



# BRAVE NEW WHORL

## HOW TO COMPLY WITH REGULATIONS SURROUNDING GENETIC INFORMATION

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In 2008, President Bush signed into law the Genetic Information Nondiscrimination Act in response to our brave new technologically advanced world. We have developed medical science to the point where we can identify genetic defects that will aid in treating illness.

But the test results also provide a novel means to fuel discrimination by employers and health insurance providers. GINA seeks to throw out the bath water and save the baby – foster genetic testing by prohibiting discrimination based on genetic information.

But GINA itself is merely a broad outline of protections. This law required regulators to flesh out the details. In late 2010, final regulations implementing GINA were adopted and became effective in January 2011. Now, when the doctors pinch a drop of blood from your employee's fingertip and determine that a flawed double helix of DNA predisposes your employee's children to sickle cell anemia or Tay-Sachs disease or cystic fibrosis, your business, and insurance company, as well as your employee, have a new rulebook.

In a nutshell, GINA not only prohibits discrimination based on genetic information, but also regulates the gathering and use of medical information. Prior laws, like the Americans with Disabilities Act, the Health Insurance Portability and Accountability Act, and the Family and Medical Leave Act, have already sensitized businesses to the need for confidentiality and non-discrimination in employment and employee health insurance. But GINA adds new requirements that address recent medical advances – and severe penalties for noncompliance.

### **JUST THE FACTS**

Generally, GINA prohibits businesses from discriminating based on genetic information or requesting, requiring or buying genetic information about an employee or job applicant or their family members. Genetic information includes information about individuals' genetic tests and the tests of their family members; family medical history; requests for and receipt of genetic services by an individual or a family member; and genetic information about a fetus carried by an individual or family member or of an embryo legally held by the individual or a family member using assisted reproductive technology.

But GINA and its regulations also impose additional significant requirements:

- Health insurers may not require genetic testing.
- Health insurers can't use an employee's genetic information to deny health insurance coverage or to establish insurance premiums or deductibles.
- Employers may not engage in the collection of information, such as background checks by internet search, in a way that is likely to result in obtaining genetic information.
- An employer may not listen to third party conversations, search an employee's personal effects or make requests for health information to obtain genetic information.
- Employer-sponsored wellness programs may not request genetic information or reward participants for providing this information.
- An employer may not retaliate against an employee in connection with a GINA violation.

### **THE EXCEPTION TO THE EXCEPTION TO THE EXCEPTION**

Some laws and regulations read like they are elaborate tricks – or even mind games dreamt up by NSA's psych ops division. GINA is no different. There are rules and then exceptions to the rules and then exceptions to the exceptions. I'm not making this stuff up.

For example, whatever genetic information that an employer may permissibly retain can't be kept in an employee's standard personnel file. But you can keep this information in the same file where you are permitted to keep certain ADA-related medical information. However, you don't need to remove genetic information put in regular employment files before Nov. 21, 2009, when GINA first became law.

There are numerous other exceptions to the new GINA rules. Notably, an employer can obtain information about the medical condition of an employee's family member as part of a leave request under the FMLA. Other exceptions apply. Businesses may obtain medical information from general news sources, such as an obituary describing a relative's cause of death; an employer may collect medical information to comply with certain workplace safety requirements, and forensic labs may continue to conduct DNA testing for law enforcement purposes or to identify human remains.

GINA also excuses inadvertent receipt of genetic information. For example, a business may make a request for medical information in connection with an employee's request for reasonable accommodation under the ADA – provided that the employer warns the employee and healthcare provider not to respond with genetic information. If, despite this warning, an employer receives genetic information, then obtaining this information will be excused.

### **PENALTIES**

What would a good law be without penalties for violating it? And this one is a doozy.

Generally, the Equal Employment Opportunity Commission is charged with fielding initial complaints of GINA violations. Absent an early amicable resolution of the claim per settlement or mediation – an EEOC investigation may ensue. Just responding to the information requests that are part of such an

investigation is tremendously burdensome and time-consuming. Then, if the EEOC finds reasonable cause to believe a GINA violation has occurred, the EEOC will attempt to resolve the situation. But, absent a settlement, the EEOC can pursue the claim or allow the aggrieved employee or job applicant to do so. A successful claim can subject your business to a judgment for damages such as lost wages, punitive damages to punish you for violating GINA and reimbursement of your opponents attorneys and expert fees. You might even be required to reinstate a former employee or hire a job applicant that you had rejected. So let's not take any of this lightly.

## **RECOMMENDATIONS**

In the inimitable words of Bob Dylan, "The times, they are a-changin'." You can keep up with the times and maybe even avoid a few lawsuits with the following:

- Get training for your HR department about the new GINA requirements.
- Revise your employment forms to comply with GINA. Start with your Equal Employment Opportunity poster and policies. The new EEOC poster can be downloaded from the organization's website. (<http://www1.eeoc.gov/employers/poster.cfm>)
- Update your personnel practices, such as maintaining separate personnel files solely for medical information.
- Confirm that your health insurance program complies with the new requirements.
- For the millionth time, consult with a qualified lawyer!

It's a brave new world. Whether it's a new technology, a new way of doing business or a new law, change is inevitable. Understanding and meeting these challenge is key to succeeding in business.

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