Sponsored Genetic Testing Programs for FTD			
Sponsor	**Alector**	**Passage Bio**	**Prevail Therapeutics**
General Information			
Eligibility Affected Individuals Unaffected w/ Family History	 ✓[1] ✓	 ✓ X	 ✓[4] ✓
Cost	$0	$0	$0 (optional pre-test counseling $125)
Testing Available to Patients Outside U.S. (Counseling limited to U.S. patients)	Yes Using Invitae in Australia	No	Yes Australia, Brazil, Canada
Laboratory Information			
Lab	Blueprint Genetics Laboratory	Prevention Genetics	Invitae
CLIA Certified	✓[2]	✓	✓
Genes Included *GRN* *C9orf72* *MAPT* Other	 ✓ X X X	 ✓ ✓ ✓ X	 ✓ X ✓ ✓[5]
ACMG Variant Classification Guidelines in Use	✓	✓	✓
Test Limitations	Excludes all genes other than *GRN*	*C9orf72* expansion test result typically does not include exact repeat number	Excludes *C9orf72*
Sample Requirement	Buccal (cheek) swab; other options may be available	Buccal (cheek) swab; other options may be available	Saliva; other options may be available
Genetic Counseling			
GC Provider	InformedDNA	InformedDNA	Genome Medical
All genetic counselors certified by ABGC	✓	✓	✓
GCs w/ experience in neurodegenerative disease licensed in all states requiring licensure	✓	✓	✓
GC Provider Experience in Neurodegenerative Disease	Patients are only scheduled with GCs on InformedDNA's neurology team	Patients are only scheduled with GCs on InformedDNA's neurology team	Patients are only scheduled with GCs on Genome Medical's neurology team
Pre-test counseling provided	✓	✓	available for $125
Post-test counseling provided	✓	✓	✓
Offers in-house physician ordering	✓ After pre-test genetic counseling	✓ 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 patient sign a healthcare surrogacy form identifying a family member to speak on their behalf	Clinical judgement; GC will ask for POA or have patient sign a healthcare surrogacy form identifying a family member to speak on their behalf	Clinical judgement; GC will defer testing and ask for POA if needed

Sponsored Genetic Testing Programs for FTD *(continued)*

Sponsor	Alector	Passage Bio	Prevail Therapeutics
Data Sharing	Results go to patient and physician No PHI is shared with sponsor. Sponsor does collect patient information through their site[3].	Results go to patient and physician De-identified information goes to sponsor, no PHI.	Results go to patient and physician De-identified information goes to sponsors, no PHI. Sponsors may receive contact information for HCPs who use program.
Consent	Sponsored testing under a research protocol; written consent to participate.	Verbal consent for testing documented in visit summary; written consent in states if required. Written consent for counseling.	Verbal consent for testing documented in visit summary. Written consent for counseling.
Links	Alector site - patient screener InformedDNA site for program	Passage Bio site - press release InformedDNA site for program	Prevail sponsorship statement Invitae site for program
Primary Program Limitations	Exclusion of genes other than *GRN*	Affected individuals only	Exclusion of *C9orf72*. Cost to patient for pre-test counseling

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

[2] Confirmation for NY is outstanding

[3] "I agree for authorized contracted service providers and clinical trial sites to contact me in relation to clinical trials for FTD and to contact me in the future to determine my/the patient's interest in related activities."

[4] Program includes testing for patients diagnosed with ALS, Parkinson's disease (PD), frontotemporal degeneration (FTD), Alzheimer's disease with onset <65 years of age, hereditary prion disease, or unaffected individuals with a family history of any of these conditions diagnosed in a relative under the age of 65.

[5] All of the following genes are tested: *ALS2, ANG, ANXA11, APP, CHCHD10, CHMP2B, DCTN1, ERBB4, FUS, GRN, HEXA, HNRNPA2B1, ITM2B, KIF5A, MAPT, OPTN, PFN1, PRNP, PSEN1, PSEN2, SETX, SNCA, SOD1, SORL1, SPG11, SQSTM1, TARDBP, TBK1, TFG, TREM2, UBQLN2, VAPB, VCP, ATP13A2, DDHD1, ERLIN1, FIG4, LRRK2, MATR3, NEFH, SIGMAR1, TIA1*

Compiled by Erynn Gordon, MS, CGC, Ripple Genetic Consulting, for The Association for Frontotemporal Degeneration (AFTD) – 6/2021