Sponsored Genetic Testing Programs for FTD		
Sponsor	**Alector**	**Passage Bio**
GENERAL INFORMATION		
Eligibility Affected Individuals Unaffected w/ Family History	 ✓ [1] ✓	 ✓ ✓ [3]
Cost	$0	$0
Testing Available to Patients Outside U.S. (Counseling limited to U.S. participants)	No	No
LABORATORY INFORMATION		
Lab	Prevention Genetics	Prevention Genetics
CLIA Certified	✓	✓
Genes Included *GRN* *C9orf72* *MAPT* Other	Panel ✓ ✓ ✓ X	Panel ✓ ✓ ✓ ✓ [6]
ACMG Variant Classification Guidelines in Use	✓	✓
Test Limitations	*C9orf72* expansion test result typically does not include exact repeat number	*C9orf72* expansion test result typically does not include exact repeat number
Sample Requirement	Buccal (cheek) swab; other options may be available	Buccal (cheek) swab; other options may be available
GENETIC COUNSELING		
GC Provider	InformedDNA	InformedDNA
All genetic counselors certified by ABGC	✓	✓
GCs w/ experience in neurodegenerative disease licensed in all states requiring licensure	✓	✓
GC Provider Experience in Neurodegenerative Disease	Participants are only scheduled with GCs on InformedDNA's neurology team	Participants have the option to schedule post-testing counseling with GCs on InformedDNA's neurology team
Pre-test counseling provided	✓	✓
Post-test counseling provided	✓	✓
Offers in-house physician ordering	✓ After pre-test genetic counseling	✓ After pre-test genetic counseling
PRIVACY/LEGAL CONSIDERATIONS		
Validation of Patient Competence	Clinical judgement; GC will ask for POA or have participant sign a healthcare surrogacy form identifying a family member to speak on their behalf.	Clinical judgement; GC will ask for POA or have participant sign a healthcare surrogacy form identifying a family member to speak on their behalf.
Data Sharing	Results go to participant and physician. De-identified information goes to sponsor, no PHI is shared.	Results go to participant and physician. De-identified information goes to sponsor, no PHI is shared.
Consent	Sponsored testing under a research protocol; written consent to participate.	Verbal consent for testing documented in visit summary. Written consent for counseling.
Links	Alector site - patient screener InformedDNA site for program	Passage Bio website InformedDNA website for program

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

[1] Participants with personal or family history of amyotrophic lateral sclerosis (ALS) or known mutation in another FTD gene are excluded.

[2] Program includes testing for persons diagnosed with FTD or related disorders in addition to individuals who might be experiencing FTD-like symptoms and do not have an FTD diagnosis. Eligibility may be determined by the use of an FTD-trained Symptom Checker. Submissions to the Symptom Checker can be entered by a loved one or care partner on behalf of the symptomatic person.

[3] Eligibility includes unaffected family members if they have a close relative (parent, sibling, adult child) with a *GRN* gene mutation.

[4] Program provides genetic counseling and testing in all U.S. states except New York.

[5] Primary findings, including any pathogenic or likely pathogenic variant in genes related to the participant's reported clinical phenotype, and secondary findings will be reported back to the participant.

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

Compiled by Erynn Gordon, MS, CGC, Ripple Genetic Consulting, for The Association for Frontotemporal Degeneration (AFTD) – 6/2021
Updated by Sherry Harlass, FTD Disorders Registry (FTDDR) – 5/2023