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## At last, law addresses genetic testing in employment, insurance

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If you have the breast cancer gene, is an employer justified in not promoting you to a key job out of fear that you'll get sick?

If you have diabetes, controlled by medication, should an employer be able to find that out and not hire you in assumption your health insurance costs will be high?

If sickle-cell anemia runs in your family, is it fair to deny your participation in the group health insurance plan at work?

I dug this week into a thick file labeled "Genetics as employment issue," a topic I've written about periodically since 1998.

The file chronicles explosive scientific advances in genetic testing and a 10-year congressional history of proposals to ban use of such information in employment and some insurance decisions.

In 1998, 2001, 2003, 2005 and 2007, **Congress** considered such a law. This year, the Genetic Information Nondiscrimination Act of 2008 passed and is scheduled to go into effect in 2009.

The **U.S. Chamber of Commerce** and the **Society for Human Resource Management** said that the law was unnecessary and that the Americans with Disabilities Act and the Health Insurance Portability and Accountability Act provided the same protections.

Attorneys for employers said it opened up another cause of potential litigation from unhappy workers or job applicants.

Proponents in the medical and civil rights communities disagreed.

The **National Society of Genetic Counselors**, the **American Society of Human Genetics**, the **American Heart Association**, the **American Academy of Pediatrics**, the **National Partnership for Women & Families**, and dozens of organizations that exist to educate and support people with genetic-influenced diseases delighted in the bill's passage.

It is, they said, a case of federal law keeping up with medical advances rather than waiting for court cases to make piecemeal policy when workers or insurance applicants allege they were discriminated against.

But, more than that, proponents say, the law may help save lives and provide early diagnosis. Nearly 1,200 genetic tests exist to help people know if they have or may be likely to have certain diseases or disabilities.

Doctors have reported that patients forgo such testing for many reasons. Some don't want to know. Some can't handle the costs. Others fear the information will be used against them by employers or insurance companies.

It's the third concern that's addressed in the new law. As of November 2009, it will be illegal for employers, agencies or labor unions to buy or ask applicants or employees for genetic testing results.

If they get such information, they're supposed to keep it confidential and separate from other employment files and not use it to make hiring, promotion, firing, compensation or other employment decisions.

The law also bans insurance companies from buying or requiring genetic information to make eligibility or premium decisions for group health plans that take effect on or after May 21, 2009.

Under the law, group health plans and insurers will not be able to require individuals to undergo genetic testing, and the use of genetic information for pre-enrollment underwriting purposes will be prohibited.

It also prohibits group health plans from changing contribution or premium amounts for the group based on genetic information.

(Once a health plan enrollee evidences a disease, though, pre-existing exclusions can continue to apply, and group premium costs can be increased. Also, insurers can request genetic information to resolve claims of individual enrollees.)

What exactly does "genetic information" mean in the context of the law?

It covers an individual worker's genetic tests, the genetic tests of his or her immediate family members, and a family history of disease or disorders.

It refers to any information obtained from analysis of DNA, RNA, chromosomes, proteins or metabolites that detect genotypes, mutations or chromosomal changes.

Will the law encourage people to get tests that could help save, extend or improve the quality of their lives?

Will the law prevent employment or insurance discrimination based on genetic information?

As with so many complex issues, and especially in respect to employment decisions that can almost always be attributed to something other than a charged act of discrimination, the answers will be yes ... and no.

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