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1 Law Seeks to Ban Misuse of Genetic Testing

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The most important new antidiscrimination law in two decades — the Genetic Information Nondiscrimination Act — will take effect in the nation’s workplaces next weekend, prohibiting employers from requesting genetic testing or considering someone’s genetic background in hiring, firing or promotions.

The act also prohibits health insurers and group plans from requiring such testing or using genetic information — like a family history of heart disease — to deny coverage or set premiums or deductibles.

“It doesn’t matter who’s asking for genetic information, if it’s the employer or the insurer, the point is you can’t ask for it,” said John C. Stivarius Jr., a trial lawyer based in Atlanta who advises businesses about the new law.

The biggest change resulting from the law is that it will — except in a few circumstances — prohibit employers and health insurers from asking employees to give their family medical histories. The law also bans group health plans from the common practice of rewarding workers, often with lower premiums or one-time payments, if they give their family medical histories when completing health risk questionnaires.

“Genetic information is very broad,” said J. D. Piro, a principal in the Health Care Law Group at [Hewitt Associates](#). “It doesn’t simply include my own genetic information, such as do I have a risk for [cancer](#). It also includes my family medical history — do I have any relatives who have had cancer or leukemia.”

Genetic tests help determine whether someone is at risk of developing an inherited disease or medical condition. These tests identify variations in genes, like whether a woman has a predisposition for [ovarian cancer](#).

Such testing can help determine which course of treatment might work best for fighting a specific cancer or for helping a patient process a specific drug.

The [new law](#) (called GINA) was passed by Congress last year because many Americans feared that if they had a genetic test, their employers or health insurers would discriminate against them,

perhaps by firing them or denying coverage. In a [nationwide survey](#), 63 percent of respondents said they would not have genetic testing if employers could see the results.

“The message to employees is they should now be able to get whatever genetic counseling or testing they need and be less fearful about doing so,” said Peggy R. Mastroianni, associate legal counsel for the [Equal Employment Opportunity Commission](#).

The act takes effect Nov. 21 for all employers with 15 or more employees. It applies to group health insurers whose plan years begin on or after Dec. 7, and it took effect for individual [health insurance](#) plans last May. The act does not apply to life insurers.

The act would ban a company from not promoting a 49-year-old to chief executive because it knew his father and grandfather died of heart attacks at age 50.

“There’s an absolute ban on the use of genetic information to make any kind of decision about employment,” said Christopher Kuczynski, assistant legal counsel with the commission.

Sharon F. Terry, chairwoman of the Coalition for Genetic Fairness, a group that backed the legislation, told of a woman who had informed her office she was having a genetic test to learn whether she was predisposed to [breast cancer](#). She was soon fired, with her boss saying the company could not afford to keep her if the results were positive.

One episode that created momentum for the legislation involved the Burlington Northern and Santa Fe Railway Company, which conducted genetic testing on several employees without their permission.

David Escher, a track maintenance worker in Nebraska who developed [carpal tunnel syndrome](#) on both wrists, said he was mystified why Burlington Northern ordered him to see a doctor who drew seven vials of his blood. Mr. Escher later learned that the railroad wanted to do genetic testing to determine whether he had a predisposition for carpal tunnel — in an effort to reduce its medical and workers’ compensation costs.

“I was really mad,” Mr. Escher said. “They were trying to do this through the back door. With genetic testing, they can learn lots of things about you that you don’t even know. If they can do genetic testing and find some problems, you might end up getting fired.”

Burlington Northern reached a \$2.2 million settlement in 2002 that was distributed to 36 workers who were either tested or asked to submit to blood tests.

While the act makes it illegal for employers to intentionally acquire genetic information, it includes a “water cooler” exception, as in a case where a manager overhears one employee telling another that his father had a stroke.

Under the act, it is legal for a manager to garner genetic information from an obituary, for instance that an employee’s mother died of breast cancer. And if a manager asks why a worker

took off a week to care for his father under the Family Medical Leave Act, it generally will not be considered illegal if the employer learns that the worker's father has [pancreatic cancer](#).

The act, however, prohibits use of such inadvertent knowledge to alter the terms, conditions or privileges of employment.

"The challenge becomes what if down the road, the employee has a lot of absences or his performance is off, and you discipline the employee," said Michael P. Aitken, director of governmental affairs for the [Society of Human Resource Management](#). "The employee could come back and say, 'That's because you knew I had a genetic marker.' "

The act and its accompanying regulations allow group health plans to request family medical histories to help determine whether an employee should be placed in a disease management or wellness program to combat, for instance, [high blood pressure](#). The rules say employees must give that information voluntarily and the group plan cannot request such information before health plan enrollment or use it in any way for underwriting.

Under the rules, group health plans, in seeking information for wellness programs, cannot attach a request for family medical history to any penalty or, as is far more common, any benefit. But wellness programs can request family medical history if there is no financial benefit attached.

"This can be a big deal," said Mr. Stivarius, the Atlanta lawyer. "A lot of people incentivize employees to provide this family medical information. They give them some extra paid time off if they participate in surveys. Now they can't do that."

Mr. Piro of Hewitt said many employers were only now realizing that their health risk questionnaires might violate the law.

"Employers have to scramble to scrub this information out," he said. "The alternative is to modify their reward structures so that they're not considered to be purchasing or requiring the genetic information."

Susan Pisano, a spokeswoman for [America's Health Insurance Plans](#), said the rules were a challenge for insurers because they take effect during the open enrollment period. She said her group disagreed with the federal agencies' interpretation that the law bans incentives to encourage employees to fill out family medical histories.