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Genetic Predictions and Social Responses*

Predicting the future always has been a human temptation. In one very important sense, we now are close to being blessed–or cursed–with getting our wish. At an increasingly rapid pace, biological scientists are using genetics research to develop ways for us to learn more about ourselves–more, in fact, than we might ever want to know.

"We used to think our fate is in our stars," observes James D. Watson, who helped unlock the secrets of DNA in the early 1950s and now directs the Laboratory of Quantitative Biology, a major genetics research center at Cold Spring Harbor on Long Island in New York. "Now we know, in large measure, our fate is in our genes."

Strung together in the almost mystical double helix form of DNA, genes are the basic unit of heredity. They are contained in chromosomes carried by every cell in our bodies. Each cell contains DNA carrying the entire human genome, or all the genetic information necessary to build a person.

Because each human's genes are unique, they are a personal map for that person's biological past and future-the traits inherited from parents and the ones to be passed on to children. Unfortunately, not all the genetic news is good. As scientists learn how to "read" genes, they can predict a growing list of potentially harmful diseases and traits.

The bad news contained in genetic information holds deeply personal implications for each individual, but it also is the reason why third parties, such as insurers, employers, schools, the military and the courts, increasingly want to be in on the secret.

The debate over who should have access to genetic information about individuals is likely to intensify in the near future as the pace of discovery picks up in the genetics field. Courts and legislators are sure to be at the center of the controversy.

Much of the spark for that explosion of knowledge about genetics comes from the Human Genome Project, co-directed by the National Institutes of Health and the Department of Energy. In the project, the federal government is spending some $3 billion to support efforts to catalog the entire human genetic blueprint by 2005.

For 20 years, genetic testing has been performed on fetuses. One of the first predictive tests for healthy adults screens for the gene that causes Huntington's disease, a debilitating, fatal neurological disorder. Young, healthy people who test positive for the inherited Huntington's mutation know it will kill them someday.

Such genetic news can be psychologically devastating. Consequently, fewer than 14 per cent of people at risk for Huntington's disease decide to undergo the genetic testing that may force them to confront their medical future.

But genetic testing is no longer limited to relatively rare diseases such as Huntington's. Similar tests are being developed for more common disorders such as heart disease, diabetes and certain cancers. Genetic testing also is being proposed for numerous behavioral disorders such as alcoholism, manic-depression and even "risk-taking" behavior. People are starting to

use genetic information to measure the consequences of major life decisions: where to live, what job to take, what type of insurance to purchase, even whether to bear a child.

No Easy Decision

Deciding whether to undergo genetic testing is not easy. Women with a strong family history of breast cancer, for instance, are faced with the prospect of learning, through testing, that they inherited a genetic mutation that poses an 80 per cent lifetime risk of the disease. But if genetic testing does reveal the breast cancer gene, the woman risks losing the health insurance she may need so badly later on.

"These are not just hypothetical fears," says Nancy Wexler, a clinical psychologist at Columbia University in New York City who has studied families that carry inherited disease. "People who are using genetic testing are losing their insurance. And other people who should avail themselves of genetic testing are losing their lives to save their insurance."

Wexler has a personal stake in her own research. As a member of a team in Venezuela that identified the specific gene for Huntington's disease in 1993, Wexler was zeroing in on what someday may kill her. The disease killed her mother, and Wexler is at 50 per cent risk of developing it as well. She has testified before Congress about her belief that people have a right not to know their genetic makeup.

Such decisions about whether to undergo genetic testing are at the heart of the growing legal debate over genetic predictability. Individuals at risk fear that test results may be used against them by employers, insurers, school officials, courts, mortgage lenders, adoption agencies, the military and other entities. At the same time, those institutions claim that individuals are not entitled to deprive them of information that could impact on the institutions' own interests.

Genetics is not totally new to the courts–just ask the juries in the O.J. Simpson criminal trial who heard reams of testimony on DNA typing of blood samples. Similar tests are also common in rape and paternity cases.

But those types of cases use genetic factors to link accused parties to incidents that occurred in the past. In the new realm of genetics, the issues are prospective: Do people have a privacy right to their genetic information, or do other parties have a right to demand that it be revealed?

Those questions are arising in a growing number of legal settings: medical malpractice, employment, education, family and civil rights.

Few laws in the United States protect intrusions on genetic privacy despite the personal nature of the information. "The highly personal nature of the information contained in DNA can be illustrated by thinking of DNA as containing an individual's 'future diary,'" says George Annas, a health law professor at Boston University. "A diary is perhaps the most personal and private document a person can create. Diaries describe the past. The information in one's genetic code can be thought of as a coded probabilistic future diary because it describes an important part of a unique and personal future."

In addition to concerns about privacy, institutional interest in an individual's genetic information raises fearsome ghosts in a century that has witnessed far too many waves of

genocide, forced sterilization and stigmatization of entire groups of people on the basis of their supposed genetic inferiority.

Moreover, there are concerns that human genetic materials may come to be viewed as commercial products. "Blood, tissue, placenta, cell lines and genes are valuable resources in the age of biotechnology, useful as sources of information and raw material for commercial products," says Dorothy Nelkin, a New York University sociologist and co-author of *The DNA Mystique: The Gene as a Cultural Icon.* "Geneticists rely on routine access to body tissues for their research. And some biopsied tissue has acquired commercial value as a source of raw material for the development of pharmaceutical products."

Despite these concerns, the law generally has upheld third-party access to a person's genetic information on a number of fronts.

Marines on the Genetic Frontline

On Dec. 16, 1991, the deputy secretary of the U.S. Department of Defense quietly issued an obscure memo that opened the largest DNA bank in the world. The directive required that every member of the U.S. armed forces and all new recruits provide the Armed Forces Institute of Pathology with a DNA sample, which would be maintained on file for 75 years. The goal of this ongoing program is to obtain specimens for all active and reserve personnel by 2001 for a very simple reason: to make it easier to identify battlefield dead.

In January 1995, two members of the Marine Corps, Lance Cpl. John C. Mayfield III and Cpl. Joseph Vlacovsky, reported for what they expected to be a routine physical. But when they were informed that they were to provide blood and saliva for DNA sampling, they refused. The two Marines agreed that using DNA to identify remains was benign, but they expressed concern that the military could, at some point in the future, use the DNA samples for some less innocuous purpose, such as the diagnosis of hereditary disease or disorders, and then could disseminate such information.

Mayfield and Vlacovsky were court-martialed for refusing to obey an order from an officer. In subsequent proceedings, the Marines asserted that the collection, storage and use of their DNA violated their rights to freedom of expression, privacy and due process under the U.S. Constitution. Their strongest argument was that unreasonable searches and seizures are prohibited by the Fourth Amendment-the same provision that protects a criminal defendant, for example, from being subjected to stomach pumping when police see the suspect swallow a bag of cocaine in efforts to destroy evidence.

In September 1995, a federal court ruled in favor of the government in Mayfield v. Dalton, 901 F.Supp. 300, holding that its interest in accounting for the fate of soldiers and assuring peace of mind to next of kin overrode the constitutional interest of individual service personnel in being free from searches and seizures. The ruling allowed the military to court-martial the Marines, but they ended up getting light sentences: a reprimand and seven days' restriction to base. The military's policy of requiring DNA testing of its members has not changed.

Members of the military are not the only people in this country with DNA profiles on record. Some insurance companies are requiring genetic testing as a condition of coverage, and others are dropping insureds or charging them higher rates on the basis
of genetic information discovered through other channels. In one instance, a pregnant woman

whose fetus was affected when she underwent cystic fibrosis testing was informed by her insurance company that it would not pay for the child's health care costs if she chose to complete the pregnancy. In another case, a woman whose mother had breast cancer was told her own health care coverage would exclude treatment of breast cancer. Even some people who participated in genetics research have subsequently lost their health insurance, including a man who underwent screening for a type of colon cancer as part of a study at the Huntsman Cancer Center at the University of Utah.

Basing Insurance on Genetics

These actions do follow a certain calculated logic. Since it is accepted policy for health insurers to exclude people with pre-existing disorders, genetic testing provides an enormous loophole for classifying numerous diseases or other medical conditions as pre-existing because they have their roots in the genes of prospective insureds.

At first glance, such a policy might seem reasonable, akin to charging smokers higher rates. After all, insurance is based on the concepts of risk-spreading and risk-sharing. When most people's future health risks are unknown, the future health care costs of a group can be predicted on an aggregate, actuarial basis and the costs spread across the whole group.

But with genetics technology beginning to identify which people in a group are likely to develop particular diseases later on, insurance companies have begun to target them for special treatment: higher rates or denial of coverage. Carried to its extreme, that approach to coverage could make everyone uninsurable, since every human being carries between eight and 12 "defective" genes that might trigger various medical disorders. Moreover, the insurance industry's developing policies on genetic predictability raise the same privacy concerns for insureds raised by the two young Marines in the face of the military's mandatory DNA screening policy. Many people do not want to be forced to gaze into their biological crystal balls.

In some states, legislators have begun passing bills to prohibit discrimination by insurers based on genetic information. But the laws passed so far may be too narrow. In Wisconsin, for instance, the legislative protection against insurance discrimination applies only to DNA tests and does not cover tests that analyze proteins contained in genes or information on family histories.

Employers, like insurers, are peering into people's genes. As early as 1989, according to a survey of employers by the U.S. Office of Technology Assessment, one in 20 companies conducted genetic screening or monitoring of workers. And even if employers themselves do not undertake genetic testing, they may receive such information about their employees in other ways. It might be found in medical records submitted by an employee in support of a health insurance claim or reported by the employee's doctor. "Physicians are increasingly being put into the role of 'double agents,' with dual loyalties to the patient and to the patient's school, employer, potential insurer, relative or child," observes sociologist Nelkin.

Genetic testing by employers has been accompanied by discrimination based on that information. In the early 1970s, a number of companies discriminated against black employees and job applicants who carried sickle-cell anemia even though that status had no bearing on an employee's current or future health, or on an employee's ability to work since the only significance of carrying the trait was a 1-in-4 chance of passing the disease on to a child if the other parent was also a carrier.

Yet few states have laws banning genetic discrimination in employment. At the federal level, the Americans with Disabilities Act provides some protection against job discrimination for people who carry genes that predispose them to diseases later in life. The compliance manual of the Equal Employment Opportunity Commission states that under the ADA an employer may not discriminate against a person on grounds of genetic information relating to illness, disease or other disorders. The EEOC indicated, for example, that an employer may not refuse to hire someone just because his or her genetic profile reveals an increased susceptibility to colon cancer. But the ADA still permits employers to order genetic testing of people who have been offered employment, even without their permission, as long as the information is not used in unfair ways.

In September 1995, the San Francisco Legal Aid Office filed a class action lawsuit by employees of Lawrence Berkeley Laboratories, a research center at the University of California at Berkeley that receives funding from the U.S. Department of Energy. The suit alleged the lab had tested African-American employees for the sickle-cell gene, without their knowledge or consent during routine physicals, and had secretly maintained that information in their files. A federal district court sided with the employer, saying that the practice did not invade the employees' privacy, who had agreed to undergo physical exams and give medical histories even though the employees had not been told about the genetic testing. The judge found that given the "overall intrusiveness" of the physical exams and the "large overlap" between the medical histories and the tests, any additional privacy intrusions due to the challenged tests were minimal. However, the Ninth Circuit Court of Appeals in *Norman-Bloodsaw v. Lawrence Berkeley National Laboratories* disagreed with the district court and held that an employer may not test employees for "highly sensitive" medical and genetic information without the worker's consent. Judge Stephen Reinhardt, writing for the unanimous three-judge panel, wrote: "One can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic makeup."

Reading, Writing and Genetic Testing

In U.S. schools, genetics is more than just a subject for science classes. In a few places, schools are using genetic tests to screen students for a syndrome that identifies borderline retardation. In the future, schoolchildren might be screened to identify genes for dyslexia or other learning difficulties, then receive special assistance to compensate for the genetic flaw. The problem with such an approach, however, is that even if such genes can be identified (and this is a big "if," given that reputable researchers from respected institutions such as Yale have in recent years claimed to have found genes for complex behaviors only to later have to retract their findings), carrying a gene and manifesting the disorder are two different matters.

Not all genes are completely penetrant; there are many genetic conditions that occur in only a minority of the people carrying the gene. Often the gene indicates only a predisposition to a disorder that needs additional intervention, such as a particular environmental exposure, to be triggered. This means some children may be labeled as deficient because they carry a gene rather than manifest a condition. The implications are profound. The work of social psychologist Claude Steele at Stanford University indicates that students perform more poorly if they know they are members of a group that traditionally has not been academically strong, a phenomenon known as "stereotype vulnerability."

Teachers' perceptions of students might be affected by such genetic stereotyping, giving lower grades to children identified as having an errant gene even if they are performing normally. That pattern has been identified in psychological studies in which teachers were

told that one group of students was better than another when there actually was no difference. The teachers gave the "better" students higher grades and more attention, presumably due to the "halo" effect of a positive label.

The use of genetic screening in higher education is even more problematic. In one case, a man who was at 50 per cent risk for Huntington's disease was rejected by medical schools on grounds that it would be a waste of money to train someone who might die young.

For judges with a full load of complex cases, the idea that genetic information might provide some guidance is seductive. Consequently, the use of genetic testing to answer an expanding variety of legal questions is growing, often without sufficient thought to the social context or impact. In a recent case in Charleston County, S.C., a judge ordered that a woman be genetically tested for Huntington's disease at the instigation of her ex-husband, who was seeking to terminate her parental rights. This type of case may foreshadow a new kind of battle in custody cases, in which the divorcing parents seek genetic testing on each other to determine who is more predisposed to die sooner from cancer or heart disease. Under this approach, the "better" parent might be adjudged to be the one with the "better" genes.

Genetic testing also could have an explosive impact on personal injury cases. Under current law, a successful plaintiff in a medical malpractice or other personal injury case generally is awarded damages for future losses on the basis of life expectancy statistics. But shrewd defendants may begin to require genetic testing on plaintiffs to find evidence that they have a predisposition to an early death, justifying a reduction in damages. Forcing parties in custody or personal injury cases to undergo genetic testing could have a strong deterrent effect on parties who fear the consequences of learning unwanted facts about their genetic makeup.

In the South Carolina custody case, the wife was adamantly opposed to being tested for Huntington's disease, even though she faced the loss of her child if she refused. Facing a painful Sophie's choice, she simply disappeared.

The most significant direct legal impact of genetics may be in criminal law, an area in which DNA evidence is already common-place. But the next step could challenge the very underpinning of the criminal justice system. Criminal law is based on the idea of free will– that individuals "choose" to engage in criminal acts for which they must be punished. But as geneticists increasingly claim to find genetic markers for antisocial behavior, the legal system will be forced to reconsider the concepts of criminal intent and guilt.

A Dutch research group says it has found a gene linked to a propensity to aggression. How should the courts rule on a defendant's claim that he murdered because it was in his genes? Judges already show some willingness to accept genetic defenses. In similar California cases, two admitted alcoholic lawyers embezzled money from their clients, but the one who claimed his alcoholism was genetic was given a lighter sentence. In a murder case, the defendant was found not guilty after her violence was linked to her having Huntington's disease.

Are All Genes Created Equal?

The great, vague specter of genetics is how it may eventually influence society's view of equality. Much of the future research in genetics will not be related to disease but will focus on human individual and group traits, such as intelligence, behavior and race. Researchers now claim that they can distinguish between blacks and whites on the basis of differences in just three of the 100,000 genes in each human.

Arthur Caplan of the University of Pennsylvania Center for Bioethics has written, "Will the information generated by the genome project be used to draw new, more 'precise' boundaries concerning membership in existing groups? Will individuals who have tried to break their ties with ethnic or racial groups be forced to confront their biological ancestry and lineage in ways that clash with their own self-perception and the lives they have built with others?"

The potential exists for genetics research to produce findings that could undermine our conceptions of equality of opportunity, and individual and social responsibility. Already, some physicians and lawyers suggest that people should have a duty to learn their own genetic status and to avoid having children who may be adversely affected by their genetic heritage. In articles in both medical and legal literature, Margery Shaw, a Texas lawyer and geneticist, recommends that states adopt policies to prevent the birth of children with genetic diseases. She suggests that the prevention of genetic disease is so important that a couple deciding to give birth to a child with a serious genetic disorder should be criminally guilty of child abuse. Shaw also suggests the imposition of tort liability for not sharing genetic information with relatives or for not undergoing genetic testing. In the case of Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 811 (1980), a California appellate court stated in dicta that a child with a genetic defect could bring suit against her parents for not undergoing prenatal screening and aborting her.

In 1991, Bree Walker Lampley, a television anchor in Los Angeles, found herself caught up in the intense emotions that these issues can breed. When Lampley, who has ectrodactyly, a mild genetic condition that caused the bones in her fingers and toes to fuse, made public her decision to give birth to a child with the same condition, a radio talk show host and her listeners attacked the decision as irresponsible and immoral.

Lampley, along with several disability rights groups, filed a Federal Communications Commission complaint against the radio station for violating its personal attack rule and failing to present both sides of the issue. The complaint was denied.

Throughout the United States, people seem to have drifted into a mindset that assumes that if genetic information exists, it should be acted on and taken into consideration in a variety of social realms. Clearly, the promise of genetics is everywhere, and much fanfare accompanies each genetic discovery. But less attention is focused on how we will use knowledge gained through genetic testing. When an article in the Journal of the *American Medical Association* heralded the discovery (later disputed) of a genetic marker for alcoholism, 140 newspapers and magazines ran articles praising the advance. Not a single article addressed the issue of what we would actually do if we identified individuals with a genetic propensity toward alcoholism.

Framing the Debate

As courts, legislators and other policymakers approach the difficult issues surrounding advances in the science of genetics, they might consider a three-prong policy framework:

• First, legislation, court decisions and other expressions of policy should assure that people have control over what genetic information is generated about them. Legislation in New Hampshire makes this point, for instance, by stating that, except with respect to paternity testing, newborn screening and forensic testing, "no genetic testing shall be done […] without the prior written and informed consent of the individual to be tested."

• Second, individuals should have control over who has access to their genetic information. This can be accomplished through measures that expand upon state medical confidentiality laws. A statute in Colorado states, "Genetic information is the unique property of the individual to whom the information pertains. Information derived from genetic testing shall be confidential and privileged. Any release, for purposes other than diagnosis, treatment, or therapy, of genetic testing information that identifies the person tested with the test results released requires specific written consent by the person tested." Moreover, those generating or collecting genetic information should explain their confidentiality protections in advance of delivering those services.

• Third, discrimination against individuals based on genetic information should be prohibited.

The vexing question of how the fruits of genetic research should be used by society is on the table. Scientists are charting the map of the human genome, but the legal system will play a crucial role in determining where that map leads.