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Senate Votes to Shield Genetic Testing Data - Aim Is to Avert Job, Insurance Discrimination

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WASHINGTON – The promise of an era of personalized medicine based on genetic testing long has been haunted by a disturbing possibility: The same data that could alert people to serious medical problems might be used to deny them jobs or insurance coverage.

But yesterday, the Senate voted 95-0 to outlaw such discrimination, with the House expected to add its approval quickly.

The bill, which President Bush has agreed to sign, does more than protect those who undergo genetic testing: It marks a significant milestone in the effort to develop a 21st-century architecture of laws to govern the changes sweeping science and medicine.

"It's the first civil-rights bill of the new century of life sciences," Sen. Edward M. Kennedy (D-Mass.) said. "We made sure today that our laws reflect the (scientific) advances we are making."

Reaching a consensus on genetic testing protections was all the more notable because, while scientific changes are occurring at a rapid pace, agreement on how to deal with the consequences is lagging. The current bill, the Genetic Information Nondiscrimination Act, was more than a decade in the making.

"Now, genetics will be protected just like race, religion and gender," said Sharon Terry, president of the Genetic Alliance, an advocacy group representing people with illnesses that have a hereditary component.

"We are on the threshold of a new era, because for the first time, we act to prevent discrimination before it takes hold," said Sen. Olympia Snowe (R-Maine), one of the original advocates of the bill in Congress.

Until recently, genetic tests were used mainly for rare conditions that could have catastrophic health consequences. But there are more than 1,200 diseases for which predictive clinical tests are available - including breast cancer, Alzheimer's and a particularly aggressive type of colon cancer. More tests are in development for conditions such as diabetes.

"We're not talking about rare genetic disorders any more; we are talking about very common traits," said geneticist Joann Boughman, executive vice president of the American Society of Human Genetics. "We are to the point where we can begin testing people, so they can make much better plans to avoid getting sick in the first place."

Genes are short sections of DNA in the nucleus of cells in living organisms. They act as an instruction manual for the body, governing physical features such as eye color, but also chemical reactions and biological makeup. Certain genes can predispose people to illnesses. Knowing an individual's specific genetic risk can help patients and doctors prevent, diagnose and treat disease.

But nearly one-third of women offered genetic testing for breast cancer risk by the National Institutes of Health turned it down, citing insurance concerns.