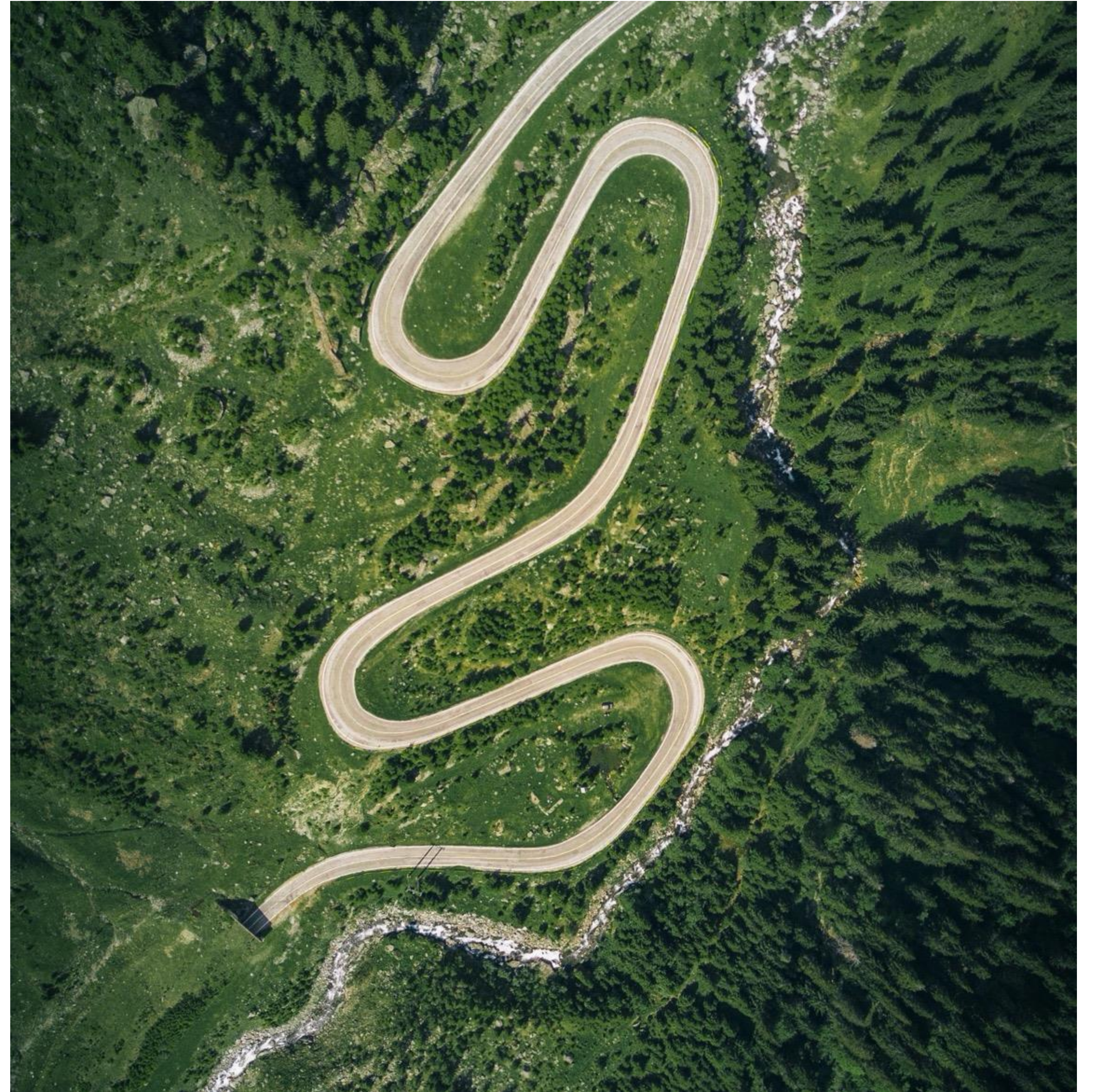




# Current legal protections and gaps in genetic antidiscrimination law

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- **Genetic nondiscrimination federal law**
- **Protections & gaps**
- **Genetic nondiscrimination state law**
- **Considerations for G X E research**



# Legal Protections for Genetic Data





# Genetic Information Nondiscrimination Act (GINA) of 2008

# Covered Entities

## Employers

- Applies to state and local governments
- Applies to private employers with 15 or more employees
- Applies to employment agencies and labor organizations
- Read to apply to federal employees
- Does not apply to Indian tribes or bona fide private clubs

# Covered Entities

## Health Insurers

- Applies to group and individual health plans
- Applies to Medigap plans
- Does not apply to Tricare, Veterans Health, the Indian Health Service, or the Federal Employee Health Benefits Plan (FEHBP) (although there are other protections for these groups)
- Does not apply to other insurances, such as life, long-term care, or disability insurance



# GINA's protections

```
graph TD; A[GINA's protections] --- B[Anti-discrimination]; A --- C[Privacy]; B --- D[GINA prohibits covered entities from using genetic information to make adverse decisions]; C --- E[GINA prohibits covered entities from collecting genetic information with few exceptions];
```

## Anti-discrimination

GINA prohibits covered entities from using genetic information to make adverse decisions

## Privacy

GINA prohibits covered entities from collecting genetic information with few exceptions

# Bans on use of genetic information

- **Employment**

- Cannot fail to hire
- No firing
- No changes in compensation, terms, conditions of employment
- Cannot segregate or classify the employee in a detrimental way

- **Health Insurance**

- No higher premiums or changes in contribution amounts
- No denials
- Cannot deny coverage renewal
- Genetic information cannot be considered a pre-existing condition





# Genetic Information

- Genetic test results (individual and family)
- Family medical history
- Participation in genetic research
- Use of genetic services
  - Genetic counseling
  - Genetic education
- Does not include manifested diseases

# GINA's protections

```
graph TD; A[GINA's protections] --- B[Anti-discrimination]; A --- C[Privacy]
```

## Anti-discrimination

GINA prohibits covered entities from using genetic information to make adverse decisions

## Privacy

GINA prohibits covered entities from collecting genetic information with few exceptions

# Collection of genetic information

- Cannot request, require, or purchase genetic information
- Applies to both health insurers and employers
- Several exceptions apply



# Exceptions to collection in employment

- The “water cooler” exception – inadvertent acquisition
- Family and medical leave certifications
- Publicly available information
- Wellness programs
  - If voluntary
- Law enforcement purposes
- *Genetic monitoring of effects of toxic substances*



# Gaps in GINA

- Does not apply to manifested disease
- Does not apply to small businesses (fewer than 15 employees)
- Does not apply to life, long-term care, and disability insurers
- Does not apply to any other entities
- Must look to state law for additional protections





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## The Problems with Patchwork: State Approaches to Regulating Insurer Use of Genetic Information

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# State Regulation of Life, LTC, and Disability Ins.

Insurance lines	Ban on use	Use with actuarial justification	Require informed consent	Bar use of particular test	Other
Life	1	7	11	4	12
Long-term Care	2	6	7	0	9
Disability	3*	8	10	1	12

# Definitions matter

**focalization** [fokəlaizən] *n.* 1. the act of focusing light; 2. Med: localization of a disease; 3. localization of a point of view in a narrative.  
**focalize** [fokəlaiz] *v.t.* 1. to focus light; 2. Med: to localize a disease; 3. to localize a point of view.  
**fo'c'sle** [fouksl] *n.* Nau: 1. gaillard *m*; f. deck, pont de gaillard. 2. (in merchant vessel) poste *m* de l'équipage.  
**focus**<sup>1</sup>, *pl.* **foci**, **focuses** [foukəs, 'fousai, 'foukəsiz] *n.* 1. Mth: *Opt: etc:* foyer *m* (de lentille, etc.); *Opt:* **depth of f.,** (i) profondeur *f* de foyer; (ii) profondeur de champ; in **f.,** (i) (of image) au point; (ii) (of instrument) réglé; out of **f.,** (i) (of image) pas au point; (ii) (of instrument) non réglé, déréglé; (iii) (of headlamp bulb, etc.) mal réglé; to bring sth. into **f.** mettre qch. au point; *phot:* **break-f. camera,** appareil à mise au point fixe. 2. **center** *m* (d'un point); **point** *m*. 3. **focus** *m* (d'une personnalité).





# Genetic Test in GINA

- The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.
- “(B) EXCEPTIONS.—The term ‘genetic test’ does not mean—
  - “(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or
  - “(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional...

# Definitional table

TABLE 1 Examples of state statutory definitions of “genetic test” or “characteristic”

Statutory example	Limitation
Genetic characteristic: “any scientifically or medically identifiable gene or chromosome, or alteration thereof, that is known to be a cause of a disease or disorder, or that is determined to be associated with a statistically increased risk of development of a disease or disorder . . .” <sup>a</sup> (CA)	To variants known or associated with disease or disorder
Genetic test: “a laboratory test . . . used to identify the presence or absence of inherited or congenital alterations in genetic material that are associated with disease or illness.” <sup>b</sup> (MD)	To tests associated with negative health effects
Genetic test: “. . . a presymptomatic test of a person’s genes, gene products, or chromosomes for the purpose of determining the presence or absence of a gene or genes that exhibit abnormalities, defects, or deficiencies, including carrier status, that are known to be the cause of a disease or disorder, or are determined to be associated with a statistically increased risk of development of a disease or disorder.” <sup>c</sup> (MN)	To a presymptomatic test

<sup>a</sup>Cal. Insurance Code § 10147(b) (2000)

<sup>b</sup>MD. Code Ann., Ins. § 27-909(5) (2016)

<sup>c</sup>Minn. Ann. Stat. § 72A.139(Subd. 2)(B) (2016).

# Considerations for G X E Research



# Thanks!

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