

NEW GINA REGULATIONS GUIDE EMPLOYERS THROUGH RESTRICTIONS ON GENETIC INFORMATION

**By Jeff Burgess, Program Coordinator
Technical Assistance for Employers
Bureau of Labor and Industries**

GINA, the federal Genetic Information Nondiscrimination Act, went into effect over a year ago, but the EEOC just recently issued final regulations that become effective on January 10, 2011. The rules explain the prohibitions on acquiring and using genetic information in employment. They also define genetic information, provide model language for employers to use when requesting medical information, and detail narrow exceptions to the prohibitions of the law.

Q: Who is covered by GINA and what does it prohibit?

A: GINA's Title II pertains to employment and covers employers of 15 or more employees. It also covers labor organizations, employment agencies and apprenticeship and training programs. The law recognizes that with advances in genetic research comes the potential to misuse genetic information. GINA makes it unlawful: (1) to discriminate against employees or applicants because of genetic information (including harassment and retaliation), (2) to use genetic information in making employment decisions, and (3) to request, require or purchase genetic information. GINA also strictly limits the disclosure of genetic information.

Q: What is "genetic information"?

A: Genetic information includes information about an individual's or family member's genetic tests as well as information about the manifestation of a disease or disorder in an individual's family members (i.e., family medical history). It also includes genetic information of a fetus carried by an individual or family member or an embryo held by an individual or family member receiving assistive reproductive services. Genetic information also includes a request for or receipt of genetic services, or participation in clinical research that involves genetic services. It does *not* include information about an individual's age or gender, or information about race or ethnicity that is not derived from a genetic test.

Q: Can you give me some examples of genetic tests?

A: The GINA rules provide a nonexclusive list of genetic tests and another list of tests that are not genetic tests. Examples of genetic tests are: determining whether someone has a variant evidencing a predisposition to breast cancer, colon cancer or Huntington's Disease; carrier screening using genetic analysis to determine the risk for such conditions as cystic fibrosis, sickle cell anemia, spinal muscular atrophy, or fragile X syndrome in future offspring; amniocentesis and other tests to determine genetic abnormality in a fetus; newborn screening analysis using DNA, RNA, protein or metabolite analysis to detect genotypes, mutations or chromosomal changes (such as a test for PKU) so that treatment can begin before a disease manifests; pre-implantation genetic diagnoses performed on embryos created using *in vitro* fertilization; pharmacogenetic tests detecting genotypes, mutations or chromosomal changes to indicate how one will react to a drug or dosage; and DNA testing to detect genetic markers that are associated with information about ancestry or to reveal family relationships such as paternity.

Examples of tests that are not genetic tests are: analyses of proteins or metabolites that do not detect genotypes, mutations or chromosomal changes; medical examinations that test for the presence of a virus that is not composed of human DNA, RNA, chromosomes, proteins or metabolites; tests for infectious or communicable diseases that may be transmitted through food handling; complete blood counts, cholesterol tests and liver-function tests; and tests for the presence of alcohol or illegal drugs. Note that a test to determine whether a person has a genetic predisposition for alcoholism or drug abuse would be considered a genetic test.

Q: Are there exceptions to the prohibition on acquiring genetic information?

A: Yes. The EEOC rules carve out six narrowly interpreted exceptions: (1) **inadvertent disclosures**, such as overheard conversations or information disclosed by the individual or a third party in casual conversation (but following up with probing questions is prohibited); (2) **wellness programs** if employee participation is voluntary and confidential, coupled with written authorization and safeguards to prevent employer access to the genetic information; (3) **family and medical leave laws** (i.e., OFLA and FMLA) allowing employers to require medical information about the employee or family member to substantiate the need for leave; (4) **commercially and publicly available information** including newspapers, magazines, television or the internet (so long as permission from the creator of the information is not required to access it); (5) **workplace monitoring** of biological effects of toxic substances after written notice and, unless the monitoring is required by law, written authorization; and (6) **law enforcement purposes** limited

to use of genetic information for quality control and to detect sample contamination of DNA identification markers.

Q: Are there situations when genetic information may be disclosed?

A: The new rules identify six exceptions to the prohibition on disclosure of genetic information: (1) to the employee upon written request; (2) to an occupational or other health researcher; (3) in response to a court order; (4) to government officials investigating GINA compliance; (5) to comply with state or federal family and medical leave requirements; and (6) to public health agencies only regarding a contagious disease that presents an imminent hazard of death or life-threatening illness.

For additional information on this and other topics of interest to Oregon employers or to order copies of the 2011 Civil Rights Handbook, please visit our website at www.oregon.gov/boli/ta or attend one of our upcoming seminars. You can also reach us at 971-673-0824.