

# Passage Bio's Sponsored Genetic Testing Program

## General Information

- Eligibility:
  - Persons affected: Yes
  - Unaffected persons with family history: Yes; eligibility includes unaffected family members if they have a close relative (parent, sibling, adult child) with a *GRN* gene mutation
- Cost: \$0
- Testing available outside the U.S.: No

## Laboratory Information

- Lab: Prevention Genetics
- CLIA Certified: Yes
- Genes Included:
  - *GRN*
  - *C9orf72*
  - *MAPT*
  - Others: *APP, CHCHD10, CHMP2B, CSF1R, DCTN1, FUS, ITM2B, PSEN1, PSEN2, SQSTM1, TARDBP, TBK1, TREM2, UBQLN2, VCP*
- Test Limitations: *C9orf72* expansion test result typically does not include exact repeat number
- Sample type: Buccal (cheek) swab; other options may be available

## Genetic Counseling (GC)

- GC Provider: InformedDNA
- Counselors certified by ABGC: Yes
- Counselors with neurodegenerative disease experience licensed in all states requiring licensure: Yes
- Counselors experienced in neurodegenerative disease: Participants have the option to schedule post-testing counseling with GCs on InformedDNA's neurology team
- Pre-testing counseling provided: Yes
- Post-testing counseling provided: Yes
- Offers in-house physician ordering: Yes, after pre-test genetic counseling

## Privacy/Legal Considerations

- Validation of Patient Competence: Clinical judgment; genetic counselor will ask for power of attorney (POA) or have patient sign a healthcare surrogacy form identifying a family member to speak on their behalf.
- Data sharing: Results go to patient and physician. De-identified information goes to sponsors, no protected health information (PHI) is shared.
- Consent: Verbal consent for testing documented in visit summary; written consent in states if required. Written consent for counseling.

## Links

- [Passage Bio website – press release](#)
- [InformedDNA website for program](#)

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## KEY

ABGC = American Board of Genetic Counseling  
ACMG = American College of Medical Genetics and Genomics  
CLIA = Clinical Laboratory Improvement Amendment  
GC = genetic counseling, genetic counselor  
HCP = healthcare provider  
PHI = personal health information, protected health information  
POA = power of attorney