

# Predisposition and Prejudice

**As scientists crack the code  
of inherited imbalances,  
policy makers confront the specter of  
genetic discrimination**

By RICK WEISS

*Ellen spent four years completing her PhD in industrial and chemical engineering. Now, wincing as a company doctor drew a few drops of blood for her pre-employment physical, she could hardly contain her excitement about the job she'd been offered at one of the country's foremost metallurgical research institutes.*

*Two days later the phone call came. You are perfectly healthy, the young doctor said. But tests have revealed you harbor a gene that can result in decreased levels of a blood enzyme, glucose-6-phosphate dehydrogenase. Without the enzyme's protection, you have a slightly increased risk of developing a red blood cell disease if you come into contact with certain chemicals in our laboratory.*

*I'm sorry, he said. The job has been offered to someone else.*

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*When Frank married at age 31 he decided to take out a life insurance policy. A swimmer and avid racquetball player with no previous hospitalizations, he felt certain his low premiums would be a worthy investment for his family.*

*Weeks later, after a routine physical exam, he was shocked by the insurance company's response. Sophisticated DNA testing had revealed in Frank's tissues a single missing copy of a so-called RB anti-oncogene and minor variations in two other genes. Computer analysis showed the molecular misprints more than tripled his risk of getting small-cell lung cancer by age 55. His application was rejected.*

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**T**hese notes from the future illustrate a potential dark side of biomedicine's present.

Scientists rightly point to the recent revolution in molecular biology and genetics as heralding a new age in medical science. In particular, ongoing efforts to create a map of the entire human genome — the DNA blueprint of heritable traits contained in every cell — promises an ever-growing range of diagnostic and therapeutic benefits.

Biochemical cartographers have already located more than 400 genetic "markers," or signposts of genetic diseases, on all 46 human chromosomes. They have mapped, for example, the exact or approximate locations of genes responsible for muscular dystrophy, Huntington's disease, some psychiatric disorders and a variety of cancers.

But as scientists home in on the molecular fine print of that corporeal contract called the human genome — and as they learn to interpret the typographical errors that can predestine an individual's medical fate — legal scholars and bioethicists express concern about the possibilities for abuse of this technology. With the newfound ability to reveal an individual's molecular secrets come significant new possibilities for discrimination.

"There are two very broad questions: who decides whether or not you'll get a test and what happens to that information," says Thomas H. Murray, director of the Center for Biomedical Ethics at Case Western Reserve University in Cleveland. "Clearly there are going to be these tests. The question is how are we going to use them and what social limits we're going to put on them."

While the case histories above are hypothetical, the tests themselves already exist. And while such testing among companies is not yet well established, neither are regulations governing their use. Eventually, experts say, as re-

searchers confirm the detailed molecular bases of physical and mental health, policy makers will have to confront an apparent discrepancy between the reality of genetic variability and the democratic ideal that all citizens are "created equal."

The issue cuts through existing social mores and legal precedents, encompassing a body of information the framers of constitutional and early statutory protections could never have envisioned — information that in many respects represents the most personal and intimate details of a person's being.

"Each new [genetic] test is going to have slightly different factual circumstances surrounding it, and each new test is going to raise slightly different ethical questions," says Murray. These questions, which relate to the overall balance between an individual's rights and those of an employer or insurer, are not new. But as scientists refine their understanding of the more than 3,000 diseases known to have genetic components, these questions "are going to come at us much faster," Murray says.

The manner in which society answers these questions, he and others say, will rival in significance the earlier, more straightforward legal and ethical challenges in the civil rights and worker's rights arenas.

**I**t's easy to draw parallels between the specters of genetic and racial discrimination. Indeed, some of the earliest documented cases of potentially discriminatory genetic screening relate to sickle cell anemia, an inherited blood disease that affects blacks almost exclusively.

This potentially fatal disease results from a single gene defect that causes a

deformation of oxygen-carrying red blood cells. It became the object of widespread screening in the United States in the early 1970s, partly in response to demands by the black community for better health care.

Almost immediately, however, observers recognized in the programs a double-edged sword, with evidence that some employers might be using test results to discriminate against blacks. Even "carriers" of the disease — whose chromosomes contain only one of two possible genes for the disease and who generally show no ill effects — were sometimes denied jobs as airline pilots, deferred from some branches of the armed forces and saddled with higher insurance premiums.

Several states have since passed laws against the misuse of sickle cell screening. But those early cases put minorities on notice that genetic testing has more than therapeutic possibilities. And now, with the genes for other diseases and medical predispositions coming into focus, every individual becomes, in a sense, a minority member with particular odds of suffering a particular medical fate.

**T**he U.S. Constitution protects citizens from government-inflicted discrimination based on immutable characteristics such as race. And to the extent the Supreme Court has ruled on the issue, federal discrimination on the basis of one's genome would appear equally precluded.

"If it's the government that wants the information for whatever reason, there are all sorts of constitutional issues that arise," says Mark Rothstein, director of the Health Law Institute at the University of Houston. "The government would seemingly have to make a strong showing to gain access to one's genetic profile because it invades the individual's bodily integrity and privacy."

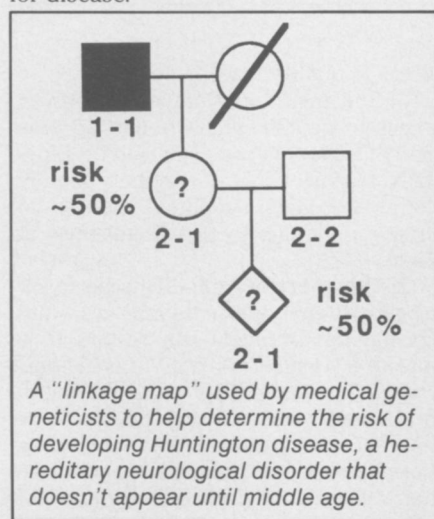
However, notes Lori B. Andrews of the American Bar Foundation in Chicago, "the Constitution protects people from the federal government and in some cases from the states, but it doesn't apply to private companies unless there is a specific statute dealing with the issue." And while Congress has extended some Constitutional protections into the private sector, the protections against private-entity genetic discrimination remain poorly defined.

"There may be a variety of reasons why an employer may want some of this information, and the legal issues are very unsettled as to whether the employer could make participation [in genetic screening] a valid condition of employment," Rothstein says.

A 1982 survey by the Congressional Office of Technology Assessment (OTA) found that only six of 366 responding

companies used genetic tests on applicants or employees. Those companies tested for genetic susceptibility to environmental or occupational hazards associated with the workplace. But another 55 companies stated they might begin genetic testing within the next five years. A 1988 OTA report, "Biology, Medicine and the Bill of Rights," says "little is known about whether the incidence of genetic screening has increased in the last five years." But other sources suggest such a trend is a near-certainty in coming years.

"Employers are obviously worried about health insurance and health care costs," says Lawrence Muike, a project director at OTA. "My guess is that a lot of employers, if they had no restraints on them, would obviously want to do some kind of testing for increased probability for disease."



In *Medical Genetics: A Legal Frontier* (American Bar Foundation, 1987), Andrews cites studies indicating that industrial physicians sometimes reject job applicants with mild diseases that have no effect on job performance. "Employment discrimination against people with potential health problems has been widespread and is likely to further increase" with the advent of better genetic tests, she writes. "The availability of genetic diagnostic technologies now raises questions about whether laws should be passed protecting people against genetic discrimination by private entities."

She concedes genetic tests may someday prove a legitimate means of screening out some workers with health-endangering sensitivities to particular workplace conditions. However, she warns, today's genetic profiles do little to assure an employer that the best person has been hired — especially when, given our incomplete understanding of genetics, job applicants at even higher risk may well be hired simply because their particular genetic weaknesses have not yet been mapped.

Andrews and others also express concern that employers may simply screen

out all but the most genetically hardy applicants rather than cleaning up an otherwise unhealthy workplace. Gene mapping "could challenge or overturn a lot of our traditional legal notions about the role of such things as occupational health and safety laws," Andrews told *SCIENCE NEWS*. Those laws today set safety limits to protect even the most vulnerable employees.

Rothstein notes another interesting and as-yet-unlitigated twist, as employers — while free to hire the most capable applicant — cannot discriminate against the handicapped. "It remains to be seen whether an individual who is currently healthy and asymptomatic but has an atypical genetic trait might not be covered under the definition of handicapped under state or federal law," he says.

**E**mployers are not the only private entities with the potential to discriminate against unusually sequenced genomes. Insurance companies, too, have a substantial financial stake in knowing an individual's propensity for illness or early death.

Already, some insurers are under fire for requiring AIDS-antibody tests as part of their underwriting procedure. While AIDS testing falls short of screening one's genetic profile, it differs from standard blood tests in revealing only an individual's exposure to a virus that years later may cause disease.

Some states — led by California — have made it illegal for insurance companies to require AIDS tests. So some insurance companies now require specialized white blood cell counts that provide indirect evidence of AIDS infection. "This gives a clue as to what's going to happen in the area of genetics and how hard it is to prohibit the acquiring of information," Rothstein says. "Maybe you can ban the use of genetic information, but it's hard to prohibit people from getting information."

Indeed, Andrews suggests, "increasingly sophisticated genetic diagnostic tests may force a total rethinking of the concept of health insurance." She notes insurance companies already exclude from their coverage — or at best charge extra for — health care costs associated with preexisting disorders. If one's genome becomes recognized as a preexisting template for future disease, genetic predispositions may be excluded from coverage.

Moreover, as insurance companies learn to make more detailed assessments of an individual's particular health risks, premiums will probably become prohibitively expensive for the most at-risk individuals. "Insurance will thus lose its social value as a means of spreading risk across groups," she concludes, adding that the apparent injustice of that situation "will provide the impetus for the

development of a national health system."

"The ramifications for the insurance industry are just startling," Rothstein says. He notes that health insurance and life insurance will be affected differently by a gene-testing trend, in part because most health insurance in the United States is written through group plans that for now don't generally require medical tests.

In contrast, most life insurance is individually written and relies more on the results of medical screening. And since policy makers see life insurance as a "luxury" compared with health insurance, legislated protections may be slower in coming.

"I can see 20 or 30 years from now that life insurance policies will be essentially accident policies, because everything else is foreseeable," says Rothstein. "The essence of insurance is you assess a risk against the unknown; if there's no [medical] unknown, the only unknown is whether you're going to get hit by a bus, right?"

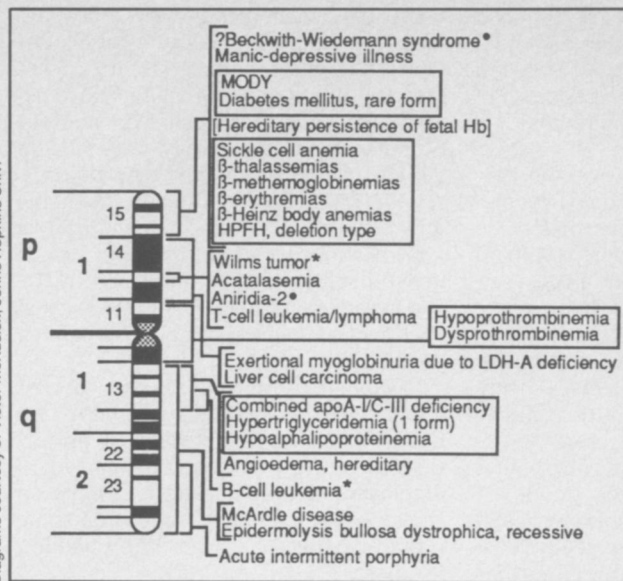
According to a 1988 OTA report, "Medical Testing and Health Insurance," such a transition appears unlikely in the near future. The report notes that genetic tests today "require considerable technical skills, may require analysis of multiple family members, are expensive to perform and are currently available for only a small number of relatively rare diseases."

However, it adds, "as genetic tests become increasingly available and used by clinicians... insurers will have to factor these test results into their underwriting decisions."

"I don't think the insurance industry will take the initial step in testing for these specific illnesses," says OTA's Miike. "But when you apply for insurance they ask you medical history questions and they also ask you to sign a waiver so they can access your medical records. So as these tests get infused more into medical practice, [insurers] are going to see these things in your medical history. And given current insurance underwriting practices, I think insurance companies are going to be faced with a dilemma of either having to raise their premiums or just not insure some of these people."

**D**eeply embedded within the issue of genetic discrimination lies the fundamental question of confidentiality. "Who should be allowed to know about my genetic profile? That is the significant question," says bioethicist Murray.

There are plenty of reasons why individuals may not want their genetic profiles revealed to an insurer, Rothstein says. "Insurers have a long history of excluding people for all sorts of medical reasons," he says. And today, "if you don't have health insurance, you don't have



Diagrams courtesy of Victor McKusick, Johns Hopkins Univ.

The "morbid anatomy" of human chromosome number 11, showing the approximate location of genes responsible for some inherited syndromes. This chromosome — one of 46 found in the nucleus of most human cells — includes the gene for sickle cell anemia, a red blood cell disease that affects blacks almost exclusively. Tests for the inherited disorder provoked accusations of racial discrimination in the 1970s.

access to quality health care."

For the insurance industry, however, access to genetic records may become critical to its survival. This will be especially true if, as some predict, genetic testing becomes simplified enough to allow individuals to test themselves at home.

The prospect of individuals performing genetic analyses on themselves — and not having to reveal the results to a potential insurer — frightens underwriters. The home diagnostics market in the United States already boasts more than 60 do-it-yourself kits, including those that detect pregnancy and some that can provide indirect evidence of colon cancer. Home testing for more specific markers of disease would boost to new heights the insurance industry's arch enemy: "adverse selection."

Adverse selection refers to the probability that people privately aware of a medical problem are more likely to seek medical insurance. The phenomenon concerns insurers because it can result in their insuring too many high-risk individuals, thus throwing off the statistical tables upon which they base their charges.

Luckily for insurers, "there are currently few home diagnostic tests that prospective insurance applicants could use to determine whether they should obtain insurance in anticipation of having to seek medical care," says the OTA.

Today, Miike says, most home tests monitor chronic conditions, such as blood sugar tests for diabetics. "But I think it's eventually going to cause a lot of problems, and I think that it will be an additional pressure on the insurers. For example, there's an HIV [AIDS-antibody] 'spot test' now that, even though it's not supposed to be used by consumers, is pretty simple to use." Still, he notes, genetic tests are "a little more complicated, because genetic disease seems to

depend mostly on a combination of factors rather than any one thing. So those tests are less likely to be done so easily or as cheaply on a mass scale."

**W**ith the balance of interests thus laid out — individuals concerned about confidentiality and discrimination, and insurers and employers concerned about adverse selection and fiscal liability — it will fall upon legislators and the courts to codify the proper use of genetic information. But one thing is certain, most scientists say: Fear of rampant genetic discrimination should not halt current gene-mapping efforts.

"I think to be an ostrich and stick our head in the sand — which is kind of what we've tended to do in the past — would be a really unfortunate way to approach this problem," says Leroy Hood, a leading developer of gene-sequencing technology at the California Institute of Technology in Pasadena. "What science does is give society opportunities. What we have to do is look at these opportunities and then set up the constraints and the rules that will allow society to benefit in appropriate ways."

In *Medical Genetics*, Andrews agrees. "The law's role in regulating uses of the knowledge gleaned from genetics has more than just medical and economic impact. The legal scheme created to handle genetics will also create the blueprint for a particular type of society."

At one extreme, she elaborates in an interview, "we could take an approach that would take us back to feudal times where you're born into your occupation and that type of thing." Or, she suggests, "we could take a more 'individual rights' approach where people could use this information individually to make better decisions about things like where they should live and work." □