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THE USE OF GENETIC INFORMATION FOR NONMEDICAL PURPOSES

MARK A. ROTHSTEIN¹

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I. INTRODUCTION

We have recently entered a great new age of genetics. The Human Genome Project, officially begun in 1990, is a fifteen-year, international research effort to map and sequence all of the human genome, including the estimated 100,000 human genes. As a result of this research, our knowledge of human genetics will expand exponentially, thereby promising to improve the quality of life and giving hope that even some of the most dreaded diseases can be cured. Nevertheless, as we accumulate vast amounts of genetic information on an individual and aggregate basis, there are legitimate concerns that this information could be misused.

My goal is to provide a broad overview of some of the ways in which genetic information may be used for nonmedical purposes. Before I get to this specific topic, however, I want to briefly note, for definitional reasons, the various medical uses of genetic information. These include diagnosis, reproductive planning, disease prevention, treatment, and research. These uses, of course, raise numerous legal and ethical issues, including informed consent, privacy,

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confidentiality, duty to warn, public health screening, and medical malpractice. These topics, however, are beyond the scope of this lecture.

When one thinks about the use of genetic information by third parties for nonmedical purposes, one of the first things that comes to mind is the question of how the third party can gain access to the information. There are three main ways. First, and most importantly, the third party may obtain records developed in the clinical setting. In other words, if someone wants a job or insurance, that person may be required to sign a release authorizing the third party to access those records. Second, the genetic records might be obtained through a genetic data bank. Third, the third party may actually perform genetic testing itself or ask questions that elicit genetic information indirectly through family histories.

I will address the following eight nonmedical uses of genetic information: (1) identification, (2) employment, (3) insurance, (4) commercial transactions, (5) domestic relations, (6) education, (7) criminal justice, and (8) tort litigation.

II. SPECIFIC AREAS OF POSSIBLE USE OF GENETIC INFORMATION

A. Identification

Although I am primarily concerned with the identification of specific human beings, I should note that DNA identification techniques may be useful in other areas as well. For example, recently in Japan DNA tests were performed on whale meat. The tests indicated that some of the whale meat being sold was from humpback whales, which are on the endangered species list. The authorities used the information to track down the individuals who were trafficking in illegal whale meat.

One of the most common uses of human genetic information is in criminal forensics (although I will have more to say about the nonforensic application of DNA technologies later). Essentially, criminal investigators use DNA evidence to determine whether samples from criminal suspects match biological evidence, such as blood on walkways outside condominiums, found at the scene of a crime. Seventeen states already mandate DNA profiling (loosely referred to as DNA fingerprinting) of all convicted felons. The FBI also has a growing DNA data bank. The proliferation of criminal databases raises concerns about privacy and confidentiality and whether in criminal investigations the police literally will "round up the usual suspects."

DNA identification techniques are also used in the identification of dead bodies. DNA samples of all military personnel are now taken for identification purposes. Indeed, the military DNA data banks were first used to identify human remains in the Gulf War. Privacy concerns, similar to those of law enforcement data banks, are raised in connection with these data banks primarily limiting who has access to the information. DNA testing is also utilized for identifying the victims of plane crashes.

Furthermore, DNA information determines parentage with much greater certainty than information from prior technology does. This information is important not only to paternity testing but to testing that already is used to reunite children with their parents or grandparents after being separated by war or political oppression.

Fourth, genetic identification methods may be used to determine heirship. Unlike blood-based tests, DNA testing may be performed on any available tissue. Therefore, DNA testing can be done posthumously, which raises interesting issues about heirship.

B. Employment

There are two main ways in which genetic information is useful to employers. Some genetic traits make individuals more susceptible to occupational diseases. For example, alpha-1-antitrypsin deficiency, the lack of a protective serum protein, greatly increases the risk of emphysema and other lung disorders. Employers might consider this risk factor in deciding which individuals to assign to work in dusty environments.

The more likely use of genetic information by employers, however, involves diseases unrelated to workplace exposures. Employers concerned with controlling escalating health care costs may be interested in knowing whether an individual is likely to contract a nonoccupational illness in the future. In any given year, five percent of health care claimants represent fifty percent of health care costs; ten percent of health care claimants represent seventy percent of health care costs. Consequently, if an employer could identify beforehand the people who were likely to become seriously ill and exclude these people (or their dependents), the employer could save a tremendous amount of money on health benefits.

The exclusion of current or potential employees because of concerns about future health costs raises serious legal questions. Nine states have enacted laws that specifically prohibit genetic discrimination in employment. Some of the laws are limited to particular genetic traits, while others define "genetic" more broadly. In my view, the enactment of specific genetic discrimination legislation is not the best way to proceed. Such legislation often fails to resolve fundamental problems, including the core issue of how to define "genetic." The most promising approach is to apply more general disability discrimination laws.

At the federal level, the Americans with Disabilities Act (ADA) applies to all employers with fifteen or more employees in the private as well as the public sector. Federal government employees, however, are excluded from coverage under the ADA, but they are protected under section 501 of the Rehabilitation Act. Under the ADA there is a three-part definition of an individual with a disability: 1) an individual with a physical or mental impairment that substantially limits one or more of the individual's major life activities; 2) an individual who has a record of such an impairment (e.g., someone who had cancer and is now in remission); or 3) an individual who is regarded as having such an impairment (e.g., an individual who has no impairment but who is perceived as having an impairment).

Individuals with expressed genetic illnesses are clearly covered under the ADA. The difficult questions are whether the ADA covers someone who is presymptomatic for a late onset genetic disease, someone who has a genetically increased risk of a multifactorial disorder such as cancer or heart disease, or someone who is the unaffected carrier of a recessive or X-linked disorder. In the latter situation, the individual will not be affected, but his or her offspring

may be and, as covered dependents under a health benefits plan, might have substantial future claims.

The ADA is silent on the issue of genetic conditions, and there is little authoritative discussion in the legislative history. It was not until March 1995 that the Equal Employment Opportunity Commission (EEOC) stated that individuals who are subject to discrimination in employment because of a genetic predisposition to disease are "regarded" as having a disability and therefore are covered under the third part of the definition of "individual with a disability."

Closely related to the permissible use of genetic information by employers is the issue of how employers gain access to genetic information. Aside from performing the tests themselves (currently not done for financial and other reasons and an unlikely prospect for the near term), there are two main ways. At the preemployment stage, before an offer of employment has been extended, employers are not permitted to make any inquiries about whether the individual has a disability or the nature and extent of any disabilities. At the "preplacement stage," however, after an employer makes an offer of employment conditioned on the individual undergoing a medical examination, the employer may require a medical examination of unlimited scope. These medical examinations need not be limited to assessing job-related physical or mental capacities.

At the same time, the conditional offerees also can be required to sign a release, authorizing their personal health care providers to disclose all of their medical records. These medical records, of course, could contain the results of genetic tests or other genetic information. The ADA provides that a conditional offer of employment may not be withdrawn based on medical information unless the medical information is job related and bears directly on whether the individual is able to perform essential job functions. Nevertheless, simply permitting access to the information will often make it extremely difficult to ensure that the information is not used.

The second way in which employers may obtain genetic information is through health insurance claims. Employer-provided health insurance is either purchased through a commercial insurer or Blue Cross/Blue Shield or through self-insurance. If an employer is self-insured, then the employer itself acts as the insurer, bearing the risks and paying the claims directly. When employees submit health insurance claims, the health care providers indicate a diagnosis or check a diagnostic code. In this way, the employer can learn the nature of the medical conditions for which the employee and any covered dependents are receiving treatment.

There are a variety of ways in which the employer may act on the basis of the health insurance claims data aside from the most drastic (and unlawful) step of discharging the employee. In fact, the employer does not even need to have the information in personally identifiable form to take action adverse to the employee's interests. For example, the employer's benefits department may determine that it is paying for a few very high cost diseases or procedures that, if eliminated from the employer's benefits package, would save thousands of dollars each year. Or the benefits department might determine that dependent coverage is costing a tremendous amount of money and should be discontinued.

Although state insurance laws frequently mandate that all policies written in the state cover certain medical conditions and limit the situations in which policies may be cancelled, self-insured employers are not subject to these laws. The federal Employee Retirement Income Security Act (ERISA) preempts these state insurance laws as to self-insured employers. Under ERISA, self-insured health benefit plans may be amended or discontinued altogether at any time, so long as the employer is not doing so as a subterfuge for disability discrimination (in violation of the ADA) and so long as the employer complies with the necessary notice provisions in the particular plan agreement it has drafted.

The impact of ERISA is important to consider. Most major employers in the United States are self-insured, including ninety percent of employers with 20,000 or more employees, eighty-two percent of employers with 5,000 or more employees, and over half of all employees. The problems raised by using health insurance claims data are not unique to genetic information. What is unique is the ability of employers to use genetic information to predict future health costs before claims are even filed.

C. Insurance

About eighty-five percent of Americans under age sixty-five are covered by health insurance of some kind. Of those who are covered, eighty-five to ninety percent are covered by group insurance. Of those people who have group insurance, about seventy percent obtain their group insurance through employment, either as the employee or as the dependent of an employee. That means that only ten to fifteen percent of insured individuals are covered under individual health insurance policies.

The central role of employers in our health insurance system arose by happenstance. During World War II, to prevent runaway wage inflation caused by labor shortages, wage and price controls were established. Because employees could not get wage increases, employers (frequently as a result of collective bargaining) provided employees with additional fringe benefits. The first fringe benefit at many companies was hospitalization coverage. Since World War II, the coverages have become increasingly comprehensive, increasingly generous (extending to dependents and retirees and covering physician visits, allied health services, eyeglasses, hearing aids, and other devices), and increasingly expensive.

Traditionally, medical underwriting was only used by insurance companies for individual insurance policies, the rationale being that, on the average, employees and their dependents were at least as healthy as the general population. Because the same can not be said of applicants for individual health insurance coverage, medical assessments of risk were used. This practice of medical underwriting, however, has recently spread into the small group insurance market. Many small employers with a high claims history or in perceived high risk industries or locations are unable to obtain health insurance at standard rates, if at all.

Medical underwriting for individual health insurance is driven by the principle of adverse selection. Individuals who know they are likely to need health insurance are the most likely ones to seek it. To prevent individuals from seeking health insurance based on medical information known only to the

applicant, insurance companies seek to have access to the same medical information as the individual. And this medical information includes genetic information. To prevent genetic-based discrimination in health insurance, twelve states have enacted legislation that specifically prohibits health insurance companies from using genetic information to exclude individuals from coverage.

Similar issues of adverse selection are raised in the context of life insurance. If someone knows that he is going to die in a year, one of the first things he might do is try to take out \$10 million of life insurance at standard rates. If everyone could do this, life insurance companies would either go out of business or they would raise their rates so high that life insurance would be prohibitively expensive. Thus, avoiding adverse selection is considered key to the viability of life insurance.

Morally, is there a difference between health insurance and life insurance? I think few people would consider life insurance to be a necessity today, whereas I think most people would say that health insurance is. Yet, allowing any insurance company to obtain access to increasingly sophisticated genetic information could have extremely deleterious consequences to public health. Individuals at risk of genetic illnesses might forego genetic testing for fear of being denied insurance coverage.

In the Netherlands, life insurance companies have started a five-year experiment in which individuals are considered for life insurance policies up to 200,000 guilders (about \$100,000) without *any* medical inquiries. One advantage of treating genetic risks the same as other medical risks is that it avoids the difficult problem of defining exactly what a genetic test or condition is. For example, is a simple blood test that reveals inherited hypercholesterolemia a genetic test? Although American insurance companies are vehemently opposed to issuing policies without medical underwriting, individual life insurance policies in very small amounts (typically \$5,000) already are available without medical underwriting. Nevertheless, I am not aware of any studies which attempt to measure empirically the monetary level at which adverse selection pressures become unacceptably high.

D. Commercial Transactions

Forensics, employment, and insurance are the three areas that quickly come to mind in the use of genetic information for nonmedical purposes. The other five areas I am going to discuss are less commonly considered, but all of them could be significant.

If you think about it, any third party with an economic interest in the future health of an individual automatically has an interest in the individual's future health—and consequently his or her genetic profile. For example, if a person applies for a thirty-year mortgage, the mortgage company would certainly want to know if that person is going to be alive in thirty years. The same can be said of any commercial loan or various business ventures.

It seems to me that it may only be a matter of time before commercial entities demand access to genetic information. Currently, there are no legal limitations on the ability of lenders or other commercial entities to require or use medical, including genetic, information. Even though this is not common practice today, there is little basis for assuming that it will not take place in the future.

E. Domestic Relations

There are three ways in which genetic information could be used in domestic relations. The first involves premarital genetic assessment of the partners, especially with regard to recessive disorders. Although this directly relates to reproductive planning, which I said at the outset would be beyond the scope of this talk, I would like to mention just one example. In New York City, Orthodox Jews have established a program called Dor Yeshorim. Each unmarried young person undergoes genetic testing for Tay Sachs disease, Canavan disease, and Gaucher's disease, but they are not told of the result. They are merely given a code number. When a couple is proposed to marry (often through arranged marriages), the central registry is called and told the two numbers. The registry then indicates whether the proposed match would be a "good" one or not. The number of rich ethical issues raised by screening programs such as this one are evident.

A second area of domestic relations that could be affected by genetic information is child custody disputes. The following example was related to me by my colleague, Professor Lori B. Andrews of the Chicago-Kent College of Law. In April 1994, a South Carolina divorce lawyer was approached by a client with a troubling request. There was a custody battle over the client's daughter, and the client wanted his ex-wife to be tested for the Huntington's disease gene. Because the ex-wife's mother had died of Huntington's disease, the ex-wife was at a fifty percent risk of developing this invariably fatal, late-onset, dominant neurological disorder. If she tested positive for the Huntington's gene, then the ex-husband was going to argue that his ex-wife should not be granted custody of their child because she would be unable to care for the child after she developed symptoms.

Interestingly, the ex-husband's lawyer was a former genetic counselor, and she realized that getting a court order requiring genetic testing was not necessarily the best thing to do. She knew that most people who are at risk for Huntington's disease do not elect to be tested for both economic (fear of losing employment and insurance) and psychological reasons. The lawyer also was concerned about her own potential liability if, on her motion, the ex-wife were tested, found out she had the Huntington's gene, and then jumped off a bridge. To make a long story short, the motion to compel testing was filed, and it was granted by the court. But the mother fled the jurisdiction with the child before the testing took place.

In other cases, it may be that a parent will come into court after voluntarily being tested. He or she might argue that, having gotten a "clean" bill of genetic health, this fact should be considered by the court. Courts consider various factors in determining what is in the best interest of the child, including the health of the parents and whether one parent smokes. It is quite possible that genetic information also might be considered.

Genetic information also could be of great interest in adoption proceedings. Each of the interested parties in an adoption—the biological parents, the child, and the adoptive parents—might be subject to genetic testing. Twenty-two states already require genetic and other available medical information from biological parents to predict the health risks of the child. As direct DNA testing becomes available for more genetic conditions, parental testing will be

unnecessary because the child can be tested directly. Eight states currently require genetic information about an adoptive child, and forty-nine out of the fifty states (Nevada being the exception) require more general health and medical information about the child without specifically mentioning genetic information.

What happens when the child being placed for adoption tests positive for a genetic disorder? Is it moral or should it be legal for adopting parents to say, in effect, we are no longer interested in adopting this child because the child is going to develop a certain disease in the future? Is there some minimum standard of genetic merchantability for adoptive children, or is this making children into commodities? Although there is a natural inclination to say that children are adopted on an "as is" basis, I suggest that the issue is more complicated than it might appear.

Suppose that a couple is about to adopt a child and the adoption agency says that the child to be adopted has the gene for Tay Sachs disease and is going to die around age two after a very terrible, painful, miserable existence. Does the couple have to go through with the adoption? Suppose the reason the couple was adopting a child is that they already had a child die of Tay Sachs disease? Is it unreasonable or morally repugnant for the couple to say that they could not handle adopting this child?

On the other hand, suppose that the child carried the gene for a late-onset disorder, such as Huntington's disease, which is fatal, but has a median age of onset of forty, or Alzheimer's disease, which would not manifest until even later in life? Suppose it is a treatable disorder, such as hemochromatosis? Or suppose the child merely has a genetic predisposition to cancer or heart disease? It seems to me that it may be very difficult to draw the lines for legal regulation of genetic testing in adoption.

The theory of testing adoptive parents, which is also a possibility, is similar to the one I raised earlier with regard to child custody. That is, a late-onset disorder would interfere with the ability to be a good parent. The courts have upheld considering the adoptive parent's age, and they have upheld considering the health status of adoptive parents. Why not also consider the likely future health of adoptive parents by looking into their genetic profile.

F. Education

Genetic information could be used at every stage of education, from preschool to graduate school. As to younger children, genetic testing may be used to identify children with a genetic trait or predisposition to learning disabilities, such as dyslexia. Based on genotype alone, children might be placed in certain educational tracks before they have had a chance to demonstrate their ability or their motivation, making those tracks self-fulfilling prophecies for the child.

Fragile X syndrome is named for the unusual constriction of the X chromosome. It is one of the most common monogenic forms of mental retardation. It is an X-linked disorder with a prevalence of one in 2,000 males and a carrier prevalence of one in 1,000 females. About one-third of carrier females show some milder form of mental retardation even though they will not be affected severely. Despite great concerns in the genetics community,

fragile X screening programs supported by commercial interests are already under way in schools in Colorado and Georgia.

Genetic information also may be used at higher levels in the educational process. Dr. Nancy Wexler, a well-known clinical psychologist and genetics researcher, tells the story of a mother who brought her two at-risk teenage children to a medical center to be tested for the Huntington's disease gene. It is unusual to perform genetic testing on minor children for late-onset disorders. Because Huntington's disease is a dominant disorder, each child had a fifty percent risk, although of these two children neither or both of them could have been affected. The mother said she wanted her children tested because she could only afford to send one of them to college.

These same sort of difficult dilemmas also could arise in professional schools. For example, medical schools make major investments in their students. As a society, we do not begin to recoup the cost of paying for medical education until the individual has completed training and has been practicing for a number of years. Would it be legal or ethical for a medical school to refuse to admit a student who already had amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease), where the mean survival after diagnosis is only two to five years? If denying admission to such an individual would not be unreasonable, what about denying admission to an individual who was presymptomatic for ALS and was likely to develop the disease within ten years? What about other late-onset disorders, such as myotonic dystrophy? When, if at all, would it be acceptable to use genetic information as a basis for admissions, internships, residency placements, or other aspects of medical education?

G. Criminal Justice

I have already discussed the forensic use of DNA evidence for identification. There are two other, less well-analyzed, areas of criminal justice in which genetic information also may be relevant. The first is the use of a defendant's genotype as a defense. The attempt to use the XYY defense, which began in the 1960's, presents an historical precedent. The theory that men with an extra Y chromosome are predisposed to violent or criminal behavior has now been thoroughly discredited. More recently, however, other types of genetic information have been proffered to bolster an insanity defense in much the same way that evidence of organic brain disease is used today.

The second possible application of genetic information is in parole hearings. Suppose that, at some point, geneticists are able to identify genetic factors that predispose an individual to violent behavior. Would it be permissible for a parole board to consider this information in assessing the individual's likelihood of recidivism? Thus, the use of genetic information in this context would raise a number of constitutional issues.

H. Tort Litigation

With new genetic discoveries being introduced into the clinical setting, the standard of care in medicine will continue to change. Consequently, there are likely to be a greater number of medical malpractice, wrongful life, wrongful

birth, and other causes of action based on genetic medicine. There are other ways, however, in which genetic information may affect tort law.

The first involves the proof of causation. For example, a case was filed in California in 1990 on behalf of a child who was born with microcephaly, an abnormally small head. He also had severe mental retardation and an IQ of 40. The child's mother alleged that the child's birth defects were caused by her prenatal workplace exposure to chemicals at the defendant's plant. Consequently, a products liability action was brought seeking \$5.6 million in damages against the mother's employer as well as several manufacturers of the chemicals to which she was exposed.

The defendants' experts asserted that the child's symptoms seemed to be remarkably similar to those of a child with fragile X syndrome, and they filed a motion to require the child to undergo genetic testing. The court ordered the genetic testing over the objection of the plaintiff. This example illustrates how genetic information could be relevant to the issue of causation in personal injury cases.

Another possible use of genetic information involves damages. Suppose, as a result of the defendant's negligence, a thirty year-old man with a \$100,000 a year income is run over while crossing the street and rendered totally disabled. The starting point in assessing compensatory damages is lost income. In this case, if the plaintiff had a work-life expectancy of forty years, then the damages for lost income would be \$4 million, exclusive of possible salary increases and inflation. Now suppose that, because of some genetic trait, the defendant could show that the plaintiff would not live to age seventy but could only be expected to live to age forty. From the defendant's standpoint, this is a bonanza and results in savings of at least \$3 million. The potential magnitude of these savings raises the issue of whether defendants might be tempted to engage in genetic "fishing expeditions" in all personal injury actions where the damages include future lost earnings or medical expenses. It is an open question, however, whether genetic testing could be ordered during discovery or whether certain genetic evidence, such as an increased risk of a multifactorial disorder, would be admissible.

III. ETHICAL AND POLICY CONSIDERATIONS

It is evident that the use of genetic information for nonmedical purposes raises a variety of fascinating legal issues. In trying to resolve these issues it may be valuable to formulate a series of broad ethical and policy principles for guidance.

First, I would strongly suggest that we should not adopt any policies that discourage at-risk people who want to undergo genetic testing from doing so for fear of the nonmedical use of the information. It is already commonplace for some people to forego genetic testing that they would prefer to have because they are afraid that their employer or their insurance company will gain access to the results. Other people pay in cash for genetic services or try to be tested anonymously or without medical records being kept.

Second, we do not want to adopt policies that coerce people who do not want to be tested into being tested. Genetic testing often creates great psychological, personal, and social turmoil. People vary widely in whether they want to know

about their likely future health. We should adopt policies that respect this important aspect of individual autonomy.

Third, I think there is a great danger in misinterpretation of genetic information by lay people. This concern applies to both single gene and multifactorial disorders. Modern genetic concepts such as variable penetrance, variable expressivity, latency, imprinting, and allelic expansion are difficult to understand. Lay people should not be put in the position of making important decisions affecting individuals based on genetic concepts that they do not fully comprehend.

Fourth, there is a paramount individual privacy interest in genetic information. There must be compelling reasons to require individuals to share such innately personal information, and in the nonmedical context this may be a difficult burden to meet.

Fifth, the confidentiality of genetic information must be maintained. Before any genetic information is acquired, it should be clear as to whom the information may be redisclosed. It has yet to be determined what rights individuals have to keep genetic information confidential.

Sixth, we should act to preserve the quality of genetic testing and counseling. Third parties using genetic information in the nonmedical setting do not have the same interest in quality assurance as the individual being tested. By applying less rigorous standards of genetic testing, or failing to provide appropriate genetic counseling, there is a risk of both laboratory error and great psychological harm.

Seventh, we should act to conserve medical resources. There are a finite number of geneticists, genetic counselors, and genetic laboratories. There is also a limited amount of money that reasonably should be spent on genetic testing. Genetic resources should be allocated with the primary goal of improving health rather than for various nonmedical purposes.

Eighth, we should be careful not to waste human resources. For example, society loses when an individual currently in good health is rendered unemployable because a genetic test indicates a risk of future health problems. It is also unjust to base decisions allocating essential societal opportunities on immutable biological characteristics. Merely drawing lines based on genes creates a danger of stigmatization -- both on an intrafamilial and a societal basis. Similarly, genetic discrimination would often be multigenerational and would often fall along racial or ethnic lines.

Finally, the use of genetic information in nonmedical settings creates great risks of unintended societal consequences. These include reductionism and determinism, loss of equality of opportunity, and altered conceptions of normality. Reductionism and determinism, as well as the other concepts, relate to the question of what kind of society we are going to have when this tidal wave of genetic information washes over us. Will we become a society of risk takers who figure that we might as well start sky diving and alligator wrestling? Or will we become a society of the paranoid, "worried well," who think that every cough is the first sign of lung cancer?

IV. CONCLUSION

As I mentioned at the outset, the use of genetic information for *medical* purposes raises enough profoundly difficult moral and legal issues. I think we should be very careful before sanctioning the use of genetic information for nonmedical purposes for the reasons I suggested and, perhaps more importantly, for the numerous other reasons that we have yet to realize.