NATIONAL COUNCIL OF INSURANCE LEGISLATORS

Discussion on Use of Genetic Testing Information in Life Insurance Underwriting

Life Insurance & Financial Planning Committee Meeting
April 25, 2025

Lisa Schlager
Vice President, Public Policy
FORCE: Facing Our Risk of Cancer Empowered

FORCE Programs

Support

- Personalized Peer Support
- Virtual Support Groups
- Private Facebook Group and Message Boards
- Helpline

Advocacy & Public Policy

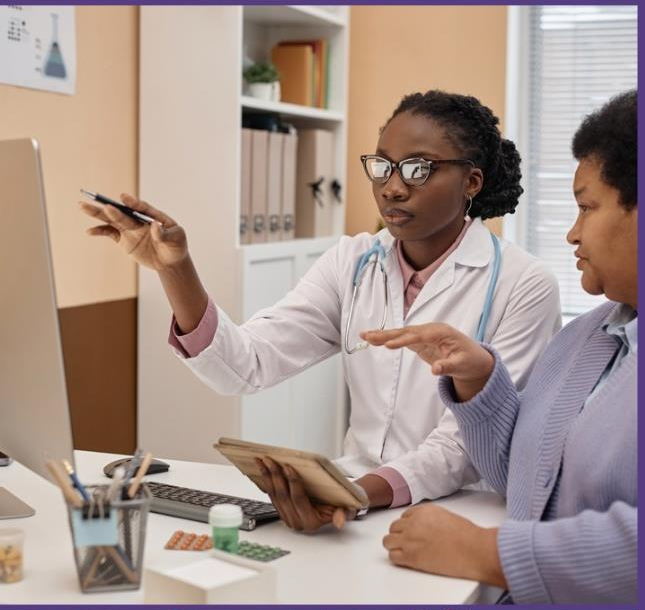
- State & Federal Advocacy
- Insurance Coverage & Access to Care
- Genetic Privacy & Protections
- Drug/Medical Device Development & Safety

Education

- Information on Genes & Hereditary Cancers
- XRAY – Behind the Cancer Headlines
- Educational Brochures & Decision Guides
- Expert Led Webinars and Videos

Research

- Hereditary Cancer Research Recruitment
- Collaborations to Advance Research
- Research Advocate Training



Personalized Medicine

Challenges “one-size-fits-all” approach

Informs screening and preventive/ risk-reduction decisions

Facilitates access to targeted therapies

Improves treatment efficacy

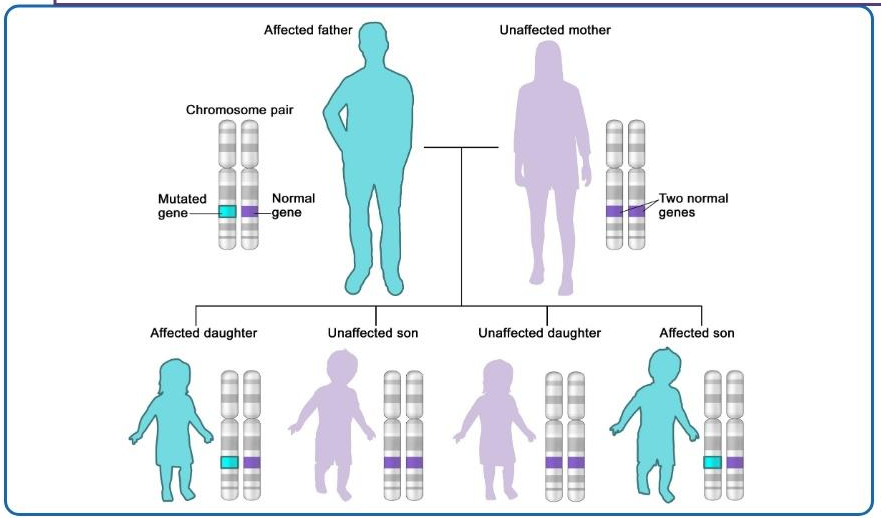
- More effective therapies
- Safer drugs (avoid predictable side effects)

Reduces trial-and-error

- Wastes time
- Undermines care
- Inflates healthcare costs

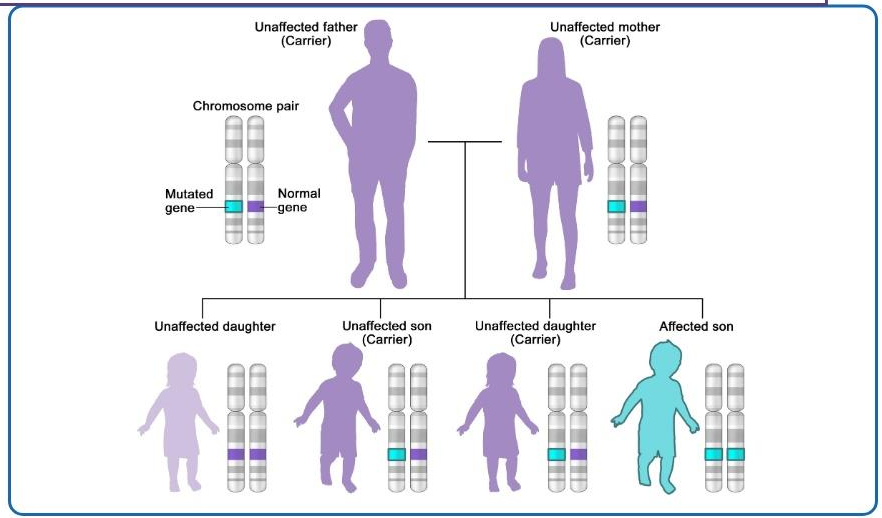
Hereditary Disease Risk

Genetic Testing - Uses blood or saliva to assess DNA and find gene mutations linked to an increased risk for certain diseases.



Autosomal **Dominant**

Only one parent needs to pass the genetic mutation on to their child for their child to inherit the mutation—50% risk of inheritance.



Autosomal **Recessive**

Both parents must pass the same genetic mutation to their child for the child to inherit the mutation—25% risk of inheritance.

Hereditary Diseases

Adult Onset

- **Cancer**

  Breast, colorectal, endometrial, gastric, kidney, melanoma, ovarian, prostate, pancreatic and others

- **Cardiovascular**

  Hypercholesterolemia, cardiomyopathy, arrhythmia syndromes, aortopathy, cardiac amyloidosis

- **Neuromuscular**

  Amyotrophic Lateral Sclerosis (ALS), Familial Alzheimer's disease (FAD) Huntington's Disease, Parkinson's Disease

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Hereditary Disease

Risk-Management and Mitigation

Cancer

- More intensive cancer screenings starting at younger ages than the general population, i.e. annual breast MRIs and colonoscopies starting age 25
- Risk-reducing/prophylactic surgeries, i.e. hysterectomy, mastectomy
- Medications to reduce risk, i.e. contraceptives, hormone therapy

Cardiovascular

- Medications, i.e. ace inhibitors, beta-blockers, statins
- Implantable devices, i.e. pacemaker, defibrillator
- Surgery, i.e. heart valve repair, coronary artery bypass

Neuromuscular

- Medications to slow progression
- Gene therapy, i.e. SOD1 suppression
- Supportive care, i.e. physical, occupational, and/or speech therapy

Knowledge is Power!

Genetic Information is Valuable for Prevention, Early Detection & Effective Treatment

Carrying an inherited genetic mutation **does not mean** the individual will be diagnosed with the disease.

Awareness and prompt intervention can facilitate **prevention** or **early detection** and treatment of the disease.

Targeted therapies are **effective treatments** developed specifically for people with certain mutations.

Federal Laws

HIPAA

Protects patient privacy and ensures data is appropriately secured

- Privacy Rule - defines allowable uses and disclosures of protected health information (PHI)
  - Gives patients access to their health data on request
- Security Rule - ensures electronic health data is appropriately secured
- Breach Notification Rule - notifies individuals of a breach of their health information

Federal Laws

GINA

Prohibits discrimination by health plans and employers based on genetic information

- Genetic test results
- Relatives' genetic test results (up to and including fourth-degree relatives)
- Information about family history of any disease or disorder
- Participation in research that includes genetic testing, counseling, or education

GINA
GENETIC INFORMATION NONDISCRIMINATION ACT

Federal Laws

Covered Entities

Healthcare

GINA

- Health insurance companies
- Group and individual health plans
- Medicare, Medicaid, and other federal health programs

HIPAA

- Health plans
- Clearinghouses
- Providers who electronically transmit health info and their business associates

Employment

GINA

- Employers with 15+ employees
- Employment agencies
- Labor organizations
- Joint labor-management training and apprenticeship programs
- Federal, state & local governments

Legal Gaps

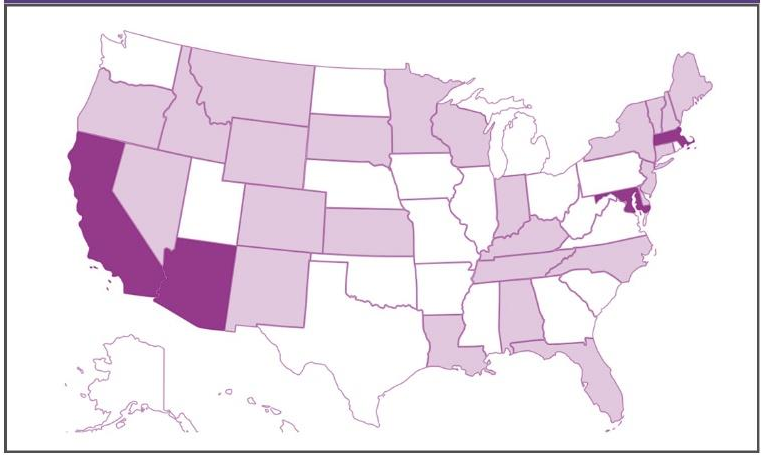
PHI and Genetic Privacy/Protections

GINA does not apply to life, long-term care or disability insurance.

HIPAA and GINA do not apply to direct-to-consumer and non-healthcare companies.

State Laws

Re: Genetic Discrimination in Life Insurance



All but Florida are limited or have flaws that undermine their efficacy in banning genetic discrimination.

- Alabama
- Arizona
- California
- Colorado
- Connecticut
- **Florida** ★
- Indiana
- Kansas
- Louisiana
- Maine
- Maryland
- Massachusetts
- Minnesota
- Montana
- Nevada
- New Jersey
- New Hampshire
- New Mexico
- North Carolina
- Oregon
- South Dakota
- Tennessee
- Vermont
- Wisconsin
- Wyoming

State Laws

Pertaining to the Use of Genetic Information

Constraints on the information insurers may use, regardless of their level of access.

There are three main methods:

1. General restrictions on the use of genetic information
2. Prohibitions for use of a particular type of test
3. Actuarial justification for use requirements

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VERSUS

State Laws

Pertaining to the Use of Genetic Information

Privacy and anti-discrimination approaches are rarely combined.

Rules generally fall into one of three categories:

- Informed consent for use requirements
- Anti-discrimination approaches
- Other approaches

Some states have statutes that cover multiple approaches, but none are a unified legislative strategy as in GINA.

State Law Weaknesses

Re: Genetic Discrimination

- Ineffective or obscure language:
  - ⊗ “Based solely on…”
  - ⊗ “Unfair discrimination”
  - ⊗ “Actuarial justification”
- Allows for consideration of an individual’s test results
- Failure to consent leads to the inability to obtain insurance

State Law Weaknesses

Re: Genetic Discrimination

§ 3701. Discriminations prohibited

A life insurance company doing business in the State shall not make or permit to be made any distinction or **unfair discrimination** between individual insureds of the same class and of equal expectation of life as to:

(1) the amount of the premiums or the terms of payment thereof; or

(2) the rate charged for policies of life or endowment insurance, or

(3) the dividends or other benefits payable thereon; or

(4) any of the terms and conditions of the policies it issues. (Added 1967, No. 344 (Adj. Sess.), § 1 (ch. 2, subch. 1, § 1).)

International Approach

Life insurance discrimination deters people from participating in research and pursuing clinical genetic testing.

- Canada: Genetic Non-Discrimination Act

  GNDA prohibits … requiring an individual to undergo a genetic test or disclose the results of a genetic test as a condition of providing goods or services to, entering into or continuing a contract or agreement with, or offering specific conditions in a contract or agreement with, the individual.

- UK: Code on Genetic Testing and Insurance

  The Code generally prohibits insurers from asking for or using results of predictive genetic tests, except for specific circumstances for life insurance policies over £500,000.

- Australia: Disability Discrimination Act

  Amended the Disability Discrimination Act 1992 to prohibit insurers from using genetic or genomic test results to discriminate between applicants for risk-rated insurance.

Individual Experiences

"I just applied for life insurance, and after a completely healthy assessment, the cost for coverage that our rep quoted me QUADRUPLED, simply because of myBRCA1 genetic predisposition."

Lexi, Colorado

"My policy was changed without notice...my **premium increased**... After looking into it, my $8,000 policy is now a $4,000 policy. We were astonished! In the fine print, it said the reason was my 'pre-existing condition.'"

Crystal, Michigan

Individual Experiences

"I'm 24 and recently had genetic testing because the guidelines say I should start cancer screenings at age 25 if I carry the BRCA mutation. My genetic counselor said I should get life insurance first, but I'm not married and don't have kids (and can't afford it right now), so I'm rolling the dice. It's sad that I'm trying to be proactive with my health, and that can be used against me."

Reena, Ohio

Individual Experiences

"I was denied life insurance by multiple insurance companies, even group plans... Other **family members have refused to get tested**, knowing they won't be able to get insurance if they test positive."

Barbara, New Mexico

"I had a life insurance policy in place. I underwent genetic testing and went for my first breast cancer screening at age 31. Ultimately, that screening led to my breast cancer diagnosis. My life insurance company **dropped my policy** after that."

Kelly, South Carolina

Individual Experiences

“I don’t smoke. I don’t drink. I don’t use drugs. I work out, and I ran a marathon last year. I take no daily medications. I am a responsible adult working a full-time job. Still, because of this genetic predisposition, I was denied a life insurance policy and told, ‘you will be hard pressed to find anyone who will cover you’.”

Daniel, New Jersey

Key Takeaways

In Summary

- Only 10% of certain diseases are linked to an inherited mutation
- Identification of a hereditary mutation can inform risk, but does not guarantee a diagnosis
- Knowledge of a mutation facilitates a proactive, tailored approach to health and risk management
- Different mutations convey varying levels of risk; science is evolving/ not exact
- Lack of a mutation (or lack of awareness) does not mean a person doesn't have equal or higher risk than someone with a known mutation
- Consumers simply want to ensure their families are taken care of
- Personal and family health history is sufficient for life insurance underwriting purposes
- Banning the use of genetic information will encourage uptake of genetic testing and may lead to better health outcomes

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National Council of Insurance Legislators
2025 Spring Meeting