

**National Association of Health Underwriters Publications**

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# Hey, Wait A Minute

## Discrimination Based on Genetic Information

Advances in the field of genetics have increased so dramatically that we are now able to clone animals. These dramatic advances and the recent announcement of the mapping of the Human Genome have also provided new ways to check for the probability of certain illnesses. The new possibilities for treatment and prevention of illness based on the availability of this new information are truly exciting. But with this new opportunity comes new responsibility. Will the person with the genetic marker for breast cancer actually get breast cancer? Can we know for certain?

In light of these rapid advances in the field of genetic testing, some people have expressed concern about whether their genetic information might be used improperly to prevent them from obtaining health insurance or by employers for hiring or firing purposes. **The Health Insurance Portability and Accountability Act of 1996 (HIPAA)** legislated many new protections for health insurance consumers, and among those protections was a provision stating that group health insurers cannot deny or take into account any individual employee's genetic information in the group health insurance underwriting process, *unless that genetic information has already resulted in a diagnosis*

*of illness.* HIPAA does not address the issue of genetic information in the individual health insurance underwriting process, nor does it address employment discrimination based on genetic information.

### **What is genetic information?**

This is the million-dollar question. Since the enactment of HIPAA we have seen a number of new bills filed relating to prohibition of the use of genetic information in the health insurance underwriting and employment process. HIPAA's definition of genetic information was vague and incomplete, and each bill introduced since then has defined genetic information somewhat differently. Five years later, we are now seeing these genetic discrimination bills define genetic information generally in one of two ways. The first is to define genetic information as "predictive" genetic information, as HIPAA does, meaning that it is genetic information where no existing symptoms or diagnosis exists. These bills further define genetic information as being limited to the results of RNA, DNA,

and related gene testing. The second definition type goes farther than the HIPAA definition and prohibits the use of genetic information even if a diagnosis is present, further extending the definition of genetic information to allow even routine tests like cholesterol screening to be considered a genetic test.

### **Why should you care what definition is used?**

If you are in a state where individual health insurance policies are still medically underwritten, you should care very much which definition is used, even without consideration of the new penalties that could accompany new legislation. The use of health status information in the underwriting process keeps costs down and offsets the impact of adverse selection. In states where individual health insurance policies must be issued without regard to health status, premiums are much higher, coverage choices are limited, and fewer insurance carriers operate in the individual health insurance market.

It may sound attractive to a consumer to have fewer health questions asked during the underwriting process, but in

the individual health insurance market where there is not an adequate mechanism to spread risk, a requirement to issue coverage without regard to health status will increase the cost for everyone. This is also the market most sensitive to those cost increases, because individual health insurance consumers do not have employers subsidizing the cost of their health plans. Many individuals and families are faced at some point in their lives with purchasing coverage in the individual health insurance market, and it is critical that the cost be affordable. If it is not, the ranks of the uninsured will rise, and costs in the small group market will also increase as people attempt to game the system to somehow change their status from an individual market buyer to a “group.”

### **The Legislative Prognosis**

There are several pieces of recently introduced federal legislation that deal with the issue of discrimination in either employment, insurance underwriting, or both, based on genetic information. One of the bills, S318/HR602, sponsored by Senator Tom Daschle and Rep. Louise Slaughter, gives individuals the right to bring unlimited action in federal or state courts for violations by insurance plans or employers.

With this type of penalty, it becomes imperative to look at what definition is used for genetic information. S318/HR602 expands the

HIPAA statute on predictive genetic information, replacing it with the term “protected” genetic information. This essentially protects this information from use even if it is used to confirm a diagnosis or symptoms of illness and is not predictive in nature.

The language is more specific in a competing bill sponsored by Senators Snowe, Jeffords, and Frist (S382), which prohibits the use of genetic information in insurance underwriting in the absence of symptoms, clinical signs, or a diagnosis of the condition related to the genetic information. It also specifically excludes cholesterol tests from the definition of genetic tests.

Both the Daschle/Slaughter bill and the Snowe/Jeffords/Frist bill expand the HIPAA standard to both group and individual policies, and the Daschle/Slaughter bill further expands the bill to apply to non-federal government plans, supplemental policies such as specified disease policies, and Medigap policies.

The Daschle/Slaughter bill (S318/HR602) also prohibits employers, employment agencies, labor organizations, and training programs from discriminating against individuals based on “protected” genetic information. Employers are specifically prohibited from refusing to hire, limiting job opportunities, or segregating or classifying employees on the basis of protected genetic

information. It also prohibits requesting, collecting, or purchasing genetic information, except for workplace safety issues with the agreement of the employee and if certain standards are adhered to. Employers who possess genetic information can’t disclose it except to the employees at their request, occupational or health researchers under certain situations, or under court orders.

If the Daschle/Slaughter bill became law, employees would be able to file suit for alleged employer discrimination through the Equal Employment Opportunity Commission, but could also bring federal or state court action against employers for violations even without completion of EEOC administrative procedures.

The Snowe/Jeffords/Frist bill (S382) does not apply to employment discrimination, although with the recent publicity associated with the Burlington Railroad genetic testing incident, such a bill seems inevitable. Hopefully, such a bill would use the more limited “predictive” definition of genetic information and would rely on existing legal remedies rather than creating a new class of litigation.

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