Genetic Testing & Life Insurance

How Legislation can Protect Consumers and Maintain a Strong Life Insurance Market

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What is ALS?

Amyotrophic
Lateral
Sclerosis

ALS is a neurodegenerative disease in which the brain stops talking with the muscles, robbing patients over time of the ability to walk, talk, eat, and eventually breathe

Thanks to recent medical advances and promising research, we are closer than ever to achieving our mission:

To Make ALS Livable For Everyone, Everywhere, Until We Cure it

Facts About ALS

5,000+
people are diagnosed per year

2-5 years
is the average life expectancy

10 percent
of cases are inherited through a mutated gene

90 percent
of cases occur without family history

$2 billion
is the estimated cost to develop a drug to slow or stop the progression of ALS

$250,000
is the estimated annual out-of-pocket cost for caring for a person with ALS

Every **90 minutes**
someone is diagnosed or someone passes away from ALS

There is NO CURE for ALS

SYMPTOMS

Progressive loss of muscle control

ALS gradually prohibits the ability to:

- Speak
- Swallow
- Walk
- Grasp objects
- Move
- Breathe

DIAGNOSIS

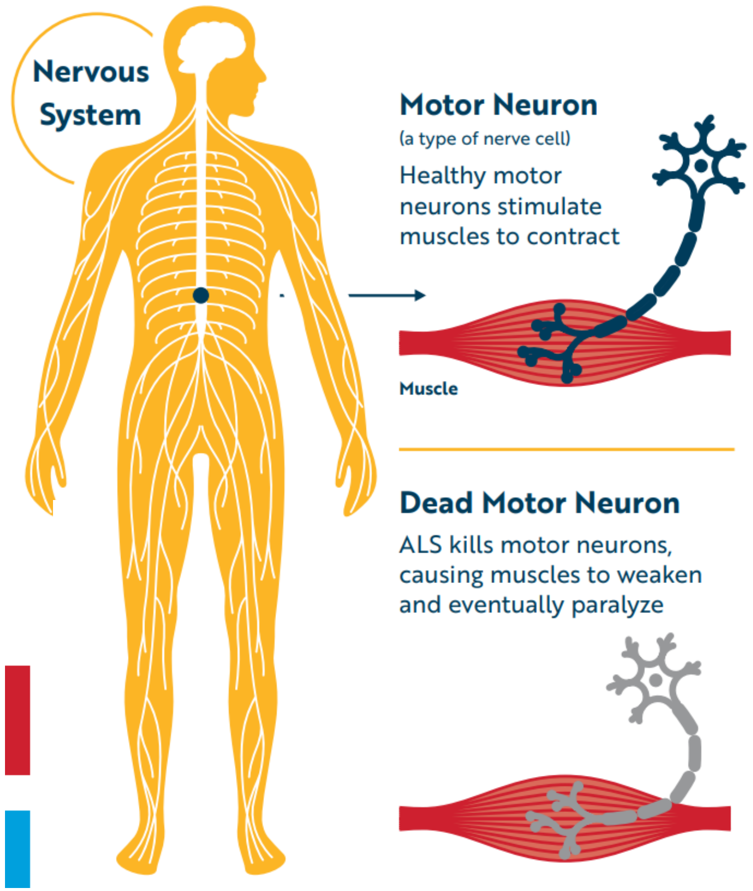
Difficult to diagnose

ALS is often diagnosed by ruling out other diseases, which may take months or years

MILITARY

Veterans are more likely to get ALS

ALS impacts veterans regardless of the branch of service served in and affects those who served in both peacetime and war



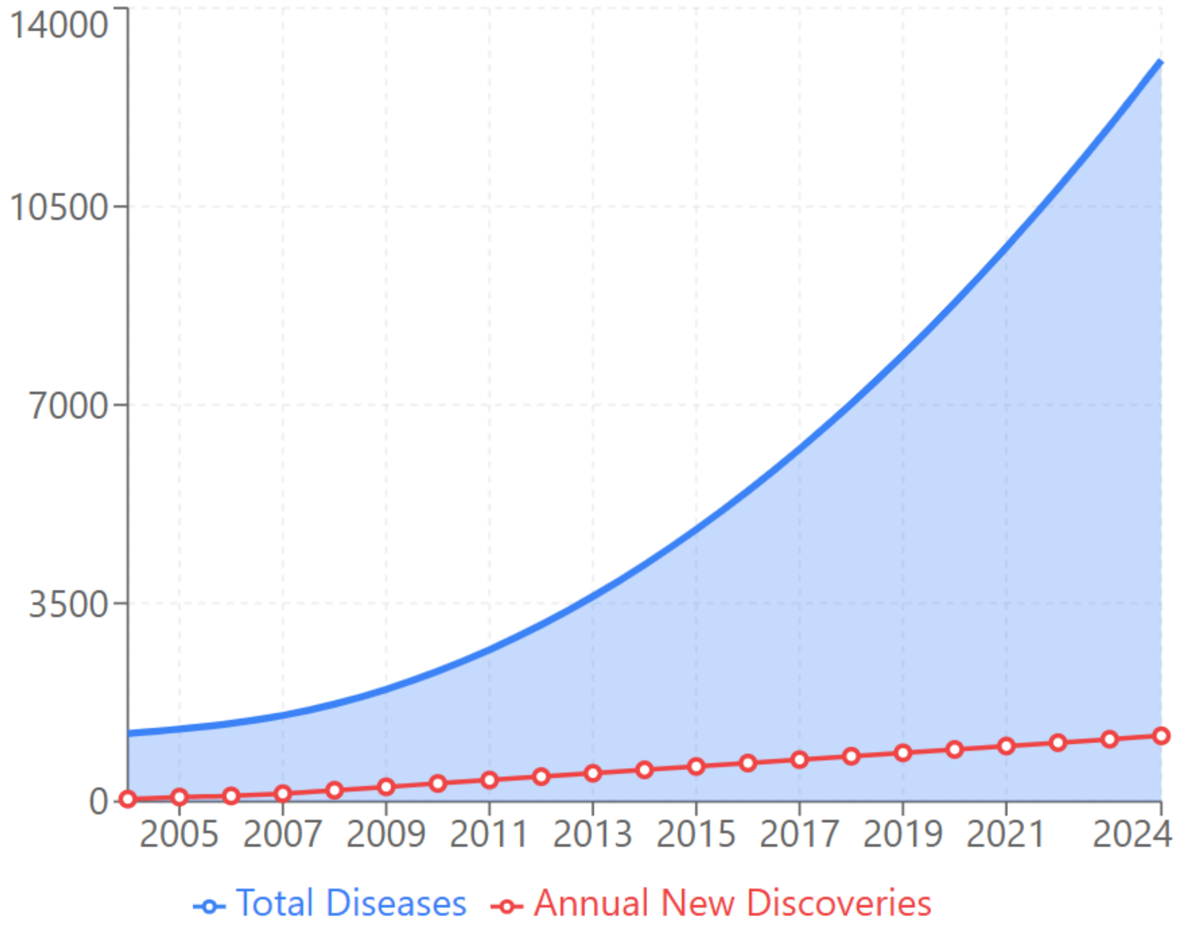
Motor Neuron
(a type of nerve cell)
Healthy motor neurons stimulate muscles to contract

Dead Motor Neuron
ALS kills motor neurons, causing muscles to weaken and eventually paralyze

The Growth of Genetic Testing

From Theory to Reality: Genetic Testing

- The U.S.-led Human Genome Project completed its work in 2003, leading to the International Human Genome Sequencing Consortium publishing the first widely available scientific description of the finished human genome sequence in 2004
- In 2004, nearly 1,500 genetic mutations were linked to specific diseases, with 80 new genetic diseases discovered in 2005
- The rate of discovery has been increasing ever since, and by the end of 2024, over 13,000 genetic mutations linked to a specific disease had been discovered, including 1,160 discovered in 2024 alone



Cumulative Number of Diseases with Genetic Links

The Benefits and Limits of Genetic Testing

What a Positive Genetic Test Can Tell Us

- That an individual has an increased likelihood of developing a specific disease
    - It is important to note that the relative increase in likelihood based on a positive genetic test can range from a very slight increase to a near-certainty
- A positive genetic test can point towards the most effective course of preventative and therapeutic treatments
- Whether an individual may be eligible for currently-available therapies for specific genetic forms of a disease
- Whether an individual is a candidate to participate in certain clinical trials

What a Positive Genetic Test Can't Tell Us

- Whether an individual will or won't develop the indicated disease with 100% certainty
- The severity of the disease, if the individual is ultimately diagnosed
- How many months, years, or decades it might be before an individual might develop the disease
- Whether current preventative actions or therapeutic treatments will mitigate the likelihood of developing the disease
- Whether and when new preventative or therapeutic treatments that could delay the development or arrest the progression of the disease will be discovered and developed

Example: ALS, the SOD1 Gene, and Qalsody

Genetic ALS and the SOD1 Gene

- While the root cause of most cases of ALS remain a mystery, roughly 10% of ALS cases now have a known genetic link
- Approximately 20% of those ALS cases with known genetic links are attributed to a mutation of the SOD1 gene, accounting for about 2% of ALS cases overall

Development of a New Drug: Qalsody (Tofersen)

- 2016: Phase 1 and 2 clinical trials begin
- 2019: Phase 3 clinical trials begin
- 2023: initial FDA approval under accelerated approval process
- 2025: confirmation study published demonstrating real-world efficacy of Qalsody in arresting the progression of the disease and in some cases restoring function

Cory Mosely, living with SOD1 ALS, with his wife and daughter

"Up until recently, there was no real way to do anything about it. So, you just kind of go through life wondering when it's going to hit. But now it feels a little different. There's some treatment that is showing promise, that's working for me. It's working for other members of my family. That's not just progress—it's a new lease on life."

The Catch-22 of Genetic Testing

Unintended Consequences of Genetic Testing

- As genetic testing becomes more accessible through both clinical settings and consumer-facing platforms (e.g., 23andMe, Ancestry), more individuals are uncovering information that can help guide their healthcare decisions.
- However, tools that empower patients are creating new risks—especially in areas unprotected by federal law.
- While the Genetic Information Nondiscrimination Act (GINA) prohibits discrimination in health insurance and employment, it does not apply to life, long-term care, or disability insurance.
- This leaves consumers vulnerable to denial of coverage or increased premiums based on their genetic information that may not accurately predict symptom onset risk.

The Catch-22 Consumers Face on Genetic Testing

- Genetic testing can help individuals understand their risk for inherited conditions—like ALS, certain cancers, and cardiovascular diseases—before symptoms appear.
- Early knowledge enables proactive medical intervention and lifestyle changes that can delay or prevent the onset of illness.
- Early identification also expand the universe of eligible research subjects for clinical trials
- But when insurers use that information to penalize individuals, it discourages people from seeking the tests that could save their lives.
- No one should have to choose between life-saving knowledge and life insurance.

Legislation Can Protect Consumers and the Market

Genetic Testing Consumer Protection Bills

- State lawmakers have an opportunity to protect consumers and maintain healthy insurance markets by establishing clear, enforceable boundaries for the use of genetic information.
- Prohibiting the use of genetic information will protect consumers from being penalized for inherited risk factors over which they have no control.
- Genetic testing is relatively new, and the robust life insurance markets we enjoy today were created and run for decades without any consideration of genetic test results
- It is reasonable to conclude that they can continue to do so without significant market risk, especially in the absence of evidence to the contrary
- If evidence emerges of potential adverse selection risk, a UK-style policy value cap may be a viable option

Opinion

The Editorial Board: Pass the Dennis Crawley Genetic Protection Act

"Dennis did not let this disease slow him down, instead he lived his last moments to the fullest…Throughout his fight he would always say 'I want to advocate for a change not for me but for our future generations.'" – Crawley Family Statement

Review of NCOIL Draft Model Language

Section 4. Life Insurers' Use of Genetic Information

Current draft language

(A) A life insurance provider shall not cancel insurance coverage for an individual or a family member of an individual based solely on the individual's or family member's genetic information.

Our suggested edit

(A) A life insurance provider shall not deny, cancel, **limit, or establish differentials in premium rates** for an individual or a family member of an individual based ~~solely~~ ***in whole or in part*** on the individual's or family member's genetic information.

Additional Considerations

Many states have contestability clauses that allow the cancellation of a policy within a specific time-period if the beneficiary withheld medical information when applying for a policy. Genetic counselors advise patients to purchase life insurance before undergoing genetic testing.

Therefore in many states it is legal for insurance companies to cancel a policy if a beneficiary has a positive genetic test result after that beneficiary has purchased their policy as long as the cancelation occurs within the contestability period.

Will this language supersede those contestability clauses where applicable, or would insurers still be able to continue this practice?

Review of NCOIL Draft Model Language continued

Section 4. Life Insurers' Use of Genetic Information

Current draft language

(B) A life insurance provider shall not request or require an individual to whom the insurer provides life insurance coverage, or an individual who applies for life insurance coverage, to take a genetic test as a precondition of insurability, and shall not require the complete genome sequencing of an individual's DNA.

Our suggested edit

(B) A life insurance provider shall not request**,** ~~or~~ require**, encourage or coerce** an individual to whom the insurer provides life insurance coverage, or an individual who applies for life insurance coverage, **to undergo genetic testing, including complete genomic sequencing,** ~~take a genetic test~~ as a precondition of ~~insurability~~ **coverage, renewal, or pricing**~~, and shall not require the complete genome sequencing of an individual's DNA~~.

Additional Considerations

While we have not heard of any cases where an insurer requires an applicant to undergo genetic testing, this language has value in ensuring that the practice is illegal.

Review of NCOIL Draft Model Language continued

Section 4. Life Insurers' Use of Genetic Information

Current draft language

(C) A life insurance provider shall not access sensitive medical information, including the genetic data of an individual, without first obtaining the individual's signed, written consent.

Our suggested edit

(C) A life insurance provider shall not access**, use, retain, or disclose** sensitive medical information, including the genetic data of an individual, without first obtaining the individual's ~~signed, written consent~~ **prior, express, written and informed consent. Such consent must be separate from any general authorization to release medical records. An insurer shall not deny, cancel, or refuse to issue or renew a life insurance policy because an individual declines to provide such consent.**

Additional Considerations

When applying for a life insurance policy, the applicant must provide consent for access to their medical records.

Genetic test results must be included in a patient's medical chart to inform appropriate risk management, such as supplemental cancer screenings, risk-reducing therapies or surgeries, and/or targeted preventive treatments. The genetic test result also substantiates coverage of these services for the health insurer.

In practice, refusal to provide signed consent granting the use of medical records means that the applicant will not be sold a policy. As such, this clause as written has negligible value for the consumer without additional protections.

Review of NCOIL Draft Model Language continued

Section 4. Life Insurers' Use of Genetic Information

Current draft language

(D) This section does not prevent a life insurance provider from requesting or obtaining existing health information for underwriting, including genetic information contained within an individual's medical record.

Our suggested edit

(D) This section does not prevent a life insurance provider from requesting or obtaining existing health information for underwriting, including genetic information **already** contained within an individual's medical record **provided that the insurer complies with all other applicable state and federal privacy laws and the individual has provided appropriate consent. Nothing in this section prohibits an insurer from considering a medical diagnosis included in an individual's medical record, even if a diagnosis was made based on the results of a genetic test.**

Additional Considerations

Life insurers should have access to an applicant's personal and family health history. However, they should not be permitted to use genetic information in determining policy eligibility or in underwriting decisions. Individuals without manifest disease (i.e. a clinical diagnosis) who undergo genetic testing to engage in research or proactive health measures are being unfairly penalized compared to those with similar health histories who do not pursue genetic testing. The vast majority of people who carry an inherited genetic mutation that increases their risk of disease are unaware. Using genetic information against those who would otherwise be proactive about their health disincentivizes them from pursuing genetic testing, negating potential benefits to their own health, the health of family members, and to scientific discovery.

If an individual had genetic testing privately, through a clinical trial, or a direct-to-consumer product, the insurer could ask if they have ever had genetic testing, and that information would have to be disclosed. This undermines patient privacy, preventative care, and scientific research.

Alternative Model Language

The Florida Model

This alternative language mirrors the policies enacted in Florida via HB 1189, which was signed into law on June 30, 2020 with an effective date of July 1, 2020.

HB 1189 passed the Florida House by a vote of 117 – 1, and then passed the Florida Senate by a vote of 35 – 3.

In the 5 years since enactment, there has been no appreciable disruption in Florida's life insurance market or increase in its life insurance premiums as a result of this law.

It is also worth noting that similar national laws already exist in Australia, Canada, and the UK.

Life Insurers' Use of Genetic Information

1. Prohibition on Coverage Denial Based on Genetic Information

(A) A life insurance provider shall not deny, cancel, limit, or establish differentials in premium rates for an individual or their family member based in whole or in part on the individual's or their family member's genetic information.

Policy Benefit - protects consumers from being penalized for inherited risk factors over which they have no control.

2. Ban on Mandatory Genetic Testing

(B) A life insurance provider shall not require, request, or encourage any individual—whether applying for or currently covered—to undergo genetic testing or genome sequencing as a condition of coverage, pricing, or renewal.

Policy Benefit - prevents coercive practices that invade privacy and deter individuals from seeking genetic testing.

Alternative Model Language

3. Informed Consent and the Right to Decline

(C) Insurers may not access, use, retain, or disclose an individual's genetic or sensitive medical data without prior, written, and informed consent. An insurer shall not deny, cancel, or refuse to issue or renew a policy because the individual refuses to provide such consent.

Policy Benefit - affirms the individual's right to control their own health information and ensures insurance access is not conditioned on surrendering that right.

4. Clarification on Use of Existing Medical Records

Nothing in this section prohibits the use of existing health information, including genetic data, already included in a medical record—provided that such use complies with applicable state and federal laws and is based on appropriate consumer consent.

Policy Benefit - preserves insurers' ability to assess risk based on known, disclosed health information without enabling new data mining or testing requirements.

Let’s Work Together

The Public Health Community is Ready and Eager to Work with You

Organizations representing the ALS, cancer, kidney disease, and Parkinson’s communities (amongst many more) are ready to work with lawmakers and the insurance industry to craft and support strong legislation protect consumers and maintain healthy insurance markets at NCOIL and in your statehouse.

ALS Advocates in action at the Michigan, Oklahoma, Pennsylvania, Texas and Washington statehouses this year

ALS Association Advocacy

Contact me at

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Thank You!