

STATEMENT OF SENATOR EDWARD M. KENNEDY
HEARING ON PROTECTING AGAINST GENETIC DISCRIMINATION:
THE LIMITS OF EXISTING LAWS
February 13, 2002

It is a privilege to be a sponsor of legislation to prevent discrimination on the basis of genetic information. S. 318 prohibits health insurers from using protected genetic information to deny health coverage or to raise premiums for it. It bars employers from using genetic information to make employment decisions. It prohibits insurers and employers from seeking genetic information, or requesting or requiring individuals to take genetic tests. It also bars disclosure of any genetic information by an insurer or employer. It provides strong remedies so that people who have suffered genetic discrimination can seek redress in court.

It is difficult to imagine more personal or more private information than a person's genetic makeup. This information should not be shared by insurers or employers. It should not be used in making decisions about health coverage or retaining a job. It should only be used by individuals, in consultation with their doctors, to make the best diagnostic and treatment decisions they can.

Protecting against discrimination on the basis of genetic information is of special importance since existing laws such as the Health Insurance Portability and Accountability Act and the Americans with Disabilities Act do not go far enough in providing this basic protection. We need strong legislation that protects individuals against this unacceptable form of discrimination.

The Americans with Disabilities Act has been interpreted to provide some protection against genetic discrimination in employment. The ADA, however, offers little protection for individuals with genetic markers that have not developed into a "disability" under the law. In light of the Supreme Court's recent decisions restricting the number of people who qualify for protection under the ADA, it is unclear whether a person with such genetic predisposition will be protected. S. 318 should be passed now to see that these individuals have the full protection they deserve.

Genetic discrimination in the employment context is a serious problem. Last summer, David Escher testified before the committee that his employer, the Burlington Northern Santa Fe Railroad, required any employee who suffered from carpal tunnel syndrome to undergo genetic testing. Employees who refused to be tested were threatened with discipline or even the loss of their jobs.

Employers should not use genetic information in hiring, firing or setting the conditions of employment. Individuals need to be protected against this abuse. We must also ensure that remedies are significant and readily available to those whose rights have been violated. Effective remedies are needed to see that employers and insurers will implement the necessary protections.

Americans should be denied health insurance or lose their job because of the results of a

genetic test or their family medical history. Discrimination on the basis of a person's genetic traits is as unacceptable as discrimination on the basis of gender, national origin, race, religion or age.

Clearly, Congress needs to act to stop these intrusions into a person's personal genetic information. S. 318 will make sure that health plans can't require genetic testing and can't use genetic information to restrict enrollment or adjust premiums. This legislation is critical to guaranteeing that genetic information is used to improve medical care, not to discriminate against any individual.

President Bush recognizes the seriousness of this problem, and supports the enactment of legislation to ban genetic discrimination. In a speech two days ago, he stated, "genetic information should be an opportunity to prevent and treat disease, not an excuse for discrimination. Just as our nation addressed discrimination based on race, we must now prevent discrimination based on genetic information." I look forward to working with President Bush to move forward quickly on this important legislation. The time to pass S. 318 is now.