

Privacy advocates warn of genetic discrimination by employers

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WASHINGTON — As scientists make daily advances with the human genetic code, Congress should act now to prevent Americans from facing genetic discrimination from employers and insurers, privacy advocates say.

Genetic research could make it possible to identify an individual's lifetime risk of cancer, heart attack and other diseases.

But that same information also could be used by employers for hiring, firing or promotions, or by insurance companies to determine how much to charge for their services or to deny coverage completely, privacy advocates said.

But health and insurance advocates say there is no proof that anyone would do this, and lawmakers would be moving far ahead of reality by banning the use of genetic information.

"There is a difference between the perception of how medical information is used and reality," said Dr. John Rowe, chairman and CEO of Aetna Inc., which sells health insurance.

"The record does not appear to include any identifiable cases in which people have been discriminated against in health insurance because of genetic information."

Rep. Steve Chabot, R-Ohio, chairman of the House Judiciary subcommittee on the Constitution, acknowledged that discrimination based on genetic information is "highly speculative.

"But "if an employer could access information about an individual's susceptibility to disease, that employer might misuse the data to avoid expenses associated with absenteeism, health benefits and risky occupational exposures," he said.

Thirty-one states already have laws against genetic discrimination in the workplace, and 41 states have laws against insurers using genetic information to discriminate, Chabot said.

There's no telling what would happen if patients lose control of their genetic information, said Dr. Deborah Peel of Austin, Texas, representing the American Psychoanalytic Association.

Using a woman going through a divorce as an example, "should the risk of her having breast cancer or a mental disorder in the future keep her from having custody of her children?" Peel said. After the divorce, "should genetic testing of the children be used to assess their potential health problems and alter the amount of financial support their mother receives?"

And later, when she needs somewhere to live, "should a mortgage company be allowed to access the results of her genetic testing to assess her life expectancy before deciding to offer a loan?" she asked.

The answer is a federal law that would require people's permission before genetic information is released, said Joanne Husted, lawyer for the Health Privacy Project and professor at Georgetown University's Institute for Health Care Research and Policy.

Politicians should be especially concerned about how available genetic information is to businesses and the public, because that information could easily be used against them in public elections, Peel said. p