

**CHAIRMAN FRANK PALLONE, JR.
OPENING STATEMENT**

**HEALTH SUBCOMMITTEE HEARING:
"H.R. 493, THE GENETIC INFORMATION NONDISCRIMINATION ACT OF
2007"**

MARCH 8, 2007

The Subcommittee will come to order. Today we are having a hearing on H.R. 493, the Genetic Information Nondiscrimination Act of 2007", a bill that would prevent the use of an individual's genetic information from being used to discriminate against them in obtaining health insurance coverage and in the workplace. As science continues to make rapid advancements in the area of genetics, I cannot stress how important this bill is to every American citizen.

Genetic testing has increasingly become an integral part of the American health care system, providing the possibility to develop better therapies that are more effective against disease and allow individuals to take steps to reduce the likelihood that they will contract a particular disorder.

However, along with the increasing prevalence of genetic testing comes the growing fear of the potential misuse of this information by way of discrimination in health insurance and employment.

For example, people known to carry a gene that may increase the likelihood of cancer may be denied health insurance coverage since insurers have an incentive to identify and avoid beneficiaries who will cost them more money than the average beneficiary. Furthermore, many genetic conditions and disorders are associated with particular racial and ethnic groups and therefore members of a particular group may be stigmatized or discriminated against as a result of their genetic information.

There have been several documented cases of genetic discrimination carried out by both insurers and employers. A 2001 American Management Association survey of United States companies found that a number of employers were conducting tests that employers acknowledged might include genetic testing as well as requesting employees' family medical histories.

The fear of genetic discrimination alone can have significant societal costs. For example, many Americans may be reluctant to undergo genetic testing because of such a fear, thereby hindering essential genetics research and clinical practices.

Many people may be deterred to participate in biomedical research that studies gene mutations associated with certain diseases because of the fear that their information could be used against them by insurers and employers.

Even more alarming, patients who could benefit from genetic testing have often avoided testing out of concern for possible repercussions, therefore losing the opportunity to receive monitoring and preventive care for conditions in which they are at higher risk.

A 2004 Genetics and Public Policy Center survey showed that 92% of respondents thought employers should not have access to their genetic test results, and 80% opposed letting insurance companies have access to results

Current laws need to be strengthened to protect against the possibility of genetic discrimination. While the Health Insurance Portability and Accountability Act (HIPAA) of 1996 created federal protections against genetic discrimination, these protections are limited.

Under HIPAA, Congress established certain restrictions for group health insurers' use of health related information in terms of coverage and setting premiums. However, these protections do not apply to individual health insurance coverage nor do they prevent insurers from denying an entire group coverage or setting higher premiums based on the results of genetic testing results from one of its members.

Many states have also enacted genetic non-discrimination laws, yet these provisions vary widely in their approach, application and degree of protection. Therefore, federal legislation is necessary to establish a national standard of protection against potential genetic discrimination

As knowledge of the human genome expands, a greater proportion of the population will likely be identified as carriers of mutations associated with a greater risk of certain diseases, indicating that virtually all people are potential victims of genetic discrimination in health insurance.

We need to work in a bipartisan fashion to tackle this issue. This legislation has tremendous support on both sides of the aisle already. It has cleared the Senate twice under unanimous consent in previous Congresses. The president has also indicated his support for the bill. We are closer to the finish line than ever before. There is absolutely no reason why we should not work together to pass this bill and get it to the President's desk.

In closing, I would like to thank the sponsors of this bill, especially Representatives Louise Slaughter and Anna Eshoo for all the work that they have put into this bill over the years. It is an immensely important bill that holds great promise.

Thank you.