Existing Federal Anti-discrimination Laws and How they Apply to Genetics

Americans with Disabilities Act (ADA)

- Prohibits discrimination against a person who is regarded as having a disability.
- Protects individuals with symptomatic genetic disabilities the same as individuals with other disabilities.
- Does not protect against discrimination based on unexpressed genetic conditions.
- Does not protect potential workers from requirements or requests to provide genetic information to their employers after a conditional offer of employment has been extended but before they begin work (Note: this is a heightened concern because genetic samples can be stored).
- Does not protect workers from requirements to provide medical information that is job related and consistent with business necessity.

In March 1995, the EEOC issued an interpretation of the ADA. The guidance, however, is limited in scope and legal effect. It is policy guidance that does not have the same legal binding effect on a court as a statute or regulation and has not been tested in court. According to the interpretation:

- Entities that discriminate on the basis of genetic predisposition are regarding the individuals as having impairments, and such individuals are covered by the ADA.
- Unaffected carriers of recessive and X-linked disorders, individuals with late-onset genetic disorders who may be identified through genetic testing or family history as being at high risk of developing the disease are not covered by the ADA.

Health Insurance Portability and Accountability Act

- Prohibits group health plans from using any health status-related factor, including genetic information, as a basis for denying or limiting eligibility for coverage or for charging an individual more for coverage.
- Limits exclusions for preexisting conditions in group health plans to 12 months and prohibits such exclusions if the individual has been covered previously for that condition for 12 months or more.
- States explicitly that genetic information in the absence of a current diagnosis of illness shall not be considered a preexisting condition.
- Does not prohibit employers from refusing to offer health coverage as part of their benefits packages.

Limitations: Applies to employer-based and commercially issued group health insurance only. There is no similar law applying to private individuals seeking health insurance in the individual market.

HIPPA National Standards to Protect Patients' Personal Medical Records, December 2000

This new regulation will protect medical records and other personal health information maintained by health care providers, hospitals, health plans and health insurers, and health care clearinghouses. Congress mandated the regulation when it failed to pass comprehensive privacy legislation (as required by HIPPA) by 1999. The new standards: limit the non-consensual use and release of private health information; give patients new rights to access their medical records and to know who else has accessed them; restrict most disclosure of health information to the minimum needed for the intended purpose; establish new criminal and civil sanctions for improper use or disclosure; and establish new requirements for access to records by researchers and others. They are not specific to genetics; rather they are sweeping regulations governing all personal health information. In 2002, Department of Health and Human Services are proposing modifications to the consent requirements due to the possible interference with the efficient delivery of health care.

Title VII of the Civil Rights Act

- Protection is available only where an employer engages in discrimination based on a genetic trait that is substantially related to a particular race or ethnic group.
- A strong relationship between race and national origin has been established for only a few diseases.

(*Genetics Privacy* 3-5)[22]

Oklahoma HB 3169

Prohibits health insurers, for the purpose of determining eligibility, establishing premiums, limiting coverage, renewing coverage, terminating coverage or any other underwriting decision in connection with the offer, sale or renewal or continuation of a policy, except to the extent and in the same fashion as an insurer limits coverage, or increases premiums for loss caused or contributed to by other medical conditions presenting an increased degree of risk:

1. requiring or requesting any individual to obtain a genetic test; and
2. conditioning the provision of the policy upon a requirement that an individual take a genetic test.

For purposes of distinguishing between or discriminating against or restricting any right or benefit otherwise due or available to an employee or prospective employee, other than in connection with the determination of insurance coverage or benefits, no employer shall:

1. seek to obtain, or use a genetic test or genetic information of the employee or the prospective employee; or

2. require a genetic test of or require genetic information from the employee or prospective employee.

Definition of **genetic information:** Information derived from the results of a genetic test. Genetic information shall not include family history, the results of a routine physical examination or test, the results of a chemical, blood or urine analysis, the results of a test to determine drug use, the results of a test for the presence of the human immunodeficiency virus, or the results of any other test commonly accepted in clinical practice at the time it is ordered by the insurer.

Definition of a **genetic test:** A laboratory test of the DNA, RNA, or chromosomes of an individual for the purpose of identifying the presence or absence of inherited alterations in the DNA, RNA, or chromosomes that cause a predisposition for a clinically recognized disease or disorder. Genetic test does not include: (A) a routine physical examination or a routine test performed as a part of a physical examination; (B) a chemical, blood, or urine analysis; (C) a test to determine drug use; (D) a test for the presence of the human immunodeficiency virus; or (E) any other test commonly accepted in clinical practice at the time it is ordered by the insurer.

Oklahoma House Bill 1368

Provides that all research records of individual subjects in genetic research studies shall be confidential and not subject to subpoena or discovery in civil suits, except where the information in the records is the basis of the suit.

Provides that the confidentiality provisions of the bill shall not apply to an insurer or to an individual or third party dealing with an insurer in the ordinary course of underwriting, conducting or administering the business of life, disability income or long-term care insurance.

Provides that stored tissues can be used for genetic research studies if informed consent has been obtained.

Provides for the publishing or use of results of genetic research studies for research or educational purposes if no individual subject is identified or if specific informed consent from the individual has been obtained.

Definition of **Genetic Research Studies:** Those genetic research studies approved by an institutional review board as defined by 21 CFR, Section 50 or conducted subject to the requirements of the federal common rule at 21 CFR, Section 50 and Section 56, and 45 CFR, Section 46.