Chapter 2

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Genetically determined individuality is a fact of life. Yet not long ago, the factors affecting heritability were, by today's standards, ill-defined and only partially known by scientists. During the past three decades our understanding of genetics has advanced remarkably as new methods for identifying, manipulating, and analyzing DNA have developed. Today, the secrets of inheritance are revealed by modern biology. At the same time, public awareness of the role that genetics play in daily lives is increasing.

Less well understood by both scientists and the public is interaction of the environment with genetics, and the role each plays in sickness and health. Nevertheless, it has long been recognized that genetic risks are posed by various workplace environments, such as exposure to radiation or certain chemicals. In an effort to reduce occupational illness, some have advocated genetic testing of workers to identify healthy individuals (or populations) at risk for, or susceptible to, a variety of work-related conditions. Such genetic testing has been heretofore viewed strictly as a tool to prevent occupational disease (23). However, recent progress in developing genetic tests to detect inborn conditions not obviously associated with worksite exposures--e.g., Huntington's disease or heart disease--and the advances expected to be made from the human genome project, has been coupled increasingly with the notion of using these tests in the workplace. A new dimension has been added to the debate surrounding genetic testing conducted at the workplace (1,2,3).

This report covers the scientific, ethical, legal, and social issues of genetic testing of workers. While the report is limited to issues central to use of genetic technologies, some discussion of other medical and biological testing of workers is presented to place genetic testing in context. What is excluded are job-associated injuries, nongenetic technologies to prevent occupational disease, and reproductive hazards in the workplace, which have all been assessed in previous Office of Technology Assessment (OTA) reports (21,22). Similarly, acquired immunodeficiency syndrome (AIDS) testing, the implications of genetic testing for health insurance, regulating carcinogens, technologies to detect heritable mutations, identifying and regulating neurotoxins, and nonmedical uses of genetic tests are topics of other OTA reports (9,10,1 1,13,20,24).

WHAT IS GENETIC TESTING?

Genetic testing includes a number of technologies to detect genetic traits, changes in chromosomes, or changes in DNA. As used in the workplace, it encompasses two activities: monitoring and screening. Thus, genetic testing of employee populations involves both examining persons for evidence of induced change in their genetic material (monitoring) and methods to identify individuals with particular inherited traits or disorders (screening). To avoid confusion, the general term "genetic testing" will not be used in the text, rather, the more specific terms genetic monitoring and screening will be used instead.

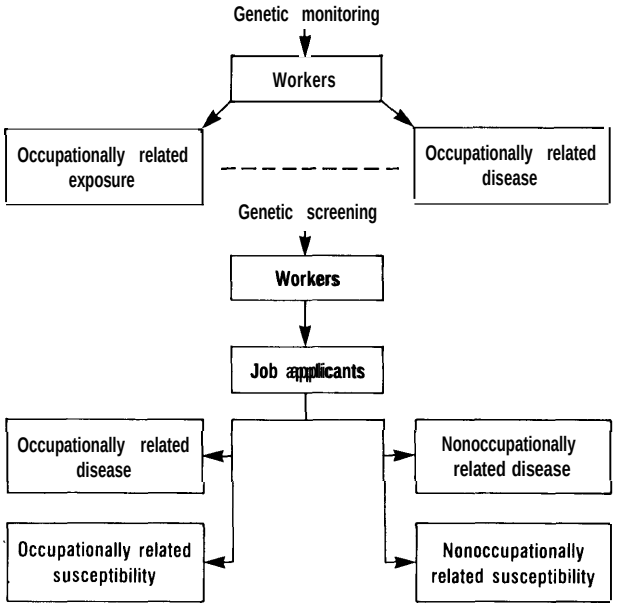
Genetic monitoring involves periodically examining employees to evaluate modifications of their genetic material-e. g., chromosomal damage or evidence of increased occurrence of molecular mutations—that may have evolved in the course of employment. The premise is that such changes could indicate increased risk of future illness. The putative cause is workplace exposure to hazardous substances. Because ambient exposures, personal habits and lifestyle decisions (e.g., tobacco use, etc.), and age can also induce changes in genetic material, genetic monitoring can be used to periodically monitor risk arising outside of the workplace. In short, genetic monitoring ascertains whether the genetic material of the group of individuals has altered over time. In general, current techniques are not exposure-specific but serve merely as an indicator of recent exposure.

Genetic screening is a process to examine the genetic makeup of employees or job applicants for certain inherited characteristics. (Employees could be screened on different occasions for different traits or with improved technology, but generally only once for each characteristic.) Genetic screening can be used in two distinct ways. First, employees could be screened for the presence of genetically determined traits that render them susceptible to a pathological effect if exposed to specific agents. An example of such genetic screening would be a test

for traits that might identify an employee with a genetic predisposition to an occupationally related disease. (Similarly, job applicants could be screened for a trait prior to being hired for a position where exposure could occur.) Second, employees or job applicants could be screened to detect general heritable conditions, not just conditions associated with occupational illness. Reasons for using the different classes of tests vary, and are discussed in the following section. In either case, whether screening for an occupationally related trait or one not related to job exposure, genetic screening tests involve examinations for inherited traits where a single measure is usually sufficient because generally these inherited characteristics do not change.

Genetic screening differs significantly from genetic monitoring. In most cases, screening requires a one-time test to detect a single trait in a worker or job applicant, while monitoring generally involves multiple tests of a worker over time. Most importantly, in genetic screening the focus is on the preexisting genetic makeup that workers or job applicants bring to the job. This is distinct from genetic monitoring, where the focus is on changes in the genetic material induced from hazardous exposures at the workplace (see figure 2-l).

Figure 2-l-Components of Genetic Testing in the Workplace



SOURCE: Office of Technology Assessment, 1990.

WHY USE GENETIC MONITORING AND SCREENING IN THE WORKPLACE?

As mentioned, genetic monitoring and screening tests are methods for identifying individuals or groups for evidence of alteration in the genetic material or with particular inherited traits. Detecting modifications or traits can inform individuals that they are potentially at increased risk for disease, or could pass a trait to their offspring. By applying genetic monitoring and screening tests to a group of apparently well persons and identifying those who have a greater probability of developing a disease, counseling, prevention, or early treatment (if available) become possible. The use of genetic monitoring and screening of selected individuals or groups at high risk through employers has not been a long-standing practice.

The recent development of tests for human genetic disorders (14) has fueled interest in genetic monitoring and screening of workers. To some extent, as interest in AIDS and drug testing of workers has increased, so has interest in genetic monitoring and screening by employers (4). Nevertheless, many aspects of genetic monitoring and screening in the workplace differ from other types of testing of workers and remain controversial. Many of the objections raised-scientific and social-are discussed in following chapters. In spite of objections, why consider using genetic monitoring and screening tests in the workplace? Genetic monitoring of employees could be performed on groups of employees to identify work areas for increased safety and health precautions, and to indicate a need to lower exposure levels for a group exposed to a previously unknown hazard. Genetic screening for occupationally related traits could be performed to ensure appropriate worksite placement of employees susceptible to certain occupational diseases, and ensure that employers place those workers most susceptible to a specific risk in the least hazardous environments. Both types of genetic screening (occupational and nonoccupational) could be performed to improve employee productivity and lower workers' compensation costs through better worker health; promote and encourage general health awareness; and improve employers' health care cost-containment efforts, especially for health insurance.

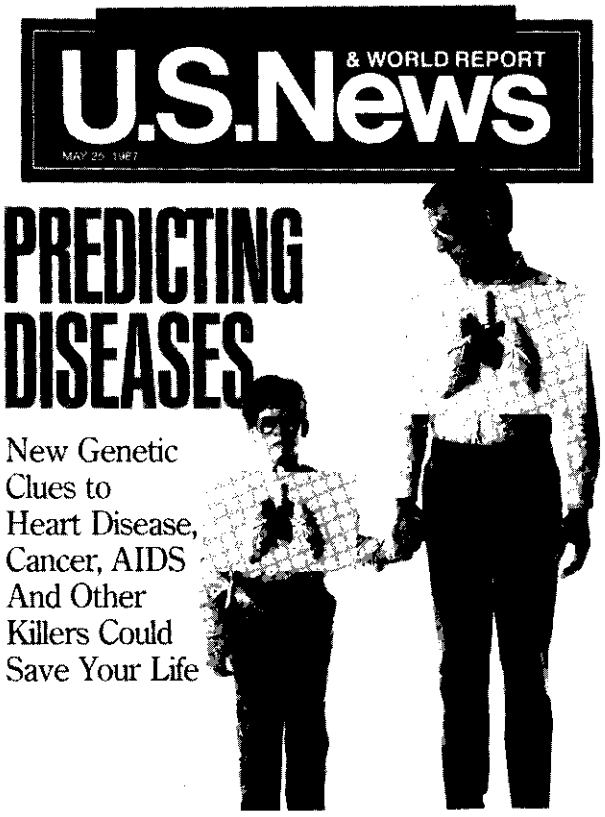


Photo credit: U.S. News & World Report, *May 25, 1987*

Media coverage of genetic monitoring and screening.

Worksite risks create costs to employers, who might be required to compensate individuals through workers' compensation for lost earnings, or workers' estates through tort liability claims for premature death. Genetic screening of workers or job applicants could be a tool to identify individuals with a particular genetic trait that indicates susceptibility to occupational illness if they are exposed to specific hazards, such as radiation or certain chemicals. Periodic genetic monitoring of employees could be used to detect induced genetic change that could indicate an increased risk for certain diseases, in particular cancer. Thus, genetic monitoring and screening could lead to improved worker health and payment of lower workers' compensation costs. On the other hand, without clear correlations between workplace hazards and occupational illnesses and without cost-effective tests, any expectations of money saved by genetic monitoring and screening for job-related conditions could be minor.

Increasingly, costs to U.S. employers of health-related benefits have skyrocketed. In particular, to avoid rising health care costs, many large companies are adopting self-insurance plans. Self-insurance plans are exempt from State mandates and other forms of State regulation (6). Business health spending between 1980 and 1987 almost doubled, from $68.1 billion to $134.6 billion (6). One company of 70 employees says that, in 16 years its health insurance premiums will exceed its payroll if both continue their present growth rates (5). Companies concerned about health insurance costs could be interested in screening workers and job applicants who are likely to develop genetically based diseases and could impose high costs on a company's self-insured health program. Similarly, companies could engage in genetic monitoring-again, to safeguard workers' health while simultaneously reducing the burden of occupational illness on their health costs.

In this respect, genetic monitoring and screening in the workplace differ. Genetic monitoring can be viewed as an extension of several types of biological monitoring in the workplace to detect changes or assess exposures that could be associated with increased exposure to occupational or nonoccupational risk. Genetic screening, on the other hand, can be used to detect both traits that indicate a predisposition to occupational disease, as well as traits not associated with workplace illness. Some argue from an economic standpoint that genetic monitoring and screening in the workplace to limit occupational illnesses could be less important in the long run than genetic screening by employers to limit general company health care expenses (2). A window on this development could be corporate "wellness" programs, or other company-sponsored health promotion programs (see box 2-A) that emphasize prevention and encourage employees to adopt healthier lifestyles (2).

From a policy standpoint, these differences—monitoring v. screening and occupational illness v. general health-could be significant. Some criticize all types of genetic monitoring and screening in the workplace as paternalistic and discriminatory, while others advocate that, properly implemented, genetic monitoring and screening (for both purposes) programs benefit both workers and employers. Others, however, maintain that it is one thing to monitor or screen workers because they are at increased risk for occupational illness induced by the workplace, but quite another to screen persons because they or their offspring-who could be covered on an employee's

Box 2-A--Cancer Detection in the Workplace

Among the greatest fears of industrial workers is the risk of cancer from exposure to hazardous substances. Although employees are concerned about cancer risk, they are not always informed about the specific dangers of the chemicals with which they work. By increasing employee and employer involvement in cancer prevention and detection, both groups stand to benefit: employees with gains in personal health, and employers with higher worker morale and productivity and reduced health expenditures. Because cancer risks vary from worksite to worksite, worker perceptions of various job hazards related to cancer and chemical exposure are important. From 1978 through 1987, the National Cancer Institute (NCI) allocated $14 million to the Occupational Safety and Health Administration (OSHA) for cancer prevention training and education of workers. In 1983, NCI awarded grants to five unions, that had participated in OSHA's education program, to evaluate the impact of the unions' cancer prevention and education programs.

A 1987 study by the International United Rubber, Cork, Linoleum, and Plastic Workers of America, one of the participating unions, questioned approximately 24,000 of its members about their knowledge of chemical hazards, the location of engineering controls, and the use of daily safety procedures. Prior to the study, employees had participated in the industry's cancer control program, which included worker education.

Despite the fact that over 10,000 different chemicals, many hazardous, are used by these workers, the study found that 22 percent of workers were not sure whether they worked with dangerous chemicals, and only 6 percent felt they were very informed about chemical hazards. Percentages of employees saying they were well-informed varied widely from company to company, ranging from 16 percent at one company to 32 percent at another. Thus, for adequate cancer education, greater understanding of chemical-specific risks is needed.

In addition to worker perception and involvement, management health programs can play an important role. Currently, several companies offer employees cancer screening clinics and other cancer detection programs. One such program, offered by Pennzoil (in conjunction with the Kelsey-Seybold Foundation) to employees at a Texas facility, began m 1984 as a cancer awareness clinic for white-collar employees to discover cancers unrelated to worksite exposure. The Pennzoil program, strictly voluntary and confidential, has since been expanded to industrial petroleum workers and other locations in 22 States, where the cancer detection procedure can include workplace risks.

The Pennzoil program involves an initial lecture on cancer risk and detection, and a personal cancer examination for those requesting one. Corporate management strongly supports these meetings, and encourages employees to attend the lectures. As part of the program, employees also complete questionnaires about cancer risk behaviors and personal medical histories. Those employees showing an increased risk of cancer are offered followup counseling sessions with Kelsey-Seybold Foundation Cancer Prevention Center physicians and medical tests, if necessary, paid for by Pennzoil. All employees also are offered yearly screening or followup examinations. Pennzoil receives only summary data on participation, cancer detection, and demographic information. Both increased employee morale and detection of potential tumors resulted. Along with Pennzoil's expansion of the program, Exxon Chemical Americas has undertaken a similar project with the Kelsey -Seybold Foundation Cancer prevention Center.

The experience of cancer screening in the workplace suggests that the cooperation of corporate management and private organizations, together with an accurate assessment of employee understanding of workplace risk, can create a healthier, more productive working environment one benefiting both employer and employee. At present, genetic monitoring detects genetic changes that could result m greater risk of cancer. Future advances in genetic technologies could result in increased cancer testing and education at worksites. As genetic technologies make detection of cancer or other health risks more accurate, programs such as those just described could serve as models. For genetic monitoring and screening, in particular, implementing successful worker education will be crucial.

SOURCES: Office of Technology Assessmcnt, 1990, based on M. Minkoff, Kelsey-Seybold Foundation Cancer prevention Center, Houston, TX, personal communication, October 1988; A.P. Schenck, A.D. Kaluzny, G.M. Hochbaum, et al., "Worker Perceptions and Actions Toward Cancer Control in the Workplace: An Analysis of Baseline Data"; and L. Zimmerman, G. Jackson, J. Hughes, et al., ''CanCer Education and Screening in the Workplace: The Corporate Perspective, " *Advances in Cancer Control: The War on Cancer—15 Years of Progress,* P.F. Engstrom, LE. Mortenson and P.N. Anderson (eds.) *(New* York, NY: Alan R. Liss, Inc., *1987).*

FORM (31 2602

PENNZOIL COMPANY
HEALTH RISK APPRAISAL

NAME		HOME ADDRESS	
SOCIAL SECURITY NUMBER	BIRTH DATE	COMPANY NUMBER	TODAY'S DATE

Health Risk Appraisal Is an educational tool. It shows you choices you can make to keep good health and avoid the most common causes of death for a person your age and sex. This Health Risk Appraisal Is not a substitute for a check-up or physical exam that you get from a doctor or nurse. It only gives you some ideas for lowering your risk of getting sick or injured In the future.

DIRECTIONS: To get the most accurate results answer as many questions as you can and as best you can. If you do not know the answer leave it blank, Questions with a • (star symbol) are important to your health, but are not used by the computer to calculate your risks. However, your answers may be helpful in planning your health and fitness program.

Please check or fill-in the appropriate numbers.

1. SEX		1 ☐ Male 2 ☐ Female
2. AGE		_____ Years
3. HEIGHT	(Without shoes) (No fractions)	_____ Feet _____ Inches
4. WEIGHT	(Without shoes) (No fractions)	_____ Pounds
5 Body frame size		1 ☐ Small 2 ☐ Medium 3 ☐ Large
6. Have you ever been told that you have diabetes (or sugar diabetes)?		1 ☐ Yes 2 ☐ No
7. Are you now taking medicine for high blood pressure?		1 ☐ Yes 2 ☐ No
8. What is your blood pressure now?		Systolic (High number) _____ | _____ Diastolic (Low number)
9. If you do not know the numbers, check the box that describes your blood pressure.		1 ☐ High 2 ☐ Normal or Low 3 ☐ Don't Know
10. What is your TOTAL cholesterol level (based on a blood test)?		_____ mg/dl
11. What is your HDL cholesterol (based on a blood test)?		_____ mg/dl
12. How many cigars do you usually smoke per day?		_____ cigars per day
13. How many pipes of tobacco do you usually smoke per day'?		_____ pipes per day
14. How many times per day do you usually use smokeless tobacco? (Chewing tobac co, snuff, pouches, etc.)		_____ times per day
15. **CIGARETTE SMOKING** - How would you describe your cigarette smoking habits?		1 ☐ Never smoked (go to question 18) 2 ☐ Used to smoke (go to question 17) 3 ☐ Still smoke (go to question 16)
16. STILL SMOKE. How many cigarettes a day do you smoke?		_____ cigarettes per day (go to question 18)
17. USED TO SMOKE -a. How many years has it been since you smoked cigarettes fairly regularly?		_____ years
b. What was the average number of cigarettes per day that you smoked in the 2years before you quit?		_____ cigarettes per day
18. In the next 12 months how many thousands of miles will you probably travel by each of the following? (NOTE: U.S. average = 10,000 miles)	a. Car, truck, or van:	_____ ,000 miles
	b. Motorcycle:	_____ ,000 miles
19. On a typical day how do you USUALLY travel? (Check one only)		1 ☐ Walk 5 ☐ Mid-size or full-size car 2 ☐ Bicycle 6 ☐ Truck or van 3 ☐ Motorcycle 7 ☐ Bus, subway, or train 4 ☐ Sub-compact or compact car 8 ☐ Mostly stay home

Photo credit: Pennzoil Co.

Health risk appraisal form from the Pennzoil program.

health plan—are at high risk for a disease not related to occupational exposure. Finally, some argue that screening per se, even if to reduce occupational illness, is unfair because it *a priori* measures heritable conditions beyond an individual's control, while genetic monitoring is similar to other forms of successful biological monitoring (e.g., benzene or lead exposure) that are performed from body fluids or tissue samples.

GENETICS IN THE WORKPLACE: A HISTORY OF CONGRESSIONAL CONCERN

Congressional interest in human genetics, genetic diseases, and genetic technologies is not new. In 1972, Congress passed the National Sickle Cell Anemia Control Act (Public Law 92-294), amending it 4 years later to the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act (Public Law 94-278).

Beginning in the early 1980s, a public debate began about the feasibility of mapping, and perhaps sequencing, the human genome. Congress held several hearings on this issue and requested an OTA assessment on the subject (12). Two agencies, the National Institutes of Health and the Department of Energy, received funding to perform research for the human genome project (25). Much of the research done for the genome project will be important to the scientific advancement of genetic monitoring and screening techniques.

The 1983 OTA Report

In the late 1970s and early 1980s, reports surfacing about genetic monitoring and screening in occupational settings captured the interest of Congress. Concern about the scientific and social issues of such testing prompted the House Committee on Science and Technology to hold hearings and request an OTA assessment of the role of genetic testing in preventing occupational disease (7,8,23). As part of its study, OTA surveyed American industry and unions to determine the extent and nature of employer genetic monitoring and screening.

In the intervening years, understanding of human molecular genetics and biotechnologies applicable to the field have expanded enormously. Both the number of applications of such technologies and the technical capability to detect genetically based disorders have increased, linked to rapid scientific developments in recombinant DNA and cell culture techniques. This has heightened congressional concern about their applications (12,14,15,16,17,18, 19). Debates surrounding the changing climate of employee testing (e.g., AIDS, drugs, and polygraph) (4) and, as described in the following section, efforts to map the human genome, also combined to stimulate congressional interest in reassessing the extent of and issues surrounding genetic monitoring and screening in the workplace.

Impacts of the Human Genome Project

Efforts underway to map and sequence the human genome stand to have a significant impact on many aspects of biology, medicine, and health-including genetic monitoring and screening. (The history and debate surrounding mapping and sequencing the human genome have been analyzed in a separate OTA report (12).) To date, genome projects have accelerated the production of new technologies, research tools, and basic knowledge. At current or perhaps increased levels of effort, they may eventually make possible the control of many human diseases-first through more effective methods of predicting or detecting disease, then, in some cases, through development of effective therapies based on improved understanding of disease mechanisms. Although not a direct result of the genome project, advances in human genetics and molecular biology have already provided insight into the origins of such diseases as cystic fibrosis, hemophilia, sickle cell disease, and hypercholesterolemia.

The new technologies developed through human genome projects research will also be used to assess public health needs. Techniques for rapidly sequencing DNA, for example, may facilitate the detection of mutations following exposure to radiation or environmental agents. Susceptibilities to environmental and workplace toxicants might be identified as more detailed genetic linkage maps are developed, and special methods of surveillance could be used to monitor individuals at risk.

However, profound ethical questions are posed by possible applications of and access to these genetic data. The complexity and urgency of these issues will increase in proportion to advances in mapping and sequencing. There is no doubt that continuing scientific advances in mapping and sequencing the

human genome accelerate diagnostic applications. Progress to date indicates that the ability to diagnose a genetic abnormality precedes the development of therapeutic interventions and that this gap may be growing. An important related issue is that of access to this information by third-parties such as insurance companies or employers and how this information is used. These questions are complex and are not likely to be resolved in the near future. It will therefore be necessary to ensure that some means for explicitly addressing ethical issues accompanies such scientific research. A working group on ethics was established in January 1989 by the Program Advisory Committee on the Human Genome, and a percentage of the genome budget will go toward studying ethical issues associated with the genome research (25).

THIS OTA REPORT

Health and safety of the U.S. workforce involves many components. This report presents the technological, ethical, legal, and personal implications of employers using, *genetic* technologies. Where applicable, other types of medical testing are discussed to place genetic technologies in context. This report addresses two entirely different purposes of genetic monitoring and screening in the workplace: to prevent occupational disease and to detect nonoccupationally linked conditions related to general employee health. To place both genetics and worker health in context, historical perspectives of genetic monitoring and screening in this country are presented, as are perspectives on the evolution of occupational health.

With this report, OTA assesses the current practice of genetic monitoring and screening by U.S. employers, as determined by surveys of 1,500 companies, the 50 largest utilities, and 33 unions. Beyond determining the extent of genetic monitoring and screening, the report also examines the attitudes of employers toward using genetic procedures in the workplace. In addition, it examines the very notion of "genetic normality,' and explores what role both genetics and a person's job play in his or her identity-and how these two parameters could conflict.

For policymakers, this report presents a series of policy issues and options for congressional action aimed at addressing the concerns that arise when personal identity, corporate interests, and Federal regulation and oversight collide over genetic monitoring and screening in the workplace.

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