Chapter 9

# Genetics in the Workplace: Perceptions and Practice

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## Tables

Chapter 9

# Genetics in the Workplace: Perceptions and Practice

The use of genetic monitoring and screening in the workplace is a multifaceted issue that has drawn scientists, ethicists, lawyers, genetic counselors, and occupational health care providers into an ongoing debate. Yet what is the extent of actual use of genetic monitoring and screening by U.S. employers and unions? Except for a 1982 Office of Technology Assessment (OTA) survey, evidence about past, present, and future genetic monitoring and screening of workers by U.S. companies and unions is anecdotal (5).

To assess the current practice of genetic monitoring and screening by U.S. employers, OTA commissioned Schulman, Ronca, & Bucuvalas, Inc. to conduct a followup survey in 1989 of current Fortune 500 companies, the 33 largest unions, and the 50 largest utilities. The comparable population surveyed by OTA in 1982 was included in this population to provide trend data. (See app. C for a discussion of the 1982 survey.) The 1989 survey was designed to include a representative sample of all other companies with 1,000 or more employees so that broader estimates of the use and pattern of genetic monitoring and screening in the workplace could be made. This chapter discusses Americans' perceptions toward genetic tests in general, examines employer practices, and reports how genetic monitoring and screening in the workplace have changed since the 1982 OTA survey.

## WORKER PERCEPTIONS OF GENETIC MONITORING AND SCREENING

Assessing worker attitudes, about genetic monitoring and screening was not possible for this report. Other recent studies, however, have examined attitudes (e.g., regarding risk v. benefit) and understanding of the general American public toward science and technology (2,3,4). Specifically, the results of a 1986 OTA nationwide survey on public perceptions of human genetics could shed light on the general attitude of Americans toward genetic tests (4). For example, in response to the question:

> If there were genetic tests that would tell a person whether they or their children would be likely to have serious or fatal genetic diseases, would you approve or disapprove of making those tests available through a physician?

Eighty-nine percent of the American populace said they approved, while 9 percent said they disapproved of having such tests available through physicians (table 9-l).

The 1986 OTA survey did not probe American attitudes toward genetic tests and their availability through employers, but approval likely would be lower than tests through private physicians. In fact, a November 1985 *Business* Week-Lou Harris nationwide survey posed the question:

> Even though they might not be able to cure a genetic disease, scientists will be able to test people to find out if they are likely to come down with one-as much as 20 years before it happens. Do you feel that an employer should have the right to make [sic] such tests before hiring someone, or not?

Eighty-nine percent of adult Americans answered that employers should not have the right to use such tests for hiring decisions. Furthermore, 82 percent of respondents felt an employer's knowledge of a job applicant's potential to have a serious disease in the future was not acceptable grounds for that candidate to be denied work. The survey also asked:

> Using the same kind of [genetic] testing, an employer may soon be able to tell how vulnerable an employee is to having a heart attack or stroke as a result of being put in a stressful work situation. Do you feel an employer should be able or not to bar people who do poorly on such tests from certain kinds of jobs?

**Table 9-l—Availability of Genetic Tests From Physicians[a]**

**Question:** If there were genetic tests that would tell a person whether they or their children would be likely to have serious or fatal genetic diseases, would you approve or disapprove of making those tests available through a physician?

| | Percent |
|---|---|
| Approve | 89 |
| Disapprove | 9 |
| Not sure | 2 |

a percentages are presented as weighted sample estimates. The unweighed base from which the sampling variance can be calculated is 1,273.

SOURCE: Office of Technology Assessment, 1987.

Thirty-five percent of Americans felt employers should be able to exclude individuals from certain jobs based on the results of such a test. And 21 percent of respondents felt that insurance companies would be justified in using genetic tests to refuse life or health insurance coverage. The *Business Week*-Lou Harris poll found that if genetic testing was not linked to employment or insurance decisions, about 50 percent of respondents were willing to be tested for incurable and fatal diseases they would develop later in life (l).

Similarly, the 1986 OTA survey explored the kinds of genetic tests Americans would be inclined to use, if available. Two-thirds of the public said they would take a test to determine whether they are likely to develop a fatal disease later in life, if such a test becomes widely available (table 9-2). Greater than 8 of 10 Americans (83 percent) reported they would use a genetic test before having children, if such a test would tell them whether their children would probably inherit a fatal genetic disease (table 9-3). And, perhaps in a measure of how workers would accept genetic monitoring and screening to benefit their own health outlook, the 1986 OTA survey found members of the general public said they were less likely to take tests to determine their own proclivity to a fatal genetic disease than to prevent heritable diseases in their offspring.

In general, the overall rate of acceptance by Americans of biotechnology, including human genetic applications, increases with the likelihood of personal benefit (4). Thus, worker attitudes toward genetic monitoring and screening to benefit personal health could be higher, if the testing were perceived to be in the individual's self-interest, not linked to corporate interests and employment decisions.

**Table 9-2—Using Genetic Tests for Personal Health[a]**

**Question: If genetic tests become available that would indicate whether or not a person was likely to develop a fatal disease later in life, would you personally take such a test or not?**

| | Percent |
|---|---|
| Would take test | 66 |
| Would not take test | 29 |
| Not sure | 4 |

a percentages are presented as weighted sample estimates. The unweighed base from which the sampling variance can be calculated is 1,273.

SOURCE: Office of Technology Assessment, 1987.

**Table 9-3—Using Genetic Tests Before Having Children[a]**

**Question: If genetic tests become available that would indicate whether or not it was likely that your children would inherit a fatal genetic disease, would you personally take such a test before having children or not?**

| | Percent |
|---|---|
| Would take test | 83 |
| Would not take test | 15 |
| Not sure | 3 |

a percentages are presented as weighted sample estimates. The unweighed base from which the sampling variance can be calculated is 1,273.

SOURCE: Office of Technology Assessment, 1987.

## STUDY DESIGN

The 1989 OTA survey was designed to provide comparability to the 1982 survey in terms of the populations sampled and the questionnaire content. At the same time, the survey was designed to go beyond the 1982 survey by sampling additional populations (non-Fortune 500 companies with 1,000 or more employees) and expanding the questionnaire content. (See app. B for a discussion of the survey methodology.)

### *Definition of Genetic Monitoring and Screening*

For purposes of the 1989 survey, genetic monitoring and screening were defined for respondents as follows:

> By *genetic monitoring, we* mean periodically examining employees to evaluate modifications of their genetic material via tests such as cytogenetic or direct-DNA tests. By *genetic screening, we* mean screening job applicants or employees for certain inherited characteristics. Screening tests may be biochemical tests or direct-DNA tests. They can be used to indicate a predisposition to an occupational illness if exposed to a specific environmental agent, or they could be used to detect any inherited characteristic such as Huntington's disease. In contrast to periodic monitoring, screening tests are generally performed one time per characteristic.

In addition, the series of questions on genetic monitoring and screening practices were preceded by this explanation:

> The following questions concern cytogenetic monitoring and/or biochemical genetic screening that may have been conducted by your company on one or more employees or job applicants. By

conduct, we mean perform, contract for, or arrange for the test as part of a routine or ongoing program.

The 1982 survey defined genetic monitoring and screening in a similar but less detailed fashion. Unlike the 1989 survey, the 1982 survey had no item covering the use of genetic monitoring or screening for diagnosis. The 1982 survey defined biochemical genetic screening as tests that screen "healthy, asymptomatic individuals." The 1989 survey contained no such requirement. Other differences in question wording are described in the following section.

### *The Questionnaire*

***The*** scope of the 1982 survey questionnaire was limited to measures of the frequency of past, present, and anticipated genetic monitoring and screening; which tests were used and under what circumstances; how the results were used; and the criteria against which tests have been measured to determine acceptability for use. Nearly all of these questions were repeated in the 1989 survey to measure change in corporate practice over time.

In order to flesh out the details of the survey data, OTA added questions that explored the use of genetic monitoring and screening in more depth. The additional questions not covered by the 1982 survey specifically asked about genetic monitoring and screening tests that may have been conducted as part of a voluntary wellness program, at the request of the employee, or for diagnosis. These questions were not part of the 1982 survey. Including the results of the new questions produced a broader definition of genetic monitoring and screening. Questions were also added to cover current use of direct-DNA monitoring and direct-DNA screening tests.

The wording of the trend questions on the 1989 survey instrument concerning current and past use of genetic monitoring and screening tests was changed slightly from 1982 to make the language more specific. For example, the survey asked whether genetic monitoring or screening tests were conducted "for research or any other reason," a phrase not present in the 1982 survey. Questions on genetic monitoring and screening practices were changed from asking about monitoring and screening of "employees or potential employees" to monitoring and screening of "any employees or job applicants. OTA believes the increased specificity attained an accurate measure of genetic monitoring and screening in 1989, established a firm base for future comparisons, and preserved general comparability to the 1982 survey.

The 1989 questionnaire was also modified to provide increased details on the use of specific genetic monitoring and screening tests. The 1982 survey asked about current or past use of four general types of biochemical genetic screening tests. In comparison, the 1989 survey asked about current use of 16 specific biochemical genetic screening tests. Similarly, the 1982 survey asked about current or past use of five types of cytogenetic monitoring tests, while the 1989 survey asked about current use of seven types of cytogenetic monitoring tests.

Health officers in companies that had conducted any genetic monitoring or screening tests were asked which specific tests their companies had conducted. It should be noted that some health officers who reported that their companies had never used genetic monitoring or screening, including testing as part of a voluntary wellness program, at employee request or for diagnosis, *did* report that their companies had conducted a specific genetic screening test. For example, some health officers who reported no corporate experience with genetic monitoring or screening also reported that their companies were testing for sickle cell trait. Thus, counting affirmative answers to specific genetic screening tests further expanded the number of companies reporting any use of genetic monitoring or screening.

## GENETIC MONITORING AND SCREENING: U.S. CORPORATIONS AND UNIONS

Before presenting the trend data from 1982 to 1989, there will first be a discussion of current, past, and combined use of genetic monitoring and screening. Following those sections, the overall and future use of genetic monitoring and screening in 1989 and 1982 will be discussed.

### *Current Use of Genetic Monitoring*

The one company reporting current use of cytogenetic monitoring in 1989 was a petroleum firm with more than 10,000 employees (table 9-4). No health officer from Fortune 500 companies surveyed in 1989 reported conducting direct-DNA monitoring, either at the time of the survey or in the past.

**Table 9-4-Current Use of Genetic Monitoring by Fortune 500 Companies**

**Q.15. Is your company currently conducting *cytogenetic monitoring* of any employees or job applicants, for research or any other reason?**

**Q.18. Is your company currently conducting *direct-DNA monitoring* of any employees or job applicants, for research or any other reason?**

**(Base: Health officers)**

| | Number of companies currently conducting | |
|---|---|---|
| | Cytogenetic monitoring | Direct-DNA monitoring |
| **Total** | 1 | 0 |
| ***Type of business*** | | |
| Electrical utility | 0 | 0 |
| Pharmaceutical | 0 | 0 |
| Other chemical | 0 | 0 |
| Petroleum | 1 | 0 |
| Electronic | O | 0 |
| Other manufacturing | 0 | 0 |
| Nonmanufacturing | 0 | 0 |
| ***Number of employees*** | | |
| Less than 5,000 | O | 0 |
| 5,000-9,999 | 0 | 0 |
| 10.000 or more | 1 | 0 |

SOURCE: Office of Technology Assessment, 1990.

**Table 9-5-Current Use of Genetic Screening by Fortune 500 Companies**

**Q.13. Is your company currently conducting *biochemical genetic screening* of any employees or job applicants, for research or any other reason?**

**Q.17. Is your company currently conducting *direct-DNA screening* of any employees or job applicants, for research or any other reason?**

**(Base: Health officers)**

| | Number of companies currently conducting | |
|---|---|---|
| | Biochemical genetic screening | Direct-DNA screening |
| **Total** | 12 | 0 |
| ***Type of business*** | | |
| Electrical utility | 0 | 0 |
| Pharmaceutical | 0 | 0 |
| Other chemical | 4 | 0 |
| Petroleum | 1 | 0 |
| Electronic | O | 0 |
| Other manufacturing | 2 | 0 |
| Nonmanufacturing | 5 | 0 |
| ***Number of employees*** | | |
| Less than 5,000 | 1 | 0 |
| 5,000-9,999 | 2 | 0 |
| 10,000 or more | 9 | 0 |

SOURCE: Office of Technology Assessment, 1990.

Questions relating to direct-DNA monitoring were not asked in 1982.

## *Current Use of Genetic Screening*

***The*** OTA survey found that in 1989, 12 companies reported current biochemical genetic screening. Of these 12 companies, 4 represented the chemical industry, 1 represented the petroleum industry, 2 represented other types of manufacturers, and 5 represented other nonmanufacturing companies. None of the 12 companies was an electric utility, pharmaceuticals firm, or electronics firm (table 9-5). Companies conducting genetic screening were disproportionately large fins, including 9 with 10,000 or more employees, 2 with 5,000 to 9,999 employees, and 1 with less than 5,000 employees. No health officers reported current use of direct-DNA screening by their companies. Questions relating to direct-DNA screening were not asked in 1982.

## *Past Uses of Genetic Monitoring*

***The 1989 survey*** asked health officers whether their companies had conducted genetic monitoring tests in the past 19 years, for research or any other reason. Five health officers in Fortune 500 companies reported that their companies had conducted cytogenetic monitoring in the past 19 years of any employees or job applicants, for research or any other reason (table 9-6). All 5 companies that formerly conducted cytogenetic monitoring reported no current use of genetic monitoring or screening, and all 5 had 10,000 or more employees. One was a chemical company, one was another type of manufacturer, and the other three were nonmanufacturing fins. None of the five was an electric utility, pharmaceutical company, petroleum company, or electronics firm.

## *Past Uses of Genetic Screening*

A total of eight health officers in the Fortune 500 companies reported that their companies had conducted biochemical genetic screening of any employees or job applicants in the past 19 years (table 9-7). This included four health officers in Fortune 500 companies that reported they were currently conducting biochemical genetic screening.

The 8 health officers who reported that biochemical genetic screening was conducted by their companies in the past 19 years were disproportionately from large companies, with 7 in companies with 10,000 or more employees, and 1 in a company with 5,000 to 9,999 employees. Four were in the chemical

**Table 9-6—Past Use of Genetic Monitoring Tests by Fortune 500 Companies**

**Q.16. Has your company conducted any cytogenetic *monitoring* of any employees or job applicants, for research or any other reason in the past 19 years?**
**(Base: Health officers)**

| | Number of companies conducted in past |
|---|---|
| | Cytogenic monitoring |
| **Total** | 5 |
| ***Type of business*** | |
| Electrical utility | 0 |
| Pharmaceutical | 0 |
| Other chemical | 1 |
| Petroleum | 0 |
| Electronic | 0 |
| Other manufacturing | 1 |
| Nonmanufacturing | 3 |
| ***Number of employees*** | |
| Less than 5,000 | 0 |
| 5,000-9,999 | 0 |
| 10,000 or more | 5 |

SOURCE: Office of Technology Assessment, 1990.

**Table 9-7—Past Use of Genetic Screening Tests by Fortune 500 Companies**

**Q.14. Has your company conducted any *biochemical genetic screening* of any employees or job applicants, for research or any other reason in the past 19 years?**
**(Base: Health officers)**

| | Number of companies conducted in past |
|---|---|
| | Biochemical genetic screening' |
| **Total** | 8 |
| ***Type of business*** | 0 |
| Electrical utility | |
| Pharmaceutical | 0 |
| Other chemical | 4 |
| Petroleum | 0 |
| Electronic | 0 |
| Other manufacturing | 2 |
| Nonmanufacturing | 2 |
| ***Number of employees*** | |
| Less than 5,000 | 0 |
| 5,000-9,999 | 1 |
| 10,000 or more | 7 |

'NOTE: Includes companies currently conducting genetic screening.
SOURCE: Office of Technology Assessment, 1990.

industry, two were in other manufacturing companies, and two were in nonmanufacturing firms.

## *Combined Genetic Monitoring and Screening: 1989 Survey Results*

A total of 20 health officers reported that their companies had conducted cytogenetic monitoring or biochemical genetic screening, either currently or in the past 19 years. This includes 12 health officers who reported that genetic monitoring or screening was currently conducted, and 8 who reported that genetic monitoring or screening had been conducted in the past 19 years, but not currently (table 9-8).

Six Fortune 500 health officers reported that their companies had conducted cytogenetic monitoring, either currently or in the past 19 years. One was in a company currently conducting cytogenetic monitoring, while five were in companies that had conducted cytogenetic monitoring in the past 19 years, but no longer conducted such monitoring.

Sixteen Fortune 500 health officers reported that their companies had conducted biochemical genetic screening, either currently or in the past 19 years. Twelve health officers reported their companies currently conducted genetic screening, while four were in companies that conducted genetic screening in the past 19 years, but not at the present time.

## *Overall Use of Genetic Monitoring and Screening in 1989 and 1982*

Trend data on the use of genetic monitoring or screening can be obtained by tabulating comparable questions in the 1989 and 1982 surveys. These are general questions dealing with the use of genetic monitoring or screening, and do not include items added in 1989 on genetic monitoring or screening as part of a voluntary wellness program, at the request of an employee, or for diagnosis. Using this narrow definition, the 1989 survey found a total of 20 health officers in the Fortune 500 sample who reported that their companies had conducted genetic monitoring or screening, either currently or in the past 19 years. In comparison, the 1982 survey found 18 health officers in the Fortune 500 companies who reported current or past use of genetic monitoring or screening (table 9-9). These figures suggest little change between 1982 and 1989 in the number of companies that had used genetic monitoring or screening in the workplace.

In the 1982 survey, six health officers (1.6 percent) reported their companies currently conducted genetic monitoring or screening. In 1989, 12 health officers (5 percent) reported their companies currently conducted genetic monitoring or screening. (These numbers do not directly correlate because of different sized survey populations in 1982

**Table 9-8-Combined Testing: Current v. Past Monitoring and Screening by Fortune 500 Companies**

**(Base: Health** officers)

| | Number of companies |
|---|---|
| Conducted genetic monitoring or screening for research or any other reason, at present or in past 19 years | 20 |
| Currently conducting genetic monitoring or screening | 12 |
| Conducted monitoring or screening in past only | 8 |
| Conducted genetic screening for research or any other reason at present or in past 19 years | 16 |
| Currently conducting genetic screening | 12 |
| Conducted genetic screening in past only | 4 |
| Conducted cytogenetic monitoring for research or any other reason at present or in past 19 years | 6 |
| Currently conducting cytogenetic monitoring | 1 |
| Conducted cytogenetic monitoring in past only | 5 |
| Currently conducting direct-DNA screening for research or any other reason | 0 |
| Currently conducting direct-DNA monitoring for research or any other reason | *0* |

SOURCE: Office of Technology Assessment, 1990.

and 1989.) The increase in the number of "current users" in 1989 could reflect slight differences in question wording between the two surveys.

Of the six companies that reported current use of genetic monitoring or screening in 1982, two were in the chemical industry, two were electric utilities, and two were in the electronics industry. In 1989, 12 companies reported current use of genetic monitoring or screening. Of those, all 12 conducted genetic screening, while one also conducted cytogenetic monitoring, Of the companies reporting current use of genetic screening four were in the chemical industry, one in the petroleum industry, two were other types of manufacturers, and five were other nonmanufacturing companies. None of the 12 companies was an electric utility or electronics firm. The petroleum firm was the only company also reporting current use of cytogenetic monitoring of any employees or job applicants in 1989.

No health officer from Fortune 500 companies surveyed in 1989 reported conducting direct-DNA monitoring or direct-DNA screening, either at the time of the surveyor in the past. No question related to direct-DNA monitoring and direct-DNA screening was asked in 1982.

**Table 9-9—Use of Genetic Monitoring or Screening: 1989 v. 1982 Survey Results**

**(Base: Health** officers)

| | Number of companies | |
|---|---|---|
| | 1989 | 1982 |
| Conducted genetic monitoring or screening for research or any other reason, at present or in the past* | 20 | 18 |
| Currently conducting genetic monitoring or screening | 12 | 6 |
| Conducted monitoring or screening in past only | 8 | 12 |

*Defined as past 19 years in 1989 survey and past 12 years in 1982 survey.
SOURCE: Office of Technology Assessment, 1990.

In summary, in the 1989 survey 12 companies reported current use of genetic monitoring or screening, while 8 companies reported conducting genetic monitoring or screening in the past but were no longer conducting such tests. The ratio of current to past monitoring and screening was reversed in 1982, with 6 companies indicating current use of genetic monitoring or screening and 12 companies indicating past but not current use of monitoring or screening. overall, OTA found that 20 companies had used genetic monitoring or screening in 1989, as compared to 18 companies in 1982.

## *General Use of Genetic Monitoring and Screening Tests*

A total of 27 health officers in Fortune 500 companies reported current or past use of genetic monitoring or screening tests of any employees or job applicants, for any reason, including research, as part of a voluntary wellness program, or for diagnosis (table 9-10). In addition, one personnel officer from a company not represented by the health officers who returned surveys reported use of genetic monitoring or screening. Thus, a total of 28 companies in the 1989 Fortune 500 sample reported current or past use of genetic monitoring or screening tests.

Health officers reporting any experience with genetic monitoring or screening included 17 who reported that their companies were currently conducting genetic monitoring or screening, and 10 who reported that their companies had conducted genetic monitoring or screening in the past, but were not currently conducting either. (Of those 17 companies, 5 are currently testing.) None reported current or past

**Table 9-10-Summary Data on Use of Genetic Monitoring and Screening: 1989 Results Among Fortune 500 Companies**

**(Base: Health** officers)

| | Number of companies |
|---|---|
| Conducted genetic monitoring or screening for research or any other reason, at present or in past 19 years, *including as* part of a voluntary wellness program, at the request of the employee, or for diagnosis | 27 |
| Currently conducting genetic monitoring or screening | 17 |
| Conducted monitoring or screening in past only | 10 |
| Conducted direct-DNA screening or direct-DNA monitoring. currently or in the past | 0 |

SOURCE: Office of Technology Assessment, 1990.

use of either direct-DNA monitoring or direct-DNA screening by his or her company.

However, a number of health officers who reported no current or past use of genetic monitoring or screening tests, including testing for voluntary wellness programs, at employee request, and for diagnosis, did report use of specific genetic screening tests listed in the survey. Thus, responses to general questions on genetic monitoring and screening appeared to somewhat understate the prevalence of these tests. Total use of genetic monitoring and screening is discussed in the next section.

## *Total Use of Genetic Monitoring or Screening*

A total of 33 health officers from the Fortune 500 companies reported that their companies had used any type of genetic monitoring or screening, either currently or in the past (table 9-11). In other words, 13 percent of the health officers from Fortune 500 companies responding to the survey reported that their companies had used some type of genetic monitoring or screening, either currently or in the past. This measure of genetic monitoring or screening included testing as part of a voluntary wellness program, at the request of the employee, or for diagnosis. It also included health officers who reported that their companies conducted one or more specific biochemical genetic screening tests or cytogenetic monitoring tests.

Counting all health officers from Fortune 500 companies who reported that their companies had conducted genetic monitoring or screening, in one

**Table 9-1 I—Total Prevalence of Genetic Monitoring or Screening: 1989 Survey Results Among Fortune 500 Companies**

**(Base: Health officers)**

| | Number of companies with any current or past use of genetic monitoring or screening |
|---|---|
| Total | 33 |
| *Number of employees* | |
| Less than 5,000 | 3 |
| 5,000-9,999 | 3 |
| 10,000 or more | 27 |
| *Type of business* | |
| Electrical utility | 0 |
| Pharmaceutical | 3 |
| Other chemical | 11 |
| Petroleum | 3 |
| Electronic | 0 |
| Other manufacturing | 5 |
| Nonmanufacturing | 11 |

SOURCE: Office of Technology Assessment, 1990.

form or another, produced the most accurate measure of the total- use of genetic monitoring or screening in 1989. It appears likely that the 1982 survey probably understated the prevalence of genetic monitoring and screening at that time, because that questionnaire included a more limited set of items on the use of genetic monitoring and screening. As the results from the 1989 survey indicate, a fuller battery of questions likely detected all forms of genetic monitoring and screening.

Twenty-seven of the thirty-three health officers surveyed in 1989 who reported that their companies had conducted genetic monitoring or screening were in large companies with 10,000 or more employees. Of the 33, 11 were in chemical companies, 3 were in pharmaceutical fins, 3 were in petroleum companies, 5 were in other manufacturing companies, and 11 were in nonmanufacturing firms.

The findings of the 1989 survey suggest that the 1982 survey may have underestimated the actual prevalence of workplace use of the technology at that time. The 1989 survey asked about past and present use of genetic monitoring and screening in a number of different contexts—screening to identify increased susceptibility to workplace risk, as part of a voluntary wellness program, at the request of the employee, and for diagnosis—in addition to the set of questions used in 1982. When all reports of genetic monitoring and screening were taken into account, the number of companies that had used genetic monitoring or screening increased to 33 from

18 companies in 1982. The larger number of companies identified as using genetic tests appeared to be almost entirely the result of additional questions about the use of genetic monitoring or screening, rather than changes in industry practices. Using the comparable measures, the number of companies that had ever conducted genetic monitoring or screening had only increased from 18 in 1982 to 20 in 1989.

### *Future Use of Genetic Monitoring and Screening*

*If* there has been little or no real growth in the number of companies conducting genetic monitoring and screening in the workplace, what do companies foresee for the future? The 1982 OTA survey found that 4 companies (1.1 percent) anticipated using the tests in the next 5 years, and 55 companies (15 percent) stated they would ' 'possibly" use the tests in the next 5 years. In order to avoid classifying an indefinite response as a positive response to future genetic monitoring or screening, the 1989 survey provided the response categories "yes," "no," and "not sure' for the same questions.

OTA found one Fortune 500 company that anticipated cytogenetic monitoring, one company that anticipated direct-DNA monitoring, and four companies that anticipated biochemical genetic screening. No company anticipated using direct-DNA screening in the next 5 years. Twenty-seven companies in 1989 indicated they were not sure whether they anticipated cytogenetic monitoring, and 27 were not sure whether they anticipated direct-DNA monitoring. For biochemical genetic screening, 25 companies were not sure whether they anticipated using it, and 23 were not sure about future direct-DNA screening (table 9-12).[1] In 1982, 55 companies said they would possibly use such test in the next 5 years. Although this number cannot be directly compared to the current survey, the 1989 OTA survey appear-s to indicate fewer companies anticipate using genetic monitoring or screening.

Intervening events offered another possible explanation for the absence of expected growth since 1982 in industry adoption of the technology of genetic monitoring and screening in the workplace. Specifically, the experience of other employers with genetic monitoring and screening-publicity, criticism, employee problems—might have dissuaded some prospective users from adopting the technology. However, the survey found fewer than 10 cases among Fortune 500 companies that had never used genetic monitoring or screening in the past, reporting that they had chosen not to use such tests as a result of the experiences of other companies.

### *Genetic Monitoring for Other Reasons: 1989 Survey Results*

Questions added to the 1989 survey covered applications of genetic monitoring that had not been specifically covered in the 1982 survey. Some health officers reporting that their companies conducted genetic monitoring and screening for these purposes, however, did not report that their companies conducted genetic monitoring or screening "of any employees or job applicants, for research or any other reason.

One health officer reported past use of cytogenetic monitoring at employee request and one reported past use of cytogenetic monitoring as part of a voluntary wellness program. One health officer reported current use of cytogenetic monitoring for diagnosis and one reported past use of cytogenetic monitoring for diagnosis (table 9-13).

### *Genetic Screening for Other Reasons: 1989 Survey Results*

Questions added to the 1989 survey covered applications of genetic screening that had not been specifically covered in the 1982 survey. Current use of genetic screening was reported by two companies for voluntary wellness, eight companies at employee request, and seven for diagnosis (table 9-14). These figures may overlap, since health officers were asked to report all types of genetic screening conducted by their companies. Past use of genetic screening for voluntary wellness was reported by four health officers, while five health officers reported past use of genetic screening at employee request, and three health officers reported past use of genetic screening for diagnosis.

[1]These numbers cannot be added because of cross counting; nor do they directly correlate to th55 companies because Of question wording. In retrospect, those who chose 'possibly' in 1982 might not have meant to indicate that genetic monitoring or screening was anticipated, they simply could not rule out the possibility they would use it in the future.

**Table 9-1 2—Consideration To Conduct Genetic Monitoring and Screening in the Next Five Years: Health Officers**

**Q.33. Does your company anticipate conducting any biochemical genetic screening, for any reason, in the next 5 years?**

**Q.34. Does your company anticipate conducting any cytogenetic monitoring, for any reason, in the next 5 years?**

**Q.35. Does your company anticipate conducting any *direct-DNA screening,* for any reason, in the next 5 years?**

**Q.36. Does your company anticipate conducting any *direct-DNA monitoring,* for any reason, in the next 5 years?**

**(Base: Health officers)**

| | Percent | | | |
|---|---|---|---|---|
| | Yes | No | Not sure | No answer |
| Biochemical genetic screening | 4 | 218 | 25 | 3 |
| Cytogenetic monitoring | 1 | 219 | 27 | 3 |
| Direct-DNA screening | 0 | 224 | 23 | 3 |
| Direct-DNA monitoring | 1 | 218 | 27 | 4 |

SOURCE: Office of Technology Assessment, 1990.

## *Specific Types of Cytogenetic Monitoring Conducted in 1989*

As with genetic screening, the 1989 survey asked health officers in companies that had conducted cytogenetic monitoring to list which specific types of monitoring were being conducted. The survey covered seven categories of cytogenetic tests. For each test conducted, health officers were asked to give the reason their companies were conducting the test. The only cytogenetic tests reported were those testing for chromosomal aberrations and sister chromatid exchanges. No health officer reported testing for mutations by assaying the DNA, enzymes/proteins, hypoxanthine-guanine phosphoribosyltransferase (HPRT) mutation rate, DNA adduct formation, or by using other cytogenetic tests (table 9-15).

Only two reasons were reported for cytogenetic monitoring: 1) testing as part of a voluntary research program, and 2) testing as part of followup diagnosis. No health officers reported conducting cytogenetic monitoring as part of routine health surveillance, as part of a voluntary wellness program, or at employee request. Moreover, only one health officer reported conducting cytogenetic monitoring for followup diagnosis. Genetic monitoring for a voluntary research program was reported by three health officers in companies monitoring for chromosomal aberrations and three in companies monitoring for sister chromatid exchanges.

**Table 9-13-Prevalence of Genetic Monitoring for Voluntary Wellness Programs at Employee Request and for Diagnosis: Fortune 500 Companies**

**Q.19. Has your company conducted any of the following tests (biochemical genetic screening, cytogenetic monitoring, direct-DNA screening, direct-DNA monitoring), as part of a voluntary wellness program, at the request of an employee, or for diagnosis? (MARK ALL THAT APPLY)**

**(Base: Health officers)**

| | Number of companies | |
|---|---|---|
| | Cytogenetic monitoring | Direct-DNA monitoring |
| ***As part of voluntary wellness program*** | | |
| Currently | 0 | 0 |
| In past 19 years | 1 | 0 |
| No | 113 | 114 |
| Not sure | 3 | 2 |
| No answer/not applicable | 132 | 133 |
| **At *the request of the employee*** | | |
| Currently | 0 | 0 |
| In past 19 years | 1 | 0 |
| No | 111 | 111 |
| Not sure | 4 | 4 |
| No answer/not applicable | 133 | 134 |
| ***For diagnosis*** | | |
| Currently | 1 | 0 |
| In past 19 years | 1 | 0 |
| No | 107 | 108 |
| Not sure | 9 | 9 |
| No answer/not applicable | 131 | 132 |

SOURCE: Office of Technology Assessment, 1990.

## *Specific Types of Genetic Screening Tests Conducted in 1989*

***The 1989 survey*** asked health officers in companies that had ever done biochemical genetic screening tests to list which specific genetic screening tests were being conducted, and for each, to indicate the

**Table 9-14-Prevalence of Genetic Screening for Voluntary Wellness Programs, at Employee Request and for Diagnosis: Fortune 500 Companies**

**Q.19. Has your company conducted any of the following tests (biochemical genetic screening, cytogenetic monitoring, direct-DNA screening, direct-DNA monitoring), as part of a voluntary wellness program, at the request of an employee, or for diagnosis? (MARK ALL THAT APPLY)**

**(Base: Health officers)**

| | Number of companies | |
|---|---|---|
| | Biochemical genetic screening | Direct-DNA screening |
| ***As part of voluntary wellness program*** | | |
| Currently | 2 | 0 |
| In past 19 years | 4 | 0 |
| No | 127 | 113 |
| Not sure | 3 | 3 |
| No answer/not applicable | 113 | 133 |
| **At the request of the *employee*** | | |
| Currently | 8 | 0 |
| In past 19 years | 5 | 0 |
| No | 116 | 111 |
| Not sure | 6 | 4 |
| No answer/not applicable | 114 | 134 |
| ***For diagnosis*** | | |
| Currently | 7 | 0 |
| In past 19 years | 3 | 0 |
| No | 116 | 108 |
| Not sure | 12 | 9 |
| No answer/not applicable | 111 | 132 |

SOURCE: Office of Technology Assessment, 1990.

purpose of the test. A total of 16 specific biochemical genetic screening tests were covered by the 1989 survey.

Genetic screening tests cited most frequently as being conducted by Fortune 500 companies included: contact dermatitis, sickle cell trait, allergic respiratory disease, serum alpha-l-antitrypsin deficiency, alpha and beta thalassemias, and glucose-6-phosphate dehydrogenase (G-6-PD) deficiency. Other genetic screening tests cited by one or two health officers included methemaglobin reductase deficiency, aryl hydrocarbon hydroxylase inducibility, slow v. fast acetylation, histocompatibility markers, other immune system markers, Bloom syndrome, and xeroderma pigmentosum. None reported conducting biochemical screening tests for Fanconi syndrome, ataxia-telangiectasia, or other heterozygous chromosomal instabilities (table 9-16).

The 1989 survey asked whether the specific biochemical screening tests were being conducted on a routine basis for health surveillance, as part of a voluntary research program, as part of followup diagnosis, as part of a voluntary wellness program, or at the request of an employee. Obtaining a followup diagnosis and responding to an employee request were the two reasons given most often for conducting biochemical genetic screening. Followup diagnosis was cited by 13 health officers in companies testing for contact dermatitis, 11 in companies testing for allergic respiratory disease, 7 in companies testing for serum alpha- 1-antitrypsin deficiency, 6 in companies testing for sickle cell trait, and 6 in companies testing for alpha and beta thalassemias. Genetic screening at employee request was listed by 12 health officers in companies testing for sickle cell trait and 5 in companies testing for allergic respiratory disease. In addition, testing as part of routine health surveillance was reported by six health officers in companies testing for allergic

**Table 9-15—Types of Cytogenetic Monitoring Conducted in 1989 by Fortune 500 Companies**

**Q.21. Which of the following types of cytogenetic monitoring are being conducted by your company of any employees?**

**(Base: Health Officers in companies that have conducted cytogenetic monitoring)**

| | Number of companies | | | | |
|---|---|---|---|---|---|
| | Routine health surveillance | Voluntary research program | Followup diagnosis | Voluntary wellness program | At employee request |
| Chromosomal aberrations | 0 | 3 | 1 | 0 | 0 |
| Sister chromatid exchanges | 0 | 3 | 0 | 0 | 0 |
| Mutations by assaying the DNA | 0 | 0 | 0 | 0 | 0 |
| Mutations by assaying the enzyme/protein | 0 | 0 | 0 | 0 | 0 |
| HPRT mutation rate | 0 | 0 | 0 | 0 | 0 |
| DNA adduct formation | 0 | 0 | 0 | 0 | 0 |
| Other (specify) | 0 | 0 | 0 | 0 | 0 |

SOURCE: Office of Technology Assessment, 1990.

**Table 9-16-Types of Biochemical Genetic Screening Conducted by Fortune 500 Companies**

*Q.20.* **Which of the following types of biochemical screening tests are being conducted by your company of any employees or job applicants? For each test conducted, mark whether the testing is being done on a routine basis for health surveillance, as part of a-voluntary research program, as part of followup diagnosis, or only at the request of an employee.**

**(Base: Health officers)**

| | Number of companies | | | | |
|---|---|---|---|---|---|
| | Routine health surveillance | Voluntary research program | Followup diagnosis | Voluntary wellness program | At employee request |
| Sickle cell trait | 1 | 0 | 6 | 3 | 12 |
| Glucose-6-phosphate dehydrogenase (G-6-PD) deficiency | 0 | 1 | 3 | 2 | 3 |
| Methemaglobin reductase deficiency | 1 | 0 | 0 | 1 | 0 |
| Serum alpha-1 -antitrypsin deficiency | 1 | 0 | 7 | 2 | 4 |
| Alpha and beta thalassemias | 0 | 0 | 6 | 2 | 4 |
| Aryl hydrocarbon hydroxylase (AHH) inducibility | 0 | 0 | 0 | 1 | 0 |
| Slow v. fast acetylation | 0 | 0 | 0 | 1 | 0 |
| Allergic respiratory disease | 6 | 1 | 11 | 1 | 5 |
| Contact dermatitis | 5 | 1 | 13 | 1 | 4 |
| Histocompatibility markers (HLA). | 0 | 0 | 0 | 1 | 0 |
| Other immune system markers | 0 | 0 | 1 | 0 | 1 |
| Bloom syndrome | 0 | 0 | 0 | 1 | 0 |
| Fanconi syndrome | 0 | 0 | 0 | 0 | 0 |
| Ataxia-telangiectasia | 0 | 0 | 0 | 0 | 0 |
| Xeroderma pigmentosum | 0 | 0 | 1 | 0 | 0 |
| Other heterozygous chromosomal instabilities | 0 | 0 | 0 | 0 | 0 |

SOURCE: Office of Technology Assessment, 1990.

respiratory disease and five health officers in companies testing for contact dermatitis.

As previously noted, some health officers who reported that their companies conducted *specific* biochemical genetic screening tests did *not* report that their companies had conducted genetic monitoring or screening, at present or in the past 19 years, including testing for voluntary wellness programs, at employee request, or for diagnosis. Each of the following genetic screening tests was reported as being currently conducted by more than one health officer who reported no current or past genetic monitoring or screening tests: sickle cell trait, serum-1-antitrypsin deficiency, allergic respiratory disease, and contact dermatitis (table 9-17). In addition, each of the following tests was reported as being currently conducted by one health officer who had reported no current or past use of genetic screening or monitoring: G-6-PD deficiency, alpha and beta thalassemias, and xeroderma pigmentosum.

## *Reasons for Conducting Genetic Monitoring and Screening*

Personnel officers in the Fortune 500 companies that conducted genetic monitoring or screening were asked: "To the best of your knowledge, which of the following were important factors in the decision to conduct genetic monitoring or screening of employees in your company?" Six possible reasons for conducting genetic monitoring or screening were listed. Only six personnel officers responded to this set of questions.

Four of the six personnel officers in companies conducting genetic monitoring and screening reported that cost-benefit analysis was an important factor in the decision by their companies to conduct genetic monitoring or screening of employees (table 9-18). Four personnel officers also reported that the evidence of a possible association between chemical exposure and illness in epidemiological studies was an important reason in the decision by their compa-

**Table 9-17-Specific Biochemical Genetic Screening Tests Reported by Companies Reporting No Genetic Monitoring or Screening Among Fortune 500 Companies**

**Q.20. Which of the following types of biochemical screening tests are being conducted by your company of any employees or job applicants?**

**(Base: Health officers in companies reporting *no* monitoring or screening)**

| | Number of companies | | | | |
|---|---|---|---|---|---|
| | Routine health surveillance | Voluntary research program | Followup diagnosis | Voluntary wellness program | At employee request |
| Sickle cell trait | 0 | 0 | 1 | 1 | 2 |
| Glucose-6-phosphate dehydrogenase (G-6-PD) deficiency | 0 | 0 | 0 | 1 | 0 |
| Methemaglobin reductase deficiency | 0 | 0 | 0 | 0 | 0 |
| Serum alpha-1-antitrypsin deficiency | 0 | 0 | 1 | 1 | 1 |
| Alpha and beta thalassemias | 0 | 0 | 0 | 1 | 0 |
| Aryl hydrocarbon hydroxylase (AHH) inducibility | 0 | 0 | 0 | 0 | 0 |
| Slow v. fast acetylation | 0 | 0 | 0 | 0 | 0 |
| Allergic respiratory disease | 0 | 0 | 4 | 0 | 1 |
| Contact dermatitis | 0 | 0 | 4 | 0 | 1 |
| Histocompatibility markers (HLA) | 0 | 0 | 0 | 0 | 0 |
| Other immune system markers | 0 | 0 | 0 | 0 | 0 |
| Bloom syndrome | 0 | 0 | 0 | 0 | 0 |
| Fanconi syndrome | 0 | 0 | 0 | 0 | 0 |
| Ataxia-telangiectasia | 0 | 0 | 0 | 0 | 0 |
| Xeroderma pigmentosum | 0 | 0 | 1 | 0 | 0 |
| Other heterozygous chromosomal instabilities | 0 | 0 | 0 | 0 | 0 |

SOURCE: Office of Technology Assessment, 1990.

nies to conduct genetic monitoring and screening of employees.

In addition, three personnel officers reported that the legal consequence of a failure to test was an important reason in the decision to conduct genetic monitoring or screening. One personnel officer reported that evidence of a possible association between chemical exposure and illness in animal studies was an important factor, and one personnel officer reported that union or employee initiative was an important factor in the decision to conduct genetic monitoring or screening. None of the six personnel officers reported "something else" as an important factor in the decision to conduct genetic monitoring and screening.

## *Actions Taken as a Result of Genetic Monitoring or Screening*

***The survey*** found relatively few instances of negative personnel decisions as a result of genetic monitoring or screening. Only one corporate personnel officer for the Fortune 500 companies reported ever rejecting a job applicant, primarily or partly, based on the results of a genetic screening test. Similarly, a single corporate health officer reported ever suggesting an employee seek a job elsewhere, as a result of a genetic monitoring or screening program. (In 1982, a comparable two companies reported that they had suggested an employee seek a job elsewhere.)

No instances were reported by personnel officers from Fortune 500 companies in the 1989 survey of cases in which employees were transferred or terminated, primarily or partly, based on the results of genetic monitoring or screening. Health officers in three Fortune 500 companies, however, reported that their companies, as a result of a genetic monitoring or screening program, had transferred or placed employees in different jobs within their companies. This is comparable to the five companies that reported transferring employees in the 1982 survey.

Although instances of genetic monitoring and screening were rare, the health officers in Fortune 500 companies that had done it were at least as likely to report that the genetic monitoring and screening

**Table 9-18-Factors in the Decision To Conduct Genetic Monitoring or Screening of Employees Among Fortune 500 Companies**

**Q.13. To the best of your knowledge, which of the following were important factors in the decision to conduct genetic monitoring or screening of employees in your company? (Base: Personnel officers answering question)**

| | Number of personnel officers | | |
|---|---|---|---|
| | Unweighed base | Important | Not important |
| Cost-benefit analysis . . . . . | (6) | 4 | 2 |
| Evidence of a possible association between chemical exposure and illness in animal studies . . . . . | (6) | 1 | 5 |
| Evidence of a possible association between chemical exposure and illness in epidemiological studies . . . . | (6) | 4 | 2 |
| Legal consequence of failure to test . . . . | (6) | 3 | 3 |
| Union/employee initiative. . . . . | (6) | 1 | 5 |
| Something else (please specify) . . . . . | (1) | o | 1 |

SOURCE: Office of Technology Assessment, 1990.

had resulted in changes in the workplace, as had resulted in changes in workers. A number of health officers reported that, as a result of genetic monitoring and screening programs, their companies had:

- recommended personal protection devices (five in 1989, compared to three in 1982);
- implemented engineering controls (four in 1989, compared to two in 1982);
- implemented a research program (four in 1989, compared to one in 1982); or
- discontinued a product or changed materials in a product (two in 1989, compared to one in 1982).

In Summary, only a small proportion of companies had conducted any form of genetic monitoring or screening, and such monitoring and screening, in most cases, had not generated personnel action against employees or changes in the workplace. The findings of the 1989 survey are virtually identical to the 1982 survey in these areas.

The 1989 survey finds little evidence that companies anticipate the use of any kind of genetic monitoring or screening in the foreseeable future. Personnel officers in this representative, national sample of companies with 1,000 or more employees were asked whether or not they anticipated that their companies would conduct biochemical genetic screening, DNA-based screening, cytogenetic monitoring, or DNA-based monitoring within the next 5 years, either on a mandatory or voluntary basis. The survey found only 2 percent of companies with 1,000 or more employees anticipated any form of mandatory genetic monitoring or screening within the next 5 years, while another 3 percent said they anticipated conducting some form of genetic monitoring or screening on a voluntary basis.

## *Survey Results without Certain Tests Included*

***In the original 1982 survey, certain*** **tests were** included in the basic definition of biochemical genetic screening tests. The 1989 survey, however, did not contain those specific tests in the definition of biochemical genetic screening. Instead, they were added to a later question that asked which types of biochemical screening tests were conducted by the company of employees or applicants. This means that the proportion of the 1989 survey findings concerning the prevalence of biochemical genetic screening attributable to certain tests (the nongenetic tests) can be identified. Two tests were identified in the 1989 survey that were included in the 1982 survey as being nongenetic tests—allergic respiratory disease and contact dermatitis.

A variable from the responses to the question asking which types of screening tests were conducted was constructed from the health officer's questionnaire. (Note: This could only be done for the long survey forms returned by mail, not the short forms conducted by telephone, which were identical to the 1982 survey-but which yielded no genetic testers.) If the respondent said yes to either allergic respiratory disease or contact dermatitis in this question, but no to other tests in this question, the respondent was labeled "nongenetic only. " Re-

spondents saying yes to either of these tests, in addition to other tests in the question, were labeled "both." Those responding yes to other tests in this section, but not to either of the two nongenetic tests, were labeled "genetic only. "

This constructed variable was run against the two questions about biochemical genetic screening—whether companies were currently screening and what their past screening history was—as well as against the general banner, which included all of the definitions of genetic monitoring and screening.

There were a total of 10 cases (weighted) in which genetic screening tests of allergic respiratory disease or contact dermatitis were reported, but none of the other biochemical genetic screening tests were specified. This includes 5 (weighted) of the 18 (weighted) cases in which respondents are identified as "current users' of genetic monitoring and screening. The other 5 cases were only picked up in the "total test' variable, which includes individuals reporting any of the tests from the question, regardless of whether they reported that they were conducting "genetic tests. '

If these are not genetic screening tests, then the prevalence of genetic screening is even less (29 percent less for both the traditional definition and the expanded definition) than previously estimated in 1982, when these tests were explicitly part of the question. In 1989, there were five respondents that said they were conducting biochemical genetic screening, and apparently these were the only tests they reported conducting (contact dermatitis and allergic respiratory disease).

### *Survey Results of the 1,000+ Companies: Current Use*

***Less*** than one-half of 1 percent of companies with 1,000 or more employees reported they were currently conducting cytogenetic monitoring of any employees or job applicants, for research or any other reason. Such cytogenetic monitoring was currently conducted by no company with 1,000 to 4,999 employees, 2 percent of companies with 5,000 to 9,999, and 2 percent of companies with 10,000 or more employees.

Three percent of health officers in companies with 1,000 or more employees reported that their companies were currently conducting biochemical genetic screening of any employees or job applicants, for research or any other reason. Seven percent of companies with 10,000 or more employees reported current genetic screening, compared with 4 percent of those with 5,000 to 9,999 employees and less than 3 percent of companies with fewer than 5,000 employees (table 9-19).

No health officer in a company with 1,000 or more employees reported currently conducting direct-DNA monitoring of any employees or job applicants, for research or any other reason. Similarly, none reported currently conducting direct-DNA screening of any employees or job applicants.

### *Survey Results of the 1,000+ Companies: Past Use*

OTA found that few companies have ever conducted genetic monitoring and screening of workers and job applicants for any purpose. Six percent of health officers in companies with 1,000 or more employees reported that their companies had conducted genetic monitoring or screening tests within the past 19 years, for research or any other reason. This included companies that had conducted genetic monitoring or screening as part of a voluntary wellness program, for diagnosis, or at the request of the employee. It also included reported use of specific genetic screening tests listed in the survey.

Larger companies were most likely to have conducted genetic monitoring or screening tests of job applicants or employees. Seventeen percent of health officers from companies with 10,000 or more employees reported that their companies had used genetic monitoring or screening tests, of some kind, in the past. By contrast, use of genetic monitoring or screening was reported by only 5 percent of health officers from companies with 5,000 to 9,999 employees and 4 percent in companies with 1,000 to 4,999 employees.

## UNIONS AND GENETIC MONITORING AND SCREENING

A total of 10 unions responded to the OTA survey, out of the 33 unions that were mailed the survey. This response rate of 30.3 percent was close to the 36.4 percent response rate (4 out of 11) reported for the 1982 survey. Unions responding to the 1989 survey represented workers in a wide variety of occupations. The 10 unions ranged in size from 1 with less than 100,000 members to 2 with more than 1 million members each. A total of 5.1 million

**Table 9-19—Current Use of Genetic Monitoring or Screening Tests Among Companies With 1,000 or More Employees**

Q.13. Is your company currently conducting biochemical genetic screening of any employees or job applicants, for research or any other reason?
Q.15. Is your company currently conducting cytogenetic monitoring of any employees or job applicants, for research or any other reason?
Q.17. Is your company currently conducting direct-DNA screening of any employees or job applicants, for research or any other reason?
Q.18. Is your company currently conducting direct-DNA monitoring of any employees or job applicants, for research or any other reason?
(Base: Health Officers)

| | | Percent of companies currently conducting | | | |
|---|---|---|---|---|---|
| | | Biochemical genetic screening | Cytogenetic monitoring | Direct-DNA screening | Direct-DNA monitoring |
| Total | (546) | 3 | • | o | 0 |
| Type of business | | | | | |
| Electrical utility | ( 39) | 1 | 0 | 0 | 0 |
| Pharmaceutical | (22) | 5 | 0 | 0 | 0 |
| Other chemical | (47) | 7 | 0 | 0 | 0 |
| Petroleum | (5) | o | 0 | 0 | 0 |
| Electronic | (21) | 2 | 0 | 0 | 0 |
| Other manufacturing | (1 79) | 4 | • | o | 0 |
| Nonmanufacturing | (233) | 3 | 1 | 0 | 0 |
| Number of employees | | | | | |
| Less than 5,000 | (272) | 3 | o | 0 | 0 |
| 5,000-9,999 | ( 99) | 4 | 2 | 0 | 0 |
| 10,000 or more | (167) | 7 | 2 | 0 | 0 |

less than 1%.
SOURCE: Office of Technology Assessment, 1990.

members were represented by the 10 unions responding to the survey.

## *Genetic Monitoring and Screening conducted by Unions*

None of the 10 unions responding to the survey reported that it now conducted genetic screening, cytogenetic monitoring, direct-DNA screening or direct-DNA monitoring of members or potential members, or had conducted such tests in the past. However, one union did report that it conducted tests for allergic respiratory disease and contact dermatitis as part of a voluntary research program. The same union wrote under "other' cytogenetic tests that it does conduct a "review of ailments & material safety data sheets." The respondent also reported that the union had conducted genetic monitoring or screening of its members based on job exposures. Three reasons were given as important factors in the union's decision to conduct genetic screening: evidence of a possible association between chemical exposure and illness in epidemiological studies; union-employee initiative; and "individual rights & privacy.' It should be noted that the respondent wrote: "Union does not conduct any genetic monitoring or screening tests." On the other hand, the respondent also indicated that the union had conducted genetic monitoring or screening of its members based on job exposures.

A second union reported arranging biochemical genetic screening tests and cytogenetic monitoring tests for a union member, at the request of the member, in the past 19 years. These tests were for allergic respiratory disease, contact dermatitis, histocompatibility markers, other immune system markers, other heterozygous chromosomal instabilities, and chromosomal aberrations. The respondent explained:

> Our own medical staff consists of two physicians on retainer, who also have faculty appointments at university medical schools. So far as I know, they have not conducted genetic monitoring and screening tests themselves. In rare cases, they have referred patients for testing to assist in diagnosis.

A third union respondent reported no genetic monitoring or screening but was 'not sure' whether the union was currently conducting biochemical genetic screening tests. Thus, a total of two unions appeared to have some limited experience in conducting one or more genetic monitoring or screening tests, or arranging these tests for their members. This

limited experience in conducting genetic monitoring and screening was consistent with the prevalence of genetic monitoring and screening reported by large companies, particularly since one union only arranged for genetic monitoring and screening without conducting it itself. None of the unions responding to the survey employed or contracted with a genetic counselor.

### *Genetic Monitoring or Screening Conducted by Companies*

***Three*** of the ten unions responding to the survey reported that companies had conducted genetic monitoring or screening tests of their members. All three unions reported that such tests were based on job exposures. One union reported that the company conducted genetic monitoring of its members to identify increased individual susceptibility to workplace risk. A second union reported that company genetic monitoring or screening were also based on family history and cofactors (e.g., smoking). A third union reported that company genetic monitoring or screening were also based on ethnic-racial background. (This was the same union that had referred a few members to outside doctors for genetic monitoring or screening.)

In addition, two union respondents reported that they did not know whether companies had conducted genetic monitoring or screening of their members. One respondent was unable to answer the survey question on whether companies had conducted genetic monitoring or screening of its members, as well as many other questions, because "there are 15,000 employers with enormous variations in size, practice and policy. No general conclusions can be drawn.

None of the 10 unions reported that genetic monitoring or screening were used by a company, primarily or partly, to reject a union member applying for a job. One union was not sure whether a company had used genetic monitoring or screening to reject a job applicant.

However, one union did report that a company had transferred or terminated a union member based on the results of genetic monitoring or screening. This case took place 1 to 2 years ago. The job action involved hypersensitivity to isocyanates. Consistent with limited union experience in job terminations involving genetic monitoring and screening, no union reported that biochemical and cytogenetic tests were used as rejection categories in statistical data on the reasons for job terminations. However, it should be noted that only one union reported maintaining statistical data on the reasons for job terminations, using medical but not genetic criteria as rejection categories.

### *Union Positions on Genetic Monitoring and Screening*

Four unions reported having a formal policy related to the use of genetic screening of employees or job applicants. Two of these unions also had a formal policy related to the use of genetic monitoring of employee health.

The only union to report making recommendations to companies as a result of genetic monitoring and screening was one whose members reported genetic monitoring or screening by companies and which had also referred a few of its members to outside doctors for genetic monitoring or screening. Specifically, the union recommended that the company(ies) implement engineering controls, provide personal protection devices, implement a research program, and discontinue a product or change materials in a product. The union also recommended that a company change its workplace practice or exposure level due to the results of genetic monitoring in establishments where the union is not represented. No other union responding to the survey reported having made recommendations for company changes in the workplace as a result of genetic monitoring or screening.

One union reported having engaged in contract negotiations covering the topic of genetic monitoring and/or screening. It reported that companies had conducted genetic monitoring of its members. The union had a formal policy for the use of genetic screening, but not monitoring. The union respondent took the following position:

> We assume that, as with many types of employer surveillance of workers, genetic monitoring and screening are going on without any formal notification to workers or the union, much less any request for consent. Notification and consent (including provision of payment for scientific peer review by trade union medical consultant) should be mandated. Furthermore, employer genetic testing should be limited to monitoring, and screening prohibited. Questions of suitability of an employee for continued work should be resolved by worker and private physician, in a confidential manner, No individual's

results should be reported to employers directly—only the collective results. In other words, employer-sponsored health research on workers should be conducted according to the same rules as any NIH-sponsored research, complete with Human Subjects Review Board oversight and doctor/patient confidentiality. Just because an employer pays for it does not justify the abandonment of these fundamental concepts.

Answers to survey questions showed that for some unions, the perceived acceptability of genetic monitoring or screening depended on the circumstances. Unions were divided on the acceptability of genetic monitoring or screening of employees or job applicants by employers:

- to make a clinical diagnosis of a sick member—five found it generally acceptable, four found it generally unacceptable;
- to monitor chromosomal changes associated with workplace exposures-five found it generally acceptable, four found it generally unacceptable; and
- to inform members of their increased susceptibility to workplace hazards-four found it generally acceptable, five found it generally unacceptable.

In contrast, genetic monitoring or screening was viewed as generally unacceptable: to establish links between genetic predisposition and workplace hazards (seven unions); to establish evidence of preemployment health status for liability purposes (eight unions); and to exclude members with increased susceptibility to workplace hazards (eight unions). Consistent with union opposition to using genetic monitoring and screening to exclude members with increased susceptibility to workplace hazards, eight unions viewed health examinations to identify job applicants with genetic susceptibility to workplace exposures as unacceptable.

Unions took issue with the idea that employers should have control over the use of genetic monitoring and screening tests. All nine unions expressing an opinion disagreed with each of these three statements:

- The employer should have the option of deciding how to use the information obtained through genetic monitoring and screening.
- The decision to perform genetic screening of job applicants and employees should be the employers.
- The decision to perform genetic monitoring of employees should be the employers.

One union qualified disagreement to the above three items by explaining that employers and unions should both have a say, but that the decision whether to perform genetic monitoring and screening was the employer's.

Unions also showed a general consensus on two other questions. Nine unions disagreed-with eight expressing strong disagreement-that ' 'it's fair for employers to use genetic screening to identify individuals whose increased risk of occupational disease poses a threat for greater costs to the employer. " Eight unions agreed strongly that "genetic screening in the workplace represents a potential threat to the rights of employees." However, there was no consensus among the unions on the desired role of government concerning genetic monitoring and screening. Five unions agreed strongly or somewhat with the statement that "government agencies should provide guidelines for genetic screening of job applicants and employees,' but four disagreed strongly. Similarly, six unions agreed that "government agencies should provide guidelines for genetic monitoring of employees," but three disagreed strongly. The survey asked:

> If an employer becomes aware that an employee has a genetic susceptibility to serious illness if he or she is exposed to substances in the workplace, do you think the employer should exclude that employee from those jobs for which he/she is at increased risk, or do you think the employer should allow the employee to take those jobs, if he/she waives corporate liability?

Three unions thought the employee should be excluded, while two thought the employee should be allowed to take the job. Another two unions said that the employee should be allowed to take the job, but there should be 'no waiver of liability' or no waiver of liability "to the point of no coverage. ' One union said the decision depended on the nature of the exposure, and the availability of work. Two union respondents did not answer the question. One of these respondents criticized the question as inherently biased because it did not offer the responses of "preventing risks by ameliorating the conditions and reducing exposure' or 'transferring susceptible

workers to other jobs with guarantees of pay and job security.'

### Unions and the Future of Genetic Monitoring and Screening

None of the 10 unions was currently considering conducting, or anticipated conducting, biochemical genetic screening, cytogenetic monitoring, direct-DNA screening or direct-DNA monitoring, for any reason in the next 5 years.

One respondent was not sure whether the union anticipated conducting cytogenetic monitoring in the next 5 years, and was also not sure whether the union anticipated conducting any direct-DNA monitoring over that period. This union was "not opposed to genetic monitoring as research, or in diagnosis, where the investigation focuses on the relationship between workplace exposure and genetic damage." This union's medical staff had referred a few patients for genetic monitoring or screening to assist in diagnosis.

Another union respondent did not answer the question on whether the union anticipated conducting any biochemical genetic screening in the next 5 years. However, it should be noted that the respondent commented that "employer genetic testing should be limited to monitoring, and screening prohibited. Questions of suitability of an employee for continued work should be resolved by worker and private physician, in a confidential manner.'

Many of these unions viewed genetic screening in the workplace as a threat to the rights of employees and were strongly opposed to employers having control over the decision to perform genetic monitoring or screening of employees. Half of the unions regarded genetic monitoring or screening as generally acceptable to diagnose sickness and monitor chromosomal changes resulting from workplace exposures. However, most were opposed to genetic screening to link genetic predisposition to workplace hazards, exclude members with increased susceptibility from risk situations or establish evidence of preemployment health status for liability purposes.

Given these views, unions may be expected to object to large-scale use of genetic monitoring or screening mandated by employers without union involvement and consent. The survey suggests that some unions might approve of genetic monitoring or screening, but only for limited purposes, under carefully controlled circumstances agreed on by unions and management.

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