

## Health Information Compliance Alert

### Genetic Privacy: WILL GENETIC DATA PRIVACY OPEN UP A BRAVE NEW WORLD?

While many argue that the collection, use and exchange of genetic information by employers and insurers are necessary for the continued advancement of scientific discovery, others envision a potentially Huxleyan environment. Will genetic data be used maliciously to discriminate against individuals with undesirable genes?

That issue found a forum for debate when members representing both sides of the controversial topic raised their concerns Sept. 12 in the House Judiciary Committee's Subcommittee on the Constitution.

But what level of privacy protection is needed at such an early stage in the process of genetic testing, inquired Committee Chairman **Steve Chabot** (R-OH). Chabot said that as of April, 41 states have enacted laws barring insurers from using genetic data to discriminate against individuals, adding that the Health Insurance Portability and Accountability Act prohibits genetic discrimination by health insurers.

Privacy advocates say that's not enough. They claim that the loopholes in HIPAA that permit the use and disclosure of genetic data will lead to misinterpretations and improper use of that information.

Dr. **Deborah Peel**, representing the **American Psychoanalytic Association**, testified that "[e]very man, woman, and child in this country will be deprived of control of his or her genetic and medical records" when the privacy rule takes effect in April. Peel argues that if one relinquishes the right to retain control of that data, that action is tantamount to allowing "control of the most sensitive information that exists about us to be taken from us."

The changes to the privacy rule, published Aug. 14 in the Federal Register, give health plans and providers "regulatory permission" to use and disclose protected health information for treatment, payment and health care operations as result of the repeal of the consent provision. That permission includes the right to release results of genetic testing. Peel argues such permission improperly disposes of an individual's right to privacy and creates greater governmental authority, an act she claims would permit the feds to deprive citizens of certain civil liberties.

And others argue that even though HIPAA ostensibly prevents nondiscrimination based on genetic information and although provisions of the reg prohibit some underwriting uses of medical and genetic information, still many gaps remain, especially in the individual insurance market.

Joanne Husted, senior counsel for **Georgetown University's** Health Privacy Project, warns that a major threat presented by the free flow of genetic information is that many patients will withdraw from participation in their own health care if they perceive they have been subjected to potential discrimination or loss of benefits due to their genetic profile.

Husted says a recent study involving genetic counselors indicates fear of discrimination is an important factor that may dictate whether an individual will undergo testing and seek reimbursement from insurers.

Genetic Data Is Still PHI, For Better Or Worse

Still, others aren't convinced we're heading for a "Big Brother" society over the disclosure of genetic data. **Tom Miller**, director of health policy studies at the **Cato Institute** in D.C., said in testimony before the Committee that privacy groups wary of how genetic information may be used are incorrectly anticipating the mishandling and misapplication of such information. Miller believes any attempt to prohibit the disclosure of genetic info will be fraught with a "host of policy complications and administrative complexities."

For instance, Miller says the Fourth Amendment would serve only to prevent government actions. He believes absolute legal control over genetic data wouldn't be necessary as long as legislative and regulatory measures were enacted to determine how to protect consumers from malevolent and discriminatory use of one's genetic ID.

And Miller adds that prohibitions of all disclosures of genetic data would discriminate against "good health risks" that seek to disclose their positive genetic information to health insurers. Knowledge of one's genetic code would enable one to "make better decisions about the insurance coverage they buy, the investments they make in other health-promoting activities," and even modify their lifestyles.

Noting that there's insufficient evidence to show genetic discrimination among insurers exists, **John Rowe**, Chairman and CEO of **Aetna, Inc.** nevertheless testified that there should be guidelines to address how genetic data should be disclosed including how health plans should make products available to their plan sponsors and their fully insured customers such as educating physicians as to the appropriate interpretation and use of genetic tests and promoting confidentiality among physicians to use genetic data to benefit the member.

Rowe also included a list of "don't's," such as not establishing rules for health care coverage based on genetic testing, refusing to use genetic testing for risk selection or classification in providing coverage, and not disclosing genetic testing results without a member's authorization.

Editor's Note: To view the testimony, go to [www.house.gov/judiciary/constitution.htm](http://www.house.gov/judiciary/constitution.htm).