

## Laws Pertaining to Genetic Information

### GINA: Genetic Information Nondiscrimination Act

- GINA is a federal law passed in 2008 that protects against insurance and employment discrimination<sup>1</sup>
- If state laws are stronger, they are enforced before GINA. GINA steps in if states give limited protection<sup>1</sup>
- Article I: Health Insurance
  - Health insurance agencies cannot request, require, or use genetic information to determine eligibility for insurance, premium, continued amounts, or coverage terms.
  - Family history or genetic test (illustrating carrier status/ or potential for a disease) cannot be considered as pre-existing condition
  - Cannot use info to discriminate even if information is obtained accidentally
  - Applies to most insurers
    - Through employer
    - Private insurance
    - Medicare supplemental policies for individuals who have Medicare
  - DOES NOT APPLY (Have policies that provide discrimination protection similar to GINA)
    - Members of US military who use Tricare
    - Vets who receive care from VA
    - IHS
    - Federal employees who get care through federal employees Health Benefits plan
    - Medicaid and Medicare<sup>2</sup>
  - DOES NOT STOP INSURERS from basing decisions about eligibility, coverage or premiums on current symptoms or diagnosis of health condition
    - Can't discriminate based on potential for disease but genetic testing can be used for insurance purposes to confirm a diagnosis with manifestation of disease
      - EX: Genetic testing that illustrates a patient *will* have Huntington's Disease cannot be used by insurance companies to raise premiums, etc. However, once a patient begins to show symptoms of Huntington's disease and is diagnosed, insurance companies can use the genetic test to confirm diagnosis and use the information to adjust premiums, justify treatment, etc.
  - Cannot request, require, or use predictive results
  - Genetic information about diagnosed conditions cannot be used against family members for their insurance purposes
  - Insurers can ask for tests to make decisions about whether or not they will pay for a test (minimum amount of information)
    - They can use genetic test results to confirm diagnosis and pay for treatment
- Article II: Employment (Agencies with 15+ people)<sup>1,3</sup>

- Illegal to discriminate because of genetic information
- Cannot be used to make decisions about employment
- Restricts employers and other entities from requesting, requiring or purchasing test results
- Limits disclosure
- Cannot be harassed because of test results
- Usually illegal for a covered entity to get information except
  - Inadvertently
  - For a voluntary wellness program
  - As a requirement to obtain FMLA
  - The information is publicly available (as long as don't go searching for it)
  - Program that monitors biological effects of toxins in the workplace when required by law
  - For law enforcement purposes
- Unlawful to disclose information

#### Texas Genetic Information Testing<sup>4</sup>

- Protection against discrimination by employers with 15 or more employees, agencies, unions, and public employers about individual genetic characteristics
- Any health plan cannot use genetic information or refusal of an applicant to submit to a genetic test to reject, renew, increase premiums for or otherwise adversely affect eligibility for or coverage under the plan
- Licensing authority may not deny, suspend, revoke, or refuse to renew an occupational license based on genetic information or refusal to submit to a test
- Penalty if information is improperly disclosed
- Must keep genetic testing confidential unless authorized or unless required to by court order or by law
- Individuals have right to know result of genetic information

#### Colorado Genetic Discrimination<sup>5</sup>

- Genetic information is the unique property of the individual to whom the info pertains
- Availability of information is limited
- Prevents denial of access to group disability insurance or long-term care
- Info confidential and privileged
- Research facilitates can use genetic information as long as information is de-identified
- Insurers can't require performance of or perform genetic test without consent

<sup>1</sup> "GINA Help," GINA Help, June 2010, [GINAhelp.org](http://GINAhelp.org)

<sup>2</sup> Payne Jr, Perry W et al. "Health Insurance and the Genetic Information Nondiscrimination Act of 2008: Implications for Public Health Policy and Practice." *Public Health Reports* 124, no. 2 (2009): 328-331.

<sup>3</sup> "Genetic Information Discrimination." U.S. Equal Employment Opportunity Commission, accessed June 6, 2018, <https://www.eeoc.gov/laws/types/genetic.cfm>.

<sup>4</sup> "Genetic Testing," Office of the Texas Governor, accessed June 6, 2018, [https://gov.texas.gov/organization/disabilities/genetic\\_testing](https://gov.texas.gov/organization/disabilities/genetic_testing).

<sup>5</sup> "Genetic Discrimination Prohibition," Casey Frank Attorney & Counselor, 2016, <http://www.caseyfrank.com/med-resources/co-laws/gdp.html>

**Author**

**Grace S. Miller**

Intern, Texas Health Institute

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