The interim final rules prohibiting discrimination based on genetic information in health insurance coverage and group health plans have been issued. The final rules will be effective December 7, 2009 and will impact calendar year plans beginning January 1, 2010. Additionally, other plans are required to comply with the new rules beginning May 21, 2009. These rules clarify the definitions of what constitutes the “collection” of genetic information, who is a “family member” and the circumstances under which a health plan may collect and use genetic information. The Genetic Information Nondiscrimination Act (GINA) may have an immediate impact on upcoming open enrollment in connection with wellness initiatives.

**THE BASICS**

GINA establishes rules that generally prohibit group health plans and health insurance issuers in the group market from: (i) increasing group premiums or contribution amounts based on genetic information; (ii) requesting or requiring an individual or family member to undergo a genetic test; and, (iii) requesting, requiring or purchasing genetic information prior to or in connection with open enrollment, or at any time for underwriting purposes.

The final rules restate the definition of “genetic information” to include information about: (i) an individual's genetic tests or the genetic tests of family members; (ii) the manifestation of a disease or disorder in family members (e.g. family medical history); and (iii) any request for genetic services or receipt of genetic services by a participant or family member.

**WELLNESS PROGRAMS**

As indicated above, GINA prohibits the collection of family medical history before or in connection with enrollment. Moreover, a group health plan that provides any reward, regardless of the amount, for completion of a health risk assessment (HRA) at any time, is in violation of GINA if the HRA requests family medical history. Whether the HRA is completed before or after enrollment doesn’t matter, as family medical history collected in return for a reward is considered to be the collection of genetic information for underwriting purposes.

Group health plans may request that a HRA be completed following and unrelated to enrollment and offer rewards for completion of the HRA when asking questions only about the individual and not the individual’s family. Furthermore, the group health plan may provide the participant with a second HRA that includes questions about genetic tests the individual has undergone and family medical history, provided that the second questionnaire: (i) is not requested before or in connection with enrollment; (ii) does not offer a reward; (iii) is well communicated as wholly voluntary; and, (iv) is unrelated to the first questionnaire.

Screening processes for disease management programs that use family medical history to identify individuals who could benefit from a program are prohibited under GINA because enrollment or eligibility in a disease...
management program based on answers to genetic questions (e.g. family medical history) is deemed to be the collection of genetic information for underwriting purposes.

Notably, general health questions may be prohibited as well depending on rewards or timing. For example, a question asking whether there is anything relevant about a person’s health that the person would like the plan to know or discuss with him could be a prohibited question unless the question explicitly states that genetic information should not be provided.

**Exceptions**

**Administration of a Health Plan:** Where an individual seeks a benefit under a plan, it is appropriate for the administrator to request family medical history or other genetic information to make a determination whether the benefit is medically appropriate for purposes of payment. In this case, the collection of genetic information is neither for underwriting purposes nor prior to or in connection with enrollment. However, the request for genetic information must be for the minimum amount of genetic information necessary to make a determination regarding payment.

The regulations make clear that this restriction is not intended to limit the ability of a health care professional who is providing health care services to an individual to request that the individual undergo a genetic test. The regulations say that, for example, a physician may recommend that an individual whose mother has Huntington’s disease, undergo a genetic test for the disease.

**Genetic Research:** Provided that specific rules are followed, a plan may request, but not require, that a participant or family member undergo a genetic test in connection with research.

**Incidental Collections:** If it is reasonable to anticipate that health information will be received as part of the collection of information, the incidental collection exception will apply only if the collection explicitly states that genetic information should not be provided. For example, a question such as “Have you had any laboratory tests in the past two years” could produce a response that includes genetic information.

**Non-Federal Governmental Plan**

Without regard to an election that exempts a non-federal governmental plan from any or all of the provisions of the Health Insurance Portability and Accountability Act (HIPAA), a plan cannot elect to be exempt from the requirements of GINA that prohibit discrimination with respect to genetic information.

**Penalties**

Plan Sponsors that improperly use genetic information can incur civil penalties of up to $100 per day per individual. Furthermore, Plan Sponsors that continue to have uncorrected uses of genetic information can incur additional penalties ranging from $2,500 to $15,000.

If you have any questions regarding this Briefing, please contact your Keenan & Associates Service Team.