

TESTIMONY BY THE HONORABLE LOUISE M. SLAUGHTER
HEARING ON PROTECTING WORKERS FROM GENTIC DISCRIMINATION
COMMITTEE ON EDUCATION AND LABOR
SUBCOMMITTEE ON HEALTH, EMPLOYMENT, LABOR AND PENSIONS
JANUARY 30, 2007

Mr. Chairman, I want to thank you for having this important hearing today and for inviting me to testify. I hope that our discussion will help lead to the timely and decisive passage of the strong genetic nondiscrimination legislation we have all been waiting for.

The Genetic Information Nondiscrimination Act, or GINA for short, is the culmination of a systematic, bipartisan effort to prohibit improper use of genetic information in workforce and insurance decisions.

GINA prohibits group health plans and health insurers from denying coverage to a healthy individual or charging that person higher premiums based solely on a genetic predisposition to develop a disease in the future. Furthermore, it bars employers from using an individual's genetic information when making hiring, firing, job placement or promotion decisions.

In the 12 years since I first introduced genetic nondiscrimination legislation, the need for it has grown exponentially. Scientific research has advanced so quickly that we cannot afford to wait any longer. What we need is a way to preserve Americans' health and protect our nation's scientific edge, all while defending the privacy of our citizens. I believe that this is what GINA will allow us to achieve.

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. From this first breakthrough, researchers have now identified genetic markers for a variety of chronic health conditions, and increased the potential for early treatment and prevention of numerous diseases.

There are over 15,500 recognized genetic disorders affecting 13 million Americans. No human being has a perfect set of genes. In fact, every one of us is estimated to be genetically predisposed to between 5 and 50 serious disorders. Fifteen percent of all cancers, for example, have an inherited susceptibility, and ten percent of adult chronic diseases (like heart disease and diabetes, America's top killers) have a genetic component.

Today, there are genetic tests for over 1000 diseases, and several hundred more are under development. To cite just one example: genetic tests can now tell a woman with a family history of breast cancer if she has the BRCA-1 mutation that can cause it - and do so long before the cancer develops.

But despite the scientific advances that are helping people prevent these diseases and diagnose them early, those who partake of this innovative technology are currently potential victims of genetic discrimination. And that is why we so desperately need to pass GINA: so that this area

of dynamic research can move forward, and so that we can focus on improving health care in America without worrying that the knowledge we gain will be used to harm those it should be helping.

It is critical to remember that simply carrying a given genetic mutation almost never guarantees that one will fall ill. A genetic flaw simply confers a level of risk upon the carrier.

And given that scientists cannot accurately predict when or whether a carrier will develop a genetic disorder, it seems criminal to allow this information to be used by health insurers or employers for discriminatory purposes. An insurance bureaucrat or human resources professional would be as accurate with a dartboard as with a genetic test result in predicting who will get sick.

Critics say that this legislation is “a solution in search of a problem” and suggest that genetic discrimination is rare, if it even happens at all. Yet there are significant examples of genetic discrimination that we can point to already.

Many already know about the 2002 Burlington Northern Santa Fe Corporation case, where the company agreed to pay \$2.2 million to settle charges that it had tested employees without their knowledge for a genetic marker dubiously associated with carpal tunnel syndrome.

Or the reports in the early 1990s that Lawrence Livermore Laboratories was found to have for years been performing genetic tests on employees without their knowledge or consent.

There is also the fact that in the 1970s, many African Americans were denied jobs and insurance based on their carrier status for sickle cell anemia – again, despite the fact that a carrier lacks the two copies of a mutation necessary to get sick.

You have likely already heard about these examples. But you may not know about the North Carolina woman who was fired after a genetic test had revealed her risk for a lung disorder, even though she had begun the treatments that would keep her healthy.

Or the social worker whom, despite outstanding performance reviews, was fired because of her employer’s fears about her family history of Huntington’s disease.

Or the 1996 study that found a number of institutions, including health and life insurance companies, health care providers, adoption agencies, the military, and schools, that were reported to have engaged in genetic discrimination against asymptomatic individuals.

Such alleged discriminatory practices included an adoption agency refusing to allow a woman at risk for Huntington’s disease to adopt a child, and an employer terminating an employee after they disclosed a risk of Huntington’s disease.

A 2001 American Management Association survey of employer medical testing practices found that 1.3% of companies test new or current employees for sickle cell anemia, 0.4% test for Huntington’s Disease, and 20.1% ask about family medical history. When asked if the results

were used in hiring, reassigning, retaining or dismissing employees, 1% of employers indicated that sickle cell, 0.8% indicated that Huntington's, and 5.5% indicated that family history results were used.

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. Studies have shown that Americans are deciding to forgo genetic testing altogether because they fear discrimination, even if early detection of a particular genetic mutation may help avert premature morbidity and mortality.

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

A 2003 study of 470 people with a family history of colorectal cancer showed that nearly half rated their level of concern about genetic discrimination as "high." Those individuals with high levels of concern indicated that they would be significantly less likely to consider meeting with a health care professional to discuss genetic testing, or to undergo testing, thus jeopardizing their ability to prevent this deadly disease.

In a recent 2006 Cogent Research poll, 66% of respondents said they had concerns about how their genetic information would be stored and who would have access. 65% said they were concerned about health insurance companies, and 54% were concerned with employers gaining unauthorized access. 72% agreed that the government should establish laws and regulations to protect the privacy of individuals' genetic information. And 85% said that without amending the law, employers would discriminate.

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.

Mr. Chairman, Congressional action on genetic discrimination is necessary and long overdue. Genetic discrimination is unjustifiable in its own right. But what is more, if individuals do not participate in genetic studies, then we will never be able to realize the potential of this technology.

In a 2003 editorial, Dr. Francis Collins and James Watson made a persuasive argument for the need for legislative action. They said, and I quote: “Genetic discrimination has the potential to affect people’s lives in terms of jobs and insurance, but there is another dimension as well: It can slow the pace of the scientific discovery that will yield crucial medical advances. ... Without protections in place, individuals who do agree to participate [in studies] will represent a self-selected group that could skew research results, producing a negative impact on all of us who look to genetics to help find better ways of diagnosing, treating, and preventing disease.” End quote.

As a scientist myself, I cannot overstate the importance of having a truly representative sample size for research and in clinical trials to ascertain valid results.

GINA will do more than stamp out a new form of discrimination, as important as that is. It will also help us to resurrect our country’s proud history of innovative, advanced scientific and medical research, and to be a leader in this burgeoning field of genetic science.

Let me close by reiterating the broad support that this bill enjoys.

It has substantial support from the health and science community. The Coalition for Genetic Fairness, which consists of over 140 organizations, has been outspoken in their support for GINA. I have here in my hand over 200 letters of support for GINA from a wide spectrum of health-related organizations.

GINA has support from the American people, as is clear from the poll results I mentioned a few moments ago.

And GINA has support from a broad array of politicians. Here in the House of Representatives, the current legislation authored by Ms. Biggert, Ms. Eshoo, Mr. Walden, and I has over 175 cosponsors, both Democrats and Republicans. The Senate has passed this bill twice with unanimous support, and even the White House has come out in support of genetic nondiscrimination legislation.

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

Mr. Chairman, once again, let me thank you for holding this hearing today to shed light on this important issue. I look forward to working with you and all the Members of this Subcommittee, as well as any other interested parties, to enact H.R. 493, so that the future of genetic science will be something to embrace, instead of something to fear.