

# DNA BANKING



**My family member is diagnosed with FTD but does not want to have genetic testing. I am concerned it could be genetic. Is there anything I can do?**

**Ask your family member to consider DNA banking.**

## **What is DNA banking?**

DNA banking is a safe and secure way to preserve a person's DNA, typically for several decades. It works like a regular bank account, only you, or a person you designate, can access the DNA. A designated person could be a spouse, relative, or another trusted person. Your banked DNA can be tested in the future and provide answers for your family by confirming a diagnosis, giving at-risk family members the option to be tested for the family variant, and shortening the time needed for relatives to get an accurate diagnosis.

Researchers are making progress in identifying ways to treat, or even cure, FTD. Just as a will or insurance policy offers financial security for your family, DNA banking offers an opportunity for future generations to better understand their inherited risk and take proactive measures, such as participating in research, for the best path forward.

## **How is DNA banking done?**

DNA banking is a simple process. It is strongly recommended you work with a genetic counselor, who can assist you with choosing the most reliable laboratory for DNA banking. You will provide a small sample of either blood or a cheek swab. In some cases, the laboratory can send a collection kit to your home. You will mail your sample in a prepaid envelope to the laboratory, where scientists will preserve your DNA in a secure place. Preserved DNA is stable and can be safely stored for several decades.

## **How much does DNA banking cost?**

The cost of DNA banking varies across labs, ranging from \$180-\$500 (USD). This is typically a one-time fee that covers several decades of DNA storage. Some insurance policies cover the cost of DNA-sample collection kit, but not the cost of storing your DNA.

Importantly, any test that is done after a person has passed away will not be covered by insurance. If the banked DNA is used for testing after the depositor has died, the cost of testing will be out of pocket. Several labs do, however, offer a reduced fee for out-of-pocket testing. For more information on DNA banking costs, please contact the HelpLine at [info@theaftd.org](mailto:info@theaftd.org) or **866-507-7222**.

**The Association for Frontotemporal Degeneration**

[theaftd.org](http://theaftd.org) | HelpLine: 1.866.507.7222 | [info@theaftd.org](mailto:info@theaftd.org)

## Reasons to consider DNA banking

- **Your genetic result was negative**

To date, researchers have found more than a dozen genes that can cause FTD and related conditions, but it is very likely that more genes will be identified in the future. If your genetic testing was negative, it may be worth re-testing if and when additional FTD-causing genes are identified.

- **Your genetic result was a Variant of Uncertain Significance (VUS)**

A VUS is a DNA change (or variant) that does not contain enough evidence to determine if it is harmless or potentially linked to FTD. In the event the VUS proves to be benign, DNA banking preserves the option to re-test in the future if you are still trying to identify the cause of your family's genetic FTD.

- **You want to take advantage of future technological advances**

Genetic testing methods have advanced significantly over the last few decades. New testing methods can detect genetic changes that we were not able to identify previously. New technologies are also reducing the cost of genetic testing, making it a more affordable option. Remember, banked DNA is preserved for several decades.

- **You want access to potential future treatments**

Research is making significant progress in developing a treatment or cure for FTD. Currently, researchers are looking at genetic forms of FTD to better understand how and why FTD develops. Once its cause is better understood, treatments can be developed for all forms of FTD, not just genetic FTD. Researchers need participants in studies to ensure their success.

- **Your relative declines genetic testing**

Genetic testing is most informative when the person diagnosed with FTD provides the DNA sample. If a family member with FTD chooses not to be genetically tested, DNA banking allows their relatives to respect their wish while maintaining the option to access the familial genetic information in the future. Relatives might learn if they qualify to participate in specific trials or access an approved treatment when one becomes available.

Genetics can play a key role in understanding medical conditions in the family. We are all predisposed to certain health concerns, whether it is FTD, heart disease, or another inherited condition. Preserving the ability to analyze a person's DNA benefits other family members and future generations. This is a particularly important option when a person is reluctant to undergo genetic testing themselves. DNA banking allows the person's wishes to be respected while preserving the opportunity for other relatives to learn their own genetic risk and access experimental treatments and/or clinical trials.

For more information or help finding a genetic counselor, please contact the HelpLine at [info@theaftd.org](mailto:info@theaftd.org) or **866-507-7222**.