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.: No
- Primary Program Limitations: Only covers GRN, C9orf72 and MAPT

Laboratory Information

- Lab: Prevention Genetics
- CLIA Certified: Yes (confirmation of NY outstanding)
- Genes Included:
  - GRN
  - C9orf72
  - MAPT
- 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: 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. De-identified information goes to sponsor, no personal health information (PHI) is shared.
- 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