

Chapter 3

**Occupational Health and
Genetic Monitoring and Screening:
An Overview**

CONTENTS

	<i>Page</i>
HISTORY OF GENETIC MONITORING AND SCREENING	41
Screening Programs for Sickle Cell Anemia and Trait	41
Industry Involvement in Genetic Monitoring and Screening	44
INTRODUCTION TO OCCUPATIONAL ILLNESS	45
Costs of Occupational Illness to the Employee	46
Costs of Occupational Illness to the Employer	46
Costs of Occupational illness to Insurance Industry	46
Costs of Occupational Illness to Society	46
FEDERAL AGENCIES INVOLVED IN OCCUPATIONAL SAFETY AND	
HEALTH	46
Occupational Safety and Health Administration	46
National Institute for Occupational Safety and Health	47
National Labor Relations Board	48
Environmental Protection Agency	50
SUMMARY AND CONCLUSIONS .	50
CHAPTER 3 REFERENCES	50

Boxes

<i>Box</i>	<i>Page</i>
3-A. Community Screening for Tay-Sachs Disease	43
3-B. Occupational Safety and Health in Finland	48
3-C. NIOSH Surveys of the Workplace	49

Occupational Health and Genetic Monitoring and Screening: An Overview

The concept of genetic monitoring and screening emerged prior to the discovery of the molecular structure of DNA by Watson and Crick in 1953. Although not always tied to the workplace, an examination of the evolution of genetic monitoring and screening can provide valuable insight to the procedures' current and potential employment applications. This chapter discusses the history of genetic monitoring and screening as they have been used in both workplace and nonoccupational settings. In addition, the economics of genetic monitoring and screening are examined by evaluating the costs of occupational illness to the employee, the employer, the insurance industry, and society. Finally, the Federal agencies either currently involved or potentially involved in the policy matters associated with genetic monitoring and screening in the workplace are introduced.

HISTORY OF GENETIC MONITORING AND SCREENING

As early as 1938, noted geneticist J.B.S. Haldane discussed "sorting out workers according to their susceptibility to occupational hazards" (7). He suggested, for example, screening out potters who had "constitutions" that could make them susceptible to bronchitis. Haldane went on to suggest that the entry into the workplace of those with the hereditary trait for bronchitis could be regulated.

One of the first cases of an individual's genetic condition reacting to either a chemical agent or drug was reported in the 1950s. During the Korean conflict, some American soldiers taking the antimalarial drug, primaquine, experienced hemolysis (the destruction of red blood cells) (4). The hemolysis was attributed to their carrier status of glucose-6-phosphate dehydrogenase (G-6-PD) deficiency, which results in less of the enzyme G-6-PD in their red blood cells (see ch. 5 for further discussion). People with this trait are often found in malaria-ridden regions, and it is common among Blacks and those with Mediterranean origins. The trait protects people somewhat against contracting malaria, but also can result in hemolysis when triggered by eating fava beans or by taking certain drugs such as

antimalarial medication. The soldiers in Korea who reacted to the antimalarial medication, as a result of G-6-PD deficiency, were characterized as "hyper-susceptible."

It was believed by the early 1960s that carriers of G-6-PD deficiency could also undergo hemolysis after exposure to certain chemicals. Since then, some employers believe that those with G-6-PD deficiency should not handle aromatic nitro or amino compounds, industrial chemicals prevalent in dynamite factories. The concept of "hypersusceptibility" was being applied to the workplace. One idea considered was the use of a preplacement examination to detect susceptible employees (3 1). Once such employees were discovered, their susceptibility would be factored into their workplace assignment. By the early 1970s, performing "hypersusceptibility" screens had been proposed for five conditions, including G-6-PD deficiency, sickle cell disease, and alpha-1-antitrypsin deficiency (32). Approximately 50 human genetic diseases have been identified as having the potential to enhance an individual's susceptibility to toxic or carcinogenic effects of environmental agents (4) (see ch. 5). Genetic screening may be justified depending on the type and severity of the condition, as well as the difficulty or the expense of performing the genetic screening test (17).

Screening Programs for Sickle Cell Anemia and Trait

Sickle cell anemia in the United States was the subject of a great deal of public attention in the early 1970s. The Black community felt that it had become a 'neglected disease' and that it had received little Federal research funding. As a result of public debate, considerable Federal interest developed in sickle cell anemia (22). President Nixon made an appeal for an effort to combat sickle cell anemia in his 1971 health address to Congress (9). Laws requiring sickle cell screening were eventually passed in at least 20 States (1). These laws targeted newborns, schoolchildren, marriage license applicants, and inmates of penal institutions (19,22).

WHAT DO YOU KNOW ABOUT YOUR GENETIC MAKEUP?

TAY-SACHS FACTS:

- TAY-SACHS DISEASE IS AN INHERITED GENETIC DISORDER OF INFANCY
- A CHILD WITH THE DISEASE CAN BE BORN TO HEALTHY PARENTS WHO ARE CARRIERS OF THE TAY-SACHS GENE
- ANYBODY CAN BE A CARRIER - CARRIER RATE IS 1:150 IN THE GENERAL POPULATION AND 1:30 IN THE JEWISH POPULATION

EARLY CARRIER DETECTION CAN PROTECT FUTURE GENERATIONS

Sponsored by: AEPi; Hillel; Stanford Genetic Counseling, Dept of Gyn/OB; Cowell Health Promotion Program

- BE SAFE - BE TESTED - Take the Carrier Detection Test

For Additional Information Call
NORTHERN CALIFORNIA TAY-SACHS PREVENTION PROGRAM - (415) 658-5568

This is a public service program supported by the State of California Department of Health

BE TESTED AT: STANFORD UNIVERSITY

WED., MAY 16 11 :00am-2:00pm Tresidder Union,
Oak Lounge West
5:30pm-7:30pm Business School,
Room 54

THURS. MAY 17 8:00am-10:00am Med. Center,
M106 (Med. Stu. Lounge)
11 :00am-2:00pm Tresidder Union,
Oak Lounge West

(over 17 and non-pregnants only, please)

Photo credit: Alpha Epsilon Pi

An advertisement for Tay-Sachs screening.

Many who participated in screening programs found the resulting information difficult to interpret. A 1975 study by the National Academy of Sciences (NAS) reinforced this notion. The study found that many of the sickle cell screening programs initially established did not provide proper genetic counseling, and did not always keep the results confidential (19). For many, the difference between sickle cell anemia and sickle cell trait was not made clear in the screening program process. (Sickle cell anemia occurs when the patient inherits the gene for sickle hemoglobin from both parents; sickle cell trait occurs when the gene for sickle hemoglobin is passed on from only one parent.)

Some who participated in screening programs and were found to be carriers of sickle cell trait experienced discrimination at work and from insurance companies that raised their premiums (9). Apparently, discrimination in the workplace sometimes occurred because it was believed that those with sickle cell trait could experience the painful episodes characteristic of sickle cell disease (which occur when sickle-shaped red blood cells occlude the normal flow of blood) (2,24). The result for some

job applicants was denial of employment based on their carrier status and removal for some who were already employed. In some cases, life insurance companies either raised premiums for carriers or denied coverage for applicants with sickle cell trait (9). At that time, laws were enacted in Florida, Louisiana, and North Carolina that prohibited such discrimination (26). Since the mid- 1970s, many of the State laws requiring mandatory sickle cell testing have been repealed. The sickle cell screening programs of the 1970s are often compared to Tay-Sachs disease screening programs (see box 3-A).

Controversy still exists over whether the carriers of sickle cell trait are at risk of having sickling episodes. A 1974 NAS report concluded "there was insufficient scientific information to form a basis for excluding carriers from the armed forces or for limiting their activities or duties" (20). However, it was not until 1981 that the U.S. Air Force Academy reversed its policy of excluding Blacks with sickle cell trait from pilot training, based on the belief that a low-oxygen environment (e.g., high-altitude exer-

Box 3-A-Community Screening for Tay-Sachs Disease

Tay-Sachs disease (TSD) screening programs were initiated in the early 1970s, around the same time the Nation's sickle cell screening programs began. While mass sickle cell screening eventually ended because of the belief that the information was sometimes used to the detriment of participants, TSD screening has been cited as a model in professional-community cooperation. TSD is a rare inherited, incurable, neurological disease most prevalent in Jews of Ashkenazi origin. It results in progressive neurologic deterioration and results in death within a child's first few years.

Many screening programs at the local level were initiated following the development of the blood test to detect TSD carrier status in 1970. Screening can determine whether one or both parents are carriers for TSD. If both are carriers, they have a risk of 1 in 4 in each pregnancy of having a child affected with TSD.

A mass screening program involving some 7,000 individuals was initiated in the Baltimore-Greater Washington, DC area in the early 1970s. Six to eight weeks prior to this program, the community received some education about TSD. Information was disseminated through the press, TV, radio, letters from religious, medical and community groups, medical presentations, and telephone contact. Eventually, similar screening programs were initiated in at least five countries.

In one survey, one-half of the TSD carriers were still uneasy with the information even though they had been informed of the meaning of carrier status through extensive educational efforts and genetic counseling. Current emphasis is on hospital- or physician-based screening for TSD with individual couples. Overall in the United States, TSD screening has reduced the incidence of TSD in the Jewish population by at least 70 percent.

SOURCES: Office of Technology Assessment 1990, based on M.J. Goodman and L.E. Goodman, "The Overselling of Genetic Anxiety, *The Hastings Center Report*, October 1982; R.H. Kenen and R.M. Schmidt "Stigmatization of carrier *status*: *social* replications of Heterozygote Genetic Screening Program," *American Journal of Public Health* 68:1116-1120, 1978.

tion or flights, or deep-water activity) would cause a carrier to undergo a sickling episode (8,14).

While States were passing sickle cell screening laws, Congress passed the National Sickle Cell Anemia Control Act (Public Law **92-294**) in 1972. **Only States that met the requirements of the act were eligible for Federal funds.** To receive funds, a State program had to be voluntary, a requirement designed to defuse the controversy over mandatory screening programs. Although the intent of the law was to reduce stigmatization of and discrimination against the carriers of sickle cell trait, many saw these concerns as continuing unabated (23).

The National Sickle Cell Anemia Control Act was updated in 1976 and renamed the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act (Public Law 94-278; hereinafter, The National Genetic Disease Act). Much broader in scope, it authorized increased Federal funds to be awarded as grants and contracts by the Secretary of the Department of Health, Education, and Welfare. Goals of the National Genetic Disease Act included increased levels of basic and applied research, training, testing, counseling, and education programs on genetic disease. Again, the emphasis of

this legislation was on voluntary participation in testing programs. It also emphasized using proper guidelines for confidentiality of results, and stressed the availability of genetic counseling for all participants (23).

Advances in the treatment of sickle cell anemia have prompted renewed interest in screening newborns. A certain percentage of infants with sickle cell anemia are at risk of overwhelming infection and sudden death in the first few years of life. If their sickle cell disease is identified early on, affected infants can be given prophylactic antibiotics that significantly reduce the risk of infection and lower the overall mortality rate from the disease in early life (6). A 1987 National Institutes of Health conference on newborn screening for sickle cell disease concluded that every child should be screened to prevent the potentially fatal complications of sickle cell disease in infancy. In addition, for a program to be effective, proper followup capabilities should be in place prior to instituting a screening program. The services available to the patients and their families should include medical care, psychosocial support, and genetic counseling (35).

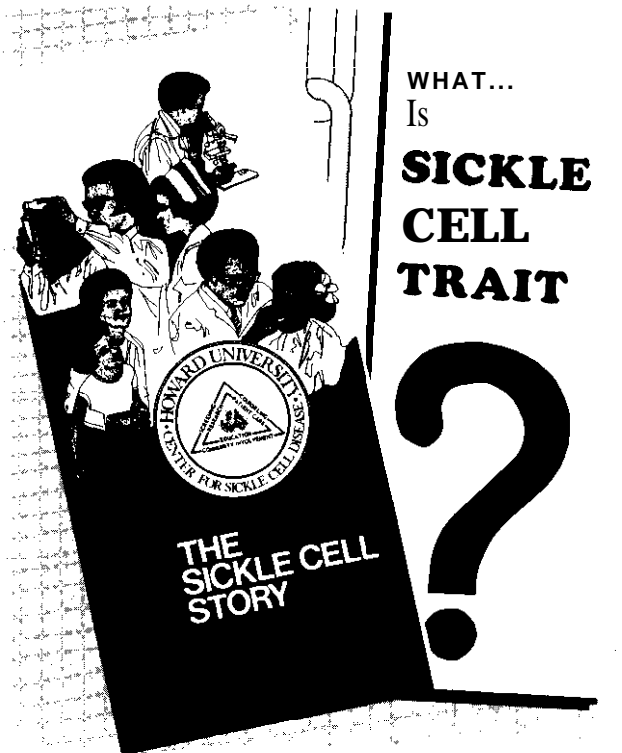


Photo credit: Howard University

Pamphlets describing sickle cell anemia and sickle cell trait.

Industry Involvement in Genetic Monitoring and Screening

Although the concept of screening out unhealthy workers has been around since the early part of this century, most screening technologies have only recently become available. Several incidents of industry involvement in genetic monitoring and screening since the 1960s have been reported. They have varied from research programs using genetic monitoring techniques for evaluating chromosomal damage to efforts in genetic screening to detect genetic conditions such as G-6-PD deficiency or sickle cell trait. Each use brings with it its own set of scientific, legal, and ethical issues.

An early pilot program of cytogenetic monitoring was initiated by Dow Chemical in 1964. (See ch. 4 for a discussion of cytogenetic monitoring.) Within 10 years, some 43,044 chromosomal profiles had been performed on 1,689 employees involved in the chemical production process. In addition, 25,104 chromosomal profiles were conducted on 1,302 applicants as part of a preemployment exam (13).

These cytogenetic analyses and preemployment exams provided a baseline for future cytogenetic analyses of an individual. By comparing an employee's current data to that taken previously, the employee served as his or her own control. In 1977, Dow conducted an evaluation of workers exposed to both epichlorohydrin and benzene which, due to the ambiguity of the findings, gave rise to a controversy regarding use of cytogenetics for population monitoring (3).

Their efforts were criticized for several reasons, which included failure to take into account the effects of personal habits and lifestyle decisions (e.g., tobacco use, etc.), and age on chromosomal change. Also, the results of these profiles were given to those employees involved without properly explaining what the results meant in terms of their risk of cancer and genetic disease in their offspring (3,1 1). The program was terminated in 1977 by Dow Chemical in response to the questions about the validity and reliability of the results, and the interpretation of differences in results between employee groups.

Another corporation, Johnson & Johnson, conducted some cytogenetic monitoring research in 1980 to examine the effects of ethylene oxide, a sterilant gas, on workers (12). The project's intent was to determine whether workers exposed to ethylene oxide experienced any more chromosomal changes than those not exposed. This was done by analyzing sister chromatid exchanges and chromosomal aberrations in workers at three plants where three levels of exposure existed (see ch. 4). These groups were then compared to three control groups not exposed to ethylene oxide. After 6 months, the study found that employees working with the highest concentrations of ethylene oxide had a significantly greater incidence of sister chromatid exchange than the control group. This prompted Johnson & Johnson to discontinue the use of ethylene oxide at that particular plant (8).

A genetic screening program for sickle cell trait took place at the DuPont Corp. in the 1970s. According to company officials, the program was initiated at the request of a group of Black employees. The resulting information was not used for employment decisions, officials later stated. Rather it was for the "information and edification" of the employees (8). DuPont was criticized by some because, although there were many employees of

Mediterranean origin at the facility, only Blacks were given the sickle cell test. (People of Mediterranean origin as well as Blacks have a higher incidence of sickle cell anemia.)

Both the Dow cytogenetics program and DuPont's sickle cell screening program were later to become the focus of a great deal of controversy. A series of newspaper reports in 1980 argued that genetic monitoring and screening programs were widespread in industry and had been used in industrial settings for several years (29). Much was made over whether DuPont was actually using the information derived from the sickle cell screening program to make hiring or job placement decisions. The Federal response to genetic monitoring and screening was also examined. The newspaper series identified a section on medical surveillance found in the Code of Federal Regulations that stated that in a preassignment examination before exposure to certain carcinogens, a worker's personal history that included genetic and environmental factors could be taken. As mentioned in chapter 2, these events heightened congressional interest.

INTRODUCTION TO OCCUPATIONAL ILLNESS

It has long been recognized that there are substantial health risks posed by various workplace environments, risks often associated with exposure to harmful agents such as chemicals and radiation. These risks can produce costs to the workers in terms of loss of earnings, ill health, and even premature death. Such risks are costly to employers who may have to compensate workers through workers' compensation schemes for lost earnings and through health insurance schemes for the costs of the medical care they require, and who may have to compensate the workers' estates (through tort liability) for the premature death of the workers.

An occupational illness is defined by the Department of Labor's (DOL) Bureau of Labor Statistics (BLS) as any abnormal condition or disorder, other than one resulting from an occupational injury, caused by exposure to environmental factors associated with employment (37). This includes acute and chronic illnesses or disease that can be caused by inhalation, absorption, ingestion, or direct contact.

The prevalence of occupational illness is unknown. On the Federal level, BLS is responsible for

collecting statistical data on occupational injury and illness. BLS statistics on occupational illness incidence rates represent only new cases that occur in a given year. Continuing conditions that were reported in previous BLS occupational injury and illness surveys are not reported (36). Gathering data on the incidence of occupational disease in the United States is extremely difficult for several reasons. Often the relationship between exposure to a health hazard and the risk of, or even onset of, disease is not well understood. Because occupational diseases may have long latency periods, it is difficult to gather the information necessary to link workers' employment history with their medical diagnostic records. Personal physicians are often not aware of their patients' prior chemical exposures or work environments, and therefore may not recognize and diagnose an occupational disease (5,10). It has been suggested that the BLS Annual Survey be modified to improve data collection and analyses (18).

Approximately 190,000 cases of occupational disease were reported in 1987 by BLS (37). This was a 39 percent increase over the 136,800 cases recorded in 1986, which represented a 9 percent increase over the 125,600 cases reported in 1985 (36). An explanation offered by BLS for the increase in illness rates was improved recordkeeping by industry as a result of new government guidelines, as well as an effort on the part of BLS to improve its statistics (41).

Costs of occupational illness affect several parties—the employee, the employer, the insurance industry, and society. The employee experiences physical pain and suffering, emotional costs, and financial costs in the form of medical bills, changes in insurance status, and loss of salary. When a member of the work force incurs an occupational disease, the employer experiences lower productivity levels, higher insurance premiums, workers' compensation claims, and potential legal fees and monetary damage assessed from any lawsuits (27). Insurance companies compensate occupational disease victims, and thereby either sustain a loss or raise others' premiums. Finally, society pays for a large portion of the care and compensation of occupational disease victims through Federal health programs.

Costs of Occupational Illness to the Employee

Costs of occupational illness for the individual employee can include loss of potential earnings (including those fringe benefits used for disability days); transfer to a lower paying job; early retirement; and direct medical expenses. In addition, the costs of such intangibles as premature death, pain and suffering, and family bereavement if an occupational illness victim dies cannot be estimated.

Costs of Occupational Illness to the Employer

An employer's costs associated with occupational illness include direct health care expenses, higher workers' compensation premiums, excess absenteeism, worker turnover, reduced productivity, and possible civil liability suits. Compensation for work-related illness can prove to be a contentious issue. Once an illness can be pinpointed to a particular employer, it is possible that employer can be sued by the employee affected even though workers' compensation is the "exclusive remedy" for such claims (28). Even within the employer's staff there may be disagreement as to the protocol for treating and compensating occupational illness cases. While occupational physicians and other employer-provided health professionals may be interested in the prevention and control of work-related disease from a purely medical standpoint, the employer may be interested in causality, and ultimately in compensation and liability from a legal standpoint. Thus, work-relatedness is defined as both a medical and a legal concept (40). Employers have a financial interest in using their resources efficiently; an interest that could be cited by members of industry as proper justification for monitoring and screening employees for genetic conditions or damage.

Costs of Occupational Illness to Insurance Industry

For the majority of Americans, access to health care, and the health insurance that makes such access possible, is provided through their jobs. Containment of ever-increasing health care costs, whether or not they are related to occupational illness, is a high priority for employers. The increasing propensity of employers to self-insure their employees' health care expenses is a reflection of this. Because these plans are not regulated by the States, there are fewer

restraints on them than on traditional health insurance plans.

Companies concerned about insurance costs may be more interested in genetic screening for workers who are likely to develop both occupational and nonoccupational diseases. Many argue that genetic monitoring and screening in the workplace to limit occupational illnesses may be less important to them in the long run than monitoring and screening in the workplace to limit company health insurance costs (21,26).

Costs of Occupational Illness to Society

Society absorbs costs of occupational illness from the private sector. These include: transfer payments and services to disabled individuals and families (e.g., social security benefits and public assistance); health care costs not paid by the individual or the company which are then passed onto Medicare and Medicaid; and the administrative costs of related government programs.

FEDERAL AGENCIES INVOLVED IN OCCUPATIONAL SAFETY AND HEALTH

Although the principal Federal organization responsible for the occupational safety and health regulatory process is DOL's Occupational Safety and Health Administration (OSHA), there are several other agencies involved. In this section, the activities of OSHA, the National Institute for Occupational Safety and Health (NIOSH), the Environmental Protection Agency (EPA), and the National Labor Relations Board (NLRB) are discussed as they relate to both general occupational safety and health and genetic monitoring and screening in the workplace.

Occupational Safety and Health Administration

In 1970, Congress passed the Occupational Safety and Health Act (Public Law 91-596) (OSH Act) "to assure as far as possible every working man and woman in the Nation safe and healthful working conditions and to preserve our human resources. Within the OSH Act there are several federally imposed statutory duties that must be undertaken by the employer.



Photo credit: Margaret Anderson

U.S. Department of Labor, Washington, DC: Headquarters of the Occupational Safety and Health Administration.

Coverage under the OSH Act does not include State and local government employees, or those covered under other occupational health and safety legislation. Prior to the passage of the OSH Act, States were responsible for regulating occupational safety and health. Little uniformity among safety codes or enforcement practices existed, with no standardized reporting and recordkeeping system for occupational illnesses and injuries (25). In addition to Federal enforcement, OSHA now oversees 23 State OSHA programs. If a State plan is approved by OSHA, the State may receive up to 50 percent of its operating costs from OSHA. OSHA will only grant this approval if it can assure that the State performance will be as effective as its own (33).

Contained in the OSH Act was a provision to create OSHA within DOL headed by a presidentially appointed Assistant Secretary of Labor. OSHA is responsible for setting health and safety standards for workplaces, inspecting worksites to ensure proper compliance with those standards, issuing citations for violations of the standards, providing educational and consultation services and programs, and monitoring State programs. Perhaps the two most important OSHA duties are standard-setting

and the enforcement of these standards. Effective March 1989, OSHA adopted new exposure standards for over 350 substances (15). Compliance with these standards is expected to reduce the number of workplace fatalities, illnesses, and lost workdays caused by work-related illnesses (38). Prior to this action, the bulk of OSHA's existing health standards were adopted when it was first formed.

At this time, OSHA does not have a formal policy on the use of genetic monitoring and screening in the workplace. Some argue that the OSH Act already provides statutory authority for the evaluation of the accuracy of genetic tests and could implement such genetic monitoring and screening programs, by having NIOSH formulate the criteria for acceptability of genetic monitoring tools and screening tests. Critics of using genetic monitoring and screening in workplace settings maintain, however, that if OSHA adopted a standard mandating genetic monitoring or screening, employers would exclude workers, rather than make the workplace safe for all.

National Institute for Occupational Safety and Health

NIOSH is a research agency of the Centers for Disease Control of the U.S. Public Health Service, which is within the Department of Health and Human Services. It was created under the OSH Act to conduct research designed to identify and evaluate workplace hazards, research concerning measurement techniques and control technologies, and education of occupational health and safety professionals. NIOSH also assists OSHA by developing criteria and recommendations to be used by OSHA in setting standards, and conducting Health Hazard Evaluations. (See box 3-B for information on an international agency similar to NIOSH.)

Congress deliberately separated the research and regulatory functions of the OSH Act to protect the neutrality of the science. However, some say the result has been less than ideal and point to lack of coordination between OSHA and NIOSH. In setting standards, OSHA is not required to follow NIOSH scientific recommendations; OSHA also considers other nonscientific factors, such as economic, social, and political factors, in its regulatory decisions (28).

Some NIOSH research requires on-site workplace investigations to gather testimony from both employers and employees, and to conduct medical examinations and tests to detect exposure to hazard-

Box 3-B--Occupational Safety and Health in Finland

In 1987, Finland's Parliament passed the Labour Protection Act which specifically directs employers to consider "possible risk for the genetic material" of the employee. Prior to the passage of this legislation, Finland's Institute of Occupational Health (101-1) was pursuing research opportunities in genetic monitoring. IOH oversees a register of employees who have been occupationally exposed to chemicals listed as potential cancer-causing agents. This enables researchers to monitor those workers for cancer. Another Federal organization, the National Institute of Radiation Protection and Safety, is conducting a longitudinal study to determine whether workers in four Finnish nuclear powerplants have suffered any chromosomal damage.

The main emphasis of IOH research is on prevention of occupational disease and injury. Projects are designed to be "multidisciplinary, problem-oriented and aimed at solving national problems." Research areas include: epidemiology, medicine, physiology, ergonomics, psychology, occupational safety, industrial hygiene, and toxicology. Most of the research in genetic monitoring and screening is performed within the Department of Industrial Hygiene and Toxicology through a wide range of toxicological, epidemiological, and medical studies. Scientists currently are using various methods of genetic monitoring techniques such as chromosomal aberrations, sister chromatid exchange, micronuclei detection and adduct formation in proteins, ribonucleic acid, and DNA. In addition, some "susceptibility assessments" have been conducted using genetic screening methods.

Scientists at IOH conduct some research and informational exchange with the international scientific community. This can be done through formal bilateral agreements with international research institutions or agencies, as NIOSH, or through international organizations as the World Health Organization. An example of a collaborative project currently underway with the other Nordic nations is a study to assess the health significance of somatic chromosome damage. Utilizing a cohort of 3,000 individuals, the project is aimed at determining worker exposure to genotoxins, and whether or not this predisposes them to ill health, particularly cancer.

SOURCES: Office of Technology Assessment, 1990 based on A. Brogger, L. Hagmar, I.L. Hansteen, et al., "An Inter-Nordic Prospective Study on Cytogenetic Endpoints and Cancer Risk," *Cancer Genetics and Cytogenetics* 45:85-92, 1990 Finnish Institute of Occupational Health, Annual Report 1987 (Helsinki Finland: 1988); Finnish Institute of Occupational Health, Institute of Occupational Health (Helsinki, Finland 1988); Finland's Parliament "The Labor Protection Act of 1987," n. 27/87.



Photo credit: Kathy Goldberg

U.S. Department of Health and Human Services,
National Institute for Occupational Safety and Health,
Robert A. Taft Laboratories, Cincinnati, OH.

ous agents (see box 3-C). Employees can contact NIOSH to request that the agency conduct worksite investigations.

At this time, because NIOSH is a research and not a regulatory agency, it cannot require usage of genetic monitoring or screening in the workplace. However, it currently conducts some research in this area (see app. D). NIOSH could be requested to formulate the criteria necessary for determining the acceptability of genetic monitoring or screening tests for use in the workplace setting (39).

National Labor Relations Board

One of the central pieces of legislation regulating labor-management relations is the National Labor Relations Act (NLRA) of 1935 (29 U.S.C. 151 *et seq.*). It encouraged the practice of collective bargaining, and offered protection to workers of full freedom of association, self-organization, and designation of representatives. Amendments to the law in 1947, 1959, and 1974 clarified NLRB organization and procedures, and increased the protection of workers and enhanced their right not to participate in union activity (16).

Box 3-C-NIOSH Surveys of the Workplace

NIOSH conducted the National Occupational Hazard Survey of 4,636 facilities in 67 metropolitan areas from 1972 to 1974. The purpose was to survey American workplaces to determine to what occupational hazards the Nation's workers were being exposed, and to examine companies' health and safety programs. NIOSH conducted a similar survey, the National Occupational Exposure Survey (NOES) from 1981 to 1983. The NOES surveyed 4,490 facilities in 98 geographic areas. A facility site visit included completion of a standardized survey questionnaire by the facility management, and a walk-through survey taken by a NIOSH employee to inventory chemical and physical agents present in that particular work environment.

Among the issues the NOES attempted to answer were: what occupational groups are exposed to what types of potential health hazards in the United States? In what types of industries are these hazards found? What control technologies are present to prevent work-related disease in terms of plant operation and occupational safety and health practice? What are the exposures by intensity, duration, and type of control? And what trade name products were present?

Both surveys gathered a representative sample from all of the nonagricultural, nonmining, and nongovernmental businesses, with eight or more employees, that were covered under the OSH Act. One difficulty of the survey has been that it has taken several years to analyze the data. This has been due, in part, to the length of time it has taken to track down the components of trade name products seen on the walk-through surveys. During the NOES walk-through investigations, NIOSH representatives saw more than 10,000 different potential exposure agents and over 100,000 trade name products. Comparisons to the data collected from 1972 to 1974 will provide NIOSH with a valuable database that can be used to identify areas for further occupational health and safety research.

By comparing the data from both surveys, NIOSH has been able to analyze some of the trends in worker access to health care in the United States. NIOSH found two related events occurring simultaneously. First, facilities are increasingly substituting other health care professionals, primarily nurses and allied medical personnel, for on-site occupational physicians. Health units staffed only by paramedics or nurses are becoming increasingly common. If physician care is needed, the worker is often sent to an off-site medical facility through contractual agreements between the employer and the medical care provider. In comparing the figures from the two NIOSH surveys, the percentage of physician care offered off-site increased from 19.1 to 57.8 percent. Worker access to health care is increasing but much of it is being offered off-site.

The NOES also gathered data concerning some screening tests, preemployment exams, and the recording of health information. The screening tests used were: ophthalmology, audiology, blood urine, and pulmonary function tests, and chest x-rays. Overall, worker access to one or more screening tests increased slightly. This increase would have been greater, except that the number of immunizations given by employers decreased. Data on recording of health information showed a decrease in recording by employers because of the increased use of off-site medical facilities. This responsibility is being left to the off-site physician. This analysis suggests that while worker access to health care is increasing, the delivery mechanism is changing from on-site to off-site, a circumstance that could have implications for the field of occupational medicine.

SOURCES: Office of Technology Assessment, 1990; based on D.H. Pedersen and W.K. Sieber, Jr., "Some Trends in Worker Access to Health Care in the United States (1974- 1983), "Journal of Industrial Medicine 15(2): 151-165, 1989; U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Institute for Occupational Safety and Health, National Occupational Exposure Survey: Volume 1 Survey Manual, J. Seta, D. Sundin, and D. Pedersen(eds.), DHHS Pub. No. (PHS) 88-106 (Washington, DC: 1988).

Under NLRA, NLRB administers the law and acts as an intermediary between workers and management. NLRB is responsible for preventing and remedying unfair labor practices, and conducting secret ballot elections to determine whether employees wish to be represented by a union. NLRB's Office of the General Counsel is charged with the responsibility of investigating and prosecuting unfair labor practices.

Although the law was enacted to assist the organization of unions, some members of the labor community have said that they would be better off if the law were repealed. Much of the criticism stems from what some see as the Board's lack of remedies to deal with unfair labor practices, as well as its backlog of pending cases (28,30). It is also argued by labor groups that they feel inadequately protected by NLRB when they confront management. In order for

an employer to have a duty to deal with a union to bargain over the issue of genetic monitoring or screening, it would have to be considered a mandatory subject of bargaining (39). Because health and safety issues are considered to be mandatory subjects of bargaining, it has been argued that health and safety includes genetic monitoring and screening (39). The extent to which unions and employers could bargain and come up with solutions to the many questions that would arise over the use of genetic monitoring or screening depends on answers to a variety of questions. These questions include issues such as the accuracy and predictive value of the tests, clinical significance of the results, access to results, how the tests are used, and who will pay for them.

Environmental Protection Agency

Established in 1970, EPA was created to protect and enhance the environment. EPA administers several environmental health statutes that include broad mandates to protect the public from environmental hazards (34) (see ch. 6). EPA has pollution abatement and control programs in the areas of air, water, solid waste, hazardous wastes, pesticides, radiation, and toxic substances. In addition, it reinforces other Federal agencies' efforts with respect to their operations' impact on the environment. EPA performs research in the area of genetic monitoring (see app. D).

SUMMARY AND CONCLUSIONS

The concept of genetic monitoring and screening is not new. Over 50 years ago, the idea of sorting workers according to their individual susceptibilities to occupational hazards was discussed. The idea of factoring "hypersusceptibility" into workplace assignments was again discussed in the early 1970s, and screens for five conditions, including G-6-PD deficiency, sickle cell disease, and alpha-1-antitrypsin deficiency were proposed.

Controversy over the negative impacts that could result from genetic screening arose following the introduction of a national sickle cell screening program in the early 1970s. The resulting information caused some carriers of the trait to be confused about their health status, as well as to be discriminated against by employers and insurance companies. As a result of this experience, some have concluded that widespread genetic monitoring and screening in the absence of clear guidelines on how

the screening results will be interpreted and used has the potential for great abuse. At the same time, legislation concerning sickle cell anemia and other genetic diseases was passed at the Federal level authorizing funds for research, training, testing, counseling, and education.

In addition to mass screening programs, there have been reported cases where genetic monitoring or screening have been used to smaller extents in the workplace. The use of these technologies in the workplace brings with it its own set of scientific, legal, and ethical issues. Discussions concerning the use by employers of genetic monitoring and screening are being heard again, partly in response to the soaring costs of health insurance and also because of new scientific discoveries in genetics that could be applied to the practice of occupational medicine and public health. Because occupational illnesses are costly to all parties involved, there is increasing interest in using genetic screening methods to detect genetic traits that would make a worker susceptible to certain illnesses. Currently there are at least four Federal agencies involved in occupational safety and health, and perhaps genetic monitoring and screening in the workplace.

CHAPTER 3 REFERENCES

1. Adelman, C. S., "The Constitutionality of Mandatory Genetic Screening Statutes," *Case Western Law Review* 31:877-948, 1981.
2. Bernhardt, J.H., East Carolina University, Greenville, NC, personal communication, February 1989.
3. Buffler, P., University of Texas at Houston, Houston, TX, May 1990.
4. Calabrese, E.J., "Genetic Predisposition to Occupationally Related Diseases: Current Status and Future Directions," contract document for the Office of Technology Assessment, U.S. Congress, January 1989.
5. Cullen, M.R., and Cherniack, M.G., "Spectrum of Occupational Disease in an Academic Hospital-Based Referral Center in Connecticut From 1979 to 1987," *Archives of Internal Medicine* 149:1621-1626, 1989.
6. Gaston, M.H., Verter, J.J., Woods, G., et al., "Prophylaxis With Oral Penicillin in Children With Sickle Cell Anemia," *New England Journal of Medicine* 314(25):1593-1599, 1986.
7. Haldane, J. B.S., *Heredity and Politics* (London, England: Allen & Unwin, 1938).
8. Holden, C., "Looking at Genes in the Workplace," *Science* 217:336-337, 1982.

9. Hubbard, R., and Henifen, M. S., "Genetic Screening of Prospective Parents and of Workers: Some Scientific and Social Issues," *International Journal of Health Services* 15(2):231-251, 1985.
10. Institute of Medicine, *Role of the Primary Care Physician in Occupational and Environmental Medicine* (Washington, DC: National Academy Press, 1988).
11. Jandl, J., "An Evaluation of the Manuscript, 'Cytogenetic Study of Workers Exposed to Benzene,'" unpublished review, June 22, 1978.
12. Johnson & Johnson, Corporate Health and Safety, "Preliminary Report of Pilot Research Chromosome Study of Workers at Sites Where Ethylene Oxide Gas Is Utilized as a Sterilant," report submitted to OSHA, Mar. 30, 1982.
13. Legator, M., "The Successful Experiment That Faded," *Scientific Controversies: Case Studies in the Resolution and Closure of Disputes in Science and Technology*, T.H. Englehardt and A.L. Kapl m (eds.) (New York, NY: Cambridge University Press, 1987).
14. Levine, M. P., "Industrial Screening Programs for Workers," *Environment* 24:26-38, 1982.
15. Long, J., "Workplace Health: OSHA Sets New Exposure Standards," *Chemical & Engineering News*, p. 4, Jan. 23, 1989.
16. McGuinness, K. C., and Norris, J. A., *How To Take a Case Before the NLRB* (Washington, DC: Bureau of National Affairs, Inc., 1986).
17. Murray, R.F., "Tests of So-Called Genetic Susceptibility," *Journal of Occupational Medicine* 28(10):1103-1107, 1986.
18. National Academy of Sciences, *Counting Injuries and Illnesses in the Workplace: Proposals for a Better System* (Washington, DC: National Academy Press, 1987).
19. National Academy of Sciences, *Genetic Screening Programs, Principles, and Research* (Washington, DC: National Academy Press, 1975).
20. National Academy of Sciences, *The S-hemoglobinopathies: An Evaluation of Their Status in the Armed Forces* (Washington, DC: National Academy Press, 1974).
21. Nelkin, D., and Tancredi, L., *Dangerous Diagnostics: The Social Power of Biological Information* (New York, NY: Basic Books, Inc., 1989).
22. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Screening and Counseling for Genetic Conditions* (Washington, DC: U.S. Government Printing Office, February 1983).
23. Reilly, P., "Government Support of Genetic Services," *Social Biology* 25:23-32, 1978.
24. Reilly, P., "There's Another Side to Genetic Screening," *Prism* 55-57, January 1976.
25. Rosner, D., and Markowitz, G. (eds.), *Workers' Safety and Health in Twentieth Century America* (Bloomington, IN: Indiana University Press, 1987).
26. Rothstein, M. A., *Medical Screening and the Employee Health Cost Crisis* (Washington, DC: Bureau of National Affairs, Inc., 1989).
27. Rothstein, M.A., "Medical Screening of Workers: Genetics, AIDS, and Beyond," *Labor Lawyer* 2(4):675-682, 1988.
28. Rothstein, M. A., University of Houston Law Center, Houston, TX, personal communications, February 1989, March 1990.
29. Severe, R., "The Genetic Barrier: Job Benefit or Job Bias?" *The New York Times*, Feb. 3-6, 1980.
30. Silver, E., and McAvoy, J., "The National Labor Relations Act at the Crossroads," *Fordham Law Review* 56:181-208, 1987.
31. Stokinger, H.E., and Mountain, J.T., "Tests for Hypersusceptibility to Hemolytic Chemicals," *Archives of Environmental Health* 6:57-64, 1963.
32. Stokinger, H.E., and Scheel, L.D., "Hypersusceptibility and Genetic Problems in Occupational Medicine—A Consensus Report," *Journal of Occupational Medicine* 15:564-573, 1973.
33. U.S. Congress, General Accounting Office, *Occupational Safety and Health Assuring Accuracy in Employer Injury and Illness Records, Report to the Subcommittee on Labor, Health and Human Services, and Education, Committee on Appropriations, U.S. Senate, HRD-89-23* (Washington, DC: U.S. Government Printing Office, 1989).
34. U.S. Congress, Office of Technology Assessment, *Technologies for Detecting Heritable Mutations in Human Beings, OTA-H-298* (Washington, DC: U.S. Government Printing Office, September 1986).
35. U.S. Department of Health and Human Services, National Institutes of Health, Consensus Development Conference Statement, "Newborn Screening for Sickle Cell Disease and Other Hemoglobinopathies," vol. 6, No. 9, Apr. 6-8, 1987.
36. U.S. Department of Labor, *Occupational Injuries and Illnesses in the United States by Industry, 1986, Bulletin 2308* (Washington, DC: U.S. Government Printing Office, 1988).
37. U.S. Department of Labor, *Occupational Injuries and Illnesses in the United States by Industry, 1987, Bulletin 2328* (Washington, DC: U.S. Government Printing Office, 1989).
38. Weisskopf, M., "Chemical-Exposure Rules Updated," *Washington Post*, p. A7, June 8, 1988.
39. Williams, J. F., "A Regulatory Model for Genetic Testing in Employment," *Oklahoma Law Review* 40(2):181-208, 1987.
40. World Health Organization, *Identification and Control of Work-Related Diseases, Report of a WHO*

Expert Committee, Technical Report Series 714
(Geneva, Switzerland: 1985).

41. Yancey, M., "Rate of Job Injuries, Disease on Rise,"
AP Wire Service, Nov. 11, 1988.