

# Frontotemporal Dementia and Genetic Counseling

FTD is the most common form of dementia in people younger than 60 years old. The cause of FTD is unknown for a majority of people with the disease. Approximately 30% of all FTD is hereditary (i.e., runs in families) due to an inherited gene mutation (a change in the genetic code is called a mutation or variant). Genetic testing is an important step for patients with FTD to determine if their disease is the result of a gene mutation. Learning whether FTD is caused by a genetic mutation may enable clinicians to intervene sooner and evaluate treatment options.

Most people with a genetic form of FTD have mutations in 1 of 3 genes: progranulin (GRN), C9orf72 and MAPT. This testing program offered by InformedDNA includes these 3 genes, as well as 15 other genes associated with hereditary dementias.



## Who is Eligible for this program?

- ✔ Adults who have been diagnosed with FTD by a doctor (such as a neurologist) are eligible for genetic counseling and genetic testing at no cost through this program.
- ✔ Unaffected family members are eligible to participate in the program if they have a close relative (parent, sibling, adult child) with a *GRN* gene mutation.

## What is genetic counseling?

Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
- Education about inheritance, testing, management, prevention, resources and research.
- Counseling to promote informed choices and adaptation to the risk or condition.



InformedDNA is providing no-cost genetic counseling and testing to patients with Frontotemporal Dementia (also known as frontotemporal degeneration or FTD).

# What to expect in a genetic counseling appointment with InformedDNA

The genetic counselors at InformedDNA working on this program are highly trained in hereditary neurological conditions. As part of this program individuals will receive initial and post-test genetic counseling over the phone.



All appointments occur over the phone. Family members or friends may participate in the call, regardless of location. Appointments are available during usual business hours as well as evenings and weekends.

If you decide to proceed with genetic testing, then the genetic counselor will coordinate the test order and sample collection (cheek swab)

- Results will be available in approximately three weeks from when the lab receives the sample

At the initial appointment, the genetic counselor will:

- Collect medical history and a 3-4 generation family history;
- Discuss the genetics of FTD;
- Review the benefits and limitations of genetic testing;

At the post-test appointment, the genetic counselor will:

- Review the genetic test result and implications for personal health and risks to family members
- Provide a written summary of the discussion and a copy of the genetic test result to the individual

InformedDNA is the largest independent provider of genetic counseling services, offering a nationwide staff of board-certified geneticists and genetic counselors. A pioneer in increasing access to genetics expertise, InformedDNA uses proprietary telephone and Internet service delivery systems, allowing patients the convenience of participating in genetic counseling sessions from the location of their choice.

## For more information, contact us!



### Flexible Appointments

- Day
- Evening
- Weekends



### Convenient Access


Talk to a genetic counselor in the comfort of your own home by telephone.



### Multi-lingual Counseling

- Counseling with interpreter assistance (most languages)
- Counseling with interpreter assistance via Video Relay Service (VRS) for the deaf and hearing impaired communities.

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This testing program is sponsored by  **Passage Bio**  
No personal identifying information of individuals participating in this genetic counseling and testing program will be shared with Passage Bio.