

# HELP & SUPPORT

## Genetic Information – Understanding My Rights



Obtaining genetic information showing if you or your family could have a genetic form of FTD can help in confirming a diagnosis, beginning financial and/or reproductive planning, and knowing if you are eligible for research opportunities, including potential treatment trials. Pursuing genetic testing is a personal decision that should be considered with the best information in hand. A genetic counselor can help you understand your rights as you navigate decisions about genetic testing.

People considering genetic testing are often concerned about how their genetic information may be used. Before moving ahead, it is important to understand how this information could impact your options for insurance and employment.

In 2009, the federal government implemented the Genetic Information Nondiscrimination Act, or GINA. This law is meant to ensure an individual's genetic information could not be used to deny or limit services and rights based on their genetic information.

What exactly is "genetic information"? Genetic information includes any personal or family history of a genetic condition. It also includes the results of any type of genetic test for yourself or a blood relative, including those related to diagnosis, future risk, carrier screening, assisted reproductive technologies, or prenatal testing. Genetic information further includes any form of genetic services, such as genetic counseling or a genetic evaluation/examination for yourself or a relative.

GINA protects individuals in two important areas: health insurance and employment.

| Genetic information may NOT be used regarding   |  |
|---|--|
| Health Insurers   | Employers  |
| <ul style="list-style-type: none"><li>• Eligibility for individual or group health insurance plans</li><li>• Health premium costs, contributions, terms of coverage</li></ul> | <ul style="list-style-type: none"><li>• Hiring or firing</li><li>• Promotions/advancement</li><li>• Terms of employment</li><li>• Treatment of an employee</li></ul> |
| <i>These terms apply to most health insurers</i>  |  |

Image attributed to: [aboutgeneticcounselors.com](http://aboutgeneticcounselors.com)

An employer cannot use genetic information for discriminatory practices or special treatment, even if they are doing so to "benefit" the individual.

GINA offers substantial protections, but there are key areas it does not protect. An insurer cannot require an individual to undergo genetic testing, nor can an insurer use genetic information as a pre-existing condition to deny coverage. However, if an insurance claim is filed, GINA does allow the insurer to request the minimum amount of genetic information necessary to determine if the claim is appropriate.

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There are other situations that GINA does not protect against:

- GINA does not protect manifested disease, where an individual is experiencing symptoms, receiving treatment, or is already diagnosed with the condition (pre-existing condition).
- GINA does not protect long-term care insurance, disability insurance, or life insurance.
- GINA does not protect U.S. military members receiving military health benefits (based on “service connection” to the benefit).
- GINA does not protect Veterans receiving services through Veterans Health Programs.
- GINA does not protect health services offered through the Indian Health Service.
- GINA does not protect federal government employees receiving federal health benefits; however, President Clinton signed an executive order to protect these individuals.
- GINA does not protect employees of small businesses with fewer than 15 employees.

Please note that many insurers offering long-term care, disability, and life insurance policies often ask about family history even if no genetic testing has been completed. Efforts are underway to expand the protections offered under GINA. Your genetic counselor will have the most current information available.

For health insurance discrimination inquiries, contact your [state insurance commissioner’s office](#). Every U.S. state, district, and territory must match and enforce the protections that GINA affords.

For employment discrimination inquiries, claims must be filed with the [Equal Employment Opportunity Commission \(EEOC\)](#). The EEOC will investigate, mediate, attempt conciliation, potentially grant a Notice of Right to Sue, or file a civil suit against an employer, if merited.

If you have additional questions regarding your protections under GINA, please review the following resources:

- [The Genetic Information Nondiscrimination Act of 2008: Information for Researchers and Health Care Professionals \(genome.gov\)](#)
- [The Genetic Information Nondiscrimination Act of 2008](#)
- [NSGC GINA Fact Sheet](#)
- [Coalition for Genetic Fairness](#)

A genetic counselor is the best resource to help you decide if and when genetic testing may be beneficial to you and your loved ones. For help finding a genetic counselor please visit [this web page](#) and select “neurogenetic” as the specialty area. A genetic counselor can review your specific situation and explain how GINA may impact your decision to pursue genetic testing to better understand the cause of FTD in your family. Often, a genetic counselor will encourage families to explore GINA protections and consider accessing long-term care, disability, and life insurance options prior to scheduling a visit.

AFTD offers additional information regarding the genetics of FTD. If you are interested in learning more, please [visit our website](#). If you have additional questions about pursuing genetic testing or GINA, please contact the AFTD HelpLine at 866-507-7222 or [info@theaftd.org](mailto:info@theaftd.org).



Scan to learn more



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

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