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Social Issues of Genome Innovation and Intellectual Property

Elaine Alma Draper*

Introduction

As a result of the $3 billion Human Genome Project to map the human genetic structure, scientists and physicians will be able to target more and more genetic predispositions and diseases in individuals.[1] Much money is going into developing genetic technologies. But what are the implications of the use of these technologies?

In the many cases in which these genetic technologies have profit potential, patents and the patent system are a useful way of recovering the costs of developing them.[2] The important issues in genome research go beyond patent law to the social and ethical issues involved in new genetic technologies. Attending to social issues can best be done as technologies are developed and patented — not just after the fact.

As a way of looking at the social issues of genome innovation and intellectual property, I will focus on applications of genetics in the workplace and the special role of employers in handling genetic information. We can learn a great deal from the workplace about the social context of the new genetics and its significance. We will consider the ways in which screening technologies and policies have been applied and associated information-control issues. Intellectual property involves information control and use. As we get more genetic information: Who will own and control it; who will use it and for what purposes?

I will focus on five sets of social issues regarding genome information and innovation: First, the problem of information access

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[1] *See* The Code of Codes (Daniel J. Kevles & Leroy Hood, eds. 1992).

[2] *See* Thomas G. Field, Jr., *Intellectual Property: Some Practical and Legal Fundamentals,* 35 Idea 79 (1994) and Robert Mullan Cook-Deegan, *Origins of the Human Genome Project,* 5 Risk 97 (1994). [A current version of Field's paper is on the Internet at http:www.fplc.edu/tfield/plfip.htm.]

and privacy, with particular attention to the large data banks and search companies that raise important questions about control of information. Second, the issue of exclusionary practices affecting individuals perceived to be at special risk and the impact of social stratification by race and ethnicity, gender, and social class on genetic information. Third, the pitfalls of screening for susceptibility as opposed to monitoring for environmental hazards. Fourth, drug screening information as a model to avoid for the use of screening technologies. And fifth, implications of fetal exclusion policies as precedent for the applications of genetic information, especially the ways in which employers require individuals and their private doctors to assume responsibility for risk. Finally, I will consider some ideas about how genome innovation could be managed more rationally and fairly, with attention to ownership rights, confidentiality, and equity.

Information Control and Data Banks

Genetic information can be used to screen workers. People with genes perceived to be defective typically do not own the information about those genes. Genetic risks raise questions of control over information and privacy, because genetic information in the workplace is unlikely to be kept confidential between patients and physicians. Doctor-patient confidentiality tends to be far weaker than in private medical practice.[3] Managers and safety officers pressure in-house physicians and nurses for information on individual workers. Physicians give many examples of this. Some doctors complain that at times they are inundated with requests for medical information from managers who want to know detailed medical information and test results, not only the fitness of the person to do the work.[4]

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[3] *See* Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act,* 29 Houston L.Rev. 23 (1992); L. N. Geller et al., *Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis,* 2 Sci. & Eng. Ethics 71 (1996); and NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, Genetic Information and Health Insurance (NIH 1993).

[4] As part of the research I did for a forthcoming book on doctors employed by corporations and conflicting loyalties in occupational medicine, I interviewed company physicians and others knowledgeable about occupational medicine across the U.S. Here I refer to confidential interviews with informants who requested anonymity.

In employment, we usually focus on confidentiality of the results from tests that employers conduct. Even when employers do not test workers themselves, they can use medical information in making decisions regarding hiring, firing, transferring or insuring people.[5] Employees and applicants describe pre-existing medical conditions on questionnaires and identify genetic characteristics that may make them predisposed to disease or make them high-risk around workplace exposures. Such information helps alert management to potential health problems and may shield them from liability and medical costs for employees' disease.

Employers increasingly turn to outside contractors to provide medical services. These firms are under contract to conduct specific tests and provide screening data. Major breaches of confidential medical records occur. Contractors are subject to competitive pressure to keep the employer's business. If they refuse to submit records, another contractor will provide what the employer demands. Many contractors send the entire employee medical record to management. Small clinics that contract to provide health services to a company do not always know the regulations regarding medical records or understand confidentiality. Rather, they often assume that since the company pays for the medical information, they are entitled to all of it, rather than just aggregate data or a determination that an employee is fit to work. A physician who has worked as an in-house company doctor and under contract to companies says:

> Confidentiality of medical records is very much of a problem. For example, companies that do periodic examinations and surveillance exams are obliged to send detailed medical reports to the personnel director. You know it's wrong, but if you don't do it, you don't get the contract, and so that puts the burden on the integrity of the vendor. Some of them do; some of them don't.

It is common for employers to look at individuals' past medical information, including their past Workers' Compensation claims. The issue of confidentiality of records is intensified now by the ability to

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[5] *See* NIH-DOE *supra* note 3; Jean E. McEwen & Philip R. Reilly, *State Legislative Efforts to Regulate Use and Potential Misuse of Genetic Information,* 51 Am. J. Hum. Genetics 637 (1992); Elaine Draper, Risky Business: Genetic Testing and Exclusionary Practices in the Hazardous Workplace (1991); and F. Allan Hanson, Testing Testing: Social Consequences of the Examined Life (1993).

accumulate records electronically and the inability to protect them effectively. Data banks and search companies pose special problems related to: Who owns genetic information? In many cases, search companies provide employers with health risk information about employees that is even more valuable than the company's own questionnaires and in-house screening program. That is, while the focus of concern about genetic data usually has been on employers' own screening tests, company testing is in fact an issue of minor importance compared with the flood of information coming from search companies, data banks, and credit reporting agencies. The potential adverse social consequences of employer testing are also minimal compared with the abuses of search companies and computer data banks available to employers, which are largely out of individual medical professionals' control.

Increasingly sophisticated data banks for health information exacerbate problems of privacy and inappropriate procedures for granting access to records. For example, employers and insurers can obtain employee medical information from data bases such as the national Medical Information Bureau (MIB) and the genetic data banks operated by biotechnology companies or the DNA forensic banks of state governments.[6] They may use this information for employment-related reasons that go beyond insurance underwriting. Such disclosures of medical information may have serious repercussions that become increasingly important as medical data continue to proliferate.

The MIB has medical records of about fifteen million people in the U.S. Part of the MIB data contains information about genetic and family diseases. When people apply for insurance, they sign a waiver authorizing the MIB to have the data and permitting the insurance company to obtain whatever records the MIB has. Insurance companies can get the data from the MIB whenever a person applies for insurance if they are among the large number that belongs to it. However, the MIB incorporates a huge amount of inaccurate data, which can lead to discrimination against a person in terms of getting life insurance, health

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[6] *See* Advances in Genetic Information: A Guide for State Policy Makers, (R. Steven Brown & Karen Marshall, eds. 2d Ed. 1993); Philip Reilly, *DNA Banking*, 51 Am. J. Hum. Genetics 1169 (1992); and Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 Am. J. Hum. Genetics 476 (1992).

insurance, and employment. Serious injustices are done because the information in data banks and credit companies is incorrect.[7]

Employers can hire a computer-search company to investigate a pool of prospective employees and get a great deal of information about them. It could be very cost-effective if the employer can avoid having two or three very expensive employees by screening them out when they apply for a job. Credit-reporting agencies like Equifax and TRW can do low-cost searches on potential employees that give companies valuable information about a person's health risks, prior exposure to health hazards, employment, and medical history, along with information regarding felony reports and legal records, driving records, insurance history, drug-treatment reports, and use of medications. These background checks often mix personal, medical, and financial information, some of which may help predict future medical costs. A physician who has provided medical services to many companies received a call from a major search company asking for personal and medical information on a recent graduate of an occupational medical residency training program in which the physician taught. He said:

> She started asking me over the phone "Have you ever been to dinner with him? Does he drink much? Does he talk about the Communist Party?" And then she got into more and more personal and medical stuff. They're one of the three largest credit-reporting agencies in the country, and it's the most incredible invasion of privacy you've ever imagined. For less than twenty dollars, they'll give you a person's last ten years of major medical and Workers' Compensation charges, and from RVS codes essentially tell you what diseases they have. They'll do sub rosa investigations to find out about alcoholism, drugs, troubled teenagers, bad marriages — the laundry list just goes on and on; you just figure out how much you want to spend.

The search companies' promotional material portrays their background checks as useful to employers evaluating potential costs that an employee might represent. Company personnel offices are besieged with sales information from search companies. The sales pitch is that the corporate doctor conducting preplacement exams, even including a drug test of the urine, does not begin to offer the company

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[7] *See* Geller et al., *supra* note 3 and NIH-DOE, *supra* note 3.

the potential cost savings that the search company does, and they can do it without the person knowing it takes place. Search companies then appear to be a bargain.

Social values and government rules regarding medical confidentiality are very much in flux. The laws governing patient-client confidentiality are murky in many instances, particularly concerning occupational medicine and employer medical programs. The extent to which medical information must be kept private — and not revealed to employers, insurers or others — is currently being redefined. Search companies describe their activities as credit reporting, which is protected under the Federal Fair Credit Reporting Act. Although legal restrictions have an effect on search companies, these companies are still in business and doing well.

Even when employers are reluctant to use genetic information to exclude workers, insurance companies may pressure companies to collect genetic information and to differentiate between high-risk and low-risk individuals. Insurance companies have a long history of screening, charging differential rates according to risk, denying service to high-risk individuals, and failing to respect medical confidentiality.

In some cases, the insurer is the employer. Employers say they have lost a sizable part of their profitability to health-care costs in the last ten years. Self-insured companies can save on medical costs and avoid the state laws and regulations that are designed to ensure adequate health insurance for employees.[8] They have access to vast amounts of information about a person's health history and use of medical services. The confidentiality problems for self-insured companies generally are even worse than for companies with outside insurance coverage. Self-insured employers have a strong incentive to reduce their own financial risk by identifying high-risk employees. These companies and others concerned with health costs choose to screen as a solution. Employers conclude that they have to spend more to do better screening of their

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[8] *See* H. Ostrer et al., *Insurance and Genetic Testing: Where Are We Now?* 52 Am. J. Hum. Genetics 565 (1993). The Employee Retirement Income Security Act of 1974 (ERISA; 29 U.S.C. §§ 1001-1381) exempts self-insured employers from state regulations and laws (such as those regarding minimum required benefits and anti-discrimination provisions) covering health benefits plans, pension plans, and other benefits that employers provide. Under ERISA, self-insured employers may eliminate or modify their medical benefits for particular medical conditions.

workers to remove the expensive people from their rolls or make them pay a higher share of the cost. One physician who has provided medical services to many companies says:

> I've never seen a company that went self-insured that didn't seriously compromise whatever little bit of corporate confidentiality of medical records existed. They become intensely interested in medical records. It is in corporations' self-interest to screen workers out, not to take measures to reduce exposure hazards, and to violate confidentiality of employee medical records. You could argue that if they don't, they won't be here.

The burden on small employers of having employees with high medical costs can be especially heavy. While a large company can support high-risk employees, an employer with 20 employees is less able to sustain several employees with large health costs. However, the small company is less likely to screen to find out what the employees' risk is.

Even when companies are not self-insured, health screening information makes its way to managers. Employees go to their private physicians and file a claim form, which is administered by an insurance company. The insurer then reports to the employer on the workers' medical treatment. Periodically, the insurer sends to the benefits or human resources manager a report delineating the people whose claims they paid. The human resources director then knows who was treated for venereal diseases, psychiatric problems or heart disease. Why should personnel managers have this information?

Social Stratification and Genetic Information

An important social issue regarding applications of genetic information concerns job discrimination and exclusionary policies based on genetic information at the point of hiring and beyond. One way of screening workers has been through testing job applicants or new employees for genetic traits. The placement of employees stemming from the application of medical information can be discriminatory. Medical discrimination remains a very real and significant problem, despite new laws and political developments.

Diseases with a genetic component are not esoteric. For example, colorblindness and diabetes have a genetic component, and employers have screened for these conditions for years. In addition, heart disease and breast cancer, along with many other diseases, are in part genetic.[9]

Insurance companies and employers claim to identify individuals who may be genetically susceptible, based on their biology. A major social problem with genetic information concerns social stratification, because the layering of our society by race and ethnicity, gender, and social class affects the use of genetic information. Important stratification issues often have been involved in workplace medical screening.

Many genetic abnormalities are disproportionately found among specific ethnic or racial groups. For example, G-6-PD deficiency and sickle cell trait are found in high proportions among blacks, so screening out people with those traits will mean screening blacks out disproportionately. Some of the new discoveries of genetic predisposition are likely to be found disproportionately in certain racial or ethnic groups, or more among women or men, as with genetic characteristics that are already known. These groups then may experience discriminatory practices by employers and insurers.[10]

Employers and insurance companies are likely to use genetic information to exclude people from relatively high-paying jobs. They seldom screen people out of low-paying hazardous jobs. The individuals screened out are more likely to be blacks or women, who have entered those jobs in large numbers only in recent years and bear the burden of genetic information about risk.

As genetic information accumulates through the Human Genome Project, more people will find it virtually impossible to obtain health insurance or be stigmatized as a bad risk for employment. People perceived as having a medical "disorder" can also be stigmatized in their personal lives. Being so labelled can make it difficult for them to be perceived — or to perceive themselves — as normal again.[11]

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[9] *See* Assessing Genetic Risks: Implications for Health and Social Policy (Lori B. Andrews et al., eds. 1993) and U.S. Congress, Office of Technology Assessment, Genetic Monitoring and Screening in the Workplace (1990).

[10] See Geller et al., *supra* note 3; Philip Reilly, *ASHG Statement On Genetics And Privacy: Testimony to United States Congress,* 50 Am. J. Hum. Genetics 640 (1992); Troy Duster, Back Door to Eugenics (1990); Kevles & Hood, *supra* note 1 and Draper, *supra* note 5.

[11] *See* Larry O. Gostin, *Genetic Privacy,* 23 J. Law, Med. & Ethics 320 (1995);

Genetic information about individuals can affect their family members' access to insurance as well. Furthermore, when new genetic information makes individuals appear to be high-risk, those individuals are likely to experience as a personal medical problem what is in fact a social problem that reflects stratification in the broader society.

The Americans with Disabilities Act (ADA) went into effect in 1991, and it prohibits pre-employment medical examinations and discrimination against the disabled.[12] The ADA limits employers' ability to restrict people — such as diabetics on insulin — from certain activities. Limitations are to be tailored to the individual rather than blanket limitations. So we might ask, if employers cannot test people prior to offering them employment, does that not eliminate the problem of job discrimination? The basic answer is no, job discrimination linked to genetics remains an important problem.

The ADA itself does not even mention genetics or genetic traits, and genetic susceptibility to disease and death was not a focus of the congressional debate on the ADA. The Equal Employment Opportunity Commission (EEOC) originally took the position essentially that individuals are not covered by the ADA until they are symptomatic. The EEOC maintained that the risk of impairment in the future was not considered a disability under the ADA. Then in its March 1995 interpretation of the ADA, the EEOC stated that disability under the ADA would include individuals who are predisposed to, or presymptomatic for, a disabling disease.[13] Under

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Bernadine Healy, *Testimony on the Possible Uses and Misuses of Genetic Information,* 3 Hum. Gene Ther. 51 (1992); Neil A Holtzman & Mark A. Rothstein, *Eugenics and Genetic Discrimination: Invited Editorial,* 50 Am. J. Hum. Genetics 457 (1992); Billings et al., *supra* note 6; and Dan W. Brock, *The Human Genome Project and Human Identity,* 29 Houston L.Rev. 7 (1992).

[12] Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. §§ 12101–12213 (1990). The ADA protects people who have, or who are perceived to have, physical or mental impairments from employment discrimination, as well as from discrimination in public accommodations and transportation and in telecommunications. The ADA explicitly states (in Title V) that prohibited discrimination does not include conventional risk underwriting by insurance companies or self-insured employers, instead leaving insurance regulation to the states. *See* Rothstein, *supra* note 3. The McCarran-Ferguson Act, 15 U.S.C. §§ 1011–1015 (1982) declared that states regulate insurance unless specific federal action seeks to regulate the industry.

[13] For discussion of the 1995 EEOC interpretation of the ADA regarding genetic disabilities, *see* M. S. Mehlman et al., *The Need for Anonymous Genetic Counseling and Testing,* 58 Am. J. Hum. Genetics 393 (1996).

the ADA, employers are allowed to collect genetic information and conduct medical examinations in order to reveal the applicant's ability to perform the job, and employment exams are permitted after a conditional employment offer is made, when all employees in a particular job category receive the test. But issues of whether impairments impede the ability to do the job, and the business necessity of excluding a person, leave a great deal of room for judgments that are far from straightforward. It becomes a question of judgment of how much effort is reasonable to put forth on job placement and what reasonable accommodation and work assignments are for someone with potential health problems. The employer is not supposed to screen out disabled individuals unless it is for a job-related disability that cannot be accommodated. However, the EEOC interpretation of the ADA did not limit the employer's ability to conduct any genetic testing or collect any genetic information after a conditional job offer, even if the information is not job related.

After employers make job applicants a conditional offer of employment, employers can give any tests they want. Even if the employers do not use that information as a reason to exclude people outright, they can in effect use genetic information to exclude people. Employers can modify their health insurance coverage to exclude those people. Workers with signs of damage may be excluded from medical coverage or charged extremely high rates as a way of reducing employers' costs — even if the high-risk workers are not fired. Employers can say to employees: As of today, people like you are not covered by our health insurance.

In one case, a man who found out he had AIDS made claims and collected payments from his employer's commercial insurer. Within a year, the company became self-insured, offering essentially the same benefits but decreasing lifetime benefits for AIDS from one million to five thousand dollars. His partner sued after the employee died but lost initially[14] and again on appeal.[15] According to this case, self-insured companies can, post-facto, change their benefit plans because of somebody's claim or because of a genetic test.

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[14] McGann v. H & H Music, 742 F.Supp. 392 (S.D. Tex. 1991).

[15] McGann v. H & H Music, 946 F. 2d 401 (5th Cir. 1991), *cert. den.,* Greenberg v. H & H Music Company, 506 U.S. 981 (1992). *See* Ostrer et al., *supra* note 8.

Through sophisticated screening, employers can continue to offer a major medical policy without being burdened by individuals with an adverse genetic profile. Then everyone with a high-risk profile can be charged a higher deductible or employers can do as insurance companies do: Tell people they are not insurable.[16] So despite the ADA and other developments, genetic discrimination remains a very real problem, and is likely to become even more significant as the Human Genome Project uncovers more and more genetic information.

One approach employers continue to pursue is to inform workers that they face special genetic risks on the job, then allow them to choose to endanger themselves or their children. Yet, the extent to which screening tests and questionnaires calling for medical information are voluntary is questionable. The rhetoric of choice is indeed tricky. It is not merely an individual and welcome choice when workers are told they may be at special risk genetically and they have a "choice" to stay on or quit their job. To what extent should people be allowed to endanger themselves or their children for wages? And are people really making an "individual" choice if they take a dangerous job?

Individuals with few job alternatives have limited choices when offered "voluntary" testing or opportunities to divulge health information. Issues of choice and coercion arise when individuals are pressured to provide medical information, when they are threatened with losing their employment or insurance, and when they find that the counseling recommended for private patients is unavailable to them.[17] Employers overlook the restrictive conditions under which choices about health and employment take place. The economic necessity of working, limited job alternatives, managerial control and incomplete employee information on hazards all serve to limit the available choices.

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[16] Hundreds of health insurers in the U.S. share their computerized data on health-care costs and risks. *See* Dorothy Nelkin & Laurence Tancredi, Dangerous Diagnostics: The Social Power of Biological Information (1989); and NIH-DOE, *supra* note 3.

[17] *See* Mehlman et al., *supra* note 13; Arthur Caplan, Moral Matters: Ethical Issues in Medicine and the Life Sciences (1995); American Medical Association, Council on Ethical and Judicial Affairs, *Use of Genetic Testing by Employers*, 266 JAMA 1827 (1991); Alexander Morgan Capron, *Hedging Their Bets*, Hastings Center Report, May-June, 1993, at 30; and Kevles & Hood, *supra* note 1.

Screening Overshadows Monitoring

Screening and monitoring are two major alternatives that have developed in response to the identification of genetic and biological traits and hazardous substances. Screening has developed as an alternative to monitoring, in that high-risk individuals have been identified and screened out as a favored means of reducing exposure to environmental contaminants. Employers increasingly favor a screening approach to environmental hazards. In fact, the screening approach is winning, which leads to some significant problems. The screening approach involves detecting individuals who then will be excluded from exposure to the toxic substance. In contrast, the declining monitoring approach involves monitoring contaminants in order to determine whether exposures are too high for those who are exposed to them — like measuring levels of air contaminants with a radiation badge.

With rising health costs and threatening liability trends, employers increasingly turn to health screening policies that focus on individuals who may pose a special risk in the workplace. The prospects of greater insurance and Workers' Compensation expenses, along with discrimination suits, make identifying those with threatening personal habits or medical conditions an especially promising strategy for companies to deal with medical and economic problems. Employers have been concerned about the catastrophic potential of allowing workers with a drug abuse problem, specific genetic traits or the AIDS virus to remain on the job. They have screened workers based on health risks related to smoking, reproductive hazards, drug use, genes or biological traits.

Many employers and company physicians are now strongly drawn to medical screening as a way of avoiding hiring or retaining workers who may pose the greatest threat to the financial health of their companies. Employers and their insurers may obtain medical information in a variety of ways: from tests, questionnaires, reports of coworkers or insurance records. In other words, workplace medical screening does not require that employers actually conduct their own testing programs. They may nonetheless use this screening information to determine the employability, job placement, insurability or general treatment of workers.

Employers who favor a screening approach often see those who oppose it as technophobic and anti-scientific. But this perspective is invalid, because opponents of screening do not oppose science and technology generally: they typically favor other advanced technologies and scientific developments.

An example of the screening and monitoring approaches is the contrast between types of genetic testing, with monitoring seeking to uncover genetic damage from pollutants and genetic screening, in which individuals are screened — usually once — to see whether they have a genetic susceptibility to disease. The approach of screening high-risk individuals is likely to become even more pervasive as the Human Genome Project uncovers more genetic information.

Employers' focus on individual hazards rather than the environment is intensifying, which shifts the attention and blame from corporate technological risks to individual predispositions. People's position in the labor force has a strong effect on how people perceive the possible benefits and dangers of genetic information. Employers are much more likely than workers to believe that people should be excluded from jobs because of genetic information. Corporate managers tend to support collecting genetic information that would enable them to identify and possibly weed out genetically high-risk individuals. In contrast, workers and union representatives tend to favor ongoing genetic monitoring, which involves periodically testing groups of people to see if there is genetic damage over time from exposure to toxic substances.[18] Monitoring information generally is used as evidence of chemical damage to groups of workers, rather than to exclude people and lay the blame for their disease on individuals' genetic makeup. Monitoring tends to lead to reducing exposure levels rather than removing individuals from the environment.

Diseases are called "genetic" and screened for as inborn biological traits despite evidence of the importance of environmental factors. Spina bifida is generally described as "genetic," although it is prevalent in highly polluted industrial areas, such as South Wales.[19] Another example of the ascendant screening perspective concerns sickle cell trait,

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[18] *See* American Medical Association, *supra;* Draper, *supra* note 5; and Willian Ryan, Blaming the Victim (1971).

[19] *See* Duster, *supra* note 10.

which is widely described as "genetic" even though it protects individuals from the environmental threat of malaria. Similarly, PKU is called "genetic," despite the fact that it can be prevented effectively through diet.[20]

A major problem with genetic screening is that it has been ineffective preventive medicine. The best the tests can do is show that certain individuals may be somewhat at greater risk for one type of ailment when exposed to one substance or group of chemicals. But they may be less at risk for another. They might be at lower risk of developing emphysema, but they may develop bladder cancer from the same substance or from other chemicals. Current screening tests suffer from both narrow applicability and limited predictiveness. Genetic screening may penalize far more people than it protects, and in some cases may not protect workers at all. Further, it can give employers and workers who remain a false sense of security, by making them think that screening out workers has eliminated the health risk.[21]

Another example of a problematic screening approach concerns the risks of cotton dust, which is regulated as a hazardous substance. Company officials have stated that only a small proportion of the work force is vulnerable to cotton dust and should therefore be screened out of jobs with exposure to it. This claim that almost all workers are safe when exposed to cotton dust, and that therefore no real need to monitor the substance exists, contributes to companies' interest in screening out certain workers as high risk. A similar example of the declining monitoring approach from outside the workplace is the arguments against monitoring and regulating potential carcinogens in the diet, which have been used as political arguments to justify potentially harmful exposures.[22]

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[20] See Andrews, *supra* note 9; Office of Technology Assessment, *supra* note 9; and Duster, *supra* note 10.

[21] *See* Office of Technology Assessment, *supra* note 9 and Draper, *supra* note 5.

[22] *See* Organizations, Uncertainties, and Risk (James F. Short & Lee Clarke, eds. 1992); Sylvia Noble Tesh, Hidden Arguments: Political Ideology and Disease Prevention Policy (1988); and Draper, *supra* note 5. Arguments against the 1958 Delaney Clause of the Food, Drug and Cosmetics Act have maintained that since such small quantities of material can now be detected, prohibiting detectable carcinogens in food is no longer necessary.

When individuals become sick, proponents of screening generally assume those people must share characteristics beyond the workplace exposure. In their conviction that only certain types of workers will have a problem, they maintain that the others are safe. So when employers say the existence of a genetic factor means that only 2% of the work force are in danger, that is another way of saying 98% are safe. Saying that a group is at risk is another way of saying that the work force is safe once that group is removed. Furthermore, people who believe current levels of contaminants are harmless and overregulated are more likely to believe that people who get sick must have something wrong with them, so we should try to identify them and screen them out.

The important underlying question here is: Do we focus on the individual or on the environment? In fact, a certain percentage of people may develop these diseases and others may not, but in most cases the idea that a biological trait of the workers themselves causes the problem is unproven. Focusing on the individuals and their possible predispositions too often is a way of inappropriately changing the subject, away from the workplace hazards.

Despite legal developments such as the ADA and *Johnson Controls*[23] barring fetal exclusion policies, employers still focus on the individual health risks of high-risk individuals. The public health orientation toward eliminating environmental hazards such as asbestos has given way to a preoccupation with individual health risks and a search for workers with an inappropriate lifestyle such as drug use or individual genetic predisposition. Two major examples of the screening approach serve as models to avoid for the application of genetic information: drug screening and fetal exclusion policies used for reproductive hazards screening.

Drug Screening As a Model to Avoid

Drug use and wellness programs are part of the search for workers with individual health risks. Drug testing is widespread in the workplace.[24] The large companies in which I interviewed doctors

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[23] International Union v. Johnson Controls, Inc., 499 U.S. 187 (1991).

[24] *See* **Under the Influence? Drugs and the American Work Force** (Jacques Normand, Richard O. Lempert & Charles P. O'Brien, eds.1994); Nancy Durbin & Tom Grant, **Fitness for Duty in the Nuclear Industry: Update of the Technical Issues 1996** (Battelle Human Affairs Research Centers); and **Drug Testing in the Workplace**

about occupational medicine, for example, test all job applicants for all positions and all new employees who are provisionally offered a job. They also periodically test workers in safety-sensitive jobs and in jobs in which the U.S. Department of Transportation or Nuclear Regulatory Commission require random testing, and test people "for cause" — after an accident or serious incident or functional deficit that creates the suspicion that drugs are involved.[25] When we consider potential applications of genetic information, this model of drug testing is a major one to avoid.

Employers use tests that they acknowledge to be ineffective in detecting many problems. Drug screening results in few positive test results, but employers argue that it deters drug users from applying to work for them and keeps some casual drug-user employees away from drugs.[26] Then it becomes the lemming effect: One company does it and the other companies line up to do preplacement testing. Employers fear that if they were not to test, drug users would gravitate to them. Some companies report that in certain locations they initially had 20–50% positive test results identifying drug users. Now corporations that carry out drug testing find a very low fraction of positives. A typical positive rate in corporations that routinely test applicants for employment and use for-cause testing is closer now to 1–4%.[27]

People who conduct drug testing in companies say that although the policing function is not particularly effective in catching drug users, they avoid workers who take drugs when they announce at the beginning that they occasionally will do random drug testing. It is not even the fact of their drug testing that has an effect, then; it is just the specter of their doing it. Their implicit belief is that the accuracy of the

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(Scott McDonald & Paul Roman, eds. 1994).

[25] Examples of jobs subject to random drug testing are trucker and power plant operator. Employers in transportation do extensive random drug testing. Workers covered by U.S. Department of Transportation rules established in 1988 typically undergo a standard, routine, formalized random drug test; generally random numbers and names are generated by computer.

[26] *See* Normand et al., *supra* note 24 and MacDonald & Roman, *supra* note 24.

[27] *See* American Management Association, 1994 AMA Survey: Workplace Drug Testing and Drug Abuse Policies and Durbin & Grant, *supra* note 24.

The former reported that in 1993, among the 794 companies responding to their questionnaire (48.1% of whom are in manufacturing and 87.2% of whom test for employee drug use), 2.5% of the over 96,000 drug tests of employees in 1993 and 4.3% of the over 97,000 drug tests of new hires in 1993 were positive.

drug testing is less important than having drug users believe it is accurate and go to another company. They say they rarely do random tests or routine spot checks on employees except in certain power plants and sensitive positions. But they make the threat of drug tests clear by displaying posters and telling the employees often that drug testing could be done, in an attempt to frighten drug users away. One chemical company physician says:

> The reason we do drug testing on all new hires is not that it's good procedure. It is that it keeps us from getting a disproportionate share of junkies.

A doctor employed by a major bank who reports that the company had a rate of positive urine drug test results of 1.4% the previous year says he recommended that management stop drug testing.

> At one point I said to them, "Just tell them we tested them. We'll just pour it down the drain." It just didn't seem worthwhile to me to find that small percentage.

An unfortunate parallel with genetic information is that employers, insurers and even scientists at times have advocated that ineffective screening policies be used in the workplace, in the belief that screening would accomplish goals that are only sometimes health-related.

Another parallel with genetic information is that drug testing generally does not detect impairment at work. It detects whether a substance is in the body, but not whether the substance causes any impairment whatsoever on the job.[28]

If company policies were consistent, they would apply to alcohol and prescription drug use. They would discourage people from abusing any substance that has an adverse impact, including alcohol. However, employers have not been nearly as concerned with prescription medication as with illegal drugs. They also have not focused on fatigue as a major cause of accidents. In general, managers avoid looking at the workplace as a cause of drug and alcohol abuse or other personnel problems.[29] A parallel concern with genetic information is that

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[28] *See* Durbin & Grant, *supra* note 24 and Robert McCunney, *Drug Testing: Technical Complications of a Complex Social Issue,* 15 Am. J. Ind. Med. 589 (1989).

[29] Durbin & Grant, *supra* note 24, conclude, Ch.3, at 23, from their review of the technical findings and survey data on drug and alcohol use:

> Despite the popular attention paid to illegal drugs, alcohol clearly

employers' focus on identifying uncommon biological traits overshadows the prevention of more pervasive health risks.

For-cause and random drug testing have been voluntary in name only, as with screening for biological traits. Discussion of informed consent and voluntary testing with both genetic and drug testing has tended to mask the coercive context of workplace screening. One physician hired by a metals company to do their testing explains:

> We had for-cause alcohol and drug testing for people who management suspected were under the influence. We didn't have mandatory testing. Well, it was called voluntary, but it was really mandatory: You didn't have to take the test; but you'd get fired if you didn't. (Laughter).

As with genetic information, drug testing information passes directly to management and can be used to affect employment. With such testing, the notion of a confidential doctor-patient relationship becomes even more tenuous. The physicians' priority of delivering health care is in tension with the screening concerns that corporate officials who do not provide health care have regarding workplace safety, the ability of workers to do their jobs and employer costs. The focus of employer screening instead should be on whether the person has a health condition that may be made worse by work, places others at risk or prevents them from doing the job.

Reproductive Hazards Policies for Targeting High-Risk Individuals

In addition to drug testing, reproductive hazards policies for targeting high-risk individuals are a model to consider in analyzing issues of choice, privacy and information control in the applications of genetic innovation. The fetal exclusion policies many companies have followed are an important example of the screening approach and one that is genetically based. These policies, in which women have been barred from particular jobs because of possible fetal damage, were most pervasive in companies in the 1980's through the early 1990's.

Employers have argued that excluding women from lead and other toxics protects the fetus from harm and protects women from

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remains the most commonly used, and abused, mind-altering drug in America. This is true for both the general population and employed workers. Survey findings show that while illegal drug use has declined among the general population over the past decade, heavy alcohol use has remained stable.

reproductive damage. For example, beginning in 1978 American Cyanamid barred women of childbearing capacity from production jobs involving lead. Five women underwent sterilization procedures as a result of this exclusionary policy.

Fetal exclusion policies have been selectively applied. Most of the jobs barred to women have been relatively high-paying and traditionally male production jobs in large companies, such as General Motors and DuPont. In general, the issue of special risk and exclusion has emerged only when women are relatively new to an occupation and a minority, as women are to the chemical industry and lead battery plants. Women's presence and different health becomes an issue when they move into jobs they had not held previously. The question of exclusion has not come up in jobs where women are a majority, such as in low-paying electronics jobs with exposure to powerful solvents or hospital jobs with exposure to ionizing radiation.[30]

As with genetic screening, although a particular group may be high risk because of their biology, many others may be at risk. It may be true that some workers are somewhat more likely than others to develop disease. But policies of banning women from jobs fail to protect workers and the unborn from job-related harm, in part because they leave remaining workers exposed to substances that can cause sperm damage and other reproductive effects, along with genetic damage and cancer. For example, lead can cause birth defects through maternal exposure, but the men who remained were vulnerable as well, because lead can also damage the heart, kidneys and nervous system in both men and women. In some cases, risks through fathers' exposure to hazards may even be greater than the maternal reproductive risks. For instance, male exposure to ionizing radiation presents a higher risk for genetic mutations and chromosome aberrations than reproductive risk through female workers.

In the widely publicized *Johnson Controls* case, the Supreme Court ruled that the corporation's policy of barring fertile women from relatively high-paying jobs with exposure to lead unjustifiably discriminated against women.[31] But physicians and others in

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[30] *See* Elaine Draper, *Fetal Exclusion Policies and Gendered Constructions of Suitable Work* 40 Social Problems 90 (1993) for discussion of the selective application of fetal exclusion policies.

corporations whom I have interviewed since *Johnson Controls* indicate that some employers have not cancelled or revised their policies of barring workers they consider high-risk — even in the face of discrimination suits, because they fear costly third-party suits on behalf of fetuses affected by work exposures. Some companies simply ignore reproductive hazards; others handle reproductive issues on a one-on-one, ad hoc basis, with no policy developed.

A parallel with genetic innovation is that purported discovery of a high-risk group diverts attention from the remaining individuals. Corporate employers resist broadening their understanding of reproductive hazards beyond women and are reluctant to focus on men, even though little evidence shows risks confined to direct exposure of the fetus. Research now sometimes involves male reproductive toxicology, so employers are more aware of reproductive hazards to men than before *Johnson Controls*,[32] although the scientific and policy aspects of reproductive hazards continue to be mired in complexity. Nevertheless, employers still focus on risks to women in part because male reproductive hazards are relatively unfamiliar to them and because women and motherhood fit together ideologically in a way that makes the evidence for excluding women more compelling than it might be if they examined these assumptions critically. Employers suspect if they focused on male reproductive hazards they might have to exclude men from jobs. In addition, they know that broadening their concern about reproductive hazards beyond women might lead to further pressure to clean up the workplace if both women and men were known to be at risk.

As with genetic information, choice rhetoric concerning reproductive hazards gets used in powerful ways to legitimate otherwise less palatable policies. Both before and after the 1991 *Johnson Controls* decision, employers have used the rhetoric of choice to legitimate their policies. The debate over reproductive hazards in corporations is a telling case of language constructions people use to justify what is in their interests.[33]

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[31] 499 U.S. 187.

[32] *Id.*

[33] The pro-choice arguments appear in hearings on fetal exclusion policies, and in the thousands of pages of briefs and transcripts related to the Johnson Controls cases

Employers have argued that they must have the choice of how best to protect people's reproductive health and therefore they must be allowed to protect the fetus from hazardous mothers and protect women from their own bad decisions. Employers recognize the power of pro-choice rhetoric and use it themselves. For example, Johnson Controls' chief counsel, Stanley Jaspan, asserted that an employer must not be "required to expose the individual, to expose the child."[34] He said some women had acted irresponsibly in ways that could endanger a fetus when the company tried a voluntary approach allowing pregnant workers to change jobs. He argued that employers rather than women workers ought to be able to choose what is safe or hazardous for the fetus.[35] This corporate perspective on reproductive risk draws on the decision-making models favored by free-market economists and rational choice theorists, who maintain that individuals are fairly compensated for dangerous work and freely choose it.

Significantly, employers' individual-decision-making stance regarding hazards at work closely resembles pro-choice arguments that equal rights advocates use against fetal exclusion policies. Opponents of corporate fetal exclusion policies typically argue that women should be given health information and be able to choose for themselves with minimal interference from outside forces whether to take the risk of possible fetal harm rather than be excluded from jobs. Thus, both employers and critics of their policies share certain misconceptions about the social context of risk, by overestimating the extent to which individuals can freely choose risk in the hazardous workplace.

Although the Supreme Court decided in 1991 that employers cannot choose to exclude women,[36] choice rhetoric remains very strong. Some large employers essentially require women to sign waivers saying the women choose to risk their reproductive health and will not hold the company liable if they want to stay in jobs that may be hazardous to fetuses. Women may be denied jobs if they refuse to sign away their rights. Employers switched to using waivers soon after the Supreme Court decision, in the belief that continuing their fetal

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in California, Illinois, and the Supreme Court (1990).

[34] 499 U.S. 187 (transcript, at 36).

[35] *See* Normand et al., *supra* note 24.

[36] 499 U.S. 187.

exclusion policies would leave them too vulnerable to a lawsuit for discrimination against women. Employers maintain that they are giving women the choice by having them sign waivers and that women themselves assume the risks, similar to the notion of "informed consent." A physician who works for an aerospace company says:

> We ask the person to sign a waiver to indicate that they prefer to stay on the job even though they recognize a hazard to the fetus.

More bluntly, a chemical industry physician who supports having women sign waivers if they remain in jobs with toxic exposures and whose company uses waivers for reproductive hazards says:

> I'm a great believer in freedom of choice, so I think people should be permitted to kill themselves.

Generally it is not permissible to exclude women from lead or other hazards because of possible fetal hazards. But signing away a third-party's rights — or the incipient or potential rights — of the fetus is also impermissible. Many people are willing to sign a statement saying they knowingly take a risk in order to keep their job and agree not to hold the employer responsible. But getting permission from the parent does not adequately protect the company in terms of the unborn child or shield the company from liability because the employer does not have permission from the unborn child to expose them. In addition, parents cannot sign away their Workers' Compensation rights granted by state law, so a company is responsible at least for Workers' Compensation. Workers can sign an informed consent saying they realize they have a higher risk of getting carpal tunnel syndrome or another cumulative trauma disorder because they pack a million widgets in boxes every day. But as soon as they get carpal tunnel syndrome, the employer still would be expected to pay part of the bill for that occupational injury under Workers' Compensation, whether or not the person knew about the risk.

Liability issues regarding reproductive hazards are a major concern for employers. One reason they are so concerned is that even just with the background rate of birth defects of 2–7%, employers anticipate that they are likely to have female employees who have birth defects. Inevitably there will be some miscarriages and defects, leading to lawsuits on behalf of a damaged child. The medical evidence that very low exposure levels are hazardous to fetuses is complex but is accumulating. By using waivers to respond to reproductive hazards, employers continue to leave themselves vulnerable to lawsuits for fetal damage and cause others to risk reproductive damage.

In addition to attempts to transfer responsibility for hazards onto workers' own choices such as through waivers, many companies try to shift the responsibility for hazards to private doctors outside the company. Employers send women to their personal doctors for their judgment about risk and ask them to sign a statement certifying that the working conditions are safe for the fetus, saying: "I guarantee conditions would be safe for her to continue working" or "I approve having this woman remain at work." This happens in a wide range of companies, including the semiconductor, defense, printing, airline and chemical companies, which represents another defense mechanism through which employers attempt to shift liability. By using waivers from private physicians, employers believe the outside doctor may then be held liable for any reproductive damage or for encouraging women to continue working if damage results.[37] A physician employed by a major airline says:

> In the medical department we provide a rather elaborate job description of work site exposures for a pregnant woman. She then takes this to her obstetrician; who looks at it. That job description describes what they do physically, whether the job involves heavy lifting and pushing or changes in temperature, environment, barometric-pressure, biorhythm or time-zone. Then *he* will sign yea or nay that this person can work for the next thirty days. The private physician may be reluctant to sign, but nevertheless, we insist that the employee get that document. We will not put the employee back into their work environment without it.

If private doctors say that pregnant or fertile women cannot work, the women may be fired. Also, some private physicians are unwilling to sign the letters and are reluctant to take on that potential liability of saying the person is safe, because they might be accountable if problems arise. Women then are excluded from jobs if their private doctor will not sign such a letter, even where the job does not present health

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[37] However, if the treating physician says the job is safe, the employer rather than the outside physician might still be ultimately liable.

problems. The company policy leads some women to believe that they are excluded because their doctor will not cooperate.

Getting private doctors to permit exposures is similar to many companies' perspective on genetic information, in that in both cases, responsibility for adverse outcomes would rest with someone other than the employer. Doctors and employers are very likely to use waivers with individuals considered genetically high-risk, then give people the choice of taking on hazardous work, as in the case of fetal exclusion, or require that private doctors sign agreements permitting environmental exposures. We can expect this pattern to become more pervasive with advancing genetic innovation.

Genome Innovation Reconsidered: Conclusions

As genetic innovation advances, the perception of a genetic defect will become broader, so that people being perceived as genetically flawed will be an increasingly prevalent problem. The expanding genetic innovation from the Human Genome Project increasingly will identify individuals as high-risk for a widening array of diseases. Several points and arenas of change need greater attention in examining health and employment practices related to genetics and in considering alternative policies. These concern access to health care, equitable applications of genetic technologies and the use of genetic information.

Universal health coverage and a single-payer health care system could mean that individuals and groups considered high-risk would no longer be denied health coverage or medical care. Universal access is a crucial concern in addressing problems of privacy, discrimination and availability of affordable health care. A single payer system of government-financed health care for those who require it could help ensure that people who need the insurance and health care are able to get it. Moreover, screening would have fewer adverse effects on those considered high-risk, because they would have less to fear about losing access to medical treatment.

The exclusion of people with a genetic defect from private insurance is a major issue, though some insurance companies, such as Blue Cross, voluntarily stopped excluding people with pre-existing conditions from eligibility for insurance coverage. Since most insurance is bought in groups, people obtain insurance virtually automatically with their employment, so that they are not excluded for preexisting conditions. However, insurance companies are resourceful in coming up with ways to exclude people when they think those people will cost them money.

An important and generally overlooked concern is employers who are self insured and who exclude people. Self-insured companies remove themselves from the state system regulating health care, so the restrictions on their actions are few. An example is the McGann case in Texas mentioned earlier. This loophole for self-insured companies should be closed, so that individuals who are among the most in need of health insurance will not be denied it.

Employers must ensure that employees know what the problems and recognized consequences are and know how to protect themselves. Also, individuals identified as high-risk for disease need more than simply information. Companies should not exclude as a way of protection and should do much more affirmatively to deal with hazards and reduce exposures. Anti-discrimination laws should extend to genetic predisposition. The ADA now covers individuals perceived to be susceptible to illness, not just those who are symptomatic, according to the EEOC guidelines. However, case law has yet to determine whether and under what circumstances an employer must accommodate someone who may be at special risk in the workplace. Government regulations could follow the lead of the OSHA lead standard, which provides that if individuals are at special risk, they could be transferred temporarily to other jobs but retain their wages and seniority. Companies could offer individuals at risk an opportunity to move to another, equal-status job in another area without any loss of pay. However, it becomes difficult to transfer workers to another position when the company is small or in a layoff or downsizing mode.

Not only are genetic screening issues of concern, but also problems of genetic information are becoming increasingly important. Doctors increasingly will market genetic tests directly to patients, so potentially individuals could be tested and keep information about their genetic makeup to themselves. But too often, genetic test results should be considered confidential when in fact they are not. Since employers and agencies can ask people on questionnaires about their genes, having tests privatized — that is, performed by one's private physician — does not solve the privacy problems by any means. Moreover, genetic information is entered into data banks when individuals apply for reimbursement from third parties.

State laws vary in terms of access to medical records. The confidentiality of medical records is important, but one problem with medical records — whether or not they are company records — is that people who do not get to see them are not in a position to know whether or not something is wrong in the record. If people were to obtain their medical records, they could help ensure that nothing inaccurate is in them. Misrepresentations of information can have devastating consequences in terms of employment, insurance and stigmatization, especially as companies increasingly do computer searches of employees and job applicants.

The approach of screening people out should not gain support without carefully looking at evidence that only certain individuals are at risk. Our ability to produce new technologies and introduce new toxic substances has exceeded our ability to envision potential consequences. Without good epidemiological evidence, it is difficult to be sure a substance is safe at low exposure levels. The reality of the workplace and environment is that people are exposed to combinations of hazardous substances, and most new chemicals undergo little or no testing.

Employers inappropriately have tended to make claims to truth about genetically high-risk individuals and safe substances without having the burden of proof. They tend to give the benefit of the doubt to the chemicals rather than to the health of workers and the public. Companies that manufacture or work with toxic substances say small quantities of substances are not of concern. They tend to hold the outside environment or people's lifestyle responsible for worker disease. Science involves many unknowns, of course, but in an environment of uncertainty, surely employers should not have the final say as to what is safe. When employers claim that substances are safe, that genetic information should be used to differentiate among risks and that individuals' diseases are produced by genetic predispositions rather than products or workplaces, they should have the burden of proof.

We have the powerful precedent of the tobacco industry saying there is no proof that smoking causes cancer and the long-standing argument that low-level nuclear radiation is safe. Now, when companies say substances are safe so that only a few high-risk individuals are genetically at risk, we must keep these precedents in mind.

Arguments that workplace hazards are inconsequential have the effect of getting companies off the hook. Company officials and their lawyers have firmly established their arguments about how the substances they use or produce are safe. But in the interest of being objective and scientific, it is important to become aware of the connections between science and society, and how these claims to safety and truth have been used.

When employers say a job is dangerous or safe, or that certain individuals are high-risk, it is hard for individuals to judge the merits of the employers' case. Workers need trustworthy information about risks to individuals as well as aggregate data that may reveal patterns of hazards, health risks and groups screened out. For that, effective regulatory power is important, and alert labor organizations can serve a critical function in protecting health. However, federal OSHA and state occupational health programs have cut back enforcement of health protections. In addition, although some unions have addressed genetic information and medical risk, overall they represent a small percentage of the work force and restrictive labor laws have curtailed their power. Such losses result in reduced regulatory and labor union oversight of policies related to genetic and health information.

Having health services with expertise outside companies could offer health information more independent of the employer. Independently funded clinics or medical groups could do screening outside of employer control and with protected medical records. This could go far to alleviate the problem of companies having access to medical data about their employees, although the problem of third-party access to genetic information would remain. The control of the health services ought to be separated from the workplace and genetic information should be controlled by individuals as much as possible.

The benefit of doubt must be given to the protection of individuals' health, not to the safety of chemical substances. Corporate concern with reproductive risks from hazardous corporate technologies has been ineffective. Rather than focus on gathering information on possibly genetically high-risk groups and presume that conditions are safe once high-risk individuals are identified and screened out, why not instead reduce the hazard to the work force and general public? We need to continue to monitor substances carefully in such a way that all who are exposed may be protected — and to continue to collect and analyze data to determine whether low-level exposures are indeed safe and to detect risks to populations. The health risk problem should be reframed so that it is conceptualized more broadly, to encompass hazards to both men and women in a wide range of jobs. The fact that hazards have not been conceptualized in this way has much to do with social stratification and the corporate context of power and control in which work hazards exist.

An important barrier to effective preventive measures is that they cost money in the short term, and many decision makers lack long-range vision or incentives. Managers are rewarded on the bottom line this year rather than in ten or twenty years, when they may not be in the same job or company.

Risks allocation should be proportional to benefits. Science, social policy, and the law should help insure that companies will bear most of the financial burden of occupational disease.

In addition, employees generally should not be able to choose life-threatening jobs or toxic work that would damage themselves or their children. Risk policies have been laden with strong and perilous rhetoric of choice. Arguments about hazards in employment have made social issues and problems appear merely to be matters of personal and individual choice, which, in fact, they are not. In this sense, then, one should not be "pro-choice" in the workplace, as much as pro-health and pro-environment.

Genetic innovation is part of a broad social picture. The applications of genetic information are shaped by our system of social stratification through information access rules, through insurance company policies, and through companies' medical testing and employment policies.

Whether technologies can be patented is a different question from whether the technologies can or should be used. Technology transfer can have negative returns to the society beyond dollars, along with the beneficial effects. As we become involved in promoting the genetic technology, we also need to be aware of its risks and likely effects.

Patents and the patent system are not a good mechanism for controlling technology. They give a mechanism for recovering R&D costs, but without addressing social issues.

Due to the power dynamics and economic interests I have discussed, expanding genetic information presents problems of inappropriate or harmful access to genetic information by employers, company physicians, and insurance companies. It also poses problems of privacy and discrimination and environmental degradation that will not be solved without adequately addressing the social context of power, control, and economic interests within which genetic information is created and put to use.

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