

GENETIC NONDISCRIMINATION

POSITION

The American Nurses Association (ANA) supports the enactment of federal legislation that protects individuals from discriminatory treatment and adverse consequences on the basis of their genetic information by employers and/or insurers.

BACKGROUND

Genomics, the study of the genome and its use of genes, has gained much attention through successes like the Human Genome Project, where experts have mapped the human genome. Even before 2003, when the human genome sequence was completed, hundreds of tests were being developed through genomic research to screen for genetic diseases.

Genomic issues are of interest to patients, providers, insurers, and/or employers alike. First are the patients, who want to take advantage of advancements in genetic screening and treatment, have the treatment covered by their health insurance, and still be able to keep a job if it turns out they have a disease or a predisposition to one. Second, health care providers also have an interest in getting the best care for the patient while preserving the patient-provider relationship. If there are no protections against discrimination, people will be less likely to authorize genetic tests: this could often prevent people from being tested or even participating in genetic research studies needed to understand, treat, and prevent diseases.

Third, the payers (i.e., health insurance companies) are interested in protecting their profits, and therefore want to know if those they are covering have a genetic disease or are pre-disposed to a disease that might require significant expenditure in health care treatments. Finally, there are the employers who are increasingly concerned about how to reduce their burden of the high costs of health care. These gaps in privacy protection and corresponding lack of legal protection makes it easy to see how an asymptomatic person with a genetic disease may be denied health care coverage, even if they never end up getting sick.

A proposed way to prevent discrimination of genetic information in the workplace and in health insurance is to enact federal laws banning such practices and enforce stiff penalties to violators. ANA has supported genetic anti-discrimination legislation ever since its initial introduction in the 104th Congress in 1996. This year, Rep. Louise

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Slaughter (D-NY) is once again championing this issue with the introduction of the Genetic Information Nondiscrimination Act of 2007 (H.R. 493). The bill would:

- Set limits on genetic testing to prevent genetic discrimination by health insurance companies and employers,
- Prohibit mandated testing, and
- Stop insurance companies from setting premiums or deciding on eligibility based on genetic information.

Introduction of a companion bill in the Senate is anticipated. President Bush has also urged Congress and business leaders to work together to pass a bill that would prevent employers from denying people jobs—and insurance companies from denying eligibility—based on genetic profiles.

RATIONALE

As a strong proponent of comprehensive health care reform that would make appropriate health care accessible for all Americans, ANA has consistently supported genetic nondiscrimination legislation. ANA supports legislation that would prevent insurance providers from regressive policies which ultimately defeat the risk sharing purpose of insurance. This position is supported by the Code of Ethics for Nurses, which requires nurses to safeguard the patient's right to privacy by protecting information of a confidential nature and furthermore states that the rights, well being, and safety of the patient should be the determining factor in arriving at any professional judgment concerning the disposition of confidential information. 🙏