

Navigating A Genetic Test Result

Genetic Test Result

Positive: The test found a genetic change that explains your child's symptoms.

Negative: The test did not find a genetic change to explain your child's symptoms. A negative result does not completely rule-out a genetic explanation for your child's symptoms; it may be related to a limitation in genetic knowledge/testing. A "true negative" result means that there is a known genetic change in the family and the person tested did not inherit it. If your test results are negative and there is no known genetic change in your family, a negative test result may not give you a definite answer. This is because you might not have been tested for the genetic change that runs in your family.

Uncertain Variant (VUS): "A variant of unknown or uncertain significance" (VUS) means that a change was found in a gene, but there isn't currently enough information to know if that genetic change is benign (not related to your child's symptoms) or pathogenic (known to cause your child's symptoms).

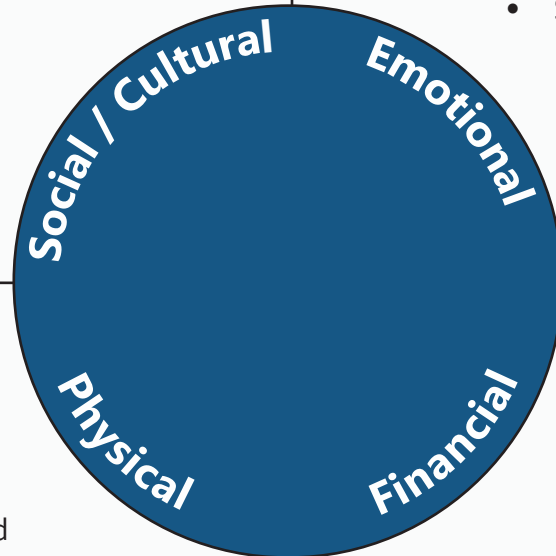
The Impact

- Some cultures may be more welcoming to genetic testing than others. You may be surprised by your communities response.
- You may face stigma or discrimination
- You may experience communication barriers when receiving your results; know that it is okay to ask questions and ask for clarification from your provider
- You may have experienced gaps in cultural understanding; feel free to share any concerns you may have about this with your providers

- You may be surprised about how these results affect you. Research shows that genetic test results can change the perception of your child's health and may impact your relationship with your child.
- Your child may experience changes in their self-concept, self-esteem, self-worth, and self-image
 - Results may lead to social isolation or behavioral problems
 - Some families experience distress, anxiety, or depression after receiving results
 - Results may lead to positive emotions like reduced uncertainty and decreased anxiety
 - Families tend to agree that over time, they are more able to adjust to the testing results

- Results can reduce worry and promote healthy planning for future children
- Children with genetic testing results may be more equipped to make decisions surrounding educational, social, and employment goals
- Results can lead to increased access to services and benefits
- Results may lead to earlier interventions, closer health monitoring, and risk-reducing screening or treatments
- Results may lead to appropriate therapies that promote maximum development and growth
- A result may lead to increased time necessary for management, appointments, travel, and assistance for your child

- Testing can be expensive especially if you did not have insurance coverage
- Results may help to avoid unnecessary additional tests
 - Results may increase your access to services that require a specific diagnosis or referral
- Results may lead to better insurance coverage for treatments, medications, or therapies



Next Steps...

The resources available to you will be dependent on your child's diagnosis. Some genetic conditions have facebook groups/websites to organize education and community events. You may be able to access these resources via the internet or by asking your providers to direct you to appropriate resources.

Understanding

Educational Websites

- National Organization for Rare Disorders
 - RareDiseases.org
- Medline Plus
 - MedlinePlus.gov
- Undiagnosed Diseases Network
 - undiagnosed.hms.harvard.edu
- Research opportunities
 - clinicaltrials.gov

Community and Support

Local community and products

- Autism Community Store
 - Located at 14095 E Exposition Ave, Aurora, CO 80012

Support and Advocacy Groups

- Facebook Support groups
- National Organizations - resources, education, community, events

Recreation and fun!

- Adaptive Recreation (Arts, Culture, Sports, and Wellness)
- Special Olympics Colorado Special Olympics CO
- Therapeutic Recreation Programs

Services

School Services

- Local Community Center School Board | <https://hcpf.colorado.gov/community-centered-boards>
- Child Find for ages 3-5 | <https://www.cde.state.co.us/cdesped/childfind>
- Request an IEP (Individualized Educational Plan) through your child's school

Developmental Services | Early Interventions Colorado for children age 0-3 | eicolorado.org

Career Assistance | <https://dvr.colorado.gov/>

For Financial/Travel assistance contact CHCO Social Work | www.childrenscolorado.org

Mental health services

- For parents and caregivers
 - <https://www.childrenscolorado.org/conditions-and-advice/parenting/mental-health-family-resources/>
- For children
 - <https://www.childrenscolorado.org/doctors-and-departments/departments/psych/>

Spiritual care at CHOC

- <https://www.childrenscolorado.org/your-visit/family-patient-resources/spiritual-care/>