BY ROBIN MARANTZ HENIG

HIGH-TECH FORTUNETELLING

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Soon, a map of your genes may be able to predict what's likely to kill you. But do you really want to know?

STRUNG ALONG THE 46 CHROMOsomes of every human cell are some 100,000 genes. Among them, in each one of us, are a few that can be deadly. Every person has a unique set of these seven or eight lethal genes. They are usually hidden, but in the wrong environment or in combination with certain other genes they can express themselves in dangerous ways.

Some people, because their families have been haunted by genetic illness for generations, know what type of lethal genes they carry. But most of us have no idea of the ways in which we are genetically defective.

The 21st century will change all that. Soon, scientists hope, tests no more invasive than a finger prick will reveal the precise location and function of each of our genes. The $3 billion, 15-year Human Genome Project, under the joint leadership of the National Institutes of Health and the Department of Energy, will allow scientists to know exactly where on our chromosomes each of our 100,000 genes resides.

In the not-so-distant future, we can expect to walk into a physician's office for an annual physical and walk out with a blueprint of our genetic inheritance — and with the knowledge of the most likely cause of our own death.

But do we really want to know? Are we willing to learn the details of our genetic destiny — especially when it involves diseases for which there is no cure? Are we capable of understanding the uncertainties inherent in this high-tech fortunetelling? For a few genetic conditions, test results are simple: either yes, you have the defective gene and you'll get the disease; or no, you don't and you won't. But most adult-onset diseases involve several genes — scientists have identified at least 17 genes responsible for just one aspect of coronary heart disease — and the genes express themselves only under certain conditions. A yes-or-no prediction is, for most genetic conditions, all but impossible.

"As geneticists learn more about diabetes or hypertension or cancer," says Nancy S. Wexler, president of the Hereditary Disease Foundation and chairman of the ethics group of the Human Genome Project, "at some point they will cross an important line. Instead of saying, as they do now, 'Lung cancer runs in your family and you should be careful,' physicians will be able to ask their patients, 'Would you like to take a blood test to see if you are going to get lung cancer?' And this will be a difficult transition to make if we don't give people something to do about it after telling them they carry a deadly gene."

Even if we did want to know our own genetic destiny, would we want others to know? Are our social institutions capable of dealing with the ambiguities of genetic flaws, of the uncertainty of a gene's likelihood to express itself as full-blown disease? Can institutions make policies that allow for predisposition rather than predestination? Or will the presence of a faulty gene be enough to prevent full access to schooling, health care, employment and the other rights and privileges of society?

THE QUESTIONS RAISED BY THIS new power of prediction hover in the background even as geneticists begin applying the technology. Already, they can test adults for the presence of a handful of relatively rare genes — among them those that cause Huntington's disease (a progressive brain degeneration); adult polycystic kidney disease (a gradual loss of kidney function); polyposis (a precursor of colon cancer); hemochromatosis (which could cause liver failure), and certain forms of cancer (retinoblastoma, some leukemias, and small-cell carcinoma of the lung).

The still-unanswered questions fall into two main categories, says Dorothy Nelkin, professor of sociology at New York University and moderator of a conference on "The New Genetics and the Right to Privacy," held last month in Washington. The first is whether knowledge of the information is itself potentially hazardous to the individual; the second, whether institutions will misuse that knowledge to foster their own dominance and control.

"The basic dilemma here," Nelkin says, "is between institutional survivability and individual rights."

Predictive tests for adults pose different problems from those presented by prenatal tests, the genetic screens most commonly used today, which inform future parents of a child's chances of inheriting a condition for which the parent is a carrier — Tay-Sachs disease, sickle cell disease, cystic fibrosis — or of inheriting a condition from which a family member has already died — muscular dystrophy, hemophilia, beta-thalassemia.

But an adult genetic test tells you about your own genetic destiny. That is why the first category of questions — whether we can bear to know — is so potent.

I, for one, apparently cannot bear to know — though

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this bit of self-discovery may come as something of a surprise. If you had asked me 10 years ago — before I knew I was at risk for a genetic condition — whether knowledge was better than lack of knowledge, the journalist in me would have answered, "Of course." But since then I have learned that my father has adult polycystic kidney disease, a late-onset degenerative condition carried on a single, dominant gene. I run a 50-50 chance of having the gene myself. And if I have it, each of my two daughters runs a 50-50 chance of having it, too.

A genetic test exists now to tell me if I have the gene. But I have not taken it; I no longer value knowledge above all else. The test will not tell me if I will get sick in my 40's, as many polycystic kidney patients do, or stay well until my late 60's, as has happened in my father's case. And even if I found out that this was my lethal gene, I would not be able to act on the information. No treatment exists to prevent kidney failure in polycystic kidney patients, and I have already made the important life decisions, about marriage and career and family, that genetic tests are supposed to inform.

"There's a certain resistance to knowing our own futures," says Dr. Susan E. Folstein, associate professor of psychiatry at the Johns Hopkins University School of Medicine in Baltimore. "It's something about being human I don't fully understand, this unwillingness to know the ways in which we are imperfect."

The experience with Huntington's disease screening is a case in point. Before a screening test was developed, surveys of those at risk for Huntington's showed that up to 80 percent would take a predictive test. Everyone with the gene, which is dominant, will develop the neurological disease, a progressive and untreatable brain and muscle degeneration with symptoms that usually show themselves in the 40's. Currently there are about 25,000 Americans with Huntington's disease, and about 125,000 of their children are at risk. As with polycystic kidney disease, every child of a Huntington's disease patient has a 50-50 chance of inheriting the gene.

But when the test became available in 1986, no more than 15 or 20 percent of the people at risk actually showed up to be screened.

Those who have been screened, including those who found they carry the Huntington's gene, seem to have handled the knowledge well. Jason Brandt, a neuropsychologist and director of the Huntington's Disease Predictive Testing Project at Hopkins, has compiled follow-up statistics for 71 patients screened. Nineteen tested positive for the Huntington's gene marker; 41 tested negative and 11 had test results that were inconclusive. Among those with positive test results, Brandt says, there were no instances of suicide and only one of severe depression, and one marital breakup.

"I have a lot of faith in humanity, and I think people will use the genetic information we provide them in a reasonable way," says Brandt's colleague Dr. Haig H. Kazazian Jr., director of Hopkins's Center for Medical Genetics. "So far, they have." On the question of how much knowledge individuals can handle, he believes it's always better to know than not to know.

But Nancy Wexler of the Hereditary Disease Foundation is less sanguine. "If the information is limiting, enervating, depressing, if it tears at your self-esteem, if it gives you nothing to do, it might be better not to know," she says. This is surprising advice from a woman who has devoted her professional life to the search for the gene for Huntington's, the disease that killed her mother and for which she and her sister are at risk. "A program in which everybody automatically gets screened for lots of genetic conditions without taking into account the risks of knowledge for particular individuals, is bad medicine," she says. The risk of knowledge is greatest in the time between the development of a predictive test and the development of a treatment — the very period in which Huntington's disease is now caught. She has even considered closing down the Huntington's testing program she runs at Columbia University until a treatment is available.

From a societal point of view, the true danger of genetic tests is not that they convey too much information, but too little — and that the information is far more ambiguous than it first appears. "There is virtually no genetic condition in which the genes alone determine outcome," says Dr. Paul R. Billings, director of the Clinic for

Scientists stress that the results of genetic testing are ambiguous: genes alone do not determine a disease's prognosis.

Inherited Diseases, affiliated with Harvard Medical School. "Even in Huntington's disease, there is much uncertainty. Yes, you can say whether or not an individual appears to have the gene, and you can say that as far as we know all who have been screened who have the gene have gone on to develop Huntington's. But you still can't say anything about when the disease will start, what will be the course of the disease, and what will be the relevant aspects of the illness."

But despite their imperfections, genetic tests carry the illusion of precision. Dr. Laurence R. Tancredi, a psychiatrist and lawyer who directs the Health Law Program at the University of Texas Health Science Center in Houston, says all types of biological information — I.Q. tests, CT scans, hormone levels — tend to look objective, inviolable, incontrovertible, especially to confused jurors and harried judges with overcrowded court schedules. "That is why admitting certain test results into evidence at criminal trials is so powerful," he says. "And that is what makes genetic testing especially pernicious."

The danger will come when imprecise tests are used as though they can predict the future, and when institutions actually use them to construct the future: when court decisions are based on the genetic profiles of the accused; when employers refuse to hire or train individuals at high risk of dying in their prime; when health-insurance companies insist on knowing the genetic profiles of their potential subscribers before paying for "pre-existing" genetic conditions; when schools require a permanent genetic record to anticipate which children will exhibit behavioral problems or learning disabilities.

Genetic discrimination already exists. Nearly 40 people responded to a request by Paul Billings of Harvard for anecdotes about such discrimination. Almost half met his criteria for inclusion in his study. One involved a man with a genetic trait for Charcot-Marie-Tooth disease, a rare neurological condition named after the three scientists who identified it. "This neurological condition can be dominant or recessive, and in the dominant, severe form the patient can get very weak in the upper and lower extremities," says Billings. "But some people who carry the trait don't get sick with it, and don't even know they have it."

Although the man had never exhibited any symptoms of the full-blown disorder, as soon as his auto-insurance company discovered that he carried the defective gene, it canceled his policy. "He had been driving perfectly well for 20 years — no accidents, no tickets," says Billings. "Insurability should be based on objective clinical findings, not on genetic tests. Say someone is disabled only when he is disabled, not when you measure a trait in his DNA that might eventually make him disabled."

This man had joined the "biologic underclass," a term used by Dorothy Nelkin and Laurence Tancredi in their new book "Dangerous Diagnostics: The Social Power of Biological Information." "If biological tests are used to conform people to rigid institutional norms," they write, "we risk reducing social tolerance for the variation in human experience. We risk increasing the number of people defined as unemployable, uneducable or uninsurable. We risk creating a biologic underclass."

Genetic tests can also identify persons who are most vulnerable to damage from workplace toxins. Some companies might use this information to prohibit vulnerable workers from certain jobs. "Should companies be permitted to select employees according to their inherited probability of contracting occupational illness?" asks Thomas H. Murray, director of the Center for Biomedical Ethics at Case Western Reserve University in Cleveland and a member of the Human Genome Project ethics group. "Or should we require that workplaces be healthful for all workers — including those predisposed to occupational illness? The cost of adapting workplaces for the most susceptible employees could be substantial."

In 1983, the Congressional Office of Technology Assessment reported that 17 companies from among the nation's top 500 had used genetic tests within the last 12 years, and another 59 were considering the possibility. This was despite the fact that at the time genetic tests did not, as the agency put it, meet "established scientific criteria for routine use in an occupational setting." A scheduled update of the 1983 report will include not only the Fortune 500 concerns but also a representative sample of other companies.

Some thinkers invoke the fearsome term "eugenics" — the deliberate manipulation of the gene pool with the idea of creating a master race — when talking about where such testing could lead us.

"We should not underestimate the eugenic dangers now," says Nelkin. "It is reflected in the language of geneticists when they talk about 'polluting the gene pool' or 'optimal genetic strategies.'" It is, she says, the dark side of our tendency to believe in "biological determinism" as an explanation for why we are who we are. Biological tests that claim to predict future function, she says, give institutions the opportunity to categorize people in dangerous and discriminatory ways.

"We will soon be able to know a lot about each other, down to the most intimate details," says Jason Brandt of Hopkins. "We'll find out there are a lot of defective people walking around, and we can, if we want, decide who is allowed to reproduce for the betterment of society."

It's not as farfetched as it seems. As Brandt sees it, many of the "conditions" that will be uncovered through genetic studies are not life-threatening, but might not fit into some societal scheme: genetic dyslexia, for example; genetic shyness; genetic arrogance; genetic left-handedness. "We know that lefties have shorter life expectancies, which is relevant to insurance companies," he says. "Do we want to eliminate all lefties prenatally? And if we do, the few lefties who are born — those who are left-handed for reasons other than genetic — will be in trouble, too. They will be marked from birth as brain-damaged." ■