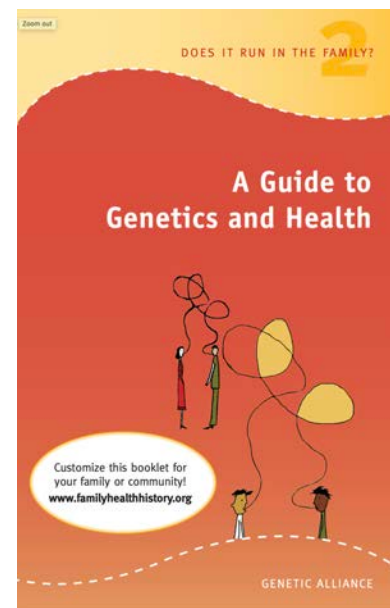
A Guide to Genetics and Health



English



Spanish



English



Spanish

## #4: Genetic Alliance Booklets

A Guide to Genetics and Health

A Guide to Family Health History

Available in both English and Spanish



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# Top Genetic Resource:

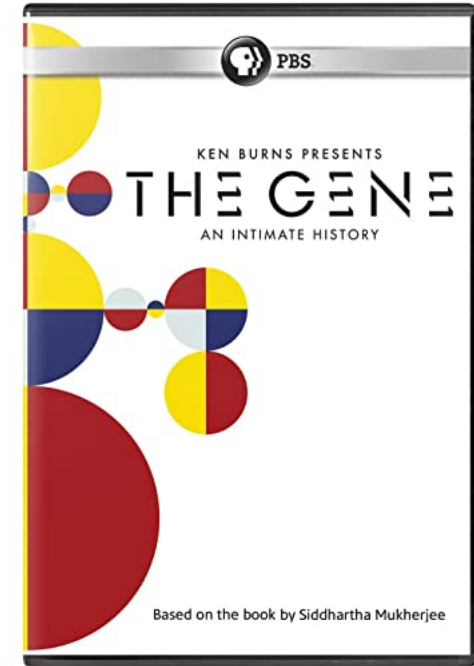
Documentary:

*KEN BURNS PRESENTS THE GENE: AN INTIMATE HISTORY*  
*part 1 & 2 free to view on PBS*

# #3 Genetic Resource: The Gene Documentary








- Aired in April 2020
- On PBS
- 2-part series
- Produced by award winning film maker: Ken Burns
- Available for FREE to watch at this website:  
• [www.pbs.org/kenburns/the-gene/watch](http://www.pbs.org/kenburns/the-gene/watch)



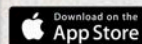





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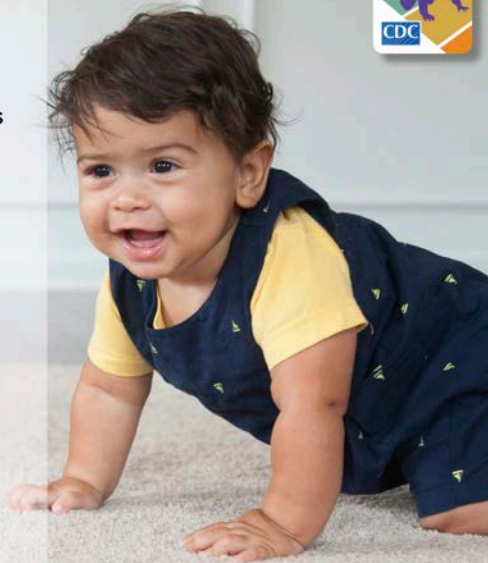
**Try CDC's FREE Milestone Tracker app today...**  
*Because milestones matter!*

-  Illustrated milestone checklists for 2 months through 5 years
-  Summary of your child's milestones to share
-  Activities to help your child's development
-  Tips for what to do if you become concerned
-  Reminders for appointments and developmental screening

[cdc.gov/MilestoneTracker](https://cdc.gov/MilestoneTracker)



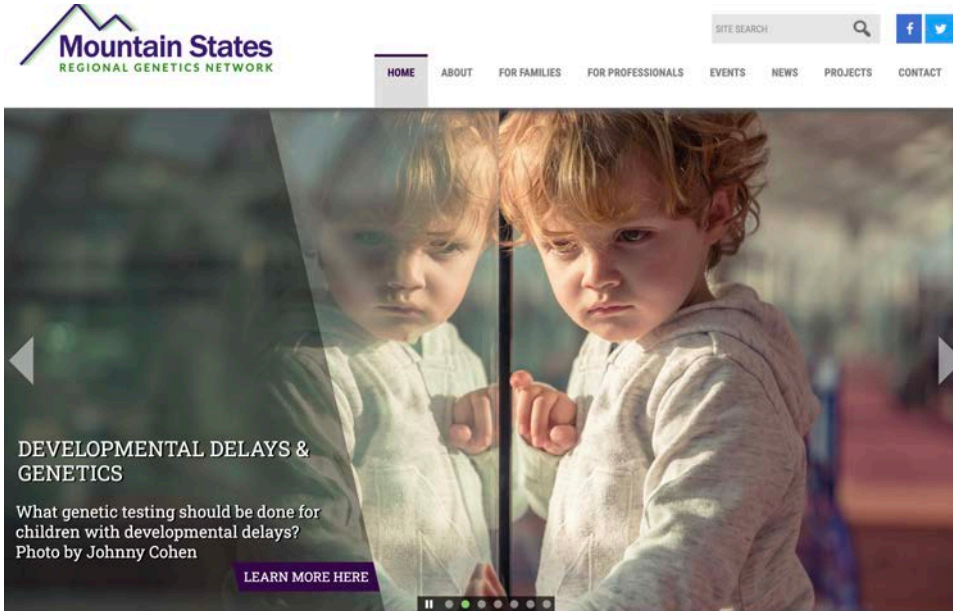


Now available in Spanish!

# Top Genetic Resource:

CDC's Learn the Signs Act Early  
Milestone Tracker App

# 1



## Top Genetic Resource:

MSRGN's Developmental Delay Algorithm Toolkit

# #1 Developmental Delay Algorithm Toolkit

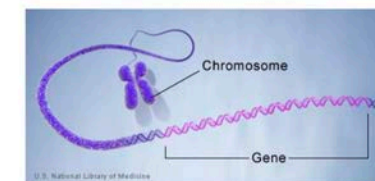
- One of the highest referral categories to Genetics in our region is for Developmental Delay diagnosis
- This algorithm was created to help Pediatricians work with families on beginning the genetics workup for a child with a developmental delay
- Online Toolkit includes info for primary care doctors and families



## Synopsis of Approach to Genetic Diagnosis in Developmental Delay

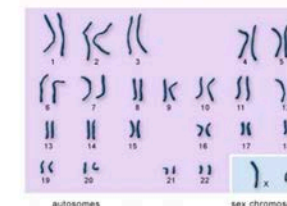
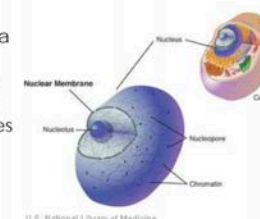
- Primary care providers may consider initiating genetic diagnostic testing for patients with developmental delay when access to genetic services is limited.
- The American Academy of Pediatrics has published their statement on appropriate genetic evaluation of children with developmental delay: see Moeschler et al Pediatrics 2014.
- Ensure that acute neurological concerns are addressed with appropriate evaluation and not deferred until after genetic testing.
- Referrals for developmental therapies should be made concurrently with a genetic evaluation.
- Our recommendations are as follows:
  - **Tier 1**
    - Chromosomal microarray
    - Fragile X trinucleotide repeat analysis
  - **Tier 2**
    - Large gene sequencing panel of developmental delay-associated genes
  - **Tier 3**
    - Whole exome or whole genome sequencing may be considered.
    - See [www.treatable-id.org](http://www.treatable-id.org) for a testing algorithm and information on diagnoses that have specific treatment and can be diagnosed with biochemical testing.
      - Serum amino acids
      - Serum homocysteine
      - Urine creatine metabolites
      - Urine organic acids
      - Urine purines and pyrimidines
      - Urine oligosaccharides
      - Urine mucopolysaccharides

## Genes: What They Are and What They Do



Each cell in the human body contains about 25,000 to 35,000 genes. They are found on tiny spaghetti-like structures called chromosomes, which are found inside cells. Your body is made of billions of cells, which are the very small units that make up all living things.

Most cells have one nucleus. The nucleus is a small egg-shaped structure inside the cell, and it has many parts. The nucleus acts like the brain of the cell. It tells every part of the cell what to do. It contains our chromosomes and genes. As tiny as it is, the nucleus has more information in it than the biggest dictionary you've ever seen.

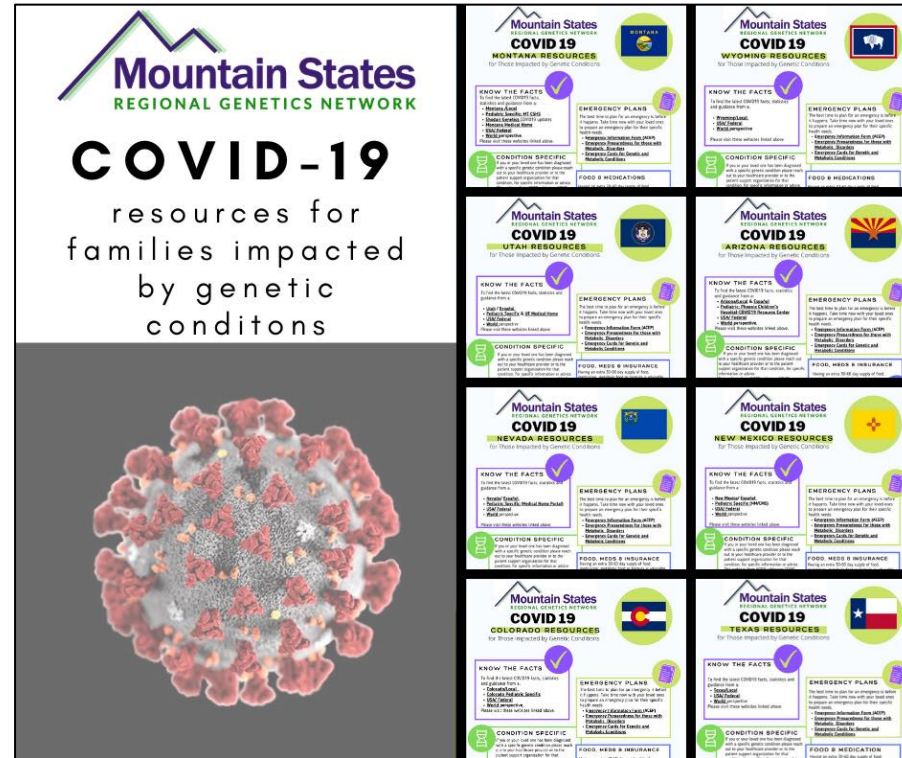


Chromosomes come in matching pairs and there are hundreds — sometimes thousands — of genes in just one chromosome. In humans, a cell nucleus contains 46 individual chromosomes or 23 pairs of chromosomes. Half of these chromosomes come from one parent and half come from the other parent.

Under the microscope, we can see that chromosomes come in different lengths and striping patterns. When they are lined up by size and similar striping pattern, the first twenty-two of the pairs are called autosomes; the final pair of chromosomes is called sex chromosomes, X and Y. The sex chromosomes determine whether you're a boy or a girl: females have two X chromosomes while males have one X and one Y.



EXTRA




# Top Genetic Resource:

MSRGN's COVID-19 Resource Sheets for families impacted by genetic conditions in our 8 states.



# 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: Hunger 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 telegenetics. Ask your provider if telehealth is available to you, in an effort to minimize your exposure to the virus.

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Colorado



### 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.

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- [Emergency Cards for Genetic and Metabolic Conditions](#)

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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: 211.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 telegenetics. Ask your provider if telehealth is available to you, in an effort to minimize your exposure to the virus.

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Texas



### 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.

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#### 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 \[www.nmcrisisline.com\]\(#\)](#)
- [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 telegenetics. Ask your provider if telehealth is available to you, in an effort to minimize your exposure to the virus.

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New Mexico



## COVID 19

### ARIZONA RESOURCES

for Those Impacted by Genetic Conditions



#### KNOW THE FACTS

To find the latest COVID19 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.

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#### 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 COVID19 FAQs](#); emergency refills of maintenance medications for 90-day supply.

#### 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 \(AZ/NM\)](#)

#### 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.

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For More Information:  
[www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)


Arizona



## COVID 19

### NEVADA RESOURCES

for Those Impacted by Genetic Conditions



#### KNOW THE FACTS

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

- [Nevada/ Español](#)
- [Pediatric Specific \(Medical Home Portal\)](#)
- [USA/ Federal](#)
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- [Insurance: Special Enrollment COVID19](#)
- [Food Access: TEFAP](#)
- [Medical Foods Access](#)
- [Medication Access: NV COVID19 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](#)

#### TELEHEALTH


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Nevada



## COVID 19

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for Those Impacted by Genetic Conditions



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- [Pediatric Specific & UT Medical Home](#)
- [USA/ Federal](#)
- [World perspective](#)

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- [Insurance: Medicaid\\*](#)
- [Food Access: UT Against Hunger and UT Food Bank](#)
- [Medical Foods Access](#)
- [Medication Access: UT Insurance Department](#)

\*COVID19 pandemic, Medicaid has suspended the community engagement/work/self-sufficiency requirement.

#### 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)

#### 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.

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For More Information:  
[www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)

Utah







## 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**

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 & 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.

**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 \(WIND\)](#)
- [Uplift- Wyoming](#)


**TELEHEALTH**

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Wyoming



## 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](#)
- [Shodair Genetics COVID19 updates](#)
- [Montana Medical Home](#)
- [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 & 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.

**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](#)

**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.

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Montana





## Top 10 Genetic Resources

To access electronic versions of the resources have shared today: please scan this code or use your camera on your smart phone and focus it on this code to open the website.



If you have any questions or would like to get involved in our activities, please contact us:

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