

Introductory Remarks of Representative Louise Slaughter (D-NY) on the Genetic Information Nondiscrimination Act - January 22, 2007

Madam Speaker, it is with great pride today that I reintroduce the Genetic Information Nondiscrimination Act. I have championed this bill for nearly 12 years, and I am hopeful that this will be the year that it is finally enacted into law.

We all watched with excitement when the first phase of the Human Genome project was successfully completed in April 2003, as scientists finished sequencing the human genome. As a result of this breakthrough, scientists have now identified genetic markers for a variety of chronic health conditions, thereby increasing the potential for early treatment and prevention of numerous diseases.

Genetic issues are insinuating themselves into not only health care decisions, but into many other facets of Americans' lives. For example, under a program called Dor Yeshorim, Hasidic youth take a battery of genetic tests to determine whether they are carriers for any of 10 serious genetic disorders. Young men and women who are both carriers for a given disorder are discouraged from courting each other, based on the fact that there would be a 25 percent chance that their children would be born with a genetic disorder.

Today, there are over 15,500 recognized genetic disorders, affecting 13 million Americans. Yet, each of us possesses some potentially lethal genes. And despite the scientific advances that are helping people prevent these diseases or diagnose them early, those who partake of this innovative technology become potential victims of genetic discrimination. This legislation works to eliminate that potential.

In the past, some have called this legislation "a solution in search of a problem" and suggest that genetic discrimination is rare, if it even happens at all. Unfortunately this is not the case. Despite the fact that these tests are potentially life-saving, many Americans have not taken advantage of this technology because they fear discrimination by insurance companies and their employers.

And these fears are not unfounded. Throughout the 1970s, many African Americans were denied jobs, educational opportunities, and insurance based on their carrier status for sickle cell anemia, despite the fact that a carrier lacked the two copies of a mutation necessary to get sick. In 1998, Lawrence Livermore Laboratories in Berkeley was found to have been performing tests for syphilis, pregnancy, and sickle cell on employees without their knowledge or consent for years. In 2000, the Burlington Northern Santa Fe Railroad performed genetic tests on employees without their knowledge or consent.

These abuses have only fed the public fear of genetic discrimination. Much to the detriment of America's public health and the future benefits of scientific research, this fear has led many individuals to decide against having genetic tests or participating in genetic research.

A study conducted from 2001 to 2003, surveyed 86,859 adults about their willingness to undergo genetic testing. The results, published in June 2005, revealed that 40 percent of

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participants surveyed felt genetic testing was not a good idea for fear that health insurance companies might deny or drop them from their insurance plan.

The Genetics and Public Policy Center at Johns Hopkins University conducted similar surveys. In 2002, 85 percent of those surveyed did not want employers to have access to their genetic information. By 2004, that number had risen to 92 percent. In 2002, 68 percent of those surveyed said their genetic information should be kept private from health insurers; by 2004, it had increased to 80 percent.

Fears about privacy do not just resonate with the public. Health care professionals are also hesitant to make their genetic information available. In one survey of genetic counselors, 108 out of 159 indicated that they would not submit charges for a genetic test to their insurance companies primarily because of the fear of discrimination. Twenty-five percent responded that they would use an alias to obtain a genetic test so as to reduce the risk of discrimination and maximize confidentiality. And, 60 percent indicated they would not share the information with a colleague, because of the need for privacy and fear of job discrimination.

Clearly, fear of discrimination plays a significant role in a person's decisions about whether to take a genetic test; whether to do it under one's own name; paying out of pocket versus seeking insurance reimbursement; and with whom the information would be shared, including health care providers, coworkers, and family members. The American people desperately want protections against genetic discrimination guaranteed under federal law and the Genetic Information Nondiscrimination Act provides these protections.

This bill has broad support from the health community. The Coalition for Genetic Fairness, which consists of 141 organizations has been outspoken in their support for GINA. Here in the House, along with my colleagues Ms. Biggert, Ms. Eshoo, and Mr. Walden, we are joined by over 135 original cosponsors. The Senate has passed it twice, and even the White House has come out in support of this bill.

GINA provides the protections from genetic discrimination that Americans want and would allow genetic research to move forward in this country so we can all live healthier lives.

I urge its quick passage.