

International Society of Nurses in Genetics

**ISONG White Paper: *The Genetic Information Nondiscrimination Act of 2008 and
Discordance with *the Patient Protection and Affordable Care Act of 2010****

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ISONG White Paper: The Genetic Information Nondiscrimination Act of 2008 (GINA)

Background:

In 1990, at the start of the Human Genome Project, many Americans expressed concern that their genetic information could be used to discriminate against them. Americans feared that health insurers would either refuse to insure them or would cancel existing health insurance if insurers discovered they were predisposed to future onset of a genetic disease. They also feared that employers would retain or hire only those individuals who were not predisposed to genetic disease, in order to secure healthy, productive employees. Additionally, they were reluctant to participate in clinical research studies, fearing that their genetic information might be used against them either in the workplace, as well as the health insurance arena (National Human Genome Research Institute [NHGRI], 2015).

Because the degree of genetic discrimination protection among state laws varied, and as a result of these fears, there was need for federal legislation to protect individuals living in the United States (U.S.) from genetic discrimination (NHGRI, 2015). After 13 years of proposed federal legislation, President George W. Bush signed the *Genetic Information Nondiscrimination Act of 2008 (GINA)* into law.

Statement of Problem: GINA's Limitations and Preservation of GINA's Protections

GINA is not a comprehensive federal genetic information nondiscrimination law as it has many limitations. GINA does not protect individuals from discrimination, based on genetic information, when qualifying for life insurance, disability insurance or long-term care insurance. Protections against genetic discrimination addressed in GINA do not apply to participants of the U.S. Military's Tricare program, U.S. veterans obtaining healthcare through the Veteran's Administration, or healthcare obtained through the Indian Health Service (Baruch & Hudson, 2008). To date, these limitations of GINA have not been addressed with amendments that could make GINA a truly comprehensive genetic nondiscrimination law. However, new federal healthcare legislation provisions, specifically a provision in the *Patient Protection and Affordable Care Act of 2010 (PPACA)*, directly conflict with a provision in Title II of GINA that limits employers from using an employee's genetic information in Employer-Sponsored Wellness Programs (ESWPs).

Discordance between GINA's and PPACA's Provisions

Under GINA, health insurers cannot use genetic information for underwriting purposes, nor can they request that individuals undergo genetic testing. Employers cannot discriminate against employees with respect to compensation, terms, conditions or privileges because of genetic information. GINA restricts access by health insurers and employers to genetic information in order to minimize potential for discrimination. Employers may not request, require, or purchase their employees' genetic information. However, an employer may offer health or genetic services as part of a wellness program, where an employee's participation is voluntary.

For the most part, GINA's Title II employer provisions, enacted in November 2009, are untouched by PPACA (Feldman, 2011). However, one PPACA provision enables employers to

tie in their employees' health insurance premium costs to the employee's participation in ESWPs (Bard, 2011). Voluntary wellness program goals, which encourage a healthier lifestyle, would not be affected by an employee's refusal to disclose his or her family health history. Mandatory wellness programs, on the other hand, require the participation of an employee, which may include disclosure of the employee's family health history, in order for the employee to receive an incentive (price reduction in their health insurance premium or a cash incentive) upon attainment of wellness goals. Thus, employees at high-risk for developing a genetic disease have concerns that failure to disclose their genetic information may prevent them from acquiring the same level of health that is expected from all employees and thus it would therefore exclude them from employers' incentives (Bard, 2011).

At present, the identified discordance in the two laws' provisions has not presented any legal issues. However, legislation to address the conflict between GINA's and PPACA's provisions was introduced on March 2, 2017 (H.R. 1313) entitled *Preserving Employee Wellness Programs Act*. According to this proposed legislation regarding the collection of information,

Notwithstanding any other provision of law, the collection of information about the manifested disease or disorder of a family member shall not be considered an unlawful acquisition of genetic information with respect to another family member participating in workplace wellness programs, or programs of health promotion or disease prevention offered by an employer or in conjunction with an employer-sponsored health plan and shall not violate title I or title II of GINA... For purposes the preceding sentence, the term *family member* has the meaning given such term in section 201 of GINA. (Text of the *Preserving Employee Wellness Programs Act of 2017*)

The above section was the same as the previous bill with the same name that was introduced in the 114th Congress in 2015 (H.R. 1189) and never made it to the House floor for a vote. What is alarming in the present proposed bill (which has passed through three House committees and now is No. 341 on the Union calendar in the House as of December 11, 2017).

Additionally, the U.S. Equal Employment Opportunity Commission amended Title II of GINA effective January 1, 2017, stating that an employer may offer a limited incentive (reward or penalty) to an employee and the employee's spouse who receive health or genetic services as part of an ESWP, providing current or past health information. and provides information about his or her current or past health status (EEOC, 2017).

Workgroup or Task Force Recommendations:

The International Society of Nurses in Genetics (ISONG) opposes the provisions within the Preserving Employee Wellness Programs Act (H.R.1313) that would repeal GINA's requirement, that a wellness program's request for an employee's genetic information be voluntary. Repealing this provision in GINA would enable employers to pressure employees into revealing their genetic information. ISONG believes that current wellness programs are able to fully operate without the collection of an employee's genetic information. Additionally, employees should not be subject to financial pressures by their health plans or employers to participate in ESWPs and should not have to disclose their genetic information.

Summary:**Statement of important points and recommendations**

ISONG members in the U.S. need to have knowledge and awareness about GINA and its applications to clinical practice and research. Understanding GINA can assist ISONG members in the U.S. by providing important genetic discrimination information when advocating for patients and extended families in clinical settings, as well as when teaching students and colleagues in collegiate and professional settings. ISONG members and professional healthcare providers should be aware of missing elements in GINA and their impact so they can offer patients and colleagues explanations of the provisions and limitations of GINA. Members of ISONG and other professional healthcare providers need to be aware of GINA's provisions, including its associated shortcomings in order to assist patients and their families to make informed decisions regarding genetic testing. Additionally, ISONG members need to be aware of the conflict between provisions of GINA and PPACA, especially if members are involved in establishing and implementing ESWPs (Bard, 2011).

Definitions:

Family member – a first- (child, sibling, parent), second- (grandchild, uncle or aunt, niece or nephew, grandparent), third- (cousin, great grandparents, great grandchildren), or fourth-degree (second cousin, great-great grandparents, great-great grandchildren) relative (*Genetic Information Nondiscrimination Act [GINA], 2010*).

Genetic information – information about an individual's genetic tests and the genetic tests of an individual's family members, as well as information about the manifestation of a disease or disorder in an individual's family members (i.e. family medical history). Family medical history is included in the definition of genetic information because it is often used to determine whether someone has an increased risk of getting a disease, disorder, or condition in the future. Genetic information also includes an individual's request for, or receipt of, genetic services, or the participation in clinical research that includes genetic services by the individual or a family member of the individual, and the genetic information of a fetus carried by an individual or by a pregnant woman who is a family member of the individual and the genetic information of any embryo legally held by the individual or family member using an assisted reproductive technology (United States Equal Employment Opportunity Commission, n.d.)

Genetic test – an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, if the analysis detects genotypes, mutations, or chromosomal changes. It does not include an analysis of proteins or metabolites directly related to a manifested disease, disorder, or pathological condition (GINA, 2010).

Manifest disease– means that an individual has been or could reasonably be diagnosed with a disease, disorder, or pathological conditions by a health care professional, not based mainly on genetic information (for exam, the results of a diagnostics test). More specifically, a disease is “manifested” when an individual is experiencing signs or symptoms of the condition (GINA, 2010).

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