

## Sponsored Genetic Testing Programs for FTD

Sponsor	Passage Bio	Sano (Prevail)
<b>GENERAL INFORMATION</b>		
<b>Eligibility</b>		
Affected Individuals	✓	✓*
Unaffected w/ Family History	✓	✓#
<b>Cost</b>	\$0	\$0
<b>Testing Available to Patients Outside U.S.</b>		
Counseling limited to U.S. participants	Brazil, Canada, Italy, Portugal, UK	USA initially, then UK, then EU
Counseling available in other countries	X	✓
<b>LABORATORY INFORMATION</b>		
<b>Lab</b>	Prevention Genetics	Fabric Genomics
<b>CLIA Certified</b>	✓	✓
<b>Genes Included</b>	Panel	Panel
<i>GRN</i>	✓	✓
<i>C9orf72</i>	✓	✓
<i>MAPT</i>	✓	✓
Other	Y**	X
<b>ACMG Variant Classification Guidelines in Use</b>	✓	✓
<b>Test Limitations</b>	<i>C9orf72</i> expansion test result typically does not include exact repeat number	<i>C9orf72</i> expansion test result typically does not include exact repeat number
<b>Sample Requirement</b>	Buccal (cheek) swab; other options may be available	Saliva, Buccal (blood can be accommodated)
<b>GENETIC COUNSELING</b>		
<b>GC Provider</b>	InformedDNA	Grey Genetics
<b>All genetic counselors certified by ABGC</b>	✓	✓
<b>ABGC</b>	✓	✓
<b>GC Provider Experience in Neurodegenerative Disease</b>	✓	✓
<b>Pre-test counseling provided</b>	✓	✓
<b>Post-test counseling provided</b>	✓	✓
<b>Offers in-house physician ordering</b>	✓	X
	After pre-test genetic counseling	After pre-test genetic counseling
<b>PRIVACY/LEGAL CONSIDERATIONS</b>		
<b>Validation of Patient Competence</b>		Participant competence will be validated through mandatory pre test genetic counseling
<b>Data Sharing</b>	Results go to participant and physician. De-identified information goes to sponsor, no PHI is shared.	Results go to participant. Participant is responsible for arranging post-test GC. De-identified information goes to sponsor, no PHI is shared.
<b>Consent</b>	Sponsored testing under a research protocol; written consent to participate.	Sponsored testing under a research protocol; written consent to participate.
<b>Links</b>	<a href="#">Passage Bio website</a> <a href="#">InformedDNA website for program</a>	<a href="#">Sano (Prevail) website</a>
<b>Primary Program Limitations</b>	Affected Individuals Only	Only three genes analyzed; C9orf72, MAPT, and GRN.

**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	

**FOOTNOTES**

\* Patients with personal or family history of amyotrophic lateral sclerosis (ALS) or a known mutation in another FTD gene are excluded.

\*\* All of the following genes are tested: *APP, C9ORF72, CHCHD10, CHMP2B, CSF1R, DCTN1, FUS, GRN, ITM2B, MAPT, PSEN1, PSEN2, SQSTM1, TARDBP, TBK1, TREM2, UBQLN2*

# Program allows family member testing for a known pathogenic variant if the relative qualifies for and enrolls in the full STP.

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