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Genie Out of the Bottle

Genetic Testing and the Discrimination It's Creating

By Wendy McGoodwin

WHEN JOHN Mayfield and Joseph Vlacovsky enlisted in the U.S. Marine Corps, they were prepared to give four years of their lives to serve their country. What they didn't bargain for was having intimate aspects of their personal lives controlled by the Marine Corps for the next 75 years. This is, however, what the Pentagon has succeeded in doing by seizing highly personal genetic information from every member of the armed services for inclusion in a "DNA registry." The stated purpose of this DNA registry is to help identify the bodies of soldiers killed in battle, but the coercive aspects of the DNA collection have raised troubling concerns about genetic privacy.

The case of the two Marines, who last month were court-martialed for refusing to submit to gene testing, highlights a growing fear of what has become known as genetic discrimination. A recent study by researchers at Harvard and Stanford universities documented more than 200 cases where healthy people were refused health insurance, fired from their jobs or barred from adopting children simply on the basis of their genes. Unfortunately, the same technology that can be used to help doctors identify and treat illness is also being misused to discriminate against people perceived to be at risk for future ill health. Nowhere is the potential misuse of genetic technology more apparent to ethicists—or frightening to average Americans—than in the potential for people to be unfairly classified and punished according to their genetic makeup.

The science of genetics is a flourishing new industry, nourished in large part by the federally funded Human Genome Project. The goal of this ambitious research endeavor is to identify every gene found in the human body, approximately 100,000 in all. Much of the research fo-

cuses on genetic diagnostics: tests designed to identify genes thought to be associated with various medical conditions. More than 50 new genetic tests have been identified in the past five years alone.

This massive scientific endeavor has also opened up a Pandora's box of ethical problems we are not yet prepared to address. It is true that 10 years ago, genetic tests were only available for relatively rare genetic conditions. Today, doctors can screen for hundreds of genetic conditions, such as cystic fibrosis, sickle cell anemia, Huntington's disease and muscular dystrophy. Scientists recently discovered two genes associated with certain kinds of breast and colon cancer, common diseases that strike millions of Americans every year. For a handful of treatable genetic conditions, such as hemochromatosis or PKU, genetic testing can save lives through early diagnosis and intervention.

But for most genetic disorders—where treatment is either unavailable or limited—it is not at all clear how rapidly genetic research will lead to new treatments or cures. In the meantime, diagnoses unaccompanied by cures are of questionable value to patients. And in the absence of clear medical benefits, genetic testing can create real harms. Scientists working with the Council for Responsible Genetics have documented numerous cases where healthy people have been denied insurance or employment based on genetic health predictions:

- A pregnant woman whose fetus tested positive for cystic fibrosis was told that her health maintenance organization (HMO) would be willing to cover the cost of an abortion but would not cover the infant under the family's medical policy if she elected to carry the pregnancy to term.

- A healthy woman who casually mentioned to her family doctor that her father had been diagnosed with Huntington's disease, and that she herself was at risk for inheriting this genetic disorder, which can cause the brain to deteriorate, was later denied disability insurance. The insurance company rejected her because they found a note about her father's diagnosis

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written in the margin of her medical records.

■ A healthy boy who carried a gene predisposing him to a heart disorder was denied health coverage by his parents' insurance company, even though the boy took medication that eliminated his risk of heart disease.

Further evidence of genetic discrimination was published recently by Harvard and Stanford medical researchers who discovered cases in which employers had used predictive genetic information to make employment decisions. A 24-year-old social worker alleges she was fired from her job after she revealed her genetic risk for Huntington's disease, even though she had received outstanding performance reviews in the months prior to the firing. An Army enlisted man who developed symptoms of a genetic disorder was discharged and denied full disability benefits when the military classified his genetic makeup as a "pre-existing medical condition." An adoption agency refused to let a married couple adopt a child because of the wife's risk for genetic disease.

Insurance companies claim they will go bankrupt if forced to insure people at risk for genetic diseases. That claim is hard to take seriously, however, since such genetic diseases have *always* existed. It's only our ability to detect them that is new.

"Genetic disorders are not epidemic, which means that the number of people with inherited conditions has been stable for as long as health insurance has existed in this country," says Stanford's Paul Billings, who co-authored the recent genetic discrimination study. "There is no justification for exclusion simply on the basis of technical developments which make detection of genetic conditions earlier, simpler or more precise."

Genetic discrimination no longer targets only those families afflicted with rare genetic disorders. With the discovery of genes linked to certain types of cancer, insurance companies are already arguing that they also should be allowed to deny insurance to people who carry these so-called "cancer genes." Not only is this discrimination unjust, it is scientifically inaccurate. Genes can tell us only part of the story about why some people get sick and others do not. Many genetic tests predict, with limited accuracy, that a disease may become manifest at an undetermined time in the future. But the severity of many diseases, such as sickle cell anemia and spina bifida, varies widely among individuals, and the presence of a "defective"

gene cannot foretell how disabling a disease will be for a specific person. People who are perfectly healthy today are being denied insurance and jobs based on unreliable predictions that they *may* become sick in the future.

Fear of this kind of discrimination can undermine whatever benefits might be derived from new developments in genetic testing technology, in part because people are already avoiding genetic testing for fear of the test results being used against them. The threat of discrimination compromises their ability to take full advantage of their medical options; they could miss out on early diagnosis, treatment and in some cases, prevention.

Beyond the risk of discrimination, society's fascination with genetic determinism has other social and political consequences. An overemphasis on the role of genes in human health neglects environmental and social factors. For example, strong evidence points to links between environmental contamination and cancer. Current research priorities, however, are skewed toward identifying genetic predispositions to cancer. If cancer is cast primarily as a genetic disease, then legislators may discard efforts to clean up environmental carcinogens in favor of a search for "cancer genes."

In effect, we encourage a "blame the victim" mindset, where we condemn people with "faulty" genes. Social conditions such as poverty or environmental pollution, which correlate directly with poor health and higher mortality rates, become less important. And economic and social resources end up being diverted into finding biomedical "solutions" while societal measures get short-changed.

All this is beginning to unfold far before the law is ready. While some forms of job discrimination may be prohibited under the Americans with Disabilities Act, no federal law prohibits genetic discrimination in insurance. Only 12 states have enacted legislative protections against genetic discrimination. And even then, employers who provide health insurance benefits through "self-funded" plans are not bound by these state laws. As evidence of mounting concern over genetic discrimination, four bills have been introduced in Congress and at least 20 state legislatures to prohibit genetic discrimination.

The military judge ruled last month that John Mayfield and Joe Vlacovsky can keep their DNA, but unless legislative safeguards are put in place, millions of other Americans remain vulnerable to genetic discrimination.