

Extra Feature Story

Congress Passes Anti-Genetic Discrimination Bill

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A new law would outlaw discrimination based on a person's genetic information, making it more attractive for people to get tested for genetic mutations that could make them susceptible to certain diseases.

The Genetic Information Nondiscrimination Act passed Congress last week and President Bush is expected to sign it into law.

"Since each of us has dozens of genetic variations that may put us at risk for disease, we all would have had a reason to be concerned about the possible misuse of genetic information," the director of the National Human Genome Research Institute, Francis Collins, said in a statement.

"With this act, Americans won't have to worry about their jobs or their health insurance being taken away because of the genes they inherited."

Advances in science

The new law, which is similar to federal law that makes race and gender discrimination illegal, encourages Americans to undergo genetic testing by alleviating the fear that the results could be used against them during hiring or insurance applications.

Genes are inherited DNA blueprints with instructions for building an organism. Scientists identified all of the tens of thousands of human genes through the government-funded Human Genome Project in 2003. The project was led by the Department of Energy and took 13 years to complete.

Now that scientists have mapped the human genome, they are working to identify specific genes linked to all sorts of medical problems, and develop new therapies and treatments.

"We are in the midst of a deluge of discovery, and a very exciting one, about genetic risk factors for diabetes, for heart disease, for cancer, for asthma, for high blood pressure, all of these conditions that have been pretty mysterious. And that's going to put us in a position, if we're interested, in finding out our own situation to plan prevention better," Collins said on the NewsHour.

Rep. Louise Slaughter, D-N.Y., who co-sponsored the bill, said that people should get genetic testing done "right away" after the bill becomes law, the AP reported.

Controversial applications

Without this new law, people were discouraged from learning about their genetic code because finding a gene linked to a disease might dissuade an employer from hiring them or a health insurer from providing health insurance.

In fact, there are examples from the 1970s of black men denied jobs or health coverage because they had a family history of sickle-cell anemia, according to Scientific American Magazine.

Genetic testing can be more specific than family history about the chances of inheriting a wide range of diseases, making the opportunities for such discrimination much greater.

According to the National Human Genome Research Institute's Web site, each person probably has six or more genetic mutations that increase the risk of developing a disease.

Armed with information about their specific genetic makeup, people may be able to prepare for, prevent or treat diseases. However, such knowledge does not come without a host of tough questions.

Sharon Terry, president of the Genetic Alliance, a group for people with genetic conditions which supported the bill, told the New York Times that Americans will have to deal with complicated genetic discrimination issues as they have had to with race and gender issues.

"Do we as a society start to make decisions like, 'I don't want kids who are going to get arthritis or who aren't going to be great basketball players?' This is only the beginning," she told the Times.

-- Compiled by Quinn Bowman for NewsHour Extra

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