

Alector's Sponsored Genetic Testing Program

General Information

- Eligibility:
 - Persons affected: Yes; patients with personal or family history of amyotrophic lateral sclerosis (ALS) or a known mutation in another FTD gene are excluded
 - Unaffected persons with family history: Yes
- Cost: \$0
- Testing available outside the U.S.: Yes, using Invitae in Australia, exploring other countries
- Primary Program Limitations: Exclusion of genes other than *GRN*

Laboratory Information

- Lab: Blueprint Genetics Laboratory
- CLIA Certified: Yes (confirmation of NY outstanding)
- Genes Included:
 - *GRN*
- Test Limitations: Excludes all genes other than *GRN*
- 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: Patients are only scheduled with genetic counselors 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. No personal health information (PHI) is shared. Sponsor does collect patient information through their site. ("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.")
- Consent: Sponsored testing under a research protocol; written consent to participate.

Links

- [Alector website – patient screener](#)
- [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