



Posted on Mon, Nov. 23, 2009

## Thanks to GINA, your genes can't affect your job

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The Kansas City Star

Some people say it's the most significant civil rights law of the new century.

But you're excused if the Genetic Information Nondiscrimination Act, which went into full effect over the weekend, isn't on your radar screen.

It's been a quiet debut for the act, which has two parts:

- Title I prohibits insurers from requiring genetic testing or using genetic testing results as a pre-existing condition to deny coverage or set health insurance premiums in group or individual policies.
- Title II bans employers from requiring genetic testing or making any staffing decisions based on genetic testing of employees or their family members.

GINA is, in fact, the first big federal expansion of employment discrimination law since the 1990 Americans with Disabilities Act.

As of Nov. 21, the law tells employers that even though they might fear higher costs, absences or turnover of employees who are genetically disposed to a certain disease or disorder, it's against the law to hire, fire, promote, assign or pay employees based on that knowledge.

Advocates say GINA addresses fear as much as actual discrimination.

"In many cases, we've seen patients who could have benefited greatly from genetic testing but didn't get it or paid out of pocket so their insurance companies wouldn't find out about their results," said Steven Keiles, president of the National Society of Genetic Counselors. "The biggest benefit of the new law may be that it frees people from some fears."

The legislation — which doesn't cover life, disability or long-term care insurance — also allows workplace law to catch up with advancements in science.

Developments in genetic testing now make it possible to get an early diagnosis and perhaps lifesaving therapies for diseases that have hereditary ties, such as prostate, breast and ovarian cancers; diabetes; Parkinson's; Huntington's; hemophilia; heart disease; and more than 1,300 other maladies.

But these tests are "absolutely useless" if the fear of workplace or insurance discrimination deters people from taking them, said Sen. Olympia Snowe, a Maine Republican.

Snowe co-sponsored the Senate bill with Edward Kennedy, the Massachusetts Democrat who died this year, and Mike Enzi, a Wyoming Republican. Louise Slaughter, a New York Democrat, and Judy Biggert, an Illinois Republican, were the prime sponsors in the House.

For many workers, the only indication of a notable legal change might be the appearance of GINA posters in the workplace.

Public and private employers with 15 employees or more must post notices, along with other nondiscrimination policies, under an Equal Employment Opportunity Commission mandate.

But for Becky Fisher and many other Americans, GINA is a big victory, won after 12 years of congressional wrangling.

"The absence of this protective legislation discouraged people from getting tests that could have saved their lives," said Fisher, a librarian and researcher in Virginia whose family members test positive for a gene mutation that indicates an elevated risk for breast and ovarian cancers.

Fisher said a relative, fearing that she'd lose coverage if her insurer knew about her disease propensity, never agreed to genetic screening tests, didn't receive early treatment and died.

"I didn't want my children to suffer that risk," said Fisher, who became a strong GINA advocate.

"In genetic counseling, you're told about the results and the risks, and the genetic counselor will end by saying, 'Don't ever be without group health insurance.' That pretty much says it all (about the need for GINA)," Fisher said.

### Why now?

Joann Boughman, executive vice president of the American Society of Human Genetics, credited a coalition of professional associations with keeping GINA alive on Capitol Hill.

"The Senate passed it unanimously twice (in 2003 and 2005) before the House got on board with it," Boughman said. "The turning point was when the breast cancer gene test became available. That broadened public interest in genetic testing beyond other diseases."

For years, the U.S. Chamber of Commerce and the Society for Human Resource Management said that GINA was unnecessary, that the ADA and the Health Insurance Portability and Accountability Act provided all the protections for health information that employees needed.

Others disagreed.

"It wasn't that the broad employer community was behaving badly," Boughman said. "Sure, there were a few bad players out there, but our goal simply was to prevent discrimination from happening in the few places it might."

GINA advocates point to a "bad player" example from 2001, when the EEOC sued Burlington Northern Santa Fe Corp.

The railway had required employees who filed claims for workplace injuries to undergo genetic testing for carpal tunnel syndrome.

The blood test searched for a marker on chromosome 17 that could indicate a genetic cause for carpal tunnel syndrome, which would help the railway fight work-related injury claims.

Another high-profile case occurred in 2000 when the University of California at Berkeley settled for \$2.2 million a lawsuit that alleged the university violated about 9,000 employees' rights by testing them for genetic disorders, venereal disease and pregnancy without employees' consent.

Most instances of genetic discrimination are more individual and, in most cases, unrecognized.

"You'd never see it. Someone in a back room made a decision off the cuff and never had to report to you that you didn't get the job because they found out you tested positive for something," Fisher said.

### The fear factor

What GINA produced, Boughman said, was federal legislation that kept up with medical advances rather than waiting for workers, claiming discrimination, to create a patchwork of genetic-related case law around the country.

In the end, proponents say, GINA's legacy will be that it saves lives.

Physician and research organizations already are reporting that it's easier to get some people to sign up for clinical trials because they're not afraid that their information could be used against them by insurers or employers.

The new law also may squelch some of the anonymous testing, or testing done under pseudonyms, by individuals who wanted their genetic information but were afraid to do it under their own names.

Phil Hardt, active in the Huntington's Disease Society of America, gave testimony in 2004 about a program set up in Arizona so that individuals could pay cash under bogus names for a genetic test.

It was "around \$900 out of pocket to find out," Hardt said at the time. "But it is completely concealed. ... But it's a shame we have to do this."

Hardt and others made a convincing case that people were reluctant to participate in research, even anonymously, for fear of being found out.

Those fears created a two-tiered health system, said Keiles, the genetic counselor. He said that "people who could afford to pay out of pocket were getting tested while others couldn't afford it."

Keiles said payment problems remain an issue. In fact, genetic counselors are lobbying for follow-up legislation to GINA — an amendment to the Social Security Act that would allow Medicare reimbursement for genetic counseling, a discipline that currently isn't covered.

Meanwhile, employment law attorneys are advising their corporate clients to be careful about running afoul of the law.

Some legal concerns are tied to the growth of company wellness programs and incentives that ask employees to undergo health risk appraisals to obtain less-expensive health insurance.

GINA provides exceptions that allow employers to ask for family medical histories and receive testing results from employees if they are produced as part of "voluntary" wellness programs and there are no related financial penalties or benefits for participation.

This will require a change in some wellness programs. Some companies allow employees who take health-risk tests to enjoy financial benefits such as more paid time off, but GINA prohibits such incentives.

America's Health Insurance Plans, a coalition representing health insurers, disagrees with that part of GINA and wants to challenge that interpretation of the law.

What is likely to remain unchallenged is the provision that employers must keep any employee health information separate from all other personnel files and not use it to affect decisions about hiring, firing, promoting or compensating.

The law also protects employers who obtain "water cooler" information — who inadvertently learn through office conversation of an employee's genetic information.

**"It's not against the law for an employer to *have* the information. It's against the law to *act* on it," Boughman said.**

That's an important proviso, given the surge of "patient community" Web sites like Inspire.com or PatientsLikeMe.com.

The online world is full of easily discoverable information, provided by patients themselves, that is only a click away for employers or insurers to read.

### **Insurance angle**

While employers are just this month falling under GINA's provisions, insurance companies had an earlier compliance deadline.

Title I took effect on May 21, banning insurance companies from buying or requiring genetic information to make eligibility or premium decisions in health policies, whether bought through work or on the individual market.

Under the law, insurers cannot require individuals to undergo genetic testing and cannot use genetic information for pre-enrollment underwriting purposes.

Group health plans also are prohibited from changing contribution or premium amounts for the group based on genetic information received about individuals in the plan.

GINA might help someone like Tonia Phillips of Virginia, who testified before a National Institutes of Health committee about her workplace experience.

Phillips' mother died of ovarian cancer, so she elected to undergo genetic testing to learn if she had the gene mutation that indicates an 80 percent lifetime chance of getting ovarian cancer. Tests showed that she did and that she had a 45 percent chance of getting breast cancer.

She chose to have a prophylactic hysterectomy and mastectomy. As a result of her medical expenses, her employer's health insurance bill skyrocketed and her boss asked her to leave the company plan.

As GINA negotiations progressed, it turned out that Phillips' former workplace would have been too small to be covered by the act.

Eliminating businesses with fewer than 15 employees from Title II coverage was the only way to get business organizations' backing, supporters found.

In addition to exempting small businesses, there's another important thing that Title I doesn't do. It doesn't prevent insurance companies from raising contribution or premium amounts in group plans based on "manifest" diseases or actual use of health and medical services.

### **For more information**

- Read the entire GINA law at [www.gpo.gov/fdsys/pkg/PLAW-110publ233/pdf/PLAW-110publ233.pdf](http://www.gpo.gov/fdsys/pkg/PLAW-110publ233/pdf/PLAW-110publ233.pdf).
- Reach the EEOC at [www.eeoc.gov](http://www.eeoc.gov), or call 800-669-4000 (toll-free) or 800-669-6820 (toll-free TTY number for individuals with hearing impairments).
- Contact any GINA advocacy organization, including the National Society of Genetic Counselors, the American Society of Human Genetics, the Council for Responsible Genetics, the Coalition for Genetic Fairness, the Genetic Alliance or any organization that represents specific genetic-influenced diseases such as polycystic kidney disease, sickle cell anemia and cystic fibrosis.

**Related state laws**

Many states, including Missouri and Kansas, have state statutes that provide some of the same protections or prohibitions as GINA. In any case, the broader legislation would apply to insurers or employers in the state.

**Jobs in genetic counseling**

The National Society of Genetic Counselors estimates that the profession will grow 23 percent a year over the next five years.

Genetic counselors must complete a two-year graduate degree from one of about 32 accredited programs in the United States and Canada. Most become certified by the American Board of Genetic Counseling and can expect to earn an average of \$63,057, depending on the market, according to society figures released this year.

Learn more at [www.nsgc.org](http://www.nsgc.org).

**On workplace walls**

The Equal Employment Opportunity Commission requires this notice, downloadable from the EEOC, to be posted at workplaces with 15 or more employees:

**GENETICS**

Title II of the Genetic Information Nondiscrimination Act of 2008 protects applicants and employees from discrimination based on genetic information in hiring, promotion, discharge, pay, fringe benefits, job training, classification, referral and other aspects of employment. GINA also restricts employers' acquisition of genetic information and strictly limits disclosure of genetic information. Genetic information includes information about genetic tests of applicants, employees or their family members; the manifestation of diseases or disorders in family members (family medical history); and requests for or receipt of genetic services by applicants, employees or their family members.

**What is genetic information?**

Genetic information is derived from blood, tissue, saliva and other body parts. Tests find markers that indicate the presence of or higher risk for diseases or disorders, many of which are inherited. It covers DNA, RNA, chromosome, protein and metabolite tests that detect genotypes and mutations.

And what isn't? Genetic information doesn't include information about one's sex, age, alcohol use, drug use, or existence of a manifested disease or disorder.

What can be tested? Genetic tests are available for more than 1,300 diseases — up from roughly 100 in the early 1990s, experts say. And the number is expected to climb even higher. The most common requests involve:

- Cystic fibrosis.
- Sickle cell anemia.
- Breast and ovarian cancer.
- Colon cancer.
- Some types of diabetes.
- Some types of cardiovascular disease.

But predictive testing is just one way genetic data are being used today. Others include:

- Carrier testing: Testing potential parents for genetic disorders even before a child is conceived.
- Prenatal testing: Testing of genetic material extracted from a fetus in the womb, including phenylketonuria, a genetic disorder that can cause severe mental retardation if not detected and treated early, and other diseases.
- Diagnostic testing: These help doctors identify genetic disorders in patients, sometimes at lower cost and less risk than traditional methods such as tissue biopsies. This is being explored as a tool for diagnosing certain cancers.
- Pharmacogenetic testing: This new field seeks to answer why some drugs affect people differently, based on differences in their DNA.
- Identity testing: Applications range from criminal cases to paternity suits.
- Ancestry testing: Examines an individual's genome for clues to ancestral roots.
- Whole genome sequencing: Companies are now offering to map your entire genetic code.

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