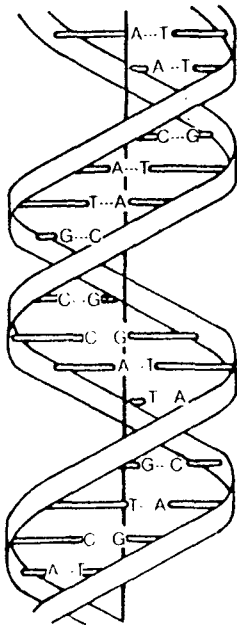


INSURERS TAKE AN INTEREST IN GENETIC FINDINGS

By Simson L. Garfinkel

People around the U.S. and Canada diagnosed with genetic diseases are being denied insurance and employment, even though they have few or no observable symptoms, according to a survey by the Clinic for Inherited Diseases at Harvard Medical School's Deaconess Hospital.



The survey, based on responses to an advertisement placed in a medical journal and mailed to 1119 genetics professionals, solicited reports of discrimination that were unrelated to physical disability.

"The people who wrote had very, very minor manifestations of genetic diseases," said Dr. Paul R. Billings, who conducted the survey. "Many are not sick in an objective way, but they are treated as if they are ill." Nearly 60 people responded to Billings' advertisement; roughly half of those met the criteria to be included in the survey. Some of the most startling instances of discrimination:

A salesman who had been driving for 20 years without an accident was diagnosed with a minor form of Charcot-Marie-Tooth disease (CMT), a neuromuscular disorder that can cause people to drag their feet. "When his auto insurer found out, they cancelled his policy," said Billings, despite a letter from the man's physician saying the condition had no impact on driving.

A woman diagnosed with a mild case of CMT mentioned that she had the disease during a pre-employment exam at a telephone company. The examiner asked her what "CMT" stood for, then looked up the disease in a medical text and denied her the job after a recruiter had offered it to her.

Two women with a parent with Huntington's disease decided to adopt rather than risk passing the gene to the next generation. The women, both free of symptoms, have a 50 percent chance of contracting the genetic illness. Nevertheless, both were deemed unsuitable to adopt.

A woman with a five-year-old with cystic fibrosis (CF) became pregnant. In prenatal screening, a physician at her health maintenance organization (HMO) discovered that the fetus was positive for CF; he told her that the HMO would not cover the delivery and infant care and would limit care for the five-year-old. She was told to abort the pregnancy. The HMO, located in the South, saw the woman's desire to give birth as proof of irresponsibility as a parent, Billings said. A nearly identical case was reported by a woman in the Pacific Northwest.

A woman whose daughter has Ehlers-Danlos syndrome (EDS), a disease that causes extremely flexible skin and spontaneous joint dislocations, was told by her insurance company that claims for EDS would no longer be covered. This came during the middle of a policy term.

Frequently, Billings learned, it was the patient who brought the disease to the attention of an insurer or employer. Or it is the physician who tells. "Doctors, in order to get paid, are being asked more and more to identify a chargeable

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condition in their clients. The breach in confidentiality is a natural consequence of the way in which third-party billing is structured," added Billings, who is now director of genetic medicine at Pacific Presbyterian Medical Center in San Francisco.

Invariably, employers and insurance companies "assume that anybody identified with a trait is going to have the worst possible outcome for that trait," the doctor said, although there is tremendous variation among individuals. Even Huntington's disease, which almost always causes mental deterioration and death, has a "great variability in the age in which severe disability occurs." Once a person is identified in any way, "You are in trouble," said Billings.

Neil Day, president of MIB Inc., a non-profit Boston-based databank of individual medical histories, argues, "There is no way that results of that test could be reported to MIB because the computer lacks the codes. It will be many, many years before genetic testing has any impact on MIB." Billings disputes this. Physicians use alternative terms for diagnoses not included among MIB's codes.

Because Billings refuses to disclose the identity of individuals surveyed, some insurance-industry professionals say it is impossible to verify his reports. "They probably were isolated cases," said Dr. Robert Pokorski, medical director of Lincoln National Life Insurance and chair of the genetic testing subcommittee of the American Council of Life Insurers. "He doesn't provide enough detail."

"It's not at all widespread," said Rob Bier, of the Washington-based council. "I've been trying for several years to see what interest there is [in using genetic screening for insurance decisions], and people aren't interested. Medical directors say, 'Gee whiz, that's off in the hazy distance.'"

Insurance companies will probably use genetic testing "sometime in the future," says Lincoln's Pokorski. "Our whole risk classification system is to determine how much risk a person has. If you are at high risk, you pay more." But because of the costs of the tests and the fact that they exist now for only a few diseases, Pokorski anticipates wide-scale testing for insurance no sooner than the year 2000.

If a patient has a genetic test done, an insurer must be told the results, he said.

The New NCIC -- The FBI's NCIC 2000 would be a totally new system, not merely an upgrade of the current National Criminal Information Center (NCIC) system, according to William Bayse, Assistant Director of the FBI's Technical Services Division. The new system will contain digitized photos and fingerprints of subjects in addition to warrants and criminal history data.

In the new system, local law enforcement officers would be able to query the federal database at the point of arrest. By supplying a person's name, the officer would receive notice of any outstanding warrants. If a "hit" is made, the officer would scan the suspect's fingerprints or a photograph at the site, and an instantaneous comparison would be made by FBI computers. If the prints or photos did not match, they would be discarded, according to Bayse.

The Federal Bureau of Investigation will collect and store DNA (genetic) test results in a computer data base separate from the NCIC 2000, Bayse said in a talk last month at the First Conference on Computers, Freedom and Privacy.