The Ethics of Genetic Commerce

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The Ethics of Genetic Commerce
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The Ethics of Genetic Commerce

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Robert W. Kolb
## Contents

*Preface*  
List of Contributors  

### Part I: Genetic Screening  
1. Is a Genetics Screening Program for Job Applicants Ethical?  
   An Analysis of the Conditions Necessary for Requiring Genetic Screenings in the Hiring Process  
   *Thomas Harter*  
   3  

2. The Business Ethics of Genetic Screening  
   *Duane Windsor*  
   25  

   *Karen S. Markel and Lizabeth A. Barclay*  
   42  

4. Geneticize Me! The Case for Direct-to-Consumer Genetic Testing  
   *Ronald Munson*  
   55  

5. Proscription, Prescription, or Market Process? Comments on Genetic Screening  
   *Eugene Heath*  
   70  

### Part II: Genetically Modified Foods  
6. Transgenic Organisms, the European Union, and the World Trade Organization  
   *Dennis Cooley*  
   87  

7. Commercialization of the Agrarian Ideal and Arguments against the New “Green Revolution”: Feeding the World with “Frankenfoods”?  
   *Johann A. Klaassen*  
   109  

8. Corporate Decisions About Labeling Genetically Modified Foods  
   *Chris MacDonald and Melissa Whellams*  
   127  

9. Moral Imagination, Stakeholder Engagement, and Genetically Modified Organisms  
   *Denis G. Arnold*  
   139
Part III: Corporate Governance and Genetic Commerce 143

   Asher Meir

11. Pharmaceutical Mergers and Genetic Technology: A Problematic Combination 177
    Michael Potts

12. Stakeholder Care Theory: The Case of Genetic Engineering and Non-human Mammals 190
    Jamie R. Hendry

13. Unresolved Issues and Further Questions: Meir, Potts, and Hendry 208
    Laura P. Hartman

Index 215
The human species is rapidly acquiring vast new knowledge about itself that is different in kind, potential, and peril, than any that has gone before. I refer, of course, to genetic knowledge about the human body that goes to the very foundation of our physical, emotional, and mental existence. This development is not merely one of knowledge, but also one of technology. For we are now extending our grasp to the very levers that control our constitution as individuals and as a species. This accession of knowledge and enhancement in technological power represent opportunities and dangers unlike any ever encountered in human history.

Perhaps the closest analogy to these sweeping changes in knowledge and power occurred in the early modern era with the “Copernican Revolution.” Suddenly an entirely new understanding of the cosmos gained sway that challenged the fundamental understanding of man’s place in the universe. No longer was man near the center of the universe, no longer did he occupy a position near the pinnacle of the great chain of being. Instead, we came to see ourselves as being located at the periphery in a world with no inherent order, lodged merely on the “third rock from the sun” in a minor solar system comprising a fragment of one galaxy among many.

Current developments in genetic knowledge will require, I believe, a similar re-ordering of our understanding. But the present condition is more dramatic and challenging that the Copernican Revolution in three important respects. First, the new genetic knowledge strikes much more directly to the core of human existence than did the new cosmological understanding. While the greater physical knowledge of the early modern period did require a new grasp of man’s place in the cosmos, today’s new genetic knowledge demands a new understanding of the very core of what it is to be human. While the Copernican Revolution eventually led to a new view of man as a moral animal, today’s Genetic Revolution raises the question of whether man is a moral animal at all. If, for example, human disposition to behave in certain ways is reliably traceable to genetic factors that largely determine how a particular organism acts in the world, what role is left for moral categories or normative appraisal of human conduct?

Second, the scientific advances of the early modern period only required a revision in the understanding of man as a static being. The place of man in the order of things may have been reappraised, but it was only the understanding of the human that changed, not the nature of the human being itself.
Today, genetic engineering not only gives us the ability, and perhaps necessity, to understand ourselves in a new way, but also it promises or threatens to give us the means to actively control and direct our very genetic makeup as we go into the future. For the first time in human history, man now has the power to direct his evolutionary future. This raises a vision of eugenics on a scale never imagined before.

Third, there is a great difference between the early scientific revolution and today’s Genetic Revolution in the immediacy and significance of the commercial potential of this new knowledge. While the new physical understanding led to the Industrial Revolution and eventually carried us to today’s globalization, it did so relatively slowly over four or five centuries. By contrast, today new genetic knowledge is acquired and commercialized almost simultaneously, with every incremental advance leading almost immediately to new products and services. A further difference in the process of commercialization ties in with our first point – today’s commercialization strikes to the very heart of what it is to be human, in contrast to the earlier commercialization of physical processes. Our rapidly expanding genetic knowledge today points toward a near future in which the elements of humanity closest to our moral core may themselves be produced, manipulated, commodified, and exchanged.

As such, I believe that the challenges of genetic commerce, both as a topic of understanding and as a process requiring direction, will be at the core of debate for decades to come. This volume attempts to contribute to an emerging understanding of the crucial questions raised by our new Promethean challenge by tackling three key topic areas. Part I focuses on “genetic screening,” the analysis and use of genetic information about individuals, an issue that arises most saliently in the employer–employee relationship. The most intensely commercialized aspect of genetic commerce today is in agriculture and foodstuffs with the rise of genetically modified foods, the topic of Part II. Of all the dimensions of genetic commerce, the issue of the genetic modification of food seems to be at the forefront of public attention and has entered the public arena most prominently in controversies about labeling such modified foods. The third part of this book addresses specific business topics tied to genetic commerce, such as patenting genetic knowledge, pharmaceutical mergers and the potential monopolization of genetic knowledge, and the implications of genetic testing on non-human mammals.

Contributors to this volume come from diverse backgrounds, both within academics and from the corporate sector, from the United States and abroad. They also represent a diversity of backgrounds in business, social science, and philosophy. Both the papers and the discussions surrounding the symposium at which these papers were presented were enriched by these diverse perspectives. I hope that you will find the exchange of ideas included in this book as enriching as did we who participated in the symposium.
Acknowledgments

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Part I

Genetic Screening

One of the most likely areas for the application or misapplication of genetic information is in the genetic screening of individuals. In the business context, employees and potential employees are perhaps most likely to face screening. Any employer who considers hiring, training, and providing health insurance to an individual might well want to know the genetic vulnerabilities of that prospective employee. But non-employees are also not immune to genetic screening. For example, health insurers would love to be able to exclude high-risk clients from the pool of their policyholders. Of course, genetic screening can have substantial benefits for the person screened. For example, an individual might well want to know whether he possesses certain genetic characteristics that might affect his future or the life prospects of an offspring. Similarly, businesses also might reasonably want to avoid placing employees with risky genetic profiles in environments that are likely to harm them particularly.

In his essay, “Is a Genetics Screening Program for Job Applicants Ethical? An Analysis of the Conditions Necessary for Required Genetic Screenings in the Hiring Process,” Thomas Harter analyzes the conditions under which employment screening can be ethically acceptable. Harter clearly believes that genetic screening of employees can be justified in certain situations, and he specified the condition under which employers can justifiably engage in genetic screening.

Duane Windsor focuses on the business ethics and public policy implication of genetic screening in his chapter, “The Business of Genetic Screening.” Thus Windsor also addresses genetic screening of employees and health insurance applicants. In the course of his analysis, Windsor considers whether markets fail to promote social welfare in matters such as genetic screening, and he analyzes the contexts in which public policy initiatives might ameliorate such presumed market failures. For Windsor issues of human rights play a considerable role in the analysis, and he ultimately concludes that, with very few exceptions, the “... weight of considerations favors a complete ban on business use of individual genetic information.”

In their chapter, “Genetic Commerce: The Challenges for Human Resource Management,” Karen Markel and Lizabeth Barclay focus on what they see as the likely consequences of completing the Human Genome Project for issues of genetic screening, particularly in the context of human resource management.
While acknowledging that issues of genetic screening may not be of paramount importance right now for human resource managers, Markel and Barclay clearly believe that these issues will become of central importance to the human resource function.

Ronald Munson focuses on individual rights in his discussion of genetic screening in “Geneticize Me! The Case for Direct-to-Consumer Genetic Testing.” He begins by noticing that those who posture as protectors of individual rights often want to restrict the autonomy of individuals. Munson finds such efforts to be well intentioned, but ultimately paternalistic. This analysis leads Munson to believe that a successful case can be made for the right of individuals to purchase genetic information about themselves directly and without regulation. Thus Munson ultimately concludes, “Given that our society is committed to the autonomy of the individual, we should endorse policies that make it possible for people, if they choose, to acquire personal, reliable genetic data without going past a gatekeeper.”

In “Proscription, Prescription, or Market Process? Comments on Genetic Screening,” Eugene Heath surveys the question of genetic screening with reference to the other chapters discussed above. In doing so, Heath takes a critical stance that focuses on maintaining the principle of individual autonomy and choice within a market context, arguing that these conditions of choice are crucial to innovation and experiment. As Heath puts it: “The freedom to choose and select, to enter and exit, are essential to a good society and good lives and these freedoms should not be disregarded in favor of proscriptions and prescriptions that are not fully justified.” Thus, Heath generally rejects the strictures others are willing to impose on genetic screening in favor of a view of rational actors able to make independent and uncoerced choices.
1

Is a Genetics Screening Program for Job Applicants Ethical? An Analysis of the Conditions Necessary for Requiring Genetic Screenings in the Hiring Process

Thomas Harter

Introduction

Genetic screening in the workplace is a two-headed problem. On one hand, all things being equal, some job applicants and employees who are qualified for certain jobs, may pose occupational risks to themselves and others because they have genetic predispositions or hypersusceptibilities that increase their risk of developing a genetic disease. On the other hand, not hiring job applicants or firing employees only because they may develop a genetic disease is a form of genetic discrimination.

Assuming employers want to minimize occupational risks without unjustly discriminating against current or potential employees, this chapter takes up the question of when, if ever, it is permissible for employers to require genetic screenings as part of the hiring process. Specifically I argue that, despite standard concerns and reasons for disallowing genetic screenings in the workplace, those concerns can be ameliorated by requiring employers to meet the conditions of justification, consent, accuracy, and confidentiality, thereby allowing employers who meet these conditions to require pre-employment genetic screenings, and disallowing pre-employment genetic screenings when these conditions are not met.

There are several key issues to address. First, I summarize the scope of the problem. Second, I look at the purpose, reasons, and benefits of genetic screenings in the workplace. Third, I discuss the reasons for disallowing genetic screenings as part of the hiring process, focusing on genetic discrimination and loss of privacy. Fourth, I show how these concerns can be resolved by requiring
employers to (1) provide adequate justification(s) for using genetic screenings as part of the hiring process, (2) receive consent from job applicants before having the genetic screening(s), (3) ensure that the genetic screenings are accurate, and (4) treat the information received from the genetic screening as highly confidential. Then having set out my main arguments, I consider two objections to my thesis: that requiring genetic screenings provides an alternative to employers cleaning up workplaces, and that enforcing these conditions for required genetic screenings may be too difficult.

**Summarizing the Scope of the Problem**

Before the 1990s and the Human Genome Project, few major companies genetically screened their employees.¹ Since then the prospect of using genetic screenings in the workplace, although still ethically debated, has become more common. One reason for this, as already stated, is employers wanting to minimize occupational risks while increasing employee safety. Other reasons for using genetic screenings, which I explore more fully in the next section, include employers wanting to efficiently manage the costs of treating employees with genetic diseases, and employers also wanting to minimize potential risks to the general public. In order to successfully argue that employers may permissibly require genetic screenings for applicants, there must be empirical evidence showing correlations between genetic hypersusceptibilities, genetic diseases, and certain workplace exposures.

Elaine Draper, in her book *Risky Business*,² gives the following examples of these kinds of correlations:

People with SAT enzyme deficiency may have increased susceptibility to emphysema and chronic bronchitis under conditions of exposure to pulmonary irritants. Exposure to certain hemolytic chemicals may trigger sickling crises among individuals with sickle cell trait. Individuals with G-6-PD deficiency may be at greater risk of anemia or hemolytic crisis when exposed to oxidizing chemicals such as nitroamino and nitroaromatic compounds. Aryl hydrocarbon hydroxylase

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¹ In one of the most famous publications on genetic screening in the workplace, the Office of Technology Assessment (OTA) report “Genetic Monitoring and Screening in the Workplace” (October 1990) included a 1982 survey of several hundred Fortune 500 companies to determine how many of them genetically screened their employees; 366 of the 500 companies responded (a 65% response rate). Of those 366 companies, 17 (4.6%) claimed to use genetic testing of some form over the previous 12 years, 4 (1.1%) anticipated using genetic screenings in the next 5 years, and 55 (15%) said they would possibly use genetic screenings in the next 5 years. While there were slight changes in the survey when it was given again in 1989, the results were nearly the same. Twenty companies in the 1989 survey, as opposed to the 17 in the 1982, claimed to have genetically screened employees. For more information about the report and survey see Office of Technology Assessment (1990).

deficiency appears to increase susceptibility to lung cancer among those encountering specific industrial pollutants. Over fifty diseases have been associated with human leukocyte antigens.

Draper (1991, p. 25)

Although there may be other types of genetic diseases with links to hypersusceptibilities and workplace exposures, Draper nicely illustrates this aspect of the problem. Namely, companies with employees who may be at risk for developing a genetic disease because they are hypersusceptible to certain workplace exposures, and believe they have a right to genetically screen employees and applicants for those hypersusceptibilities because doing so helps minimize occupational risks. However the other aspect of this problem is whether genetically screening employees and applicants is ethical because doing so identifies those individuals with hypersusceptibilities, presumably with the intention of removing them from whatever workplace exposures are putting them at risk for developing a genetic disease.

Draper also successfully illustrates this aspect of problem by discussing DuPont’s highly publicized genetic screening program. From 1972 until the early 1980s, DuPont screened all of its African American employees and applicants for the sickle cell trait and sickle cell disease. Yet without proof that the program was beneficial in some way, it seems DuPont was not justified in screening its African American applicants and employees, and thus likely they were engaging in genetic and racial discrimination. From this the full scope of the problem is clear, while companies may cite an obligation to identify, and consequently remove, hypersusceptible employees or applicants from workplace exposures that may put them at risk for developing a genetic disease, doing so may lead to various forms of unjustifiable discrimination. Before showing how it is possible to ethically require genetic screenings for applicants without unjustly discriminating against them, it is necessary to show the purpose, reasons, and benefits of genetic screenings in the hiring process.

**Purpose, Reasons, and Benefits for Genetic Screenings in the Hiring Process**

In his article, “Warning: Screening Workers for Genetic Risk,” Thomas Murray gives four general purposes of genetic testing in the workplace. These include

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3 See Draper (1991, p. 130).
4 See Murray (1983).
diagnosis, research, information, and exclusion:

First, the tests could be used in the clinical diagnosis of an individual ill worker. Second, 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 consideration. Fourth, the tests could be used to exclude workers from jobs where they had a genetic condition believed to result in a heightened susceptibility to the hazards normally encountered in that job.

Murray (1983, p. 6)

By using genetic screening in the workplace, employers can determine which applicants are “hypersusceptible” to certain genetic diseases. That is, genetic screenings help determine which applicants are more likely to fully develop a genetic disease if they come in contact with certain workplace exposures that increase their risk. Consider Draper’s example of an employee with the trait for sickle cell anemia. Assuming that the employee is not exposed to hemolytic chemicals there is a chance that the sickling gene may remain dormant. However, if that employee happens to work in an area exposing her to hemolytic chemicals, she is then considered hypersusceptible to have a sickling crisis.

Both Murray and the Council on Ethical and Judicial Affairs for the American Medical Association (CEJA) discuss the justifications employers give for implementing a genetic screening program for the purpose of detecting these hypersusceptibilities. Murray states,

First, they can point to their moral duty to protect workers. Paternalism originally meant taking care of those with less power – the parent and child is the paradigm. Second, companies can cite their financial obligation to use the company’s resources in the most efficient way possible, including preventing the loss of employee time due to illness, or money through the workman’s compensation system. Third, they can emphasize their desire to avoid lawsuits alleging a failure to adequately protect genetically susceptible workers from harm.5

Murray (1983, p. 6)

Likewise, CEJA claims in their report “Use of Genetic Testing by Employers,”

Employers will have a number of potential justifications for genetic testing in the workplace. In some cases, there may be an argument in favor of testing for

5 Emphasis added. I believe that Murray’s third justification fits better under both the first and second arguments. The failure to adequately protect workers is an extension of their moral duty to protect them, while the obligation a company has to use its financial resources efficiently precludes its desire to avoid a lawsuit.
public health reasons. Companies have expressed concern about the possibility of an employee’s genetic susceptibility to illness from exposure to a chemical or other substance in the workplace. In addition, employers may not want to hire individuals with certain genetic risks for jobs that bear on the public’s safety. Other justifications are based not on concerns about health but on concerns about costs, specifically the costs to the *company* of hiring workers with a genetic risk of disease. Individuals who have a heightened risk for certain illnesses may be less attractive as employees; on average, they may be able to spend fewer years in the work force, and they may impose greater health care costs on the employer.6

CEJA (1991, p. 1827)

Detecting which applicants are hypersusceptible hinges on three primary benefits that apply across multiple industries: benefits to applicants, benefits to the general public, and benefits to the company. First, determining which applicants are hypersusceptible allows employers to prevent those applicants from being placed in jobs that increase their risk of either developing or manifesting a genetic disease. Second, determining which applicants are hypersusceptible may help prevent current employees, as well as the general public, from being placed in harm’s way. For example, consider a bus driver applicant who suffers seizures caused by a genetic form of epilepsy. These seizures can be brought on in numerous ways, including exposure to certain light patterns. Although most forms of epilepsy can be controlled with medication, an employer would presumably still want to know if an applicant were epileptic because of the possibility that the applicant may have a seizure driving a bus full of people. Lastly, the ability to determine which applicants are hypersusceptible may help companies (1) avoid costly lawsuits stemming from a failure to protect those applicants, current employees, or the general public from possible harms, (2) avoid paying higher insurance premiums,7 or (3) avoid having to cover the cost of applicants needing time off from work to treat their illnesses. Yet despite the potential benefits, there are many arguments for why employers should not use genetic screenings in the hiring process.

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6 See Council on Ethical and Judicial Affairs, American Medical Association (1991). It is possible that the justifications of using genetic screenings to determine hypersusceptibilities cited by Murray and CEJA could extend in their scope to include screening workers who already have burgeoning genetic diseases.

7 While the 1996 Health Insurance Portability Accountability Act (HIPPA) “prohibits group health plans from using any health status-related factor, including genetic information, as a basis for denying or limiting eligibility for coverage or for charging an individual more for coverage,” it is unclear whether or not this prohibits insurance companies from legally charging higher premiums to companies with workers who have genetic diseases or hypersusceptibilities. National Human Genome Research Institute, National Institutes of Health, January 2004. See National Institutes of Health (2005).
Reasons against Using Genetic Screening in the Hiring Process

On May 6, 2002, Burlington Northern Santa Fe Railway Co. paid $2.2 million to thirty-six employees in a settlement with the Equal Employment Opportunity Commission (EEOC). The settlement was reached after Burlington Northern “admitted to conducting undisclosed genetic testing after the workers complained of carpal tunnel syndrome stemming from work related activities” (French, 2002, p. 1). In their defense, Burlington Northern claimed they were screening employees to confirm the existence of carpal tunnel syndrome, but that this was done in conjunction with “a comprehensive medical examination” (French, 2002, p. 1). On September 12, 2002, there was a Congressional hearing before the Subcommittee on the Constitution, questioning the “Privacy Concerns Raised by the Collection and Use of Genetic Information by Employers and Insurers.” Both the Burlington Northern case and the Congressional hearing highlight what many articles on genetic screening in the workplace quickly point out: two dangers of requiring genetic screenings in the hiring process are genetic discrimination and invasion of privacy.

Genetic Discrimination

Larry Gostin states the problem with genetic discrimination is that it “violates basic tenets of individual justice and is detrimental to public health” (1991, p. 112). He continues,

Discrimination based upon actual or perceived genetic characteristics denies an individual equal opportunity because of a status over which she has no control. Discrimination based on genetic factors can be as unjust as that based on race, gender, or disability. In each case, people are treated inequitably, not because of their inherent abilities, but solely because of pre-determined characteristics. The right to be treated equally and according to one’s abilities in all the diverse aspects of human endeavor is a core social value.

Gostin (1991, p. 112)

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11 While I agree with Gostin that some forms of genetic discrimination are unjust, I do not believe it is the case that all forms of genetic discrimination are unjust. Although I do not specifically argue for this point in the article, my project is guided by the belief that not only are some forms of genetic discrimination just, but also that genetic discrimination is required in certain cases when jobs bear on public safety.
Genetic discrimination can manifest in several ways. First is future unemployability. Because genetic screenings determine which applicants have hypersusceptibilities, “Employers may be reluctant to hire individuals who have a genetic predisposition for developing a disabling illness . . . because these individuals may become prematurely unable to work” (CEJA, 1991, p. 1827). Thus, applicants with specific career training or job skills may be unable to find work if they have a noted genetic hypersusceptibility. Requiring genetic screenings may also lead to hiring practices that would be in violation of the EEOC and the Americans with Disabilities Act of 1990 (ADA), as employers may be tempted to hire applicants without hypersusceptibilities who do not appear in danger of developing a genetic disease.12

Genetic discrimination can also manifest through over-reliance on the results of genetic screenings. In both their 1991 articles, CEJA and Gostin note that the results of genetic screening are not as accurate as the public may believe. CEJA reports,

Genetic tests are poor predictors of diseases and even poorer predictors of disabling diseases. Genes are often characterized by incomplete penetrance; that is, many individuals who carry the gene will never show manifestations of the gene. When the gene manifests itself, it will be characterized by variable expression – the extent of the gene’s effects may differ widely from person to person. Among individuals with sickle cell anemia, some die within the first years of life, while others survive into their 50s. In many cases, behavioral modification can limit gene expression . . . Even in cases in which the gene will ultimately cause disabling disease, the effects of the gene may not appear for some time. For example, the onset of Huntington’s disease does not occur until the patient is between the ages of 30 and 50 years. Consequently, the use of genetic tests would result in individual’s being denied employment well before they became unable to work. In sum, genetic tests would have a high false-positive rate and, therefore, would result in many individuals being denied employment unfairly.

CEJA (1991, p. 1827)

12 William Murry, James Wimbrush, and Dan Dalton state that, “Genetic markers that would indicate proclivity towards future illness or disease in individuals may or may not constitute a disability. The ADA defines a disability as, ‘(A) A physical or mental impairment that substantially limits one or more of the major life activities of such individual, (B) a record of such impairment, or (C) being regarded as having such an impairment (Americans with Disabilities Act of 1990).’” They further claim, the “Equal Employment Opportunity Commission (EEOC) interpretative guidelines in 1995 expanded on this definition specifically to include genetic testing when they indicated that in order to make a claim under the ADA ‘. . . an employee must show he or she has a genetic defect, the employer knew about the defect, and the employer took discriminatory action based on that knowledge’ (Workplace Visions, 1998, p. 5)” (pp. 366–367). For further information, see Murry and Dalton (2001).
Echoing these claims, Gostin states, “For most genetic diseases the onset date, severity of symptoms, and efficacy of treatment and management are highly variable” (1991, p. 114). He concludes,

The reliability and predictive value of genetic tests are limited by the extent to which mutations are known and prevalent in the target population. Variability exists in the onset, presentation and outcome of disease, and predictions are confounded by a multiplicity of genetic, biomedical, and environmental factors. For all these reasons, significant scientific uncertainty surrounds much genetic testing.

Gostin (1991, p. 114)

However, because both CEJA’s and Gostin’s articles were published in 1991, it is important to examine the current accuracy of genetic tests. This is an issue I take up in the next section discussing the conditions for required genetic screenings.

Another possible manifestation of genetic discrimination is through ethnic or racial discrimination. This is because certain ethnic groups have been linked to particular genetic diseases. For example, people of African descent have been linked to sickle cell anemia, and Ashkenazi Jews to Tay-Sachs. One concern is that “screening could stigmatize and negatively impact historically disadvantaged groups (cf. Task Force on Genetic Information and Insurance)” (MacDonald and Williams-Jones, 2002, p. 237). Thus, genetic testing could lead to increased racial discrimination. However, it is also possible that racial discrimination could lead to genetic discrimination. Imagine an employer who requires only African American applicants to be screened for the sickle cell trait and then removes from the candidate pool any applicant with a positive test.

**Invasion of Privacy**

Genetic screenings are also considered inappropriate in the hiring process because they unduly invade the applicant’s privacy. As Joseph Kupfer explains,

Many different sorts of information can be obtained, most of it valuable to the company. Some information concerns such things as credit ratings or religious

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13 Sickle cell anemia is also commonly linked to people in “Spanish-speaking regions (South America, Cuba, Central America), Saudi Arabia, India, and Mediterranean countries, such as Turkey, Greece, and Italy.” See Sickle cell anemia. *Webster’s New World Medical Dictionary* (2nd edition, 2003).

14 See MacDonald and Williams-Jones (2002).

15 While racial discrimination is illegal in the hiring process, current debates about the legality of genetic discrimination in the hiring process are ongoing. For further information, see Gostin (1991), Murry et al. (2001), and Strudler (1994).

16 See Kupfer (1993).
affiliations, other involves ascertaining physical facts by monitoring drug use. Is genetic screening any different in principle from drug screening, polygraph tests, or surveillance? In at least one regard it seems to be. Although in most cases we have some control over whether a gene is expressed as a disorder, we cannot control whether we have the gene in the first place. Whether we have the disposition, the vulnerability to the disorder, is out of our hands. We have some say over our work, religion, credit rating, and most of us can choose to use drugs or not. But not so with genes. They are in us and of us, forever. This lack of control is especially compounded in the workplace because of related lack of power in this context.

Kupfer (1993, p. 21)

Hence genetic screenings are different from other types of personal information applicants may be required to give employers because they reveal information individuals have no control over and cannot change. But how exactly is revealing genetic information about oneself an undue invasion of privacy? Kupfer makes two presumptions here. One, individuals tend to guard information about themselves they believe make a part of their personhood. Two, part of what dictates personhood are our genes. So because individuals cannot control or change their genetic make-up, being required to reveal this information for the sake of employment seems in some regard an undue invasion of privacy. However if individuals did have some control over their genetic make-up, or at least have some control over how their genetic information is used by employers, Kupfer might be reduced to saying that although genetic screenings do invade privacy to some degree, genetic screenings are not an undue invasion of privacy.

In addition to the fear that genetic screenings unduly invade privacy, other concerns include the psychological burdens genetic screenings place on applicants, the nature and scope of the information revealed, and confidentiality of that information. For instance, genetic screenings may force applicants to learn information about themselves they might not otherwise want to know. One reason for this might be a fear of social stigmatization associated with certain genetic diseases, like Alzheimer’s. Another reason might be the shame and embarrassment some applicants may feel about themselves; applicants who learn they are hypersusceptible to a genetic disease may somehow feel inferior to those who are not. Applicants may also feel embarrassed by special requests their families or employers may have regarding their hypersusceptibilities, perhaps by having those applicants fill out special insurance forms, or visit with a genetic counselor. MacDonald and Williams-Jones discuss these and other psychological burdens in “Ethics and Genetics: Susceptibility Testing in the Workplace”:

Genetic information can be a significant psychological and social burden, especially if one is told one has “a defective gene,” or is “at risk.” Such news might
affect a person’s conception of health and identity, lead to stigmatization, or even make a person unemployable or uninsurable . . . Forcing employees to undergo genetic screening also forces the employee to deal with the resulting information, and studies on the psychological impact of genetic testing have shown that it may sometimes be better “not to know”.

MacDonald and Williams-Jones (2002, p. 237)

Murry et al. add in “Genetic Screening in the Workplace: Legislative and Ethical Implications,”

It has been shown that individuals who have found out they are carriers of a genetic mutation have negative feelings and react with varying levels of distress. The negative connotations that are associated with genetic testing, particularly with respect to potential employment opportunities, create for an employee the inevitable perception of inadequacy.

Murry et al. (2001, p. 373)

These psychological burdens may be perpetuated in part by the nature and scope of the information revealed. Genetic screenings are primarily used to determine whether individuals have a genetic disease or hypersusceptibility. While employers may use that information, for the reasons cited by Murray and CEJA, a yet unanswered question is, how much personal information should applicants be required to disclose for the sake of employment? Assuming employers want to hire those whom they feel are the best applicants, they should have a right to know information about those applicants relevant to the job for which they are applying. Yet genetic screenings offer detailed information about applicants that they may wish to keep private and are not necessarily relevant to the job. Consider a young applicant whose screening reveals the trait for Alzheimer’s. Although this is a debilitating disease, its onset is not until late in life, and presumably has little relevancy during the time the applicant is actually employed. However, because there is a social stigma associated with Alzheimer’s, the applicant may wish to keep the information private. So there is reason to believe there are limits to an employer’s access of an applicant’s genetic information. But what are these limits and why is the privacy of an applicant something that ought to be valued?

Kupfer grants that employers do have rights and interests to prevent potential occupational risks resulting from hypersusceptibilities. However he also believes that,

Such interests are not overriding, not in a society which claims to value the individual’s autonomy and privacy. The employer has no more right to a total genetic profile than he has to information about one’s sexual habits, recreational activities, or religious and political beliefs – even though knowledge of these and other details of our lives might well be of use to him.

Kupfer (1993, p. 22)