The Fear of Genetic Discrimination

a Hidden Burden to Patients

END THE LEGACY
GENETIC ALS & FTD

Every year, improved survival and better quality of life for people impacted by a wide range of diseases are revealed as science unlocks the secrets within our genes. We are seeing genetic markers for disease and, in some cases, are learning how to turn off genetic triggers. This field will explode in the coming decade as artificial intelligence and other tools are brought to bear.

Unfortunately, before patients can use genetics to guide their medical care, they must contend with the fear of **genetic discrimination** - that the same information that can save their lives can lead to added expense and uncertainty. Most notably, this fear is distilled in the form of possible discrimination in insurance products (beyond health insurance, which has protections in the Federal law GINA).

But there is hope!

Florida outlawed genetic discrimination in most insurance products in 2020. There has been no impact on the insurance industry since this passed.

Importantly, the Florida law did not change existing practices around using family history of disease in making coverage decisions; it only protects the decision to use genetic testing as part of screening, diagnosis, and treatment decisions.

If we export this model across the country and at the federal level, there is no reason to expect a different result.

We need to take fear out of the exam room and allow patients to consider genetic medicine where indicated by a clinician, without the possibility that they will be denied coverage or lose their insurance altogether.

We must work together to protect patients!

Contact Us

For more information, please reach out to us:

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This educational flier was created by Genetic ALS & FTD: End the Legacy.