

# BREAKING BARRIERS

AN RDDC HEALTH EQUITY INITIATIVE

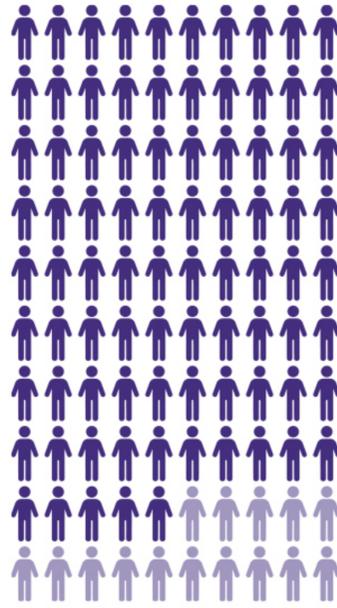


## GENETIC TESTING & WHOLE GENOME SEQUENCING INFORMATION

# 85%

MORE THAN 85% OF INDIVIDUALS REPORT THEY WERE NEVER OFFERED GENETIC TESTING OR COUNSELING.

Individuals from historically marginalized communities are less likely to be referred for genetic testing. This leads to delays in diagnosis.



# 80%

APPROXIMATELY 80% OF RARE DISEASES HAVE UNDERLYING GENETIC CAUSES.



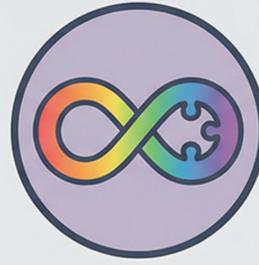
SEIZURES



MISSED MILESTONES



INTELLECTUAL DISABILITY



AUTISM SPECTRUM



### NOT ALL TESTS ARE THE SAME

**PANEL TESTS:**  
CHECKS SELECTED GENES.

**EXOME SEQUENCING:**  
CHECKS 22,000+ GENES

**GENOME SEQUENCING:**  
CHECKS NEARLY ALL DNA.

## 2x

THESE TESTS ARE 2X MORE LIKELY TO LEAD TO A DIAGNOSIS THAN STANDARD SCREENINGS.



### BUILDING TRUST & SAFETY



#### PRIVACY:

Your results are part of your medical record and protected by HIPAA.



#### PROTECTION:

The GINA act prohibits health insurers and employers from discriminating based on genetic info.



#### CONSENT:

Informed consent is not just a form; it is a conversation. You decide if your data is used for research.



### HOW TO ACCESS TESTING



#### Talk to Your Doctor:

Ask if Exome or Genome testing is right for you.



#### Explore Health:

Use video consults if specialists aren't local.



#### Find Support:

Financial assistance is available.



### FREQUENTLY ASKED QUESTIONS

#### Can genetic testing help adults?

Yes. While often discussed in pediatric settings, adults with unexplained symptoms may also benefit from testing.

#### Is genetic testing required?

No. Testing is voluntary and should always be based on the informed consent of the patient or their authorized representative.

#### Will my genetic data be shared?

Your data is protected by privacy laws. Research participation is optional and requires consent.

#### Will insurance cover genetic testing?

Coverage varies. Many insurers now cover exome/genome testing in specific cases, but prior authorization may be required. For individuals who are uninsured, under insured, or facing high out-of-pocket costs, some laboratories and nonprofit organizations offer patient assistance programs or subsidized testing options to help reduce financial barriers.



### QUICK LINKS

#### GENETIC TESTING ASSISTANCE PROGRAMS (LABS/CLINICAL TESTING SUPPORT)

#### ADVOCACY-LINKED GENETIC TESTING SUPPORT PROGRAMS



Equity in rare disease starts with access.

#RareWithinRare | <https://www.rarediseasediversity.org>