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THE DNA AGE

Fear of Insurance Trouble Leads Many to Shun or Hide DNA Tests

By AMY HARMON

Victoria Grove wanted to find out if she was destined to develop the form of emphysema that ran in her family, but she did not want to ask her doctor for the DNA test that would tell her.

She worried that she might not be able to get health insurance, or even a job, if a genetic predisposition showed up in her medical records, especially since treatment for the condition, alpha-1 antitrypsin deficiency, could cost over $100,000 a year. Instead, Ms. Grove sought out a service that sent a test kit to her home and returned the results directly to her.

Nor did she tell her doctor when the test revealed that she was virtually certain to get it. Knowing that she could sustain permanent lung damage without immediate treatment for her bouts of pneumonia, she made sure to visit her clinic at the first sign of infection.

But then came the day when the nurse who listened to her lungs decided she just had a cold. Ms. Grove begged for a chest X-ray. The nurse did not think it was necessary.

“It was just an ongoing battle with myself,” recalled Ms. Grove, of Woodbury, Minn. “Should I tell them now or wait till I’m sicker?”

The first, much-anticipated benefits of personalized medicine are being lost or diluted for many Americans who are too afraid that genetic information may be used against them to take advantage of its growing availability.

In some cases, doctors say, patients who could make more informed health care decisions if they learned whether they had inherited an elevated risk of diseases like breast and colon cancer refuse to do so because of the potentially dire economic consequences.

Others enter a kind of genetic underground, spending hundreds or thousands of dollars of their own money for DNA tests that an insurer would otherwise cover, so as to avoid scrutiny. Those who do find out they are likely or certain to develop a particular genetic condition often beg doctors not to mention it in their records.

Some, like Ms. Grove, try to manage their own care without confiding in medical professionals. And even doctors who recommend DNA testing to their patients warn them that they could face genetic discrimination from employers or insurers.

Such discrimination appears to be rare; even proponents of federal legislation that would outlaw it can cite few examples of it. But thousands of people accustomed to a health insurance system in which known risks carry financial penalties are drawing their own conclusions about how a genetic predisposition to disease is likely to be regarded.

As a result, the ability to more effectively prevent and treat genetic disease is faltering even as the means to identify risks people are born with are improving.

“It’s pretty clear that the public is afraid of taking advantage of genetic testing,” said Dr. Francis S. Collins, director of the National Human Genome Research Institute at the National Institutes of Health. “If that continues, the future of medicine that we would all like to see happen stands the chance of being dead on arrival.”

Caught in a Bind

For Ms. Grove, 59, keeping her genetic condition secret finally became impossible. When her symptoms worsened she was told to come back to the clinic before antibiotics would be prescribed. But there had been a snowstorm that day, and she could not summon the strength to drive.

“I have alpha-1,” she remembers sobbing into the phone. “I need this antibiotic!”

The clinic called in the prescription.

Ms. Grove, who does freelance accounting from home and has health insurance through her husband’s employer, allowed herself to be identified here because she said she felt an obligation to others — including some in her own family — to draw attention to the bind she sees herself in.

“Something needs to be done so that you cannot be discriminated against when you know about these things,” she said. “Otherwise you are sicker, your life is shorter and you’re not doing what you need to protect yourself.”

Employers say discrimination is already prohibited in the workplace by the Americans with Disabilities Act and existing laws governing privacy of medical records. But employee rights advocates say nothing in those laws explicitly prevents employers hard-pressed to pay for mounting health care costs from trying to screen out employees they know are more likely to get sick.

Courts have yet to rule on the subject. When the Equal Employment Opportunities Commission sued the Burlington Northern Santa Fe Railway for secretly testing the blood of employees who had filed compensation claims for carpal-tunnel syndrome in an effort to discover a genetic cause for the symptoms, the case was settled out of court in 2002.

And in 2005 when Eddy Curry, then the center for the Chicago Bulls, refused a genetic test to learn if he was predisposed to a heart ailment, the team traded him to the New York Knicks.

Insurers say they do not ask prospective customers about genetic test results, or require testing. “It’s an anecdotal fear,” said Mohit M. Ghose, a spokesman for America’s Health Insurance Plans, whose members provide benefits for 200 million Americans. “Our industry is not interested in any way, shape or form in discriminating based on a genetic marker.”

Still, a recent study by the Georgetown University Health Policy Institute found otherwise. In 7 of 92 underwriting decisions, insurance providers evaluating hypothetical applicants said they would deny coverage, charge more for premiums or exclude certain conditions from coverage based on genetic test results.

The Medical Cost

Regardless of whether discrimination actually occurs, many health care professionals say the pervasive anxiety over it demands legislative action. Geneticists complain that discrimination fears prevent them from recruiting research participants, delaying cures and treatments for disease. At Memorial Sloan-Kettering Cancer Center in New York, the same concern is a leading reason people cancel appointments for tests that detect cancer risk.

“We are dealing with potential lifesaving interventions,” said Dr. Kenneth Offit, chief of the center’s clinical genetics service. “It’s a tragedy that people are being scared off by this.”

The Genetic Information Nondiscrimination Act, which passed the House of Representatives by a wide margin last year, would prohibit insurers from using genetic information to deny benefits or raise premiums for both group and individual policies. (It is already illegal to exclude individuals from a group plan because of their genetic profile.) The bill would also bar employers from collecting genetic information or using it to make decisions about hiring, firing or compensation. But it has yet to reach the Senate floor.

Meanwhile, a $300 genetic test for prostate cancer risk announced last month immediately drew callers to a public radio station in Washington that was discussing the test, voicing fears of insurance discrimination. Dr. Karim Kader, who made the test possible with his discovery that men who carry certain DNA variants are four to five times likelier to develop prostate cancer, assured one caller that the test would be “very private.”

For some, that is not good enough.

Linda Vahdat, director of the breast cancer research program at NewYork-Presbyterian Hospital/Weill Cornell Medical Center, estimates that 20 percent of her patients choose to pay for the DNA test for inherited breast cancer risk with cash, to avoid submitting insurance claims.

And last year, hundreds of customers paid the start-up company DNA Direct for tests that range in cost from $175 to $3,456 to ensure that no third party, not even a doctor, had access to their results. Mary, a freelance camera assistant in Brooklyn, for instance, sent a swab of her cheek cells to DNA Direct to find out if her extreme fatigue was caused by hemochromatosis, a genetic condition in which the body retains too much iron.

“I would rather not lay out the $200 myself,” said Mary, who requested that her last name be withheld for the same reason she paid for her own test. “But it seemed safer.”

Treatment for hemochromatosis typically involves removing a unit of blood twice-weekly by phlebotomy. But that would mean disclosing the condition to a doctor, so Mary is planning on becoming a frequent blood donor.

Kathy, a financial analyst in Houston who would like to know if she, like her two sisters, has a genetic predisposition to breast cancer, said she was not going to take even an anonymous test. “Then,” she said, “I’m just in a position of having to lie.”

The culture of secrecy around genetic information is stronger in the United States, some experts say, than in countries where people are guaranteed health care. Among Americans at risk for Huntington’s disease, an incurable brain disorder, only 5 percent take the DNA test to determine if they will develop it, compared with 20 percent of Canadians in the same position, according to Michael R. Hayden, a professor of human genetics at the University of British Columbia in Vancouver.

Here, doctors often feel obligated to inform patients of the potential financial downside.

“I always warn them,” said Dr. Stephen Moll, director of the Thrombophilia Program at the University of North Carolina, who uses a genetic test to determine the best treatment for patients with blood clots. “Especially if they are self-employed, I don’t want it to be a surprise if their health insurance premium goes up.”

Unknown Risks

After receiving a similar warning from her doctor, Katherine Anderson’s parents did not allow her to be tested for Factor V Leiden, a genetic condition she might have inherited from her father that increases the risk of blood clots.

But last year, with nothing in Ms. Anderson’s record to indicate reason for concern, a gynecologist prescribed a birth control pill to regulate her uneven periods. Six weeks later, Ms. Anderson, then 16, developed a clot that stretched from her knee to her abdomen. The pill, combined with the gene she had indeed inherited, had increased her clotting risk by 30-fold.

Now largely recovered, her primary concern is whether she will be viewed as a health insurance liability for the future.

“I don’t want to have to work for a big business just to get insurance,” she said. “This could be determining what I can do for my whole life.”

For Judith Berman Carlisle, the price of privacy was forgoing the DNA test that would have convinced her not to have surgery. Ms. Carlisle, 48, who was setting up her own therapy practice, was afraid testing positive for the high-risk breast and ovarian cancer gene that runs in her family would prevent her from buying health insurance.

But her sister had developed ovarian cancer the year before, an aunt had died of it, and Ms. Carlisle was desperate not to get it herself. Her doctor agreed to remove her ovaries based on her family history — the way such decisions were commonly made before a genetic test was available.

Ms. Carlisle was convinced the surgery would be less damning than proof that she carried a defective BRCA1 gene, which also confers a very high chance of developing breast cancer.

“There’s a big difference between someone saying, ‘I have a strong family history,’ ” Ms. Carlisle said, “and saying, ‘I only have a 13 percent chance of not getting breast cancer during the time you’re insuring me.’ ”

Last fall, after the surgery to remove her ovaries, she began to consider a double mastectomy to remove any chance of breast cancer, the disease her grandmother and another aunt had died of. Having secured health insurance, she took the test for the BRCA1 mutation. It came back negative.

“The first thing they said to me,” Ms. Carlisle said, “is that I have no higher risk than anyone on the street.”

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