

# Genetic Information Nondiscrimination Act Is A First Step; Won't Solve The Problem

*This article is based on an interview of Mark Rothstein, Herbert F. Boehl Chair of Law and Medicine at the University of Louisville, Louisville, KY, and Director of the University of Louisville School of Medicine's Institute for Bioethics, Health Policy and Law. Professor Rothstein conducts research and advises state legislatures, the Centers for Disease Control and Prevention, the National Institutes of Health (NIH) and other groups on a variety of issues related to genetics and the law. The interview was conducted by Cynthia L. Hackerott, J.D., and Martha Pedrick, J.D., analysts with CCH, Wolters Kluwer Law & Business. Wolters Kluwer Law & Business is the new identity for all CCH and Aspen Publishers Human Resources, Employment and Labor Law products.*

If enacted, the Genetic Information Nondiscrimination Act (GINA) (H.R. 493) would make it illegal for an employer, employment agency, labor organization, or training program to discriminate against an individual or deprive an individual of employment opportunities because of genetic information. GINA would also make it illegal for group health plans and health insurers to deny coverage to healthy individuals or charge them higher premiums based solely on a genetic predisposition to a disease.

But enacting GINA will do little to change the very real problem of people fearing that employers will have access to their genetic information, said law professor Mark Rothstein. Even though it is valuable, in a symbolic sense, to have the country enact a law that says it's a bad thing to discriminate on the basis of genetic information, Rothstein fears that GINA could possibly delay enactment of better, more meaningful, and more effective legislation.

"Because it took 12 years to do so, if GINA is enacted, Congress probably wouldn't want to touch this issue, even if the law really does very little," said Rothstein, the Herbert F. Boehl Chair of Law and Medicine at the University of Louisville, Louisville, KY, and Director of the University of Louisville School of Medicine's Institute for Bioethics, Health Policy and Law.

## Focus On Predictive Genetic Information

Rothstein explained that genetic information is really of two kinds – predictive information and diagnostic information. Only the former kind raises novel issues; once someone is already affected, the cause of the illness really doesn't matter from an ADA or other statutory standpoint. So, the issue of genetic discrimination is mostly about predictive genetic information.

## Impact Of Federal Law On Existing Laws

Currently, 35 states have laws prohibiting genetic discrimination in employment. Executive Order 13145, issued by President Clinton in 2000, prohibits discrimination in federal government employment on the basis of genetic

information. GINA would not preempt state laws that are more stringent. For example, to be covered under Title VII, or GINA for that matter, an employer must have 15 or more employees, but states often have a lower threshold for coverage.

Rothstein noted that when GINA was first introduced there were fewer state laws, and so the initial goal was to have more comprehensive coverage in every state. Even today, GINA would add 15 states to the list.

GINA would extend beyond the provisions of some state laws, Rothstein pointed out. For example, only 19 of 35 states with state genetic nondiscrimination laws prohibit an employer from requesting genetic information, which is one of the express prohibitions under GINA. And if a federal statute is enacted, some states would modify their laws to track the language of the federal statute to make it easier for multi-state employers.

## The Problem: Disclosure Of Health Records That Include Genetic Information

There are concerns that GINA fails to address, stressed Rothstein. It's not that there are multitudes of employers that are discriminating against individuals on the basis of genetic information. "I can count on one hand the number of confirmed cases of predictive genetic information used as the basis for a claim of employment discrimination," he noted.

Rather, the number one problem pre-GINA is that many at-risk individuals, who would benefit from predictive genetic testing because of some family risk factor, decline to do so because they fear their employer or insurer will gain access to the results and use the information against them.

GINA does nothing to prevent that from happening, said Rothstein. GINA makes it unlawful for an employer to request, require or purchase genetic information about an employee or applicant. This provision has to be read in conjunction with section 102(d)(3) of the ADA, which permits an employer to require a signed authorization to release all of the individual's health records after a conditional offer of employment. The problem, notwithstanding existing state laws, is that when a conditional offeree signs an authorization, *all* records are sent to the employer.

## Narrowly Tailored Authorizations

Suppose, said Rothstein, that GINA also required (as drafted, it does not) employers to use narrowly-tailored authorizations that say specifically to a health care provider "send us everything about Joe Smith, but don't send us any genetic information because we are not allowed to ask for that." California and Minnesota already have comparable laws (not enacted specifically with genetics in mind) requiring that any time an employer seeks a medical examination or requests medical information, it must be strictly job-related.

Practically speaking there is no way – using current technology with either

paper or electronic medical records – for a health care provider to sort out the genetic from the non-genetic information or to categorize the information as "job-related" or "non-job-related," Rothstein observed.

Without this capability, it's not feasible for the custodians of health records to distinguish between different kinds of information. "Irrespective of what the law provides," Rothstein emphasized, "they will continue to send complete health records."

Similarly, under the ADA, if an employer withdraws a conditional offer of employment, the individual has no right to learn why. There is no requirement that the employer specify, for example, "I didn't hire you because I didn't like your medical test," Rothstein commented. And in many instances, the reasons have absolutely nothing to do with health conditions. He explained: "It's very difficult to know if one was subject to discrimination. If a woman applies for a wait staff job at a restaurant, is turned down, then discovers that the entire wait staff is male, she might have an idea. But if she suspects it's based on some latent health information, how is she going to know?"

Rothstein's research suggests that in the United States there are at least 10 million authorizations for the release of health information each year for employment reasons. "Unless we limit what is disclosed pursuant to these authorizations," he said, "people will continue to be justifiably concerned about the disclosure of sensitive health information to employers, insurers and others." Meanwhile, noted Rothstein, while most supporters assume that this is a great piece of legislation and that it's necessary, unless it addresses the disclosure of health records under these circumstances, he has "grave misgivings" about it.

## Genetic Information And Employment Decisions

According to Rothstein, there are two possible motivations for an employer's use of genetic information in making employment decisions. One would be to save money on health care costs by excluding people who are believed, based on genetic factors, to be more likely to get sick. That's the same motivation as employers who prefer not to hire smokers or someone who is obese.

The second motivation, said Rothstein, would be an employer's concern that people with a particular genetic make-up could become ill after exposure to certain substances in the workplace. Even though saving money on health care costs is purely in the employer's interest, this second reason can be both financial and altruistic. The use of genetic information to prevent occupational disease is relatively rare, however; he suggested that there are only a handful of substances that might be relevant. And some employees would say that they should have the choice whether to assume the risk of working in an unhealthy environment.

## GINA's Health Insurance Provisions

Employers don't have much incentive to use genetic discrimination to save on employer-sponsored health care, which is largely group-based, Rothstein pointed out. It's not worth it to employers, either financially or for morale or PR reasons, to try to sift through health records to find predictive genetic information.

**Group plans.** Most people who have health insurance are covered by employer-sponsored group health plans. There is a little-known provision in HIPAA that makes it unlawful for group health plans to discriminate against people in their coverage or in their premiums on the basis of health information, including genetic information. So, said Rothstein, it's already illegal to discriminate on the basis of genetic information in group health plans.

**Individual plans.** Approximately 44 states have enacted state laws that apply to individual health insurance plans making it unlawful to discriminate in health insurance on the basis of genetic information. GINA would take basically the same approach by making it unlawful to discriminate in individual health insurance on the basis of genetic information.

That means that if a person applies for an individual insurance policy and somewhere in that individual's record it says that he or she is genetically predisposed to colon cancer, it would be unlawful for the health insurer to discriminate on the basis of this genetic predisposition.

## Post Diagnosis, GINA Does Not Apply

Note that GINA and these state laws only apply to *asymptomatic* individuals. Once the individual is diagnosed with colon cancer, Rothstein stressed, he or she is now in the same boat as anyone else who has a serious health condition and applies for renewal of the policy. Whether the insurer is legally allowed to raise premiums or decline to renew the policy depends on state insurance law and, according to Rothstein, in virtually every state the insurer is given wide leeway to either cancel the policy or to increase the rates. A few states have guaranteed reissue provisions, but that's very unusual.

This problem is not really one of genetic discrimination, advised Rothstein; rather, it involves who has a right of access to health insurance and health care in the individual market. "Enacting 'feel good' legislation like GINA or state genetic nondiscrimination in health insurance laws is not going to help very much. It takes a more comprehensive tackling of how health care is funded in the country. GINA is an important first step in addressing the problem of genetics in employment and health insurance, but it does not solve these problems," he concluded.

## GINA: Where It Stands

The House passed GINA by a 420-3 vote on April 25, 2007, and the Bush administration says it supports the bill. A similar Senate bill was approved by the Senate Health, Education, Labor and Pensions Committee in January; it filed a written report in April.