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GINA: Expanding the Scope of Patient Privacy

On May 21, 2008, President Bush signed the Genetic Information Nondiscrimination Act ("GINA") into law.[1] GINA is the first federal law to protect against genetic discrimination in health insurance and employment.[2] In the preamble to GINA, Congress acknowledged that as genetic research continues to expand the ability to identify the genetic components of illnesses, there is an increased likelihood that health insurers and employers could use genetic information in a negative way.[3] Congress' intent in enacting GINA was to encourage individuals to take advantage of genetic technologies, without worrying that their genetic information could be used against them in a discriminatory manner.[4]

GINA adopts a broad definition of "genetic information." Genetic information is defined as information about (1) an individual's genetic tests, including genetic tests done as part of a research study; (2) genetic tests of the individual's family members; (3) genetic tests of any fetus of an individual or family member who is a pregnant woman, and the genetic tests of an embryo legally held by an individual or family member using assisted reproductive technology; (4) the manifestation of a disease or disorder in family members; (5) the request for, or receipt of genetic services or participation in clinical research, including genetic testing, counseling or education services by an individual or family member.[5] Genetic information does not include information about an individual's sex or age.[6]

One of the particularly relevant provisions of GINA for health care providers is the way GINA amends the Health Insurance Portability and Accountability Act ("HIPAA"). GINA amends the definition of "protected health information" in HIPAA to include genetic information.[8] Protected health information means identifiable information that relates to the individual's past, present or future physical or mental health condition or to payment for health care.[9] As a consequence of GINA, HIPAA applies to a significantly broader amount of information.

Some states, including California, have enacted separate genetic anti-discrimination laws, which amplify the impact of the federal law. The California Genetic Information Nondiscrimination Act ("CalGINA") went into effect on January 1, 2012, and offers more robust protection than its federal counterpart. CalGINA amends the Unruh Civil Rights Act and California Fair Employment and Housing Act and expands the bases upon which discrimination is prohibited in California. CalGINA prohibits genetic discrimination in a number of areas including housing, mortgage lending, education, and public accommodations.

Existing law requires California-licensed hospitals to adopt a policy prohibiting discrimination in the provision of emergency services care based on any characteristic listed or defined in the Unruh Civil Rights Act. Now, hospitals will have to expand discrimination policies to prohibit discrimination based on genetic information.

In the next century, genetic information and genetic testing will become a major issue for individuals, policy makers, patients, and health care providers. Understanding federal and state genetic privacy issues will be a crucial responsibility and risk issue for health care providers in the twenty-first century.

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1. Morse Hyn-Myung Tan, *Advancing Civil Rights, The Next Generation: The Genetic Information Nondiscrimination Act of 2008 and Beyond*, 19 Health Matrix 63, 72 (2009).
2. Genetic Information Nondiscrimination Act of 2008, Pub, L. No. 110-233, 122 Stat. 881 (2008)(codified in scattered sections of 26, 29, and 42 U.S.C.).
3. *Id*.
4. *Id*.
5. 42 U.S.C. 2000ff(4).
6. *Id*.
7. Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936 (1996). HIPAA is a federal law which prohibits covered entities from using or disclosing protected health information unless the individual has authorized the use or disclosure. *Id*. If a covered entity violates HIPAA, they may be subjected to monetary fines from the United States Department of Health and Human Services. 45 C.F.R. 160.402(a).
8. 42 U.S.C. 1320d-9.
9. 45 C.F.R. 160.103.