

## EEOC'S GINA REGULATIONS

The Equal Employment Opportunity Commission (EEOC) has issued final regulations implementing Title II of the Genetic Information Nondiscrimination Act (GINA). Title II generally prohibits employment discrimination based on genetic information, as well as collection, use and disclosure of genetic information in connection with employment. President Bush signed GINA into law in May 2008 and it is currently in effect. The EEOC's new regulations are effective January 10, 2011, and employers may want to implement some compliance measures in response to the regulations.

### BACKGROUND

GINA includes two parts that regulate employers:

- **GINA Title I** applies to employer-sponsored health plans (including those that provide benefits through health insurance). An employer that sponsors and administers a health plan is generally responsible for ensuring its compliance with applicable laws and may incur liabilities for non-compliance. GINA Title I prohibits collecting, using or disclosing genetic information prior to or in connection with enrollment in a health plan or for underwriting purposes. This part of GINA is the subject of regulations issued in 2009 by the Departments of Labor, Treasury, and Health and Human Services (see *Willis Human Capital Practice Alert*, Vol. 2, No. 10, "GINA Changes the HRA Rules").
- **GINA Title II** applies to employers and certain other entities, such as employment agencies (for convenience this article just refers to employers). GINA Title II generally prohibits collecting, using or disclosing genetic information in connection with employment. It also prohibits firing, refusing to hire or otherwise discriminating against workers with respect to compensation and other terms of employment based on genetic information. Title II took effect on November 21, 2009 and, as noted above, is the subject of the new EEOC regulations discussed in this article.

### GINA TITLE II'S REQUIREMENTS FOR EMPLOYERS

Technically, GINA Title II consists primarily of prohibitions rather than requirements:

- Employment **discrimination** based on genetic information is prohibited
- **Collection** (i.e., requesting, requiring or purchasing) of genetic information about employees and their family members is prohibited
- **Disclosure** of genetic information about employees and their family members is prohibited

### AVOIDING GENETIC INFORMATION IS DIFFICULT

Most employers believe that they have never collected or received any genetic information regarding their employees and assume that GINA will not require any special compliance efforts. Unfortunately, GINA's definition of genetic information includes family medical history, which means that every employer who has ever obtained

information about the health status of an employee's spouse, parent or child is in possession of genetic information. Moreover, inquiries about the health of an employee's family members may constitute requests for genetic information.

Because the definition of genetic information is so broad, employers have little chance of avoiding GINA issues altogether by simply avoiding genetic information. A conversation about an employee's child may be overheard or an employee may volunteer, when requesting bereavement leave, that his parent died of cancer. There also are many legitimate reasons for employers to collect and disclose employees' genetic information (e.g., obtaining medical certification that an employee's parent has a serious health condition allowing for FMLA leave). And there are good reasons to condition certain employment benefits on employees' genetic information (e.g., payment of certain medical claims). Therefore, employers need to understand both the GINA Title II prohibitions and the GINA Title II exceptions that allow for employers' collection, disclosure and use of genetic information.

## DISCRIMINATION BASED ON EMPLOYEES' GENETIC INFORMATION

### PROHIBITION

GINA Title II's primary objective is to prevent employment discrimination based on genetic information. The EEOC gives the example of an employer violating GINA Title II by reassigning an employee who has a high-stress job after learning that the employee has a family medical history of heart disease. Even if the employer's intent is to protect an employee, employment decisions made on the basis of genetic information, including family medical history, generally will violate GINA Title II.

The EEOC regulations also provide that an employer's actions involving its health benefits plan may violate GINA Title II because health benefits are within the definition of compensation, terms, conditions or privileges of employment. For example, an employer that conditioned health plan eligibility on employees undergoing genetic testing (or, presumably, answering questions about family medical history) would violate GINA Title II.

### EXCEPTIONS

The EEOC regulations explicitly identify only one exception to GINA Title II's general nondiscrimination requirement. An employer will not be deemed to have discriminated based on genetic information if it limits or restricts an employee's job duties based on genetic information because it is required to do so by a law or regulation mandating genetic monitoring, such as regulations administered by the Occupational and Safety Health Administration.

### IMPLIED EXCEPTION

There is an implicit exception to the general nondiscrimination rule that applies with respect to employer-sponsored health plans. The EEOC's new regulations specifically provide that GINA Title II does not apply to or prohibit any group health plan from engaging in any actions that are authorized under GINA Title I. Among other things, employer-sponsored health plans are allowed, under GINA Title I, to base a benefits decision on an individual's genetic information if the health plan conditions a particular benefit on an individual having a particular genetic background. For example, a plan might provide that, if a woman has one or more close relatives who have been diagnosed with breast cancer, the plan will cover the full cost of testing for genetic characteristics indicating a predisposition to breast cancer.

**GINA and Employer-Sponsored Health Plans.** The EEOC's statement that GINA Title II does not prohibit a *health plan* from engaging in actions authorized under GINA Title I is not as protective of employers as it might first appear. To provide the protection employers might expect, the EEOC's regulations should provide that an *employer* will not violate GINA Title II solely as a result of sponsoring, administering or contracting with third parties for a health plan to take actions authorized under GINA Title I. Instead, the EEOC regulations prohibit employer "actions that violate [GINA] Title II, even where those actions involve access to health benefits." The EEOC also explains that "compliance with these GINA Title II regulations does not relieve [employers] of their responsibility to comply with [GINA] Title I."

If the standards under GINA Title I and GINA Title II were the same, this might be a reasonable approach. Even when addressing similar or overlapping topics; however, the regulations under GINA Title I and GINA Title II apply differing standards and, when addressing health plan issues, it is difficult for employers to know when they can rely on one set of regulations or the other and when they must ensure compliance with both. As a result, the compliance suggestions relating to health plans in this article are based on avoiding these ambiguities whenever possible. Some employers will find these suggestions overly restrictive and may wish to consult with legal counsel on strategies more appropriate to their business practices.

Because of the potential conflicts among the various GINA regulations that affect employer-sponsored health plans, employers should protect themselves against potential GINA Title II liability by:

- Reviewing their health plan provisions and practices to identify any uses of genetic information involved in determining benefits, rates, eligibility, etc. While most plans do not explicitly use genetic information, employers may discover some provisions or practices that rely on information about family members' health conditions.
- Any identified use of genetic information should be discontinued unless specifically approved under GINA Title I. For details on activities permissible under GINA Title I for employer-sponsored health plans, see **Willis Human Capital Practice Alert, Vol. 2, No. 10, "GINA Changes the HRA Rules."**
- Even if a use is specifically approved, consider discontinuing it in order to minimize the chances of incurring liability under GINA Title II. Employers administering wellness programs in connection with a health plan are particularly vulnerable to situations in which a use of genetic information approved for a health plan by GINA Title I would violate GINA Title II if attributed to an employer. This vulnerability is further discussed below in connection with voluntary wellness programs that collect genetic information.

## COLLECTION OF EMPLOYEES' GENETIC INFORMATION

### PROHIBITION

As noted above, GINA Title II generally prohibits employers and other covered entities from collecting (i.e., requesting, requiring or purchasing) genetic information about employees or employees' family members. This prohibition means that an employer may have liability for a GINA violation even if it does not use any of the information it collects. Simply requesting genetic information is deemed a violation.

For this purpose, the EEOC has defined a "request" for genetic information as including:

- An internet search on an individual that is done in a way likely to result in obtaining genetic information
- Eavesdropping on third-party conversations for the purpose of obtaining genetic information
- Searching an individual's personal effects in order to obtain genetic information
- Requests for information about an individual's current health status made in a way likely to result in obtaining genetic information

In addition, an employer that requires medical examinations related to employment (e.g., post-offer, pre-employment medical exams) violates GINA Title II unless it directs the health care provider conducting the examination not to collect genetic information, including family medical history, as part of the examination. If an employer learns that genetic information is being collected despite directions to the contrary, it must take additional steps, which might include discontinuing use of one or more health care providers.

## EXCEPTIONS

There are several exceptions to the prohibition on collecting genetic information. For most employers, three of those exceptions will be particularly important:

- Inadvertently collecting genetic information
- Requesting family medical information in connection with leave requests, including requests for FMLA leave needed in order to care for a family member with a serious health condition
- Offering health or genetic services, including those offered through a voluntary wellness program

Other exceptions regarding collection of genetic information include those allowing receipt of genetic information from publicly available sources and for purposes of monitoring toxic substances in the workplace.

### EXCEPTION FOR INADVERTENT COLLECTION OF GENETIC INFORMATION

The EEOC regulations indicate that the inadvertent acquisition exception applies in situations that include, but are not limited to:

- Overhearing a conversation that includes genetic information, unless overhearing turns into eavesdropping, as noted above
- Receipt of genetic information during a casual conversation, which may include a general health inquiry or an expression of concern, unless the initial or follow-up questions explore whether other family members are affected, whether tests have been done on other family members, etc.
- Receipt of genetic information without having solicited or sought the information, such as an e-mail sent to an individual's co-workers regarding a family member's health condition
- Learning genetic information from a social media platform to which access was granted by the creator of the profile

More significantly for many employers, the EEOC regulations provide a means for employers to ensure that the inadvertent acquisition exception will apply to any genetic information received in response to a request for medical information, provided the request does not violate any laws. So, for example, if an employer requires a medical certification when an employee requests FMLA leave for the employee's own serious health condition, the employer is making a lawful request for medical information. If the medical certification received in response includes genetic information, its acquisition **"generally will not be considered inadvertent unless the [employer] directs the individual...from whom it requested medical information...not to provide genetic information."** The regulations provide the following sample language to include with a request for medical information:

The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits employers and other entities covered by GINA Title II from requesting or requiring genetic information of an individual or family member of the individual, except as specifically allowed by this law. To comply with this law, we are asking that you not provide any genetic information when responding to this request for medical information. "Genetic information" as defined by GINA, includes an individual's family medical history, the results of an individual's or family member's genetic tests, the fact that an individual or an individual's family member sought or received genetic services, and genetic information of a fetus carried by an individual or an individual's family member or an embryo lawfully held by an individual or family member receiving assistive reproductive services.

Other situations in which an employer might use this sample language (or a modified version) to ensure that any receipt of genetic information will be deemed inadvertent include:

- Verifying a request for accommodation in accordance with the Americans With Disabilities Act or a similar state or local law
- Determining that an employee qualifies for sick pay or leave under an employer's policy or as provided by state or local law
- Requiring a return to work certification as allowed under the FMLA

Even if an employer fails to include the statement set out above with a request for medical information, receipt of genetic information in the response may still be deemed inadvertent if the request was not likely to result in obtaining genetic information. A request that is carefully tailored to the situation is most likely to benefit from this provision, but that outcome is not as certain as it would be if the statement quoted above were included with the request. Therefore, many experts recommend that employers add the statement – modified as appropriate – to any forms that include a request for medical information, including FMLA medical certification forms, regardless of whether the information is to be provided by the employee or a health care professional or other third party.

## EXCEPTION FOR MEDICAL CERTIFICATION OF A FAMILY MEMBER'S SERIOUS HEALTH CONDITION

The EEOC regulations allow an employer to request information on a family member's health condition when an employee requests leave to care for the family member. The employer's request must be made in compliance with the medical certification provisions of the FMLA (or a similar state or local family and medical leave law) or pursuant to a policy of the employer that permits the use of leave to care for a sick family member. If the request is made pursuant to an employer's policy, all employees who request leave to care for a family member must be required to provide information about the health condition of the family member.

## EXCEPTION FOR VOLUNTARY WELLNESS PROGRAMS CAUSES SEVERAL PROBLEMS

The EEOC regulations provide that an employer offering health or genetic services – including services under a voluntary wellness program – may qualify for an exception to the GINA Title II rule prohibiting collection of genetic information of an employee or family member. Unfortunately, qualifying for the exception is difficult and it is unclear when GINA Title II requirements apply to various types of wellness programs. In addition, if both GINA Title I and GINA Title II apply to a single program, there are several mismatches between their requirements, making compliance difficult. Even if a wellness program does not violate GINA simply by requesting genetic information, allowed uses of the information limit its value. As a result of these factors, an employer's best strategy may be to simply avoid the GINA issues raised by wellness programs, as explained below.

**Wellness Programs and GINA.** Wellness programs generally raise issues under GINA by directly or indirectly requesting genetic information in the form of family medical history. Although wellness programs can include a wide variety of features, any of which might involve genetic information, the wellness program activities that most often request genetic information are:

- Health risk assessments (HRAs) which are intended to gather information about respondents' health risks. They usually include questions regarding health conditions and personal habits. In some very limited cases, HRAs may include questions about family medical history, as explained below. (In the past, most HRAs included questions about family medical history.)
- Disease management, health coaching or other wellness services for which, in limited cases, a health plan may ask individuals to provide genetic information as a means of demonstrating that the services are medically appropriate and therefore covered under the health plan. In the past, family medical information gathered in HRAs was used to identify individuals who could benefit from disease management, health coaching or other wellness services, but that practice is no longer permitted.

Many wellness programs focus on current health conditions and behaviors. For example, a wellness program might provide a discount on health plan premium contributions to non-smokers, regular exercisers and those whose cholesterol, blood pressure and other biometric measures meet certain standards. While those wellness programs must meet a number of regulatory requirements, they typically do not involve genetic information, so they do not raise GINA issues. The GINA Title II regulations specify, however, that complying with GINA does not assure compliance with other laws, including the nondiscrimination requirements in the Health Insurance Portability and Accountability Act (HIPAA) and the Americans With Disabilities Act (ADA). The effect of the HIPAA rules on wellness programs is discussed in *Willis Employee Benefits Alert*, #128 – “More Guidance, More Flexibility on Wellness Programs.” Potential issues with HRAs under the ADA are discussed in *HR Focus*, Issue 24, “EEOC Moves to Oppose Mandatory HRA Screenings.”

## WELLNESS PROGRAMS CAN AVOID GINA ISSUES

The surest way to avoid GINA issues is eliminating all requests for family medical history from wellness program materials and adding to those materials the statement described in the previous section regarding inadvertent acquisition. Programs that take this approach ensure compliance with both GINA Title I and GINA Title II, avoiding difficult questions about which rules apply and how to coordinate their mismatched provisions.

- **Avoiding genetic information in HRAs.** The regulations under both GINA Title I and GINA Title II provide for an employer-sponsored health plan to rely on the inadvertent acquisition exception if it uses a health risk assessment that has no items requesting genetic information and also includes a request that respondents not provide genetic information in their responses. Both sets of regulations include sample language for this type of request, but the samples do not match. A combined version of the sample language from both sets of regulations might read:

In answering these questions, do not include any genetic information. The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits employers and other entities covered by GINA from requesting or requiring genetic information of an individual or family member of the individual, except as specifically allowed by this law. To comply with this law, we are asking that you not provide any genetic information when responding to this request. “Genetic information” as defined by GINA, includes an individual’s family medical history, the results of an individual’s or family member’s genetic tests, the fact that an individual or an individual’s family member sought or received genetic services, and genetic information of a fetus carried by an individual or an individual’s family member or an embryo lawfully held by an individual or family member receiving assistive reproductive services. Please do not include any family medical history or any information related to genetic testing, genetic services, genetic counseling or genetic diseases for which an individual may be at risk.

- **Avoiding genetic information in programs providing disease management, health coaching or other wellness services.** A wellness program of this type might provide enhanced benefits to those having or at risk for a chronic condition such as diabetes. As noted above, such a program might be able to accept family medical history as one means of establishing that an individual qualifies for enhanced benefits related to the condition. If, however, the program eliminated family medical history as a qualifier (and both deleted requests for family medical history from its forms and added the statement described above), the program would avoid several difficult questions about compliance with GINA.

## RELYING ON THE VOLUNTARY WELLNESS PROGRAM EXCEPTION TO REQUEST GENETIC INFORMATION IN HRAS

Family medical history helps identify an individual’s predisposition to several chronic conditions (e.g., diabetes) that can be prevented or ameliorated through appropriate disease management, health coaching or other services. Accordingly, employers and health plans may still be interested in collecting genetic information on HRAs. While there arguably is a limited window in which such collection is allowed, health plans and employers are so limited in the use of any family medical history information gathered on an HRA, that the value of collecting it is debatable.

- No variations in health plan eligibility (including eligibility for specific benefit options) or premium contributions may be based on whether an individual completes the HRA or on any genetic information provided on the HRA.
- No disease management or health coaching program and no enhanced health plan benefits may be provided based on whether an individual completes the HRA or on any genetic information provided on the HRA.
- Genetic information gathered on an HRA generally cannot be disclosed to the employer.

In short, the only value to be obtained from having individuals complete an HRA that requests family medical history would be the increased awareness of their own history that results from completion of the HRA by those individuals. At the same time, the requirements that must be met in order to avoid violating GINA simply by requesting genetic information on an HRA are onerous.

- In the case of an HRA completely unrelated to a health plan, the requirements that must be met in order to avoid a GINA violation include obtaining each respondent's prior knowing, voluntary and written authorization on a form that, among other things, describes the purposes for which requested genetic information will be used and the restrictions that apply to disclosure of any genetic information the individual provides. An HRA would be unrelated to a health plan if, for example, all employees were asked to complete the HRA and any reward for completion (such as a gift card, cash or paid time off) were delivered outside of the health plan.
- In the case of an HRA that a health plan requests its participants to complete, the requirements that must be met in order to avoid a GINA violation include administering the HRA after (and not in connection with) enrollment and stating that completing the HRA is voluntary and no reward or penalty may be applied for completing or not completing it.

## **DISCLOSURE OF EMPLOYEES' GENETIC INFORMATION**

### **PROHIBITION**

GINA prohibits employers from disclosing any genetic information, including genetic information collected before November 21, 2009 (the GINA Title II effective date). In addition, GINA makes the ADA's confidentiality requirements for medical information applicable to all written genetic information in an employer's possession. This means that the employer must keep written genetic information in its possession apart from other personnel information in separate confidential medical files (which may be the same files in which the employer stores medical information that is subject to that ADA's confidentiality requirements). For this purpose, written genetic information includes information in electronic format.

If genetic information was placed in personnel files before November 21, 2009, employers are not obligated to move that information immediately to confidential medical files. Employers must, however, ensure that the genetic information is not used or disclosed in any manner that would violate the confidentiality requirements.

### **EXCEPTIONS**

The EEOC's regulations provide several explicit exceptions to the nondisclosure rule, of which the following are likely to be of most interest to employers:

- An employer may disclose genetic information to the individual to whom it relates, if the individual makes such request in writing.
- Disclosure is permitted to the extent consistent with the FMLA or similar state or local leave law. For example, a supervisor who receives an employee's request for FMLA leave to care for a sick child may forward the request (including the information regarding the child's illness) to one or more individuals who handle FMLA requests on behalf of the employer.

- An employer may disclose genetic information in compliance with a court order specifying that genetic information must be disclosed, but only if the disclosure is carefully tailored to the terms of the order. In addition, unless the employer knows that the employee is aware of the court order, the employer must inform the employee about the court order and the information disclosed. This exception does not allow an employer to disclose genetic information in response to discovery requests or subpoenas that are not governed by a court order specifying that genetic information must be disclosed.
- An employer may disclose relevant genetic information to government officials investigating compliance with GINA.

In the preamble to its regulations, the EEOC explains that GINA's use of "the confidentiality regime required by the ADA" in some way implies that an agent of an employer, such as an attorney, could be permitted access to relevant genetic information because the EEOC has "not seen any charges challenging these types of communications."

## **CONCLUSION**

Employers typically do not intentionally base employment decisions on genetic information, so GINA compliance may not be a priority for early 2011. In light of the EEOC's new regulations under GINA Title II, however, employers should consider some "preventive" compliance measures. Employers that provide health benefits or wellness programs should pay particular attention to implementing such measures.

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