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Genetics, Insurance, Discrimination, and the Law

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November 17, 2007

Genetic Discrimination

- Different treatment based on:
 - Presence of inherited condition in self or family member
 - Genetic test result in self or family member
 - Family history of a disease
- Mostly viewed in terms of:
 - Health insurance cost and availability
 - Life insurance
 - Disability insurance
 - Employment
- ****Usually addresses healthy/asymptomatic carriers****

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Example of Genetic Discrimination

- T.S. was a young, healthy woman who recently tested positive for a hereditary condition identified in her family
- She began preventive treatment at a cost of ~\$4,000/month, which was covered by her employer-provided health insurance.
- One month later, she was fired despite excellent performance reviews and a 3-year employment history in good standing
- In 2000, the Equal Employment Opportunity Commission ruled in her favor

<http://labor.senate.gov/goldman.pdf>

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Research on Genetic Discrimination -Impact of Laws-

- Reviewed various laws to evaluate extent of genetic discrimination protections and interviewed insurers, patients and clinicians
- No well-documented cases of health insurers asking for or using presymptomatic genetic test results in underwriting decisions
- Insurers: A person with a genetic condition who is presymptomatic faces little difficulty obtaining health insurance
 - Looking at information is not cost effective
 - Does not significantly contribute to underwriting accuracy
 - If easily available, would use it if legal
- Patients and clinicians have a high rate of fear of genetic discrimination, but only for adult-onset conditions

Hall & Rich, 2000. Am J Hum Genet.
Hall & Rich, 2000. Genet Med.; Hall, 1999. Jurimetrics

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Research on Genetic Discrimination -Life Insurance-

- 2003 Survey of 636 women who underwent genetic counseling and/or testing for breast cancer
- 4% increased life insurance
- Concern about life insurance discrimination was associated with lower uptake of genetic testing
- 0 participants reported being denied or losing their life insurance

Armstrong et al, 2003. Am J Med Genet A.

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Entity	Less trust (%)	More trust (%)
Your doctor	0	86
Researchers studying genetics	0	66
Your health insurer	75	0
Your employer	83	0

Responses to the Question "How Much Do You Trust Each of the Following to Have Access to Your Genetic Test Results?"

Data are from a survey of 1199 adults conducted from February 27 through March 4, 2007, by the Johns Hopkins Genetics and Public Policy Center (www.dnapolicy.org).

Hudson KL (2007). NEJM.

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What are the Laws?

- Federal Laws
 - HIPAA (Health Insurance Portability and Accountability Act)
 - Americans with Disabilities Act
 - Family Medical Leave Act
- Individual State Laws

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What is the purpose of HIPAA?

- Standardize electronic patient information
- Ensure unique identifiers for patients, employers, health plans, and providers
- Security standards for protection of privacy and personal information in the healthcare field
 - Patients have right to own information
 - Restrict/minimize access by others

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HIPAA

HIPAA does:

- Prohibit excluding an individual from **group** coverage because of a past or present medical conditions
 - Genetic condition is NOT a preexisting condition
 - Limited exclusion for preexisting condition to 12 months
 - Cannot exclude if insured >12 months with condition
- Prohibit charging a higher premium to an individual than to others in the group
- Restrict group health plans from disclosing information to employers

HIPAA, Public Law No. 104-191 (1996)
*Group = employer-based or commercial

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Health Insurance Portability and Accountability Act (HIPAA)

HIPAA does not:

- Prohibit the use of genetic information as a basis for charging an entire group more for health insurance
- Limit the collection of genetic information by insurers
- Prohibit insurers from requiring an individual to take a genetic test
- Apply to individual health plans or the uninsured

HIPAA, Public Law No. 104-191 (1996)

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Discrimination in Employment

- The Americans with Disabilities Act (ADA) has been interpreted to protect against employment discrimination based on genetic information
- Some states also have passed laws to prevent genetic information from being used in employment considerations

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Texas Law on Genetic Discrimination

- Protects against discrimination by employers with 15 or more employees based on information about an individual's **genetic characteristics** or on the refusal of an individual to take a genetic test or submit a family health history.
- Provides that **any health plan** may not use genetic information or the refusal of an applicant to submit to a genetic test to adversely affect eligibility
- Provides a civil penalty if a person improperly discloses genetic information.
- Employers must **keep genetic testing confidential** unless an individual specifically authorizes release of such information, or unless they are required to release information pursuant to a court order, or otherwise required by law.
- Individuals have the **right to know** the results of any genetic tests.

Texas Labor Code, Sections 21.401 - 21.405
Vernon's Texas Civil Statutes - Title 132
Texas Insurance code, Section 546.002

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National Conference of State Legislatures
<http://www.ncsl.org/programs/health/genetics/ndishlth.htm>

State	Citation	Type of Insurance Policy	May not Establish Rules for Eligibility based on Genetic Information	May not Require Genetic Tests/Genetic Information	May not Use Genetic Information for Risk Selection or Risk Classification Purposes	May not Disclose Information Without Informed Consent
Alabama	§§27-53-1 to 4, 13	Individual and Group	X ^c		X ^c	
Arkansas	23§§86-304, 306, 23§66-320	Individual and Group	X	X	X ^c	
Louisiana	22§213.7	Individual and Group	X		X	X
Texas	Ins §21.73	Individual and Group	X		X ^c	X

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Genetic Information Nondiscrimination Act of 2003

- S.1053 - A bill to prohibit discrimination on the basis of genetic information with respect to health insurance and employment.
- Senate passed in 2003 and again in 2007
- Held in House since introduction in 2003

<http://www.genome.gov/11508845>

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The Genetic Information Nondiscrimination Act

What the Legislation Does	What the Legislation Does Not Do
Prohibits group and individual health insurers from using a person's genetic information in setting eligibility or premium or contribution amounts.	Does not prohibit medical underwriting based on current health status.
Prohibits health insurers from requesting or requiring that a person undergo a genetic test.	Does not mandate coverage for any particular medical tests or treatments.
Prohibits employers from using a person's genetic information in making employment decisions such as hiring, firing, job assignments, and promotions.	Does not interfere with the ability of a treating health care professional to request that a person or family member undergo a genetic test.
Prohibits employers from requesting, requiring, or purchasing genetic information about an individual employee or family member.	Does not subject employers to remedies and procedures that are different from those in other civil-rights laws, such as Title VII of the Civil Rights Act of 1964 and the Americans with Disabilities Act.
	Does not prohibit workplace collection of genetic information for genetic monitoring programs, employer-sponsored wellness programs, administration of federal and state family and medical-leave laws, and in certain cases of inadvertent acquisition of information. However, this genetic information may not be used or disclosed by the employer.

Hudson KL (2007). *NEJM*

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Summary

- Fear of genetic discrimination affects peoples' decisions to seek genetics services
- Documented cases of genetic discrimination are rare
- Perception of risk is probably much greater than actual risk
- State and Federal laws have been enacted attempting to protect individuals, but there are limitations

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Thoughts to Consider...

- Genetic testing can provide tremendous information about risk and significantly impact management
- VHL is a "Group 1" disorder – genetic testing is part of the standard management for at-risk family members (ASCO 2003).
 - Children at-risk
- VHL is essentially 100% "penetrant"
- Patients must individually weigh the benefits of knowing their genetic information against the potential for genetic discrimination

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Genetic Discrimination Resources

- For updates about **state** protections against insurance and employment discrimination, as well as current information about federal protections, follow the "Policy and Ethics" link at <http://www.genome.gov>
- For updates about **federal** bills: search the Library of Congress website on legislative information at <http://thomas.loc.gov>
- Genetics and the Law
 - www.genelaw.info
- Health Privacy Project
 - www.healthprivacy.org
- Council for Responsible Genetics
 - www.gene-watch.org

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