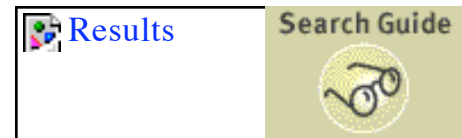



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**THE WALL STREET JOURNAL.**

## Health & Medicine (A Special Report): Living With Change --- A Change in **Policy: Genetic testing** threatens to fundamentally alter the whole notion of **insurance**

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**Abstract:**

Already, people are undergoing **genetic testing** for susceptibility to breast, colon and ovarian cancer. And researchers are pushing ahead in their endeavors to discover **genetic** mutations that may predispose people to heart disease, other types of cancer, diabetes and other illnesses.

The concept of a pre-existing condition, which many insurers use to weed out bad health risks, could come to encompass potential illnesses as well as actual ones. People with unlucky **genetic** legacies could be deemed uninsurable, or at least subject to sky-high premiums. Meanwhile, people with "clean" **genetic** profiles could find themselves courted by insurers.

**Genetic testing**, if it becomes cheap and widely done, could offer insurers a powerful new tool to know ahead of time which people are the greatest health risks for which particular illnesses -- and, consumer advocates fear, to weed them out of coverage accordingly. At the same time, insurers probably would aggressively court people with clean **genetic** profiles by offering them cheaper **policies**, just as insurers now in the individual market try to attract younger, healthier people with cheaper rates, Mr. (J. Robert) Hunter says.

**Full Text:**

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Over the next 10 years, advances in genetic testing will have a profound impact on medical care. But they also may have an equally huge effect in another area: insurance.

Already, people are undergoing genetic testing for susceptibility to breast, colon and ovarian cancer. And researchers are pushing ahead in their endeavors to discover genetic mutations that may predispose people to heart disease, other types of cancer, diabetes and other illnesses.

But a future of routine genetic testing may also be a future in which the very nature of insurance is fundamentally altered.

The concept of a pre-existing condition, which many insurers use to weed out bad health risks, could come to encompass potential illnesses as well as actual ones. People with unlucky genetic legacies could be deemed uninsurable, or at least subject to sky-high premiums. Meanwhile, people with "clean" genetic profiles could find themselves courted by insurers.

The result: People who need coverage the most might not get it -- or they could eschew genetic tests altogether, for fear of how the results could be used against them.

"A trend which is very positive from a scientific point of view has some very frightening ramifications from an insurance point of view," says J. Robert Hunter, director of insurance for the Consumer Federation of America, a consumer advocacy group in Washington.

Insurers dispute the bleak scenarios, but some experts believe that genetic testing will become such a fixture -- and deprive so many people of coverage -- that it may eventually bring about a huge backlash. In fact, some say, it may even lead to the creation of a system that has been resisted in this country for years: national health coverage.

The grim scenarios are plausible, consumer advocates say, because of how insurance works. The whole concept of insurance is based upon spreading risk. In the case of health insurance, for example, those risks are the potential medical costs for the broad range of illnesses that can befall both healthy and less healthy people. In the individual insurance market, insurers try to minimize risk and make profits by covering as many good risks -- younger, healthy people -- as possible to balance out the bad risks.

They try to improve their chances by separating or weeding out less-healthy people with pre-existing conditions, such as heart disease or cancer, by raising premiums, imposing waiting periods before coverage begins, excluding them from coverage for their particular illness -- or denying them coverage altogether. In the group market, insurers spread risk by charging higher rates to companies with older, sicker work forces, raising premiums for everyone in that work force.

Genetic testing, if it becomes cheap and widely done, could offer insurers a powerful new tool to know ahead of time which people are the greatest health risks for which particular illnesses -- and, consumer advocates fear, to weed them out of coverage accordingly. At the same time, insurers probably would aggressively court people with clean genetic profiles by offering them cheaper policies, just as insurers now in the individual market try to attract younger, healthier people with cheaper rates, Mr. Hunter says.

"The ideal dream of any insurer is to find people who won't file claims, and they'll be more able to do that with this sort of information," Mr. Hunter says. For people who have done well in the genetic lottery, those policies would be very attractive because of their low prices.

The other upshot of such genetic risk-classification would be some very strange-looking policies. For example, an insurer might offer a bare-bones policy at the lowest rate that covered only routine procedures such as checkups and emergency hospitalization. The policy would come with riders that people could buy separately to get coverage for each disease, such as heart disease, colon cancer, diabetes and Alzheimer's disease. Those genetically predisposed to a particular disease might be charged a much higher rate to get that additional coverage than someone at average risk -- or they might be denied that coverage altogether if the insurer deemed them too great a risk.

Another possibility is that insurers might offer several different types of policies, ranging from minimal to a deluxe policy covering most illnesses. But, as has sometimes happened with homeowners' insurance, insurers might engage in a sort of medical redlining, denying Cadillac policies to inhabitants of bad genetic "neighborhoods," Mr. Hunter says. For example, "there would be a 'breast cancer ghetto' in the minds of the insurance companies," Mr. Hunter says.

The "ghettoes" would depend on the type of insurer, experts say. Many insurance specialists and consumer advocates believe insurers that issue life, disability and long-term-care policies have a greater stake in genetic-testing information that could tip them to a person's likely health status some 20 years down the road than health insurers that won't have to bankroll many of the long-term health conditions genetic tests signal.

For example, a medical director might have little concern about insuring a 35-year-old person with a hereditary predisposition to Alzheimer's disease, says William Osheroff, medical director for Empire Blue Cross & Blue Shield in New York.

But if he were in a state that let him deny coverage based on a patient's medical history (New York doesn't) "and I had a 40-year-old lady with a series of breast biopsies, a strong family history and an abnormal [breast-cancer genetic] test, I probably would exclude her," Dr. Osheroff says.

Of course, for many consumers, such a fragmented system would defeat the very purpose of insurance: to offer comprehensive protection against financial catastrophe should their health take a turn for the worse. And that might lead to a backlash, consumer advocates say. As more people from all economic backgrounds would find themselves pushed to the margins of the private insurance system because of bad genes, society might well find itself forced to adopt some sort of national health-insurance system to provide coverage for them.

"People who are going to be born with the wrong chromosomes aren't going to be limited to the poor," Mr. Hunter says. "There will be a lot of people with political clout who will say, 'Wait a minute, I need insurance,' and you are going to find more and more pressure to fund some sort of universal plan."

Despite such scenarios, insurers themselves maintain -- and consumer advocates acknowledge -- that so far there is little indication that insurers are using the results of genetic testing at all, much less to discriminate against certain types of people.

"There isn't any evidence that this stuff is going on," says Dean Rosen, a senior vice president for the Health Insurance Association of America, an industry group in Washington. Arthur Leibowitz, chief medical officer for Aetna Inc.'s Aetna U.S. Healthcare unit, says the HMO pays for breast-cancer genetic testing in cases where it is appropriate but typically doesn't get a copy of the results. "No insurance company in America today uses genetic-screening information to provide underwriting or change premium structure," he says.

Dr. Leibowitz says that federal rules already prevent some HMOs from excluding people because of pre-existing health conditions. But many people belong to other HMOs or other types of health plans that don't fall under those rules.

Dr. Osheroff says he believes that down the road, insurers will use the results of genetic testing to assess the health status of different employer groups to set premiums. If the information is out there, it will simply be too valuable to ignore, consumer advocates agree.

Moreover, in states that allow it, health insurers are likely to use genetic-testing results to decide on individual coverage, he says. (Dr. Osheroff says Empire is forbidden by New York law to use people's medical conditions in individual-coverage decisions and currently doesn't ask for genetic-testing results in issuing group policies.)

Right now, insurers face few legal barriers to entering the brave new world of genetic testing. A 1996 federal law on health-insurance portability for job-switchers provides some minimal protection by preventing group health plans from considering the results of a genetic test alone to be a pre-existing condition that could delay eligibility for coverage.

Several proposals in Congress would go much further in limiting insurers' ability to require or ask for genetic

testing, and such a provision is part of the Republican patient bill of rights recently passed by the Senate. More than 30 states have passed some type of law limiting health insurers' use of genetic testing. But these laws vary widely in the protection they provide and don't apply to self-insured health plans, which cover about a third of people with private, workplace health insurance.

Health insurers oppose such legislation because they fear it is overly broad and would interfere with some of the questions they currently ask when issuing individual policies, such as inquiring about a person's family medical history or the results of a cholesterol test, says Mr. Rosen, of the health-insurance association. Even more than health insurers, life insurers have fiercely lobbied against proposals that would limit their access to genetic information and have successfully defeated such efforts in many states.

Roberta Meyer, senior counsel for the American Council of Life Insurance, a trade association in Washington, says life insurers are concerned that legislation would prevent them from continuing their traditional "risk classification" method of charging higher premiums to the highest-risk people as determined by their family medical history, cholesterol and blood tests and sometimes a physical. She says such underwriting is key to keeping insurance widely available and affordable for most people.

Ms. Meyer also says that while life insurers currently don't require genetic-testing information, they want the option to do so in the future if such testing becomes commonplace. If legislation is enacted, "our concern would be that companies would be prohibited from ordering those tests forever. We would hope not to be," she says.

In the midst of all the wrangling, there's another possible scenario: People simply will reject genetic testing out of fear about how insurers will use the information, denying themselves and their children the potentially huge health benefits of continuing efforts to map the human genome. Genetic counselors say concerns about insurance discrimination already are having a chilling effect, dissuading some people from getting tested if their family history makes it advisable.

Many people already are worried about how insurers may use genetic information. Barbara Bernhardt, a genetic counselor at Johns Hopkins Hospital in Baltimore, says some women are declining to get the breast-cancer genetic test because they are worried that their insurers will get hold of the results. Other women who could get covered for the tests are choosing to pay out of pocket, footing bills that can range from \$350 to \$2,400. "Women are increasingly concerned," Ms. Bernhardt says.

When one 50-year-old small-business owner recently decided to undergo genetic testing that would tell her whether she was at increased risk for breast cancer, she delivered a clear message to the testing center. She wanted even the fact that she had undergone a genetic test, much less any results, kept out of her medical records.

"I didn't want there to be any way my insurance company could check," says the woman, who has a family history of breast cancer on her mother's side. She asked that her name not be used for this article out of concern that her health insurer would learn she had taken the test.

The woman, whose mother was diagnosed with breast cancer at 30 and died at 51, tested positive for one of the genetic mutations that put her at increased risk of breast cancer, although so far she has not shown any signs of the disease, she says. Those results prompted her to start taking the cancer-preventive drug tamoxifen.

But while taking the test has had a salutary effect, the woman, who pays \$400 a month for health-insurance coverage for herself and her husband, says she has no doubt that the test could hurt her future prospects for insurance coverage if her insurer ever found out her results.

"I'm sure they wouldn't cover any kind of breast disease if they found out I had a mutation," she says. "I'd get an exclusion on my next insurance." If ever asked by an insurer whether she has had genetic testing for the disease, she says, she simply would deny that she had ever had it done.

"It's a shame that you would have to do this," she says.

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