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## Senate passes bill banning genetic discrimination

The legislation, which the House is expected to approve quickly and President Bush has promised to sign, would prevent information gleaned from genetic testing to be used against people.

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WASHINGTON — The vast 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 Thursday, the Senate voted 95 to 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 revolutionary 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.

Meanwhile, a stalemate continues on the far larger question of embryonic stem cell research -- which may offer cures for diseases including Parkinson's and diabetes but also raises ethical and religious objections.

Controversy also continues to swirl around such issues as human consumption of genetically engineered food, irradiated hamburger and meat from the offspring of cloned animals.

In the case of genetic testing, despite the potential advantages of early identification of vulnerability to disease, the lack of information safeguards had made many patients leery of being tested.

"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 J. Snowe (R-Maine), one of the original advocates of the bill in Congress.

"We are taking a stand that, as we look to the future, genetic discrimination will not be allowed to flourish, to take root."

Until recently, genetic tests were used mainly for rare conditions that could have catastrophic health consequences. But there are currently 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 anymore; 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 such physical features 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.

Currently, it is standard practice for physicians and genetic counselors to advise patients that testing can lead to problems with insurance and other such consequences. Some patients pay out of pocket to keep the information from insurers.

"Since no one is born with perfect genes, each one of us is a potential victim of genetic discrimination," said Rep. Louise M. Slaughter (D-N.Y.), who first introduced a genetic discrimination bill in 1995.

The current legislation would bar health insurers from asking for or using genetic information to make a decision about coverage or to set premiums.

Although people with group health insurance already are protected to some degree under existing federal laws, those who are self-employed and buy their own coverage previously had no guarantees that their genetic information would not be used against them.

Under the bill, insurers also would be prohibited from raising premiums for a group because one or more members have genes that would predispose them to an illness.

That particular protection is seen as important for small businesses that offer health coverage, because a sudden increase in rates can lead them to cancel coverage altogether.

Employers, unions and employment agencies would be forbidden to request or use genetic information for hiring, promotions, assignments or firing.

The bill's protections do not extend to other forms of insurance coverage, such as life insurance and long-term care.

Advocates say the government should also address major shortcomings in the regulation of labs and the tests themselves, to ensure accurate results.

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