

Introductory Remarks of Senator Olympia Snowe (R-ME) on the Genetic Information Nondiscrimination Act - January 22, 2007

Mr. President, I rise today to introduce the Genetic Information Nondiscrimination Act of 2007 and I am joined in doing so by a number of my colleagues including the Chairman and Ranking Member of the Senate HELP Committee, Senators Kennedy and Enzi. The bill we are introducing today represents a triumph of bipartisan collaboration--true consensus-building which is so vital to achieving substantive action for our constituents. Such efforts are certainly not always easy--as so many here today know--I have worked with many of you for more than 10 years on this issue.

Today we are on the threshold of a new era, as for the first time, we act to prevent discrimination before it has taken firm hold. Indeed, Senator Gregg described this legislation so well when he said it is, truly, "the first civil rights act of the 21st Century."

And that is what makes this legislation so unique. For in the past Congress has had to act to address existing discrimination. But today we are acting proactively to address genetic bias, before discrimination becomes entrenched.

This type of discrimination is so different than other forms. Because most discrimination is a response to an obvious trait, such as one's gender or the color of your skin. But discrimination based on one's genetic makeup involves actively looking for information on which to discriminate. Because it is so deliberate, one cannot even argue it was--on any level--subconscious or unintentional.

It used to be difficult to find such information on which to discriminate. You might be asked if you had a family history of a disorder. But today things have changed dramatically.

We have long known about a small number of genes, which play a role in some diseases--such as Huntington's Disease, and early onset Alzheimer's. Yet the progress of discovery and study was so slow and tedious. But the Human Genome Project changed all that. Today, with new technology we are seeing an explosive increase in our understanding of genetics and human health.

That growing genetic knowledge offers the potential of disease cures and even customized therapies. Even more promising, genetic advances will enable us to actually prevent the development of disease. But this potential and the billions spent in discovering genetic relationships and developing treatments and preventive agents will certainly be in vain if Americans do not avail themselves of these advances.

To do so, Americans will need to take genetic tests. But would you do so if you knew that the information about your genetic makeup would be used against you--to deny you employment or health coverage?

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Some say that kind of discrimination is but a future possibility--that we can afford to wait until genetic discrimination begins to take a toll. But it already has done so. I learned from the real life experience of one of my constituents, Bonnie Lee Tucker. In 1997, Bonnie Lee wrote me about her fear of having the BRCA test for breast cancer, even though she has nine women in her immediate family who were diagnosed with breast cancer, and she herself is a survivor. She wrote to me about her fear of having the BRCA test, because she worried it will ruin her daughter's ability to obtain insurance in the future. And Bonnie Lee isn't the only one who has this fear. When the National Institutes of Health offered women genetic testing, nearly 32 percent of those who were offered a test for breast cancer risk declined to take it citing concerns about health insurance discrimination. Mr. President, what good is scientific progress if it cannot be applied to those who would most benefit?

And we have seen cases where some attempted to mandate genetic testing. Even when this is done to improve the delivery of health care, it must be recognized that once that information is disclosed and is unprotected a future employer or insurer may not necessarily use that information in such a benign way. Yet we recognize that if an individual can avail themselves of a genetic test, they may be able to take action as a result which prevents disease or premature death, and reduces the burden of high health costs. And wouldn't everyone want to see that?

I recall the testimony before Congress of Dr. Francis Collins, the Director of the National Human Genome Research Institute, without whom we wouldn't have reached this day. In speaking of the next step for those involved in the Genome project, he explained that the project's scientists were engaged in a major endeavor to “uncover the connections between particular genes and particular diseases,” to apply the knowledge they just unlocked. In order to do this, Dr. Collins said, “we need a vigorous research enterprise with the involvement of large numbers of individuals, so that we can draw more precise connections between a particular spelling of a gene and a particular outcome.” Well, this effort cannot be successful if people are afraid of possible repercussions of their participation in genetic testing.

The bottom line is that, given the advances in science, there are two separate issues at hand. The first is to restrict discrimination by health insurers. The second is to prevent employment discrimination based simply upon an individual's genetic information.

Some of us saw this danger 10 years ago and the threat it could pose to millions of Americans. I think back to when Representative Louise Slaughter and I first introduced our bills to ban genetic discrimination in health insurance back in the 104th Congress. At that time the completion of the human genome seemed far away. But the science has certainly out-paced Congressional action.

The following year, with the commitment of Senators Frist and Jeffords to address this issue, I introduced a bill to ensure we would effectively provide the needed protections to

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prevent genetic discrimination in the health insurance industry. In turn, that bill was the basis for an amendment offered by Senator Jeffords, to the Fiscal Year 2001 Departments of Labor, Health and Human Services Appropriations bill which passed the Senate by a vote of 58-40.

While that victory was a notable step forward, unfortunately, it was not followed by the enactment of our bill. It did, however, re-spark the debate--which helped lay the foundation for our subsequent efforts.

Indeed, in March of 2002, I was again joined by Senators Frist and Jeffords in introducing an updated version of our bill with the added support of Senator Gregg and Senator Enzi. That bill not only addressed what had become the real threat of employment discrimination but also captured the changing world of science as this was the first bill to include what we had learned with the completion of the Genome Project.

In June of 2003, after sixteen months of bipartisan negotiation, we achieved a unified, bipartisan agreement to address genetic discrimination. Today we again introduce the legislation encompassing that agreement, which the Senate has twice passed unanimously.

The bill we are introducing again today addresses genetic discrimination in both employment and health insurance based on the firm foundation of current law. With regard to health insurance, the issues are clear and familiar, and something the Senate has debated before, in the context of the consideration of larger privacy issues. Indeed, as Congress considered what is now the Health Insurance Portability and Accountability Act of 1996, we also addressed the issues of privacy of medical information.

Moreover, any legislation that seeks to fully address these issues must consider the interaction of the new protections with the privacy rule which was mandated by HIPAA--and our legislation does just that. Specifically, we clarify the protections of genetic information as well as information on the request or receipt of genetic tests, from being used by the insurer against the patient.

Because the fact of the matter is, genetic information only detects the potential for a genetically linked disease or disorder--and potential does not equal a diagnosis of disease. At the same time, it is critical that this information be available to doctors and other health care professionals when necessary to diagnose, or treat, an illness. This is a distinction that begs our acknowledgment, as we discuss protect patients from potential discriminatory practices by insurers.

On the subject of employment discrimination, unlike our legislative history on debating health privacy matters, the issues surrounding protecting genetic information from workplace discrimination is not as extensive. To that end, our bipartisan bill creates these protections in the workplace--and there should be no question of this need.

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As demonstrated by the Burlington Northern case, the threat of employment discrimination is very real, and therefore it is essential that we take this information off the table, so to speak, before the use of this information becomes more widespread. While Congress has not yet debated this specific type of employment discrimination, we have a great deal of employment case law and legislative history on which to build.

Indeed, as we considered the need for this type of protection, we agreed that we must extend current law discrimination protections to genetic information. We reviewed current employment discrimination law and considered what sort of remedies people would have for instances of genetic discrimination and if these remedies would be different from those available to people under current law--for instance under the ADA or the EEOC. The bill we introduce today creates new protections by paralleling current law and clarifies the remedies available to victims of discrimination. Ensuring that regardless of whether a person is discriminated against because of their religion, their race or their DNA, these people will all receive the same strong protections under the law.

Indeed, I believe those who have questioned the need for this legislation will see that if we can provide these protections, then individuals can avail themselves of medical knowledge which will not only improve their health, but will reduce health care costs. For employers attempting to address the escalating cost of coverage, isn't it essential to utilize our investment in advancing medical knowledge to prevent disease and disability? Isn't that just the sort of action we need to encourage to reduce health costs and make our businesses, large and small, more competitive?

Indeed we have seen the business community recognizing the critical importance of putting our medical investment to work to reduce health costs not discouraging employees from undergoing tests that could prevent disease or death. To that end, I noted during the last Congress that IBM pledged to not use genetic information in its hiring practices or in deciding eligibility for health insurance coverage. This demonstrates an admirable understanding of how such discrimination can harm both individuals and business.

It has been more than six years since the completion of the working draft of the Human Genome. Like a book which is never opened, the wonders of the Human Genome are useless unless people are willing to take advantage of it. This bill is the product of over a year of bipartisan negotiations and is a shining example of what we can accomplish if we set aside partisan differences in order to address the challenges facing the American people. Certainly this bill was only possible due to the commitment of members working together--setting aside partisanship--and for that I am grateful.

I know I speak for my colleagues when I say that it is my hope that we shall see this bill again receive the unanimous support of the Senate and that this will allow the House of Representatives to act swiftly to pass this legislation so that the President can sign this bill into law and finally ensure the American public is protected from this newest form of discrimination.