

## **GENETIC TESTING AT THE WORKPLACE: SCIENTIFIC, LEGAL AND ETHICAL CONSIDERATIONS\***

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### **ABSTRACT**

This article examines the various scientific, legal, and ethical issues involved in genetic testing at the workplace. On the basis of this examination, the adequacy of current policies to deal with the unanticipated issues related to genetic screening is assessed. Finally, certain public policy options to narrow the hitherto widening gap between and among science, law, and ethics are suggested.

Advances in biotechnology since the Nobel-prize-winning discovery of DNA (deoxyribonucleic acid) by James Watson and Francis Crick in 1953 and its application to human genetics (DNA fingerprinting) have been described as the development of the biological time bomb, and its implications for humanity are perceived to be as earthshaking as the atomic bomb.

The rapid development of genetic engineering since the 1960s has not allowed us enough time to pause and consider the long-term implications of this scientific breakthrough. We appear to be in a muddled state of mind and willing to go along with the dubious proposition of "if we *can*, we *should*."

What have hitherto been just scientists' nightmares and doctors' dilemmas regarding the slippery slope of genetic engineering have at last begun to attract the attention of experts in law, ethics, philosophy, and public policy.

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It is recognized by all concerned that the very essence of humankind and its diversity is at stake if technological imperatives were to be allowed to undermine human will, autonomy, equality, and choice.

The above concern is the focus of the public debate about the risks, costs, and benefits of the recent developments in biotechnology. The most widely discussed applications of biotechnology are in medicine and health care, particularly in the area of genetic testing and screening. While the use of this technology in a medical setting is itself not completely devoid of controversies, to extend its use, given its scientific infancy, to a nonmedical setting, such as the workplace, to test and screen employees and applicants to identify genetic traits that *may* indicate their *potential* for hypersusceptibility to certain occupational diseases, raises a series of scientific, legal, ethical, and social questions.

### SCIENTIFIC, LEGAL, AND ETHICAL QUESTIONS

1. Is there a consensus among scientists on the sensitivity, specificity, predictive value, reliability, and reproducibility regarding genetic screening and testing?
2. To what extent are genetic factors separable from other variables, when screening is applied for the purpose of preemployment testing, postplacement testing, job denial, or job transfer?
3. The fact that false positives and false negatives are relative to “normal” limits raises a series of other questions, such as: what is the “norm”? What is “normality”? Are “abnormality” and “hypersusceptibility” coterminous with actual “sickness”?
4. Once data are collected through medical surveillance, is there a serious problem of interpretation of the results and an opportunity for abuse of information collected?
5. What is the role of the occupational physician (“company doctor”) in medical surveillance at the workplace? Does he have the same doctor-patient relationship as he would in a medical and clinical setting? Is s/he an “agent” of the corporate employer, whereby his/her primary duty, loyalty, and ethics have become compromised and questionable?
6. Does the employer have authority (*quo warranto*) to require an employee to submit to a screening and monitoring procedure?
7. May an employer require a prospective employee to submit to genetic or biological screening as a precondition to employment?
8. What are the consequences of either a refusal to take genetic testing or a consent to undergo the test?
9. Is there a legal or moral requirement on the employer to obtain from an employee or an applicant an informed consent to undergo these tests? What is the procedural and substantive content of this informed consent?

10. If an individual's genotype indicates that s/he is hypersusceptible to an occupational illness in a given job, will that justify a refusal to hire him/her solely on the basis of that individual's immutable and inherited genetic constitution?
11. Will the hypersusceptible employee have the right to self-determination and continued employment even though such conduct would increase the risk of occupational illness?
12. If the above question is affirmatively answered, should the employer be shielded from other legal responsibilities at the workplace, such as a worker's compensation claim, if the individual contracts the occupational illness?
13. Does the employer have the authority to require the genetically "defective" employee to waive certain legal rights to which s/he is otherwise entitled through public policy? Under these circumstances, does that employee have any other viable option except to opt out?
14. Will it matter that many genetic deficiencies tend to fall along the lines of race, ethnicity, sex, age, and socioeconomic status?
15. If genetic screening identifies a susceptible individual, does the employer have a responsibility to reduce the hazards in the workplace or does the right to remove workers at risk become an easy way to avoid cleaning up the workplace?
16. Given the dichotomy of "ethics v. expertise," even if scientific validity and technological sophistication of genetic testing were to achieve the status of infallibility, should science and technology be the two sole criteria used to determine the rules of the society and public policy?
17. How can worker, employer, and societal interests be promoted equally and fairly in making these decisions?
18. In achieving distributive justice, should inequalities in the distribution of natural goods (intelligence, vigor, genetic traits etc.) be compensated through a concept of equality-based distribution of various social goods (opportunity, power, wealth, etc.)?
19. Or, since we now have the biotechnology know-how, should we rearrange the genetic material (natural goods) so as to promote the "survival of the genetically superior and the fittest"?
20. In this process, do we have an ethical justification to create a new class of "genetically unemployable" human beings amongst us "for their own good"?

With the exception of the first few questions, which are related to scientific aspects of genetic testing, all the other questions raised above are not necessarily examined in this article in the same sequence for various reasons. The issues raised are not discrete. In some of these questions (e.g., numbers 5, 9, 11, 13, 14, 16, 18, 19, and 20), law, ethics, philosophy, and public policy intersect. For these

reasons, this article is organized under three broad divisions, namely, the scientific aspects, the legal and constitutional aspects, and the ethical and public policy issues, with appropriate subheadings under these broad divisions.

## SCIENTIFIC ASPECTS

### Components of Genetic Testing

The generic term “genetic testing” refers to techniques used to determine the existence of inherited genetic traits or environmentally induced genetic changes that might cause a predisposition to certain illnesses. There are two main types of testing: genetic monitoring and genetic screening [1-3].

Genetic monitoring ascertains whether the genetic material of a group of individuals has altered over a period of time. It involves periodically examining employees to evaluate modifications of their genetic material—such as chromosomal damage (cytogenetic test) or occurrence of molecular mutations (non-cytogenetic test)—that might have evolved in the course of employment.

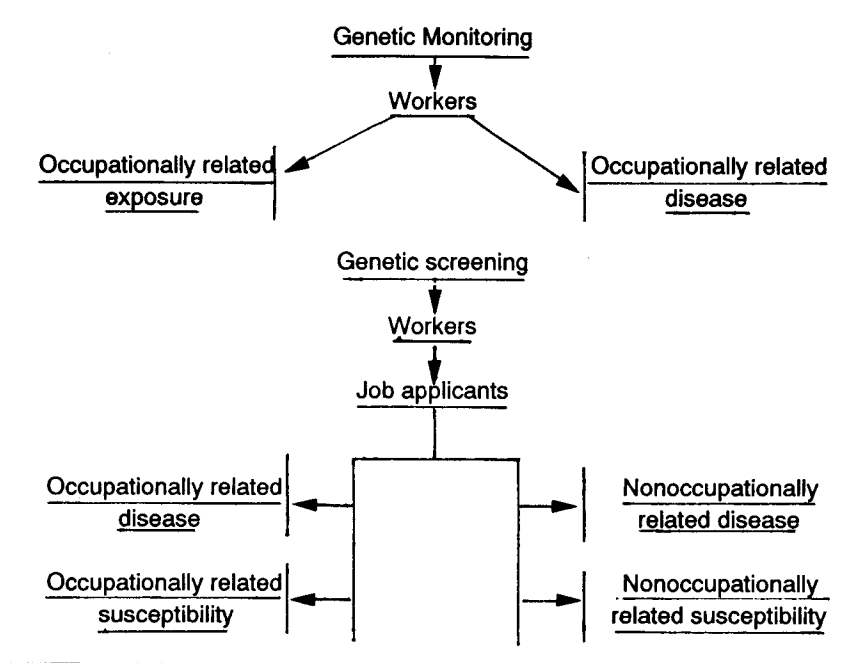
Blood and other body fluid samples are collected for this purpose. Generally, such medical surveillance is conducted in an attempt to determine whether environmental exposures of a specific population, such as workers in the same job category, to particular substances causes changes in genetic material in statistically significant (correlation, not causality) numbers above background levels.

Genetic screening is a one-time testing process. It is used to establish the existence of an inherited genetic trait that may cause a person to be at increased risk (hypersusceptibility) for certain occupational diseases when exposed to chemicals present in the workplace, such as exposure to minerals, chemicals, and ionizing radiation. This test is usually done as part of a preemployment or pre-placement examination. Laboratory tests on body fluids, commonly blood, usually identify these traits (see Table 1 and 2).

The information obtained from the above two biological monitoring techniques can be used in conjunction with environmental monitoring. Environmental monitoring measures the concentration of harmful agents in the workplace, while the other two surveillances involve tests performed on the workers. Environmental monitoring may combine both work area monitoring and worker monitoring. One should not be treated as a substitute for the other; these are complementary measures to achieve the objectives of occupational health and safety policy [1].

Two other techniques, routine medical surveillance and biological monitoring, are used at the workplace. The former is a nonspecific and nonselective test that may detect a disease or abnormality after possibly serious and irreversible adverse health effects have occurred. This technique is based on a definition of “normal” and identification of a “fence” around it to determine the “abnormality.” This determines the impairment but not the cause.

Table 1. Components of Genetic Testing in the Workplace



Source: Office of Technology Assessment [3].

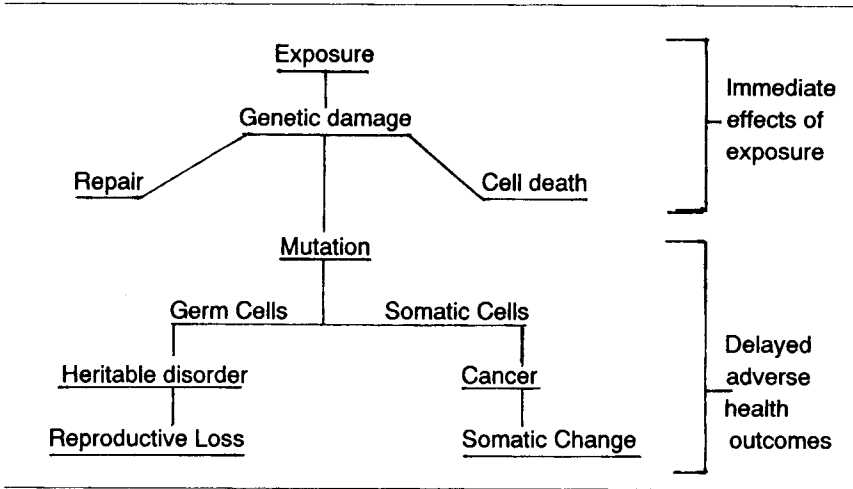
Biological monitoring determines both the occurrence and exposure and the uptake (or presence) of a particular substance or its metabolites in body fluids or organ. This method may be combined with medical surveillance and environmental monitoring (see Table 3).

The current controversies regarding genetic monitoring and screening revolve around the question of employers' use of genetic testing as a substitute for environmental monitoring. Does a biological standard provide an incentive for employers to intervene in altering specific parameters in their workers? Do biological standards reinforce a "blame the workers" attitude among employers with regard to specific employees, rather than focusing attention on the workplace? Does biological testing meet the rigorous canons of proof and research protocols required in science and medicine?

**Canons of Proof and Research Protocol**

Any test, including a genetic test, should meet the scientific standard of acceptable sensitivity, specificity, predictive value, and reliability [2-9].

Table 2. Biological Consequences of Exposure to Mutagenic Agents



Source: Office of Technology Assessment [3].

Table 3. Temporal Characteristics of Tests for the Four Types of Human Monitoring

	Medical Surveillance	Genetic Monitoring	Genetic Screening	Biological Monitoring
Preemployment	X		X	X
Preplacement	X	X	X	X
Periodic	X	X		X
Post-illness or injury	X			X
Episodic	X	X		X
Termination/ Retirement	X			

Source: Ashford, et al. [1].

The validity of a test is defined as the degree to which a test measures what it is intended to measure.

The predictive value of a test depends on three factors: 1) the test's sensitivity (a measure of the test's accuracy in correctly identifying persons with the condition); 2) the test's *specificity* (a measure of the test's accuracy in correctly identifying persons free of the condition); and 3) the actual *frequency* of the condition in the population being screened [3, Chap. 4].

The reliability of a test refers to the degree to which the test consistently reaches the same result in any given time.

The "cutoff point," determined on the basis of the preceding definitions, serves the purpose of finding the demarkation between those testing positive and those testing negative. This is the crux of the problem involved in genetic testing.

For example, if the test is established to identify all workers with a genetic defect, it is likely that these so-called "true positives" will be detected. However, it may be overly inclusive, or nonspecific, and therefore result in many "false positives." The effect would be to label nonsusceptible workers as genetically susceptible. Therefore, follow-up tests must be conducted to determine which workers actually possess the genetic trait. On the other hand, where only a certain number of workers are to be identified, some may go undetected, indicating an underinclusive test [3, 6].

In 1983, a U.S. Congress study by the Office of Technology Assessment (OTA) [6], evaluated the state of the art in genetic testing. This assessment took a two-stage approach to analyzing the scientific data available on genetic testing. First, the laboratory tests themselves were evaluated to determine their reliability and validity. Then the available studies were evaluated to determine whether a correlation exists between the genetic damage or trait in question and an increased risk for disease. *None of the genetic tests evaluated by OTA met established scientific criteria for routine use in an occupational setting* [6].

Another comprehensive study reported by OTA in 1990 reconfirmed the above finding regarding genetic testing in terms of its pitfalls concerning its validity, reliability, predictive value, and relative risk [3] (see Table 4).

### **GENETIC VARIATIONS IN SUSCEPTIBILITY TO ENVIRONMENTAL ASPECTS: RACIAL AND ETHNIC ASPECTS**

A relatively new discipline known as ecogenetics deals with the study of genetically determined differences among individuals in their susceptibility to physical, chemical, and biological agents in the environment [10-11]. In these studies environment is broadly defined to include physical, chemical, infectious, atmospheric, and climatic agents, as well as food substances. The purpose of this broader approach is to arrive at a composite and total picture of ecogenetics consisting not only of the occupational environmental factors but also nonoccupational environmental variables, innate characteristics (age, sex, race, ethnicity) and behavior-based factors (geographical location, diet, lifestyle, and overall health factors).

The interactive and additive or synergistic role of the above variables confound establishing even a correlation, let alone causation, between and among these ecogenetic factors. Under these circumstances, there is a quantum leap in logic, science, and ethics in the following chain: gene-genome-genetic

Table 4. Pitfalls of Classical Epidemiological Studies in Identifying Hazardous Chemicals in the Workplace

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Difficulty identifying suitable study populations:
—inadequate size
—unreliability of death or birth medical records
—lack of reliable incidence data
Long latency period in onset of effects (excluding in utero exposure for major anomalies):
—complicates data collection
—prevents detection of effects of new exposures
—requires assessment of current risks based on much earlier exposures
Lack of sensitivity:
—normal incidence of specific diseases can obscure increased rates
—multiple exposures confound attempts to establish cause-effect relationship
—effects of ubiquitous exposure are difficult to detect
—large populations are required to detect common effects
Substantial population exposure to agent prior to detection:
—dilution of exposed population
—failure to consider power of study

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**Source:** Office of Technology Assessment [3].

drift-genotype-genetic monitoring and screening-susceptibility-hypersusceptibility-“bad” gene-prevalence-incidence-high risk groups-“defective workers”-exclusion.

Innate deficiencies or traits—such as glucose-6-phosphate dehydrogenase (G-6-PD) deficiency, sickle-cell trait, and thalassemia—are not undetectable, but the critical issue is the legal and ethical foundation of the personnel actions resulting from the medical determination of these deficiencies and traits (see Table 5).

The G-6-PD deficiency has been a common subject of genetic screening. In fact, it was the second most frequently tested trait of the 366 companies responding to the OTA Survey [6]. This deficiency is a biochemical genetic condition involving red blood cells. The G-6-PD enzyme is the first enzyme in the energy-generating process; a deficiency in this enzyme interferes with the oxidation of glucose [7].

Chemicals suspected of presenting risks to G-6-PD-deficient workers include some common household and prescription drugs, several dye intermediates, aromatic nitro and amino compounds, arsine and related metal hydrides, and lead and its components.

While the gender of a worker is an important criterion in testing for this type of deficiency, racial and ethnic background is also relevant, as indicated in Table 5.



Table 5. Frequency of Genetic Factors That May Affect Exposure Risks

Genetic Abnormality	Groups with Disproportionately High Rates	Frequency in Subpopulation <sup>a</sup>
G-6-PD deficiency (homozygotes, all males)	Blacks, Filipinos, Mediterranean Jews, also Chinese	13-16% U.S. blacks 12-13% Filipinos 11% Mediterranean Jews 1-8% Scandinavians 2-5% Chinese 1-2% Greek 1% European Jews 0.1% British and U.S. whites
Sickle cell trait (heterozygotes)	Blacks, also Sicilians, Arabs, American Indians, Greeks, and Mexicans	8-13% U.S. blacks 0.1% whites
Alpha1-antitrypsin deficiency (heterozygotes)	Swedes, Danes, Norwegians, Irish, Russians, Germans, English, other Northern and Central Europeans	7-9% Scandinavians, Irish, English, Germans, Russians, and Central Europeans 4-5% French and Belgians 3-4% General U.S. population 2-3% Jews 1-2% U.S. blacks
Beta thalassemia trait (heterozygotes)	Italians, Greeks	2-5% Italian and Greek Americans 2-7% U.S. blacks

<sup>a</sup>The frequencies in subgroups of the population are in dispute. Estimates vary, and even the estimates for frequency rates among the population as a whole differ.

Source: E. Draper, *Risky Business* [12, p. 84].

The evidence accumulated in past studies reflects a strong correlation between the G-6-PD deficiency and occupational exposure as the cause of illness. Nevertheless, many of these observations have been made in vitro, thus requiring further research under actual exposure situations [9].

Some genetic markers appear much more frequently in certain racial and ethnic groups than others. Practically all racial and ethnic groups are predisposed to some

illness based on one or more genetic traits, even though some groups are more often tested than others and some others may not be tested at all.

Sickle-cell anemia and sickle-cell trait are found almost exclusively in persons from equatorial Africa, parts of India, the Middle East, and the Mediterranean. They are not usually found in other racial groups [3, 7].

Sickle-cell anemia and sickle-cell trait result from the presence in red blood cells of an abnormal hemoglobin molecule (HbS v. normal HbA). The symptoms of sickle-cell anemia include insufficient levels of hemoglobin in the blood, or anemia; impaired circulation, leading to local damage to internal organs; episodes of excruciating pain in bones and joints; and a reduced life span [13].

There are four reasons for the controversies surrounding sickle-cell anemia and trait testing and screening [9]: First, because it predominantly affects blacks, there exists a heightened concern for racial discrimination. Second, despite the lack of evidence proving that sickle-cell anemia is triggered by chemical exposures, a survey of major industries revealed that the majority of occupational genetic screening has been for the sickle-cell trait. Third, many confused the trait with the disease, even though persons possessing the sickle-cell trait may never experience the effects of sickle-cell anemia. Finally, if an individual were to possess the genetic condition, it would become active during childhood and, at that time, would be made known to the carrier. This eliminates the need for it to be detected through preemployment screening test. Furthermore, no studies or data exist to support the theory that individuals with sickle-cell trait may be at increased risk from hemolytic chemicals.

Thalassemia is a deficiency in the production of hemoglobin that results in small red blood cells. The disease is inherited in an autosomal recessive pattern and varies in severity and type (there are alpha and beta forms of the disease). It has been suggested that beta thalassemic individuals are at increased risk after exposure to several chemicals, including benzene and lead. Again, while limited clinical observations have suggested that persons with thalassemia could be at increased toxic risk from benzene and lead, data since 1983 remain insufficient and unconvincing. Continued assessment, epidemiological investigations, and a predictive animal model to test lead- or benzene-induced blood toxicity will be required before an association can be made between this genetic trait and enhanced occupational illness [3].

The weak link between a genetic trait and occupational illness has been well-recognized by scientists. Levy and Wegman cautioned of the need to distinguish between hypersusceptibility and hypersensitivity (cited by Ashford et al.). According to them, the term hypersusceptibility indicates

an unusually high response to some dose of a substance. This term requires careful interpretation, however, because it is used in several different ways. It may refer to a *genetic predisposition* to a toxic effect; it may indicate a statistically defined *deviation from the mean* [average]; it may reflect an

observer's *subjective impression*; or it may be used, incorrectly, as a *synonym for hypersensitivity [which] is one form of hypersusceptibility*, characterized by an acquired, immunologically mediated *sensitization* to a substance, [1, p. 311]. [Emphasis added]

Given the infancy and confusing state of the art of genetic monitoring and screening, the potential for discriminatory testing, or discriminatory use of the results, is at the forefront of the debate because genetic traits are often directly related to a person's racial or ethnic background. There are legitimate fears that the technology could be used to exclude from the workplace persons of particular racial or ethnic groups because of an assumption that they possess genetic vulnerability.

Does the screening program concentrate on groups with a history of having suffered discrimination? Doctor Thomas H. Murray, director of the Center for Biomedical Ethics at Case Western Reserve University, answered the question as follows:

It is in the nature of genetic traits to fall along racial lines. When the trait in question occurs disproportionately often among members of an historically mistreated group, there is likely to be suspicion and mistrust on the one hand, and a feeling that this is just one more obstacle placed in the way of fair and equal treatment. We should scrutinize with great care any exclusionary screening program having a focus or disproportionate impact on such groups [4, p. 453].

Because of this, Du Pont's previous policy of testing blacks for the sickle-cell trait has been described as "scientific racism":

"This policy of Du Pont's is very clearly a eugenic policy," said Dr. Jonathan King, a molecular biologist at the Massachusetts Institute of Technology. "There is no evidence that heterozygotes for sickle-cell trait are substantially more sensitive than other people. Du Pont's position is scientific racism. They say they are not bigots because all this is based on science. But the fact is that people are not going to get sick because they are hypersusceptible, they are going to get sick because they are being poisoned" [8, p. 1205].

The barrier of genetic screening could prove to be unsurmountable for some job seekers. In a better economic climate, a rejected job applicant could merely go and apply for a job with another employer. But in a high unemployment economic environment, there may be no other jobs available. Thus, the genetically screened-out job applicant might effectively be foreclosed from all employment. It is this situation that prompted Dr. Ernest Dixon to make the following observation:

Can we and should we create a race of susceptibles consciously sacrificed on the altar of the "greatest good for the greatest number" . . . Who would

employ these susceptibles, who would protect their dignity and place in the community? Here is the stuff by which war and revolution have been made and by which human progress has been destroyed [8, p. 1186].

The lack of scientific validity of genetic testing does not seem to deter some employers from persistently pursuing their utilitarian objective of the “greatest good for the greatest number.” Therefore, there is an urgency to address the legal and ethical ramifications of genetic testing. The following two sections deal with these aspects.

## LEGAL ISSUES IN GENETIC TESTING

Employers usually assert their legal right or obligation to apply genetic monitoring and screening on the basis of common law and various statutes that are collectively known as employment law.

In the absence of any statutory restrictions, employers have the common law authority to assess the suitability of applicants and employees in terms of skill, training, experience, ability, interests, personality, and, at times, medical fitness. Employers also may require applicants, and under certain circumstances even employees, to submit to examinations and other tests to demonstrate their ability, skill, and fitness, so long as the tests are administered fairly and meet certain standards of relevance, reliability, and validity.

The master is expected to apply a standard of reasonable prudence in providing a safe workplace for servants and apply due care and caution so as not to endanger servants' health and safety. Employers also have a vicarious liability toward third parties for any omission or commission of their employees.

Failure to avert any harm either to third parties or to their employees themselves may constitute a willful negligence resulting in employers' tortious liability or statutory liability. Many of these legal aspects are common elements found in judge-made law as well as in various statutes, such as occupational health and safety legislation and workers' compensation plans [14].

In some circumstances, employers are required by law to conduct medical examinations of candidates. In the U.S., as well as in Canada (federal and provincial jurisdictions), occupational safety and health legislation imposes a general duty on employers to maintain a workplace free from recognized health hazards.

Employers' right to “test” applicants and employees is generally advanced not only on the basis of the above legal principles but more specifically on the basis of economic interests. Testing can assist employers in the following respects: to assure the safety of workers, customers, and the public; to improve worker productivity, accuracy, morale, and customer relations; to lower employee absenteeism and turnover, health insurance costs, workers' compensation costs, and general liability insurance costs [15].

But all of these legal and economic claims of employers to apply genetic testing at the workplace are on a shaky foundation not only under the common law but also under statutory and constitutional law [3, 6, 14].

Where the fundamental rights and freedoms are applicable, employers must justify genetic testing with reference to the following principles:

- the right to life, liberty, and security of the persons;
- the right not to be deprived thereof except in accordance with the principles of natural justice (due process right);
- the right to be secured against unreasonable search and seizure; and
- every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and in particular, without discrimination based on race, national or ethnic origin, color, religion, gender, age, or mental or physical disability.

Where these constitutional rights and freedoms are inapplicable, employers still have to justify genetic testing under the appropriate civil or human rights legislation that incorporates the above constitutional principles in a more explicit and elaborate fashion.

Apart from the above constitutional and human rights protections against genetic testing, the various occupational health and safety laws themselves may require employers contemplating genetic testing to meet one or more of the following requirements:

- not to dole out disparate treatment;
- to consider whether disparate impact would result;
- is testing a business necessity?
- what is a bona fide occupational qualification?
- provide proof of the absence of less intrusive, least discriminatory, and equally effective alternatives to genetic testing;
- if genetic syndrome and trait were to be “handicaps” or “mental or physical handicaps,” employers’ have a duty to reasonably accommodate these qualities;
- the duty not to use the genetic testing as a substitute for cleaning up the workplace in the first place; and
- not to engage in a genetic-based exclusionary policy and a “blaming-the-victim” orientation toward occupational health and safety.

Since further elaboration of these legal and constitutional principles is beyond the scope of this article, we now turn our attention to the ethical issues surrounding genetic monitoring and screening, or what is currently known as “genetics” [13].

## ETHICAL ISSUES

Generally, there are four common purposes of genetic testing: diagnosis, research, information, and exclusion [4]. Apart from these purposes, the setting within which such testing takes place also has a bearing on the ethical issues involved. For example, testing in a clinical or health care setting qualitatively differs from that of a workplace setting, as indicated in Table 6.

First, the tests could be used in the clinical diagnosis of an individual ill worker. Second, the tests could be used in research to establish links between genetic predispositions and reactions to workplace hazards. Third, information gained from the tests, along with any established or reasonably suspected link with work-related illness, could be presented to workers for their job consideration. Fourth, the tests could be used to exclude from jobs workers who had a genetic condition believed to result in a heightened susceptibility to the hazards normally encountered in that job.

Table 6. Ethical Issues:  
Health Care and Workplace Setting Contrast in Testing

Factors	Medical Setting	Workplace Setting
1. Diagnosis	Individualized	Collective/Selective
2. Research	Ethics in Human Subjects Research	Canons of Proof/Research Protocol Violation
3. Information	Strict Confidentiality	Serious Violations
4. Exclusion/Treatment	Primacy of Treatment	Exclusion Main Purpose
5. Counseling	Pre- and Posttesting	None or Superficial
6. Consent	Informed Consent	Uninformed/Coerced
7. Stigmatization	Avoided	Invariably Present
8. Subject's Privacy, Integrity and Autonomy	Medical Ethics Based	Serious Violation: "Company Doctor Syndrome"
9. Power Relationship	Professional-Client orientation	Economic Power/ Dependency/Survival orientation
10. Freedom of Choice/ Second Opinion	Available	Limited or unavailable
11. Scientific Rigor	High	Low or None
12. Scientism-Based Paternalism	Absent or Low	High
13. Overall Purpose	Reducing Illness	Reducing Cost

In Table 6 we have identified thirteen factors that are not discrete but somewhat overlapping. All of them have, in different degrees, two components, namely, the purely utilitarian (pragmatic) component and the socioethical component. In a medical setting these two components may overlap; or, in the case of divergence between them, there are built-in canons, protocols, and principles under which either an appropriate balance between them is achieved or, where there is no scope for such a reconciliation, socioethical, normative principles may take precedence over short-range, narrow, and pragmatic qualities such as convenience and expedience.

The absence of such checks and balances in genetic testing in general, and particularly at the workplace, threatens the ethical core of commitment to the values attached to the following: diversity of genetic traits as a human heritage; human dignity, autonomy, free will, and choice; beneficence, nonmaleficence; procedural, structural, and substantive justice; egalitarianism; meritocracy; privacy, confidentiality, and accountability; humaneness and compassion vis a vis efficiency; right to safe and healthy workplace; and societal orientation.

Values related to societal interests may be in conflict with those related to individual interests, creating ethical dilemmas [16]. Many of these ethical dilemmas associated with genetic knowledge and technologies arise from the conflicting interests of involved parties, conflicts between applications of competing ethical principles, and the range of opinion on specific issues. The involved parties include: individuals with genetic “disorders” or “susceptibilities”; their families; the fetus; society; future generations; geneticists and related researchers; health care delivery personnel; politicians and bureaucrats; and special interest groups.

Another factor that adds to the magnitude of ethical dilemmas is the gap between and among science (technology), ethics, and law:

The approaches of ethics and of law to issues arising in medical care often result in conclusions which coincide, but the two disciplines are distinguishable, and their interaction merits attention. Both address questions of values, but the law must be constantly monitored to test whether it produces ethical effects . . . One can identify circumstances, not only by reference to political oppression, in which the law may fail to protect significant ethical values . . . *There is an important sense in which law is a minimal ethic. When the law is not considered to be ethically deficient, its proper observance often discloses areas of unguided choice, where a legitimate discretion exists to act in different ways. The exercise of such discretion is a matter for ethical judgment and not for law* [17, p. 3]. [Emphasis added]

Such an ethical judgment in genetic screening and monitoring at the workplace can be achieved only by operationalizing the core values identified above.

The first value that comes into conflict with genetic-based exclusionary personnel decisions is heritage, which means: that which comes or belongs to one by

reason of birth; something reserved for one; that which has been inherited by legal descent; the synonym for heritage is patrimony, meaning any quality or characteristic that is inherited from one's father or ancestors.

For the biologist, heritage is both a collective and an individual notion. Diversity in the gene pool arises over time through the process of mutation. As a result of the biological processes of mutation and meiosis, each individual is unique. This diversity of heritage falls along the lines of ethnicity, race, and nationality. The unity of mankind and the diversity of genetic traits are not contradictory but complementary. A genome (an individual's genetic material) is a personalized package based on race and ethnicity, and the gene pool is the sum of the genomes in the population, both of which are under a public trust [18].

The second value that comes into conflict with genetic screening is human dignity, which includes autonomy, free will, and choice [19]. Human dignity is a normative concept recognized in various international covenants. The *Universal Declaration of Human Rights*, proclaimed by the United Nations General Assembly (December 10, 1948), recognizes the inherent dignity and equal and inalienable rights of all members of the human family as the foundation of freedom, justice, and peace in the world. In this declaration, a respect for human dignity is seen as a *sine qua non* for the elaboration and construction of all other fundamental human rights, including the right to self-determination (autonomy), free will, and choice, without social, legal, or economic coercion. Freedom must surely be founded in respect for the inherent dignity and inviolable rights of the human person.

The right to human dignity negatively refers to the absence of coercion or deliberate institutional barriers, such as the exclusion of people with certain genetic traits from employment. The positive component of it is the enhancement of opportunities, whereby choices can be made through the operation of human free will. Scientific knowledge should be used only to promote dignity and preserve the integrity of human beings, but not to stigmatize some of them with terms such as "wrongful birth," "wrongful life," and "genetically unemployable."

The right to live in dignity, the right to make a living in dignity, and the right to die in dignity has an organic (body) dimension, a psychic (mind) dimension, and a symbolic (spirit) dimension. The literature on biomedical ethics deals with the relationship of these moral principles to rules and obligations and is relevant to decision making regarding the applications of genetic technologies and information. The four basic principles of biomedical ethics are: autonomy, or respect for the wishes of competent persons; beneficence, or doing good; nonmaleficence, or doing no harm; and justice, or a fair distribution of benefits and burdens in an egalitarian manner and in consonance with the fundamental principles of procedural, structural, and substantive justice [16; on justice: 20-22]. Related values include truthfulness, disclosing information to the patient or subject, and confidentiality.



The workplace setting discourages the application of these moral principles in screening applicants and employees on the grounds of cost-effectiveness; and the current policy of genetic screening and exclusion meshes very poorly with our egalitarian and meritocratic ideals [4]. The enthronement of efficiency as the supreme value in our workplaces causes employers to abhor humaneness and compassion. These are not the appropriate concerns of the economic man.

In addition to this economic optimization, other variables at the workplace further dilute any commitment to ethical principles: the economic power relationship, the nature of applicants' or employees' consent, and the role of company doctor in the whole process of genetic screening and monitoring to determine the biological "fate" of people.

In genetics, the truth of Francis Bacon's aphorism "knowledge is power" seems vastly magnified because of the nature of the search and the resulting discoveries:

For the most part, their discoveries are exploited in ad hoc, piecemeal fashion—with *no regulatory system to coordinate* the nature and pace of scientific application in ways that would protect cherished human values. Instead, the application of scientific knowledge is determined to a large extent by the turbulent, often *value-free forces of the marketplace and an overriding economic imperative to profit* quickly from new discoveries. *In such a society, those individuals who wield little political power and lack the technical expertise to anticipate the threat posed by some new scientific technologies such as work-related genetic screening are often the most vulnerable to abuse* [13, Chap. 7]. [Emphasis added]

The current and prospective employees' economic dependency and the superior economic power of employers create this vulnerable situation wherein the consent to undergo any test becomes almost automatic, particularly in a nonunion plant. Even a union does not have any legal obligation to protect the applicants. Very often, consent will be linked directly to the scarcity of jobs. The fear of being fired or demoted for refusing to undergo genetic screening is a principal concern of employees. The health and safety issue and the opportunity to make an informed choice of employment may be far from many workers' minds [14].

To obtain informed consent, before applying any invasive procedure, including the taking of samples such as blood, urine, or saliva, the individual should be informed of the following:

- purpose of the test
- risk of the test itself
- validity of the test (the possibilities of false results)
- implications of a positive result (medical and social)
- nature of the condition for which the test is being conducted
- assurance that testing is not a fishing expedition with a wide net for the purpose of "catch-as-catch-can"

- built-in pretesting and posttesting counseling to reduce the psychological anxiety and stress created by the test situation and the possible stigmatization
- options available to reduce the burden of disease in the event of a confirmed positive test result
- alternatives if the individual decides not to have the test [3, pp. 159-160].

These prerequisites for obtaining informed consent are conspicuous by their absence in workplace genetic testing. It is not possible to obtain informed consent when a disclosure is incomplete, constructed to prejudice the subject toward a desired action (e.g., exclusion) or obtained under pressure. The process of obtaining informed consent in the medical sense has not been practiced in the workplace, which has resulted in the violation of ethico-legal principles of autonomy, beneficence, nonmaleficence, and justice [23]. Even in a medical setting, informed consent is at times questioned [24].

When we add the role of the company doctor to the preceding imbalance of economic power relationships and the absence of informed consent in the whole process of genetic screening and monitoring to determine the “biological fate” of people, the workplace almost resembles a “total organization,” such as a prison or a concentration camp, where paternalistic scientism and scientific racism may thrive.

“Whose agent is the occupational physician?” [25]. Ideally, the physician is a professional who works for no other purpose than the benefit of his patients; in occupational medicine that is the worker. The physician is not an agent of industry or the company. Does the reality synchronize with this ideal? Invariably not. The occupational physician is a professional-cum-paid-employee and as such there is a role-set-conflict. Expediency and pragmatism seem to resolve this conflict between the agent and his/her avowed commitment to the Hippocratic oath. (See Table 6-B.)

Something may be rotten in the state of occupational medicine. The bias of occupational physicians in favor of physical examinations and testing relates more to their concern for job security than to valid medical reasons [7, p. 1417]. A physician’s relevant as well as incidental findings and medical records are made available to the company, which is ill-equipped to interpret this scientific information and take a morally acceptable personnel action.

There is little or no guidance for company medical personnel regarding fitness determinations and employment decision making. Second opinions or multiple physician review, which increase the chance for a correct diagnosis, are normally not sought by employers as a prerequisite to an adverse personnel decision [26]. In the absence of such a review, the more tests performed by a company physician on a healthy subject, the more likely is the discovery of an “abnormal result”; the greater the number of “defective” workers discovered, the greater the indispensability of the physician to the company.

Table 6-B. Features of Three Major Role Sectors

	Role Sector		
	Medical Adjudication	Health-Care Service	Environmental Medicine
Historical roots	Verification of eligibility and claims processing (workers' comp. and benefit associations)	Emergency treatment in remote locations; accident prevention and public health reforms	Accident prevention and public health reforms
Functions	Medical interpretations for industrial relations applications	Early detection, health conservation, case management	Risk assessment and management; organizational intelligence
Technique/expertise	Medical administration	Clinical medicine	Epidemiology, biostatistics, toxicology
Conflicts	Worker vs. supervisor; inside M.D. vs. outside M.D.	Organized medicine, regulators, labor, public health vs. occupational medicine	Costs vs. health mission; line vs. staff conflicts
Conflict-escaping devices	"Medical Taylorism" (science as a neutral mediator between management and labor: Work is therapeutic and abetting a malingering employee is iatrogenic behavior.	The credo: (to act in the best interest of the individual employee is by definition to serve the employer)	Life in general is hazardous and work is relatively safe. The media are alarmist in the portrayal of workplace risks.

Source: [27, p. 185].

Under these circumstances, it is not at all surprising that there appears to be a much more negative feeling toward the occupational physician than toward the occupational nurse, industrial hygienist, or safety engineer. The following are some workers' perceptions of the company doctor:

- The physician is a "good guy" but his hands are tied because he must dance to the company's tune.
- The good physicians don't last long because they are forced out.
- There is a feeling of distrust because the workers believe the physician's primary obligation is the welfare of the company and not that of the workers.

- The workers never want to be evaluated by the physician because of the perceived belief that adverse medical information will be used against them in a discriminatory manner.
- The physician is called “bum,” “quack,” “veterinarian,” or some other disparaging term [25, p. 735; 28].

There are also a few other scientifically, legally and ethically questionable employment policies related to genetic aspects. Many of the largest North American companies—Allied Chemical, American Cynamid, B.F. Goodrich, Dow Chemical, Du Pont, Firestone, General Motors, Goodyear, Gulf Oil, Monsanto, Olin, St. Joe’s Minerals, and Sun Oil—frequently remove fertile women, but not fertile men, from jobs involving possible exposure to teratogenic substances [29, p. 50]. As a result, 100,000 jobs already are closed to women. This policy denies jobs to women of childbearing age who lack medical evidence of infertility.

Some employers prefer to hire only men over the age of fifty for work where there is exposure to a potent carcinogen with a long latency period. By the time the cancer manifests itself, the man would be dying of old age anyway [7, p. 1423]. The burden of proof is too heavy on those who survive this poisoning to collect any compensation from the employers, and this policy also creates a disincentive to clean up the workplace. Altogether, it is the most cost-effective method.

Some employers have the applicant or employee sign a waiver for the employer to use the information as it deems necessary. For example, Exxon Corporation has a twenty-five page, 185-item questionnaire that applicants and employees are required to complete before submitting to a compulsory physical examination and tests [7, p. 1411]. The questionnaires ask about extremely personal matters, which include: the medical history of family members, medication taken, hobbies, sleeping habits, workers’ compensation claims filed, insurance records, military records, community and home environmental profile, plumbing, rodents, home repairs, sexual orientation and practices, venereal disease, and fertility. Information from genetic screening and monitoring is added to these questionnaire-based data.

The computerized information data bank on applicants and employees is accessible not only to the personnel department but also to other departments within the organization. In addition, this information is accessible to third parties without the knowledge and consent of the subjects. The legal and ethical components of privacy are thereby seriously violated. (See Table 7.)

Some employers have required “genetically defective” employees or applicants to waive certain legal rights to which they are otherwise entitled through public policy [3, p. 335]. This waiver approach may appear to have the advantage of respecting an individual employee’s autonomy in making an employment decision. Such a waiver requirement, however, raises several legal, ethical, and policy objections. First, it is questionable whether the employer has the

Table 7. The Legal and Ethical Prerequisites of Privacy at Workplace

Minimizing intrusiveness	Data collection	Limits on collection and methods: balance between individual privacy interest and institutional informational interests
Maximizing fairness	Datause	Limits on use: accuracy, timeliness, completeness, relevancy, rights of access and correction
Creating legitimate expectations of confidentiality	Data dissemination	Creating, defining, and enforcing obligations in collection, use, and dissemination

Source: [19].

unqualified authority to require an employee to opt her/himself out of a public policy. Second, it is not clear whether the employee can waive certain public-policy-based rights. Third, even if such a waiver agreement is made, there is doubt about its enforceability, as well as about the employer's absolution from liabilities. Fourth, courts are usually skeptical of waiver arrangements, especially when the employment relationship unduly pressures employees to waive their rights. Finally, to condition employment on waiver of employee rights directly conflicts with the policies of occupational safety, health legislation, and regulations to provide a safe workplace. Ethically, employees' health is not a salable commodity for transaction, and hence the purported promotion of employee autonomy through waivers is a morally repugnant proposition.

The most recent U.S. Supreme Court decision in *International Union, UAW v. Johnson Controls* [23] illustrates the dubious claims of the employer that its policy of exclusion was based on beneficence, nonmaleficence, and moral and ethical concerns. This case was a class action challenging Johnson Controls' policy of excluding fertile women employees from certain jobs that could endanger fetuses the women might conceive.

Johnson Controls uses lead as a primary ingredient in manufacturing batteries, and lead exposure presents a risk of harm to the fetus as well as the reproductive health of both men and women. The Occupational Safety and Health Administration (OSHA) had previously determined blood lead levels that were critical for a worker planning to have a family. After eight Johnson employees with blood lead levels exceeding the OSHA standard became pregnant, the company issued a policy barring all women, except those who could medically prove their infertility, from jobs that might expose them to amounts of lead in excess of the OSHA standard.

The class of plaintiffs in this case included a fifty-year old woman who suffered a pay loss when she was transferred out of a job involving lead exposure; a man who unsuccessfully requested a leave of absence for the purpose of lowering his lead level because he intended to become a father; and a woman who had chosen to be sterilized to avoid losing her job.

The plaintiffs alleged that Johnson Controls' fetal-protection policy constituted sex discrimination under Title VII of the Civil Rights Act of 1964.

The district court granted a summary judgment for the company, and the seventh circuit court en banc affirmed it on the ground that the petitioners had "failed to establish that there is an acceptable alternative policy which would protect the fetus" and therefore the company's policy satisfied the "business necessity" standard [23, p. 1200].

In a unanimous opinion by Justice Blackmun, the Supreme Court reversed the above decision, holding that Johnson Controls' sex-specific fetal protection policy was facially discriminatory against women because fertile men, but not fertile women, could choose whether they wished to risk their reproductive health for a particular job. The Court found that such explicit discrimination could be justified only by the defense of a bona fide occupational qualification (BFOQ) and that the business necessity test used by the seventh circuit court was inapplicable here. A narrow exception to Title VII, the BFOQ statutory defense has been defined as a

bona fide occupational qualification reasonably necessary to the normal operation of a business encompasses ethical, legal, and business concerns about the effects of an employer's activities on third parties [23, p. 1201].

Johnson Controls' policy classifies on the basis of gender and childbearing capacity, rather than fertility alone, and hence the Court found that "its policy does not effectively and equally protect the offspring of all employees" [23, p. 1203]. Moreover, the Court observed that the "*absence of a malevolent motive does not convert a facially discriminatory policy into a neutral policy with discriminatory effect*. Whether an employment practice involves disparate treatment through explicit facial discrimination does not depend on *why* the employer discriminates but rather on the explicit terms of the discrimination. . . . *The beneficence of an employer's purpose does not undermine the conclusion that an explicit gender-based policy is sex discrimination*. . . ." [23, p. 1204, emphasis added].

On the question of human autonomy, self-determination, and choice, the Court made the following observation:

. . . *In other words, women as capable of doing their jobs as their male counterparts may not be forced to choose between having a child and having a job* [23, p. 1206].

. . .

... With the PDA, Congress made clear that *the decision to become pregnant or to work while being either pregnant or capable of becoming pregnant was reserved for each individual woman to make for herself* [23, p. 1207].

• • •

... *Johnson Controls' professed moral and ethical concerns about the welfare of the next generation do not suffice to establish a BFOQ of female sterility. Decisions about the welfare of future children must be left to the parents who conceive, bear, support, and raise them rather than to the employers who hire those parents.* Congress has mandated this choice through Title VII, as amended by the Pregnancy Discrimination Act. Johnson Controls has attempted to exclude women because of their reproductive capacity. Title VII and the PDA simply do not allow a woman's dismissal because of her failure to submit to sterilization [23, p. 1207]. [Emphasis added]

Nor can concerns about the welfare of the next generation be considered a part of the "essence" of Johnson Controls' business. Judge Easterbrook in this case pertinently observed: "It is word play to say that 'the job' at Johnson [Controls] is to make batteries without risk to fetuses in the same way 'the job' at Western Air Lines is to fly planes without crashing." *International Union, UAW, v. Johnson Controls* 886 F.2d, at 913, 1991. [31, p. 913]

## CONCLUSION

The thesis of this article is not an antiscience condemnation of all genetics-based diagnosis, research, information, treatment, or even exclusion as a last resort after having exhausted all other less drastic and more humane alternatives. Nor is the resolution of the perennial dispute between biological reductionism and the creationistic fatalism within the scope of this article. The dialectical approach (in a Socratic sense not in the Kantian sense) taken in this article in examining issues related to genetic testing is that "It is in our genes and it is also not in our genes."

What characterizes human development and actions is that they are the consequence of an immense array of interacting and intersecting causes. Our actions are not at random or independent with respect to the totality of those causes as an interesting system, for we are material beings in a causal world. But to the extent that they are free, our actions are independent of any one or even a small subset of those multiple paths of causation: that is the precise meaning of freedom in a causal world [32, p. 118].

• • •

For biological determinists we are unfree because our lives are strongly constrained by a relatively small number of internal causes, the genes for specific behaviors or for predisposition to these behaviors. But this misses the essence of the difference between human biology and that of other organisms. Our brains, hands, and tongues have made us into creatures who

are constantly re-creating our own psychic and material environments, and whose individual lives are the outcomes of an extraordinary multiplicity of intersecting causal pathways. Thus, it is our biology that makes us free [32, p. 118].

It was established in this article that some employers have already begun to rely on screening tests more frequently in preemployment situations and less frequently among actual employees. Also we found that abuses have resulted due to deficiencies in our occupational health and safety regulations as well as poor enforcement of these regulations. Because of the inherently controversial nature of genetic screening, the exclusionary and demotional practices made possible through technology are justifiably confronted with heightened legal, ethical, and scientific scrutiny [9].

Scientific acceptability is a precondition for legal acceptability. Ethical and moral acceptability should precede scientific and legal acceptability to avoid the pitfalls of the axiom "can means should." It is on these grounds that biomedical ethicist Dr. Thomas H. Murray suggested several prerequisites to promote more morally defensible genetic testing and an exclusionary policy equally applicable to public policy revision and corporate policy making:

1. There must be a sound scientific basis linking a specific illness to a genetic variation.
2. The relative and absolute risks for workers with the genetic anomaly should be very large.
3. Incidents of mislabeling (stigmatization) and misclassification of applicants and employees should be at an absolute minimum and errors easily reversible.
4. The number of persons excluded should be very small.
5. There should be relatively few jobs involved so as to avoid severe limitations on workers' employment choices.
6. The disease should be severe, irreversible, and not readily diagnosed in its preclinical phases.
7. The tests should not be disproportionately administered to groups that have traditionally experienced discrimination.
8. Along with economic cost-effectiveness factors, moral and political costs are influential in evaluating exclusionary policies.
9. Such programs should be the least restrictive alternatives to other available means of improving occupational health [4, p. 454].

The centrality of work in human life has various dimensions: the spiritual and temporal values as well as the intrinsic and extrinsic values. Work has always been connected to moral and ethical, as well as economic values. Although our laws and moral codes do not specifically recognize a right to work, they do acknowledge strong protectable interests in fair work opportunities and freedom



from occupational injury and illness. We have established in this article that genetic monitoring and screening present a moral dilemma [33].

The distribution of natural endowments (intelligence, vigor, genetic traits, etc.) is neither just nor unjust but simply a fact [20]. Rather, it is the way that institutions deal with this fact that gives rise to justice or injustice. Thus, inequalities of opportunity arising from one's genetic constitution could be minimized through intervention in this natural biological lottery. Genetic inequalities should be dealt with by a readjustment of inequalities in a way that would work for the good of the genetically less fortunate.

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