

# GENETIC CONNECTIONS

**for Early Intervention Providers**



*A Workshop for Early Intervention Providers*



# A Note from our Funders

**This program 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 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).**

# MODULE 4

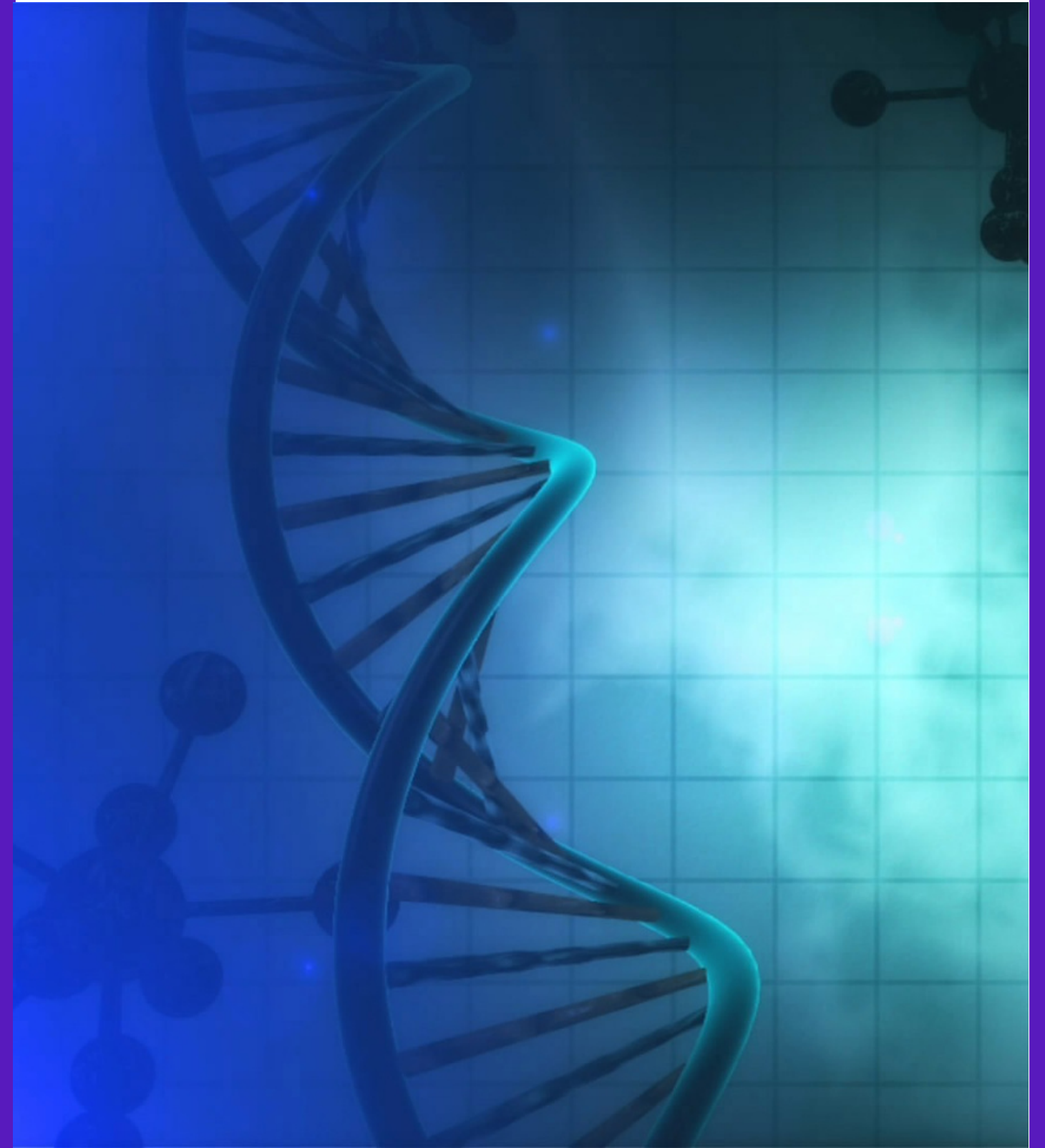
## Red Flags and Next Steps

# Learning Objective

The learner will be able to identify 3 red flags suggesting a need for genetics.

The learner will understand the importance of a primary care provider/medical home in the path to genetics.

The learner will be able to explain how to connect with a MSRGN Genetic Navigator.





## Module 4: Red Flags and Next Steps

# A G E N D A

### Topics Covered

Recognizing Red Flags 4 Genetics

A Path To Genetics

The Importance of a Pediatric Medical Home & Neighborhood

Connecting with a Genetic Navigator

Resource: Genetic Navigators

# RED FLAGS 4 GENETICS

Do you have concerns about your child?  
Below are **red flags** or warning signs and symptoms that were self-reported by families whose child went on to receive a genetic diagnosis. 89% of reported **red flags** were noted before 4 years of age.

 <h2>Developmental Delay</h2>		<ul style="list-style-type: none"> <li>Physical/motor delay (not rolling over, crawling or walking)</li> <li>Speech (not babbling or responding to name)</li> <li>Adaptive (coordination of hands and fingers)</li> <li>Cognitive (unable to or not interested in play)</li> <li>Social/emotional (difficulty interacting with others, not smiling)</li> <li>Loss of any milestone (regression)</li> </ul>
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# SEÑALES DE ALARMA SOBRE GENÉTICA

**¿Tiene preocupaciones sobre su hijo?**  
Abajo le brindamos señales de alarma o señales de aviso y síntomas las cuales fueron reportadas por familias con hijos que recibieron un diagnóstico genético.. El 89% de las señales de alarma notificadas se notaron antes de los 4 años de edad.

	<h2>Retraso del desarrollo</h2>		<ul style="list-style-type: none"><li>• Retraso físico/motor (no se da vueltas, no gatea ni camina)</li><li>• Retraso del habla (no balbucea ni responde a su nombre)</li><li>• Adaptable (coordinación de manos y dedos)</li></ul>	<ul style="list-style-type: none"><li>• Cognitivo (no puede o no tiene interés en jugar)</li><li>• Social/emocional (dificultad para interactuar con los demás, no sonríe)</li><li>• Pérdida de logros del desarrollo (regresión)</li></ul>
	<h2>Características físicas</h2>	<ul style="list-style-type: none"><li>• Dedos adicionales en los pies o manos</li><li>• Tamaño de la cabeza grande/pequeño (macrocefalia/microcefalia)</li><li>• Estatura baja/alta</li></ul>	<ul style="list-style-type: none"><li>• Paladar hendido</li><li>• Diferentes rasgos faciales (mentón pequeño, frente ancha)</li><li>• Dislocación frecuente de las articulaciones (displasia de la cadera)</li><li>• Deformidades de la columna vertebral (escoliosis)</li></ul>	
	<h2>Problemas de alimentación</h2>		<ul style="list-style-type: none"><li>• Dificultad para pasar los alimentos</li><li>• Problemas con la lactancia</li><li>• Mal agarre del pecho</li><li>• Dependiente de la sonda de alimentación</li></ul>	<ul style="list-style-type: none"><li>• Nunca se siente saciando</li><li>• Falta de apetito</li><li>• Vómitos</li><li>• Se atraganta con la comida</li></ul>
	<h2>Comportamiento</h2>	<ul style="list-style-type: none"><li>• Desorden del Espectro Autista (ASD)</li><li>• Movimientos repetitivos</li><li>• Está constantemente molesto o llorando</li><li>• Falta de contacto visual</li></ul>	<ul style="list-style-type: none"><li>• Dificultad en la escuela o en entornos sociales</li><li>• TDAH/Comportamiento impulsivo o hiperactivo</li><li>• Se distrae fácilmente</li><li>• Llora o tiene un tono de voz agudo, como un grito</li></ul>	
	<h2>Falta de crecimiento</h2>		<ul style="list-style-type: none"><li>• Crecimiento lento</li><li>• Aumento de peso lento</li><li>• Falta de desarrollo</li></ul>	<ul style="list-style-type: none"><li>• Se fatiga rápidamente cuando está activo</li><li>• El peso o la tasa de aumento de peso es mucho más bajo que el de otros niños</li></ul>
	<h2>Fuerza y tono muscular</h2>	<ul style="list-style-type: none"><li>• Tono muscular flácido o bajo (hipotonía)</li><li>• Tono muscular rígido o alto (hipertonía)</li><li>• El bebé no intenta darse la vuelta ni mantiene la cabeza eruida al estar boca abajo</li></ul>	<ul style="list-style-type: none"><li>• Debilidad muscular</li><li>• Tiene el cuerpo flácido</li><li>• Incapacidad de levantar o controlar la cabeza (deja caer la cabeza hacia atrás)</li></ul>	
	<h2>Otras Señales</h2>	<ul style="list-style-type: none"><li>• Convulsiones</li><li>• Falta de sueño</li><li>• Fatiga</li><li>• Letargo</li><li>• Preocupaciones auditivas/visuales</li><li>• Problemas inmunológicos</li><li>• Dolores de cabeza/migrañas</li><li>• Preocupaciones neurológicas</li><li>• Preocupaciones pulmonares /cardíacas</li><li>• Problemas del sistema digestivo</li><li>• Moretones</li></ul>		<p><b>Si su hijo muestra alguna 'señal de alarma' aquí mencionada, hable con el pediatra o médico de atención primaria de su hijo. Para obtener más recursos y ayuda para tener esa conversación, visite:</b></p> <p><a href="http://www.mountainstatesgenetics.org/redflag">www.mountainstatesgenetics.org/redflag</a></p>
<p>Este proyecto está respaldado por la Administración de Recursos y Servicios de Salud (HRSA) del Departamento de Salud y Servicios Humanos (HHS) de los EE. UU. bajo el número de subvención UH7MC30776, por \$600 000. Esta información o contenido pertenecen al autor y no deben ser considerados una opinión oficial o políticas de la HRSA, HHS ni del gobierno de los EE. UU. ni se debe asumir ningún apoyo por parte de ellos.</p>				

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Red Flags 4 Genetics:



7

C A T E G O R I E S



Mountain States

REGIONAL GENETICS NETWORK

**Red Flags 4 Genetics Category:**

**D E V E L O P M E N T A L**



**D E L A Y S**



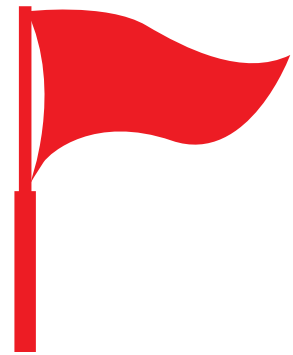


# Developmental Delays

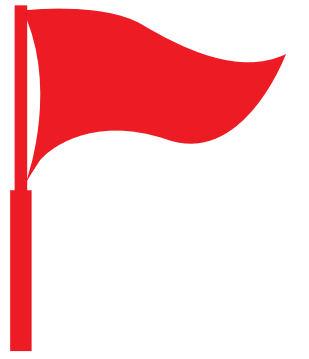
- Physical/motor delay (not rolling over, crawling or walking)
- Speech (not babbling or responding to name)
- Adaptive (coordination of hands and fingers)
- Cognitive (unable to or not interested in play)
- Social/emotional (difficulty interacting with others, not smiling)
- Loss of any milestone (regression)



**Red Flags 4 Genetics Category:**



**P H Y S I C A L**



**F E A T U R E S**



**Mountain States**  
REGIONAL GENETICS NETWORK



# Physical Features

- Extra fingers or toes
- Large/small head size (macrocephaly/microcephaly)
- Short/tall height (stature)
- Cleft palate
- Facial feature differences (small chin, wide forehead)
- Frequent joint dislocations (hip dysplasia)
- Spinal deformities (scoliosis)





**Red Flags 4 Genetics Category:**



**F E E D I N G**



**I S S U E S**

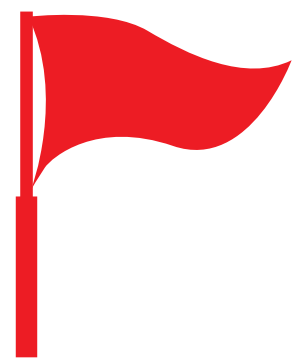


# Feeding Issues

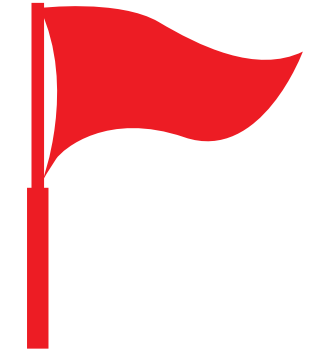
- Difficulty swallowing
- Struggles with breastfeeding
- Poor latching
- Feeding tube dependent
- Never feeling full
- Poor appetite
- Vomiting
- Gagging on food



**Red Flags 4 Genetics Category:**



**BEHAVIOR**





# Behavior

- Autism Spectrum Disorder (ASD)
- Repetitive movements
- Constantly upset or crying
- Lack of eye contact
- Difficulty in school or social settings
- ADHD/impulsive or hyperactive behavior
- Easily distracted
- High pitched cry/tone of voice



Red Flags 4 Genetics Category:

 FAILURE TO   
THRIVE



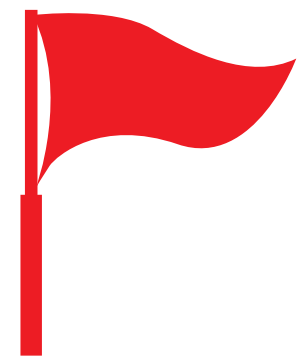


# Failure to Thrive

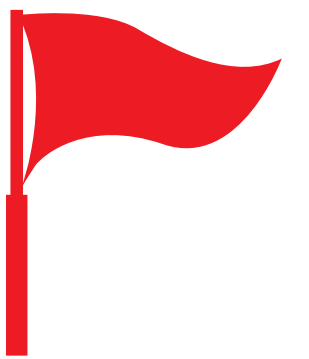
- Slow growth
- Slow weight gain
- Not thriving
- Fatigues quickly when active
- Weight or rate of weight gain being much lower than that of other children.



**Red Flags 4 Genetics Category:**



**S T R E N G T H**



**& T O N E**





# Strength and Tone

- Floppy or low muscle tone (hypotonia)
- Stiff or high muscle tone (hypertonia)
- Baby not attempting to roll over or hold head up when on tummy
- Muscle weakness
- Body is floppy
- Inability to lift or control head (head lag)





**Red Flags 4 Genetics Category:**



**O T H E R**



# Other Red Flags 4

## Genetics

- Seizures
- Sleep concerns
- Fatigue
- Lethargy
- Hearing/vision concerns
- Headaches/migraines
- Neurological concerns
- Pulmonary/cardiac concerns
- GI issues (reflux/bowel concerns)
- Bruising
- Immune issues





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**Mountain States**

REGIONAL GENETICS NETWORK

# A Path 2 Genetics



## Referral by PCP

Most Genetics Clinics in the MSRGN region request that a PCP/Pediatrician make a professional referral and provide documentation to support the referral to genetics.



## Early Intervention Provider Notes

EI Providers can be important eyes and ears for the family and can document observations that are helpful for genetics referrals.



## A Genetic Navigator can Help the Family

A genetic navigator can serve as an important connection for the family on this path 2 genetics.

**M E D I C A L**

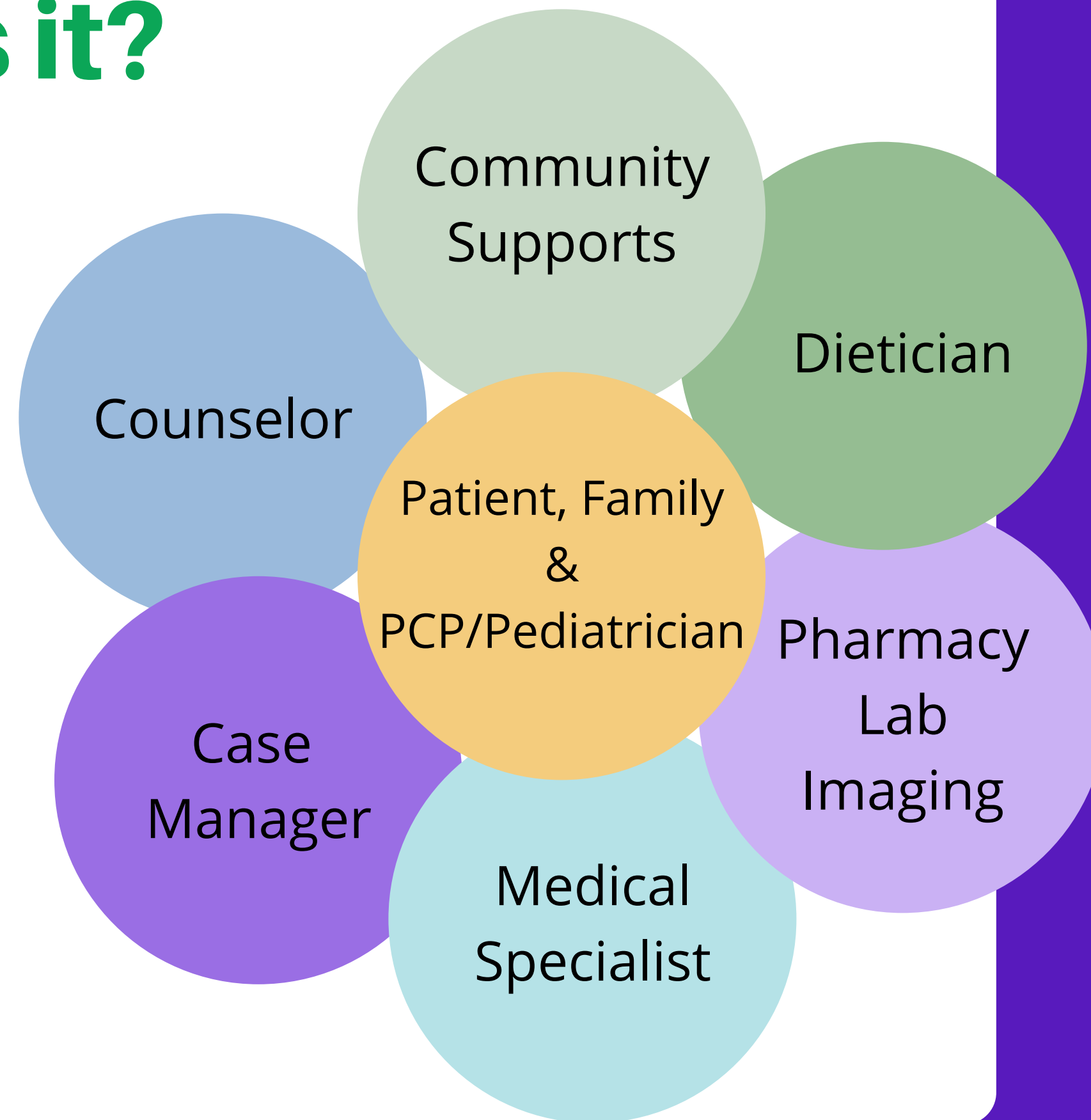
**H O M E**



# Medical Home- What is it?

The Medical Home (also known as Patient or Family Centered Medical Home) is an approach to providing comprehensive **primary care** that facilitates partnerships between patients, clinicians, medical staff, and families. It is a medical practice organized to produce higher quality care and improved cost efficiency.

source: AAP.org





# The importance of a Medical Home



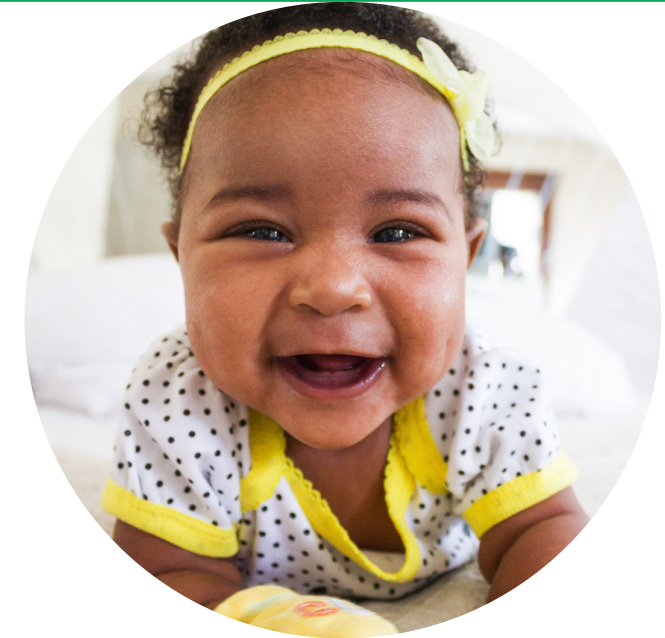
**It is not a place but a  
partnership**

with a primary care  
provider and staff



**Who ?**

At the core is a  
knowledgeable, compassionate  
health care provider and care  
team chosen by a patient and  
their family to take care of  
a child/youth's health needs.



**What are some benefits?**

Access, teamwork and  
coordination of care with  
other specialist



# Medical Neighborhood-

## What is it?

The "medical neighborhood" is defined as a clinical-community partnership that includes the medical and social supports necessary to enhance health, with the Medical Home serving as the patient's primary "hub" and coordinator of health care delivery. A medical neighborhood may also include: non-clinical partners like community centers, faith-based organizations, schools, employers, public health agencies, YMCAs, and even Meals on Wheels.

source: [www.pcpcc.org](http://www.pcpcc.org)



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Resource:  
Genetic Navigators  
&  
How to connect to them

How to Connect with a MSRGN

# Genetic Navigator

You can email them directly, or email introduce the family (with family permission), or give email address to the family to reach out when they are ready:

Arizona ~ arizonagenetic@gmail.com

Colorado ~ coloradogenetic@gmail.com

Montana ~ montanagenetic@gmail.com

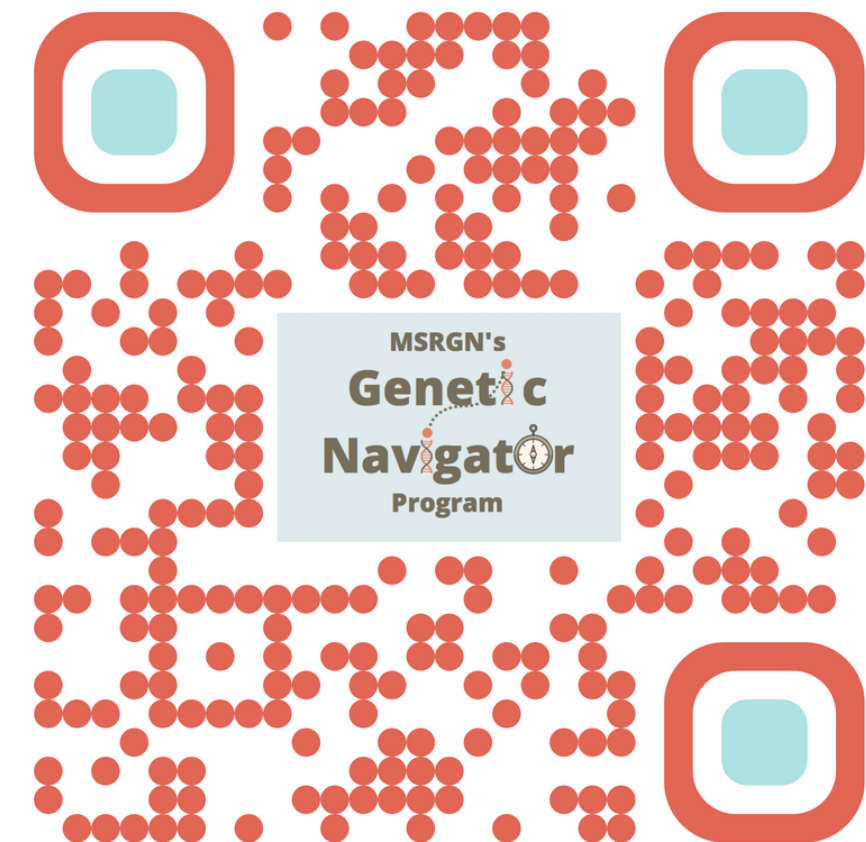
Nevada ~ nevadagenetic@gmail.com

New Mexico ~ newmexicogenetic@gmail.com

Texas ~ texasgenetic@gmail.com

Utah ~ utahgenetic@gmail.com

Wyoming ~ wyominggenetic@gmail.com





How to Connect with

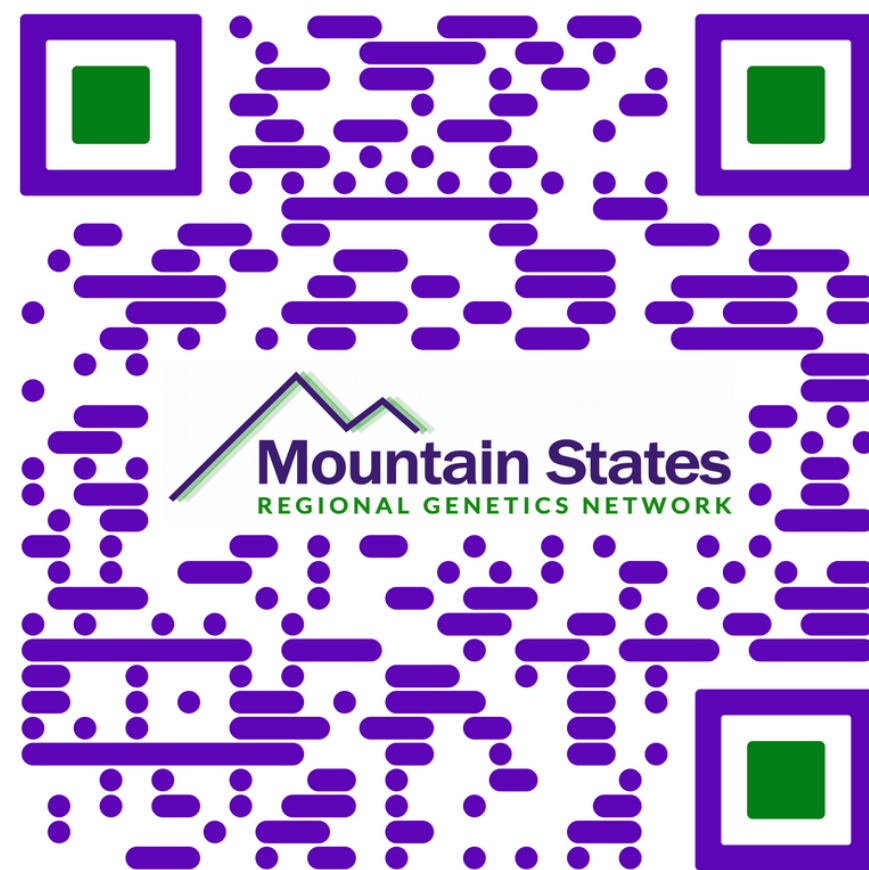
**MSRGN**

[www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)

Kristi Wees

Projects Manager

[kwees@montainstatesgenetics.org](mailto:kwees@montainstatesgenetics.org)





WHAT'S DNA HAVE TO DO WITH IT?

DON'T NAVIGATE ALONE

DO NAVIGATE ALONGSIDE

**T H A N K**  
**Y O U**

**This concludes  
the 4 Modules of our Genetic  
Connections Workshop for  
Early Intervention Providers**