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USE OF GENETIC TESTING BY EMPLOYERS AND INSURANCE COMPANIES

*Michael Landau**

Mr. Landau: Thank you and good afternoon. As my biography mentions, I was a Visiting Professor of Law teaching courses in intellectual property and also contracts here at Dickinson last year. The Dickinson School of Law is a special place to me, and it's good to be back for this Symposium. I now teach at Georgia State University College of Law down in Atlanta. You can tell by my pronounced southern accent!

I would like to start this afternoon by saying that my fellow panelists are some pretty tough acts to follow. I thank them for their enlightening comments during their respective presentations. Now it is time for me to get down to business.

The topic that I will address is listed in the Program as *Use of Genetic Testing and Employment and Insurance*. In addition to discussing those areas, I am going to take a bit of academic liberty, and go a bit broader by briefly discussing a few other issues related to modern genetic technology, as well, for I view that the areas of genetic engineering, genetic testing,¹ and patentability of genetic inventions raise questions that relate much broader than merely to employment and insurance. I will, of course, devote time to employment, by discussing Title VII of the Civil Rights Act of 1964,² Section 1981,³ the Americans With Disabilities Act ("ADA"),⁴ and insurance. However, as professors often tend to do — living in the hypothetical "what if" and contemplative world, instead of only the "what is" world — I deliberately want to scratch the surface in some other areas to pique your curiosity, and give you some additional things about which to think. I hope that all of you leave here today with both answers, and yet still more questions.

EMPLOYMENT:

First, I would like to discuss genetic testing and employment. In the employment context, the main concern is actual or potential job discrimination based upon some perceived risk of the potential employee's inability to do the job based upon some "genetic defect." In traditional employment discrimination analysis, there are usually two doctrines that arise: (a) "disparate treatment" and (b) "disparate impact."

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¹ "Genetic Testing" is actually a broad term that includes two types of testing, "genetic screening" (i.e., testing to determine the genetic makeup of an individual) and "genetic monitoring" (i.e., testing to determine whether genetic changes, in response to exposure to chemicals, carcinogens, or other elements, have occurred). For purposes of this presentation, I am concentrating on "genetic screening," and am using the term "genetic testing" to mean that.

²42 U.S.C. § 2000e-16

³42 U.S.C. § 1981 (1988).

⁴42 U.S.C.A. §§ 12101-12213 (West Supp. 1992).

“Disparate treatment” is found when someone of a specific racial, ethnic, or religious group is treated differently solely because of the category. “I will not hire you because you are [ethnic group] or because you are from [place of national origin].” “Disparate treatment” is relatively easy to detect, for it usually occurs in a blatant manner. “Disparate impact” may often be much more subtle. It arises in situations in which an employer has specific, allegedly objective tests or requirements for the job, and it just so happens that a disproportionately large number of people from a certain racial or ethnic group end up being excluded.⁵

Employment and genetic testing. There is a good article on employment and genetic testing in the American Journal of Law and Medicine by Larry Gostin. It appears in Volume 17, and begins on page 109.⁶ Mr. Gostin discusses the extent to which genetic testing was being used in the employment context as of 1991. According to the author, as of that time, genetic testing was not being used by many employers at all, and very few claimed that they were planning on using it in the near future.⁷ The same is reflected in a government report, *Genetic Monitoring and Screening in the Workplace*, published by the United States Office of Technology Assessment in 1990.⁸

Let me give you some of the statistics reported in the Gostin article and the OTA study. In 1982, fifty-five “Fortune 500” companies said that they might use genetic testing in five years, according to Office of Technology Assessment study.⁹ In the OTA’s 1989 study, less than six percent of 330 “Fortune 500” companies engaged in either genetic screening or genetic monitoring.¹⁰ Most of these companies were in the petroleum and chemical industries, so a good deal of the testing was monitoring and not screening. However, a 1989 survey conducted by Northwestern National Life Insurance Company stated that up to fifteen percent of employers might use some form of genetic screening by the year 2000.¹¹ As of 1990, when the results of the OTA study were published, and in

⁵See, e.g., *Griggs v. Duke Power Co.*, 401 U.S. 424 (1971); *Albermarle Paper v. Moody*, 422 U.S. 405 (1977), *Dothard v. Rawlinson*, 433 U.S. 321 (1977); *Watson v. Fort Worth Bank and Trust*, 487 U.S. 977 (1988); see also, Civil Rights Act of 1991, 42 U.S.C. § 2000e (k)(1)(A) (1988) (establishing the burden of proof in a disparate impact case, and overruling *Wards Cove Packing Co. v. Atonio*, 490 U.S. 642 (1989)); see also J. Rigler, *Title VII and the Applicability of Disparate Impact Analysis to Subjective Selection Criteria*, 88 W.VA. L. REV. 25 (1985).

⁶Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests By Employees and Insurers*, 17 AM. J. L. & MED. 109 (1990) (hereinafter Gostin); see also Jack F. Williams, *A Regulatory Model for Genetic Testing in Employment*, 40 OKLA. L. REV. 181 (1987)(hereinafter Williams).

⁷*Id.* at 116-119.

⁸U.S. Congress, Office of Technology Assessment, *Genetic Screening and Monitoring in the Workplace*, OTA-BA-455 (Washington, D.C.:U.S. Government Printing Office, October 1990)(hereinafter *Genetic Screening*).

⁹*Id.* at 115.

¹⁰*Id.*

¹¹*Id.* The difference in results between the OTA and Northwestern National studies may either be attributable to differences in questions asked, or to the fact that one survey was performed by the government, and the other was performed by a private company.

1991 when the Gostin article was written, in actuality, the practice was rarely utilized by corporate America.

Now, that may just be the result of the level of sophistication of the genetic map and testing techniques at the times of the studies. Recently, several important new genetic markers have been discovered, and more and more companies, if asked the same questions previously asked by the OTA might answer them differently today, in 1994. With the Human Genome Project progressing, and with more genes that relate to specific diseases being discovered, more employers may, in the future, want to know the genetic makeup of their employees. Time will tell.

Let me get into some of the specific employment discrimination laws. Title VII of the Civil Rights Act of 1964 prevents discrimination on the basis of race, color, religion, or national origin. Section 1981 prevents discrimination in the making of private contracts. The legal elements and facts necessary to support an employment discrimination claim under either Title VII or Section 1981 are quite similar. Title VII, and Section 1981, in recent years have been dramatically expanded to allow intra-racial discrimination suits. For example, in *Walker v. Secretary of the Treasury (IRS)*, in the Northern District of Georgia the court held that a light-skinned black may have a discrimination action against a dark-skinned black if the discrimination is based upon a difference in their skin color. The defendant's motion for summary judgment was, therefore, denied. When the case was decided on the merits, it was determined, however, that the termination was based upon poor job performance, and not any hostility between light-skinned and dark skinned blacks. There was, therefore, no statutory violation.

The Supreme Court expanded the coverage of Section 1981 in *Saint Francis College v. Al-Khazraji*, a case involving the denial of tenure of an Arabic American. The district court dismissed the case, holding that people of Arabic descent are classified — under current classifications — as “Caucasians,” and, therefore, that Section 1981 does not reach discrimination claims based upon Arabic ancestry. (If you look at affirmative action forms or many application forms in general asking for “ethnic” information,, the definition of “white” is one who can trace his or her ancestry to the original peoples of Europe, Northern Africa, with a carve-out for Hispanics.) The Third Circuit reversed the district court's decision.

The Supreme Court affirmed the Third Circuit's reversal, and allowed the plaintiff to proceed with his case. On pages 610 and 611, there's a discussion about how “race” is very different from the Caucasoid/Mongoloid/Negroid notion of race years ago:

There is a common popular understanding that there are three major human races—Caucasoid, Mongoloid, and Negroid. Many modern biologists and anthropologists, however, criticize racial classifications as arbitrary and of little use in understanding the variability of human beings. It is said that genetically homogeneous populations do not exist and traits are not discontinuous between populations; therefore, a population can only be described in terms of relative frequencies of various traits. Clear-cut categories do not exist. The particular traits which have generally been chosen to characterize races have been criticized as having little biological significance. It has been found that differences between individuals of the same race are often greater than the differences between the

“average” individuals of different races. These observations and others have led some, but not all, scientists to conclude that racial classifications are for the most part sociopolitical, rather than biological, in nature.

Now, you are probably asking, “where does all of this fit in with genetic testing and discrimination?” Let me read some more language, from the Supreme Court’s opinion. “Section 1981, at a minimum, reaches discrimination directed at an individual because he or she is genetically part of an ethnically and physiognomically distinctive subgrouping of homo sapiens. . . It is clear from our holding that a distinctive physiognomy is not essential to qualify for § 1981 protection.”

If “physiognomy,”¹² or outward appearance, is not an essential element of a § 1981 claim, might not there be a situation in which groups of people with the same common gene that leads to a propensity toward a specific disease could be a sufficiently “genetically distinctive subgrouping of homosapiens” to support a successful Title VII or Section 1981 claim? With courts expanding the coverage of those statutes to permit causes of actions between members of the same “group”, then people with a common “bad gene” may also be protected. It should be noted that several states, including California, Florida, New Jersey, and Louisiana have already enacted legislation to protect groups with gene-specific diseases or hereditary conditions.¹³ In addition, Oregon, Iowa, Wisconsin, and Rhode Island have passed legislation preventing or restricting genetic testing by employers.¹⁴ How Congress will respond remains to be seen.

On July 26, 1990, President Bush signed The Americans with Disabilities Act (“ADA”) into law. Title I, which deals with employment discrimination, became effective in July of 1992.¹⁵ The citation for the ADA is 42 U.S.C. §§ 12101-

¹²Webster’s Seventh New Collegiate Dictionary defines “physiognomic” as relating to physiognomy or “external aspect.” See Walker, 713 F. Supp. at 405. The American Heritage Dictionary (Second College Edition) defines “physiognomy” as “Divination based upon facial features.”

¹³E.g., Cal. Health and Safety Code §§ 150, 151, 555, 309, 341 (West 1990); Fla. Stat. Ann. §§ 385.206 and 488.075 (1993); Illinois 1990 Public Act 86-1028, Iowa Code § 136A.2; La. Rev. Stat. Ann. § 462:254 (West 1982); Md. General Health Code Ann § 13-101; Mo. Rev. Stat. § 191 (1989); N.J. Rev. Stat. § 26:5B-3; N.J. Stat. Ann § 10:5-12a (West 1982); Va. Code Ann. § 32.1-68 (Michie 1990); The California Statute is the most comprehensive and prohibits “stigmatization” and “discrimination” against “carriers of most deleterious genes.” (Cal. Health and Safety Code § 150). The Statutes in New Jersey protect against any “atypical hereditary or blood trait.” (N.J. Stat. Ann §10:5-12a). The Statutes in Florida and Louisiana protect against those with sickle-cell disorder. (Fla. Stat. Ann § 488-075 (1993); La. Rev. Stat. Ann. § 46.2254); See Gostin at 141-142.

¹⁴Or. Rev. Stat. §659.227 (1993); Iowa Code §729.6 (1992); Wisc Stat. §§ 111.372, 631.89 (1991); R.I. ch. 171 (1992) 92-H-8182, reported in EMPLOYMENT TESTING LAW & POLICY REPORTER, Vol. 1, No. 8 at 136 (Sept. 1992); see also, EMPLOYMENT TESTING LAW & POLICY REPORTER, Vol. 2, No. 10 at 176 (Oct. 1993) (The new Oregon law prevents the use of genetic testing by employers if the information is available from other sources.)

¹⁵At the signing ceremony, President Bush stated:

This Act is powerful in its simplicity. It will ensure that people with disabilities are given the basic guarantees for which they have worked so long and hard. Independence, freedom of choice, control of their lives, the opportunity to blend fully and equally into the right mosaic of the American mainstream.

Transcript of Pres. Bush’s address, reported in Mark. A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 Hous. L. Rev. 23, 34 (1992) (hereinafter, *Rothstein*). The Rothstein article is quite comprehensive in its coverage of the subject. For another good discussion of the ADA and genetic testing, see, Bonnie P. Tucker, *The Americans with Disabilities Act of 1990: An Overview*, 22 N. Mex. L. Rev. 13 (1992) (hereinafter *Tucker*).

12213.¹⁶ The ADA was promulgated to prevent discrimination against a qualified individuals having disabilities.¹⁷ "Disability" is a defined term in the statute, and means: "(A) a physical or mental impairment that substantially limits one or more of the major life activities of the individual; (B) a record of having such impairment; or (C) being regarded as having such impairment."¹⁸ It should be noted that later in the Act, the statute expressly excludes certain forms of sexual orientation or preference and conditions caused by the current use of illegal drugs from "impairment", and therefore from the definition of "disability."¹⁹

Although the ADA prevents employment discrimination against qualified persons with disabilities, it contains a "carve out" provision that allows employers to treat employees differently for purposes of insurance or benefits if based upon actuarial data.²⁰ An employer may, therefore provide different benefits for different employees based upon their physical or health status.

Some of the most sweeping changes brought about by the enactment of the ADA deal with employer mandated medical examinations.²¹ Section 101(d) prevents employers from "conduct[ing] a medical examination or making inquiries of the job applicant as to whether such individual is an individual with a disability."²² Thus, employer "pre-screening" of job applicants is forbidden. The employer may, however, require a medical examination after a conditional offer has been made, but the same medical exam must be given to all new employees, regardless of disability.²³ (If genetic testing becomes relatively inexpensive in the future, it could possibly become part of the "post-offer" medical exam given to all.) Any information obtained through these examinations must be maintained as "confidential."²⁴ Thus the ADA provides some protection, with regard to genetic testing.

Although the ADA contains numerous sections, and is still too new to know completely

¹⁶42 U.S.C.A. §§ 12101-12213 (West Supp. 1992).

¹⁷Section 102 (a) of the ADA provides as follows: "No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment. 42 U.S.C. § 12112(a).

¹⁸42 U.S.C. § 12102(2).

¹⁹Sections 508 and 511 exclude transvestism, homosexuality, bisexuality, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, other sexual behavior disorders, compulsive gambling, kleptomania, pyromania, and psychoactive substance use disorders resulting from the current use of illegal drugs. See, 42 U.S.C. §§ 12208, 12211 (1988). Section 508, which excluded transvestism was added to the bill after a floor amendment by Senator Jesse Helms. See 135 CONG. REC. S10, 776 (daily ed. Sept. 7, 1989). Section 511, which excluded many of the other conditions was added by Senators William Armstrong and Orin Hatch. Id. at S10, 785; see Rothstein, *supra* note 29, at 36, n. 75.

²⁰42 U.S.C. § 12201(c).

²¹See Rothstein, *supra* note 29, at 38.

²²42 U.S.C. § 12112(d) (2) (A).

²³42 U.S.C. § 12112(d) (2) (B).

²⁴42 U.S.C. § 12112(d) (3) (B).

how reaching its effect will be, the gist of it is this: If a disabled person is able to perform an essential job function, and the employer can make modifications to accommodate to the disability, the employer must hire the person with the disability and make such modifications, unless the modifications or adaptations place an "undue hardship"²⁵ on the employer.²⁶

Here's the hypothetical to ponder: If, today, I have a disability that would prevent me from doing the essential function of my job, and would cause an undue hardship on my employer to make accommodations to my disability, even under the ADA, he could choose to not hire me because of my condition. But what happens if I am perfectly fine today, but after we know everything about the entire map of the human gene system, and after I have voluntarily undergone genetic testing, it is determined that I have an almost one hundred percent certainty that in fifteen years I will not be able to do the job without causing an undue hardship on my employer. Today I'm healthy, I cannot be discriminated against. If, today, I had the disease that I will get in exactly fifteen years to the day, I could legally be denied employment. May I be discriminated against today on the basis of getting a disease fifteen years in the future? How about in year seven? How about in year twelve?

There are a few issues to consider. One, is my right to work. The other is an employer's right to hire efficient workers. Another factor to consider is the reality of the job market in the mid-1990s.

Companies such as IBM and GE and other large companies have recently been laying off thousands of workers. At the two large New York City law firms in which I practiced before I went into academia, the average stay of a recent law school graduate or even a lateral mid-level associate was about two years. If the odds are that you probably would have changed jobs three times by the time that disability sets in, is there any rational or reasonable basis for an employer to discriminate against you now? Would there be a rational basis to deny employment at some point in the future?

INSURANCE:

With respect to insurance companies, I'll raise some interesting questions in terms of use of the genetic information and use of actuarial data, in general. Although, at present, there are not many restrictions imposed by law regarding genetic testing by insurers, it should be noted that a few states, such as Arizona, Montana, Florida, and Wisconsin, have actually passed legislation that restricts the use of genetic testing by insurance companies.²⁷ (As I will discuss in a few moments, at present, very few insurance companies engage in that practice.)

I find it interesting that with regard to insurance and insurance companies, there are certain actuarially-based practices that are just fine and palatable and acceptable and wonderful to all, and others that make everyone scream "foul!" Should it be that way?

Let me give you some example. Assume that I am an inherently clumsy person, not an entirely erroneous assumption. Although in reality I have not, for purposes of this exercise,

²⁵42 U.S.C. § 12112 (5) (A).

²⁶See Tucker, *supra* note 29, at 33-34.

²⁷See Ariz. Rev. Stat. § 20-448(E)(1989); Mont. Code Ann. §33-18-206(1991); Fla. Stat. § 760.40(1990); Wisc. Stat. § 631.89(1991), reported in EMPLOYMENT TESTING LAW & POLICY REPORTER, Vol 1., No.8 at 135-36 (Sept. 1992).

assume that I have been involved in five accidents and I have run four red lights in the last year. None of this is the result of excess consumption of any intoxicating material. I am just clumsy. I have synaptic delay; I have bad depth perception; whatever the cause is, it is beyond my control. Also, assume that, despite my hypothetical bad driving record, the State has not revoked my license.

If my insurance company canceled my policy the following year or raised my rates to an exorbitant amount, would any of you say, "That's unfair. His accidents are beyond his control?," or, rather, would you say, "That's life; this guy's a bad driver? Too bad. He deserves to have his policy canceled or his premiums raised." My guess is the latter.

With respect to health insurance or life insurance, what if I decided to be "self-insured" instead of buying a policy? When I lived at home as a kid, my parents took care my insurance. While I was in college, I was covered at some absurdly low rate through school. Then, after I graduate, I either become self-employed, or work for an employer who does not provide health insurance. I obtain a few estimates from insurance companies, and they all seem rather excessive. I then say to myself: "You're now 21; \$1,500 a year for health insurance? This is nuts! I haven't even had a cold in five years. I think I'll take this money and I'll put it in a mutual fund and I'll hope that I don't get sick. I have automobile insurance so that if I'm in an accident, I'm covered!" I decide to take my chances, to take the risk, to be "self-insured."

Now, ten, twenty, thirty years go by; everything's fine. I've made wonderful investments. My emergency medical fund grows and grows and grows. Bingo! I get a heart attack and I need bypass surgery. But, that's fine, for I have lots of money in my fund, so I just write a check. Then, a few years later, I need surgery again. I write another check from my magic medical account.

Then finally, in my mid 50s, after several heart attacks and surgeries, my reserve medical fund is running out and I apply for the first time for medical insurance. Would any of you say, "oh, isn't that terribly unfair that he cannot get medical insurance coverage, "if an insurance company refused to issue one, or if they did, refused to pay a claim because I had a preexisting condition? Or would you think that I took the risk and lost. After all, had I not had my heart problems, I could have enjoyed quite a "nest egg" that I had accumulated in my account.

Is giving genetic information to insurance companies like my walking into Atlantic City or Las Vegas — or one of the Indian reservations now, with that controversy going on — with x-ray vision or with x-ray eyes. I'm not card counting. It's not like in the movie *Rainman*, in which the Dustin Hoffman character said, "you know what we did in Las Vegas? We were counting cards. Yeah, we were counting cards!" In my case it's different. I have absolute x-ray vision. I can see what is in the deck. I know the odds!

I, of course, then decide to play Blackjack. I go to the table. My first hand equals "10." I look at the deck, and see that the next card is an "ace." "Hit me," I say with a perfectly straight face. On the next hand, I'm dealt an "8" and then a "7", and I see that the next card is a "King." I make it look as though I am thinking about it, and then slowly say, "Pass!"

Well, is that the same thing as giving the insurance companies genetic information? Does it defeat the business of insurance, which assumes some kind of risk, or are insurance companies getting some genetic information anyway, through their questionnaires. Why

do they include questions such as, "Has anyone in your family ever had kidney problems, heart disease, circulatory problems, mental problems, et cetera, et cetera?" Well, isn't that a way to obtain information about your potential genetic make-up? Actually, at present, given the current scope and cost of genetic testing, it's the insurance industry's preferred way. According to a 1992 OTA study, very few insurance companies engage in genetic testing; the majority of insurance companies claim that they can obtain all the genetic information that they need, cheaply, through records and questionnaires.²⁸ Although this may change as more genetic markers are discovered, and as costs go down.

Once we get to the point where the Human Genome Project has progressed and we have the perfect map — or a more complete map, since there is nothing that is perfect, even in this best of all possible worlds — what happens if, lo and behold, through some miracle, I discover that I have no genes whatsoever that predispose me toward any disease, except for one that will make my heart will just stop at the age of 115? Should my insurance be five dollars a year? Is that balancing the risk?

If the insurance companies can cancel someone's policy or raise the rates because that person is predisposed to developing a certain disease or has a preexisting condition, once all the cards are on the table, so to speak, should everything be purely actuarial? If some people's rates go up, then some people's rates should go down. . . way down! All right, five dollars a year may be unrealistic. How about a premium that reflects administrative costs plus a reasonable return as opposed to it being what the costs are today? Actually, assuming that, years in the future, most maladies may be detectable in advance, total disclosure to both the insurer and the insured would eliminate the business of health insurance. All parties involved would know the risks. (People would, however, still probably need accident insurance and automobile insurance owing to the risky variable of *other people*.) Would the insurance companies actually want *total* disclosure? Partial disclosure still creates some risk. Some risk still creates some profits.

The other question is: Who pays for the uninsurable or the uninsured? I currently live in the State of Georgia. In Georgia, there's a wonderful practice that goes on. I got a real kick out of it the first time I heard about it. It may happen here, too. In Georgia, in order to get new vehicle tags each year, one first needs to present the State Department of Motor Vehicles with proof of insurance. (In Georgia, it's *in-sur-ance*; In Pennsylvania, it's *in-sur-ance*.)

People go into the Motor Vehicle Department with proof of insurance in order to get their new tags. The problem is what happens soon thereafter. Many people are on a monthly installment payment plan with their insurance companies. Shortly after they get their tags, they allow their policies to lapse, and drive around uninsured. Then the following year at registration time, they find another insurance company to write a new policy, and do the exact same thing. Believe it or not, despite the fact that they know that this practice is widespread, there are plenty of automobile insurance companies who will give insurance to people who have let their coverage lapse. There's a big problem in the State of Georgia with people who cancel their insurance after a month and are driving around uninsured.

²⁸U.S. Congress, Office of Technology Assessment, *Genetic Tests and Health Insurance: Results of a Survey - Background Paper*, OTA-BP-BA-98 (Washington, D.C.: U.S. Government Printing Office, Oct 1992), 33.

So, there's an extra premium added to my insurance called "uninsured motorists' insurance." The insured are essentially paying for the uninsured.

Well, that it gets to the whole question — and this is part of the debate that's going on in general right now in Congress — of who pays for whom? Should there be an uninsured fund, so that if you have a disease that no one will cover, then everyone else takes care of it? Should there be a universal health care plan that's financed by a flat tax on everyone, in which case information that the insurance companies have would be irrelevant because everybody would be covered?

Here's the other "insurance" area where most people don't scream "foul!" My parents' generation is receiving a major multiple of the Social Security that they contributed, both because of the rates going up every year and the caps going up every year. It's not a situation where they're getting their money back. It's a transfer from my generation to theirs. Society doesn't scream about that. I could do a lot better for myself in the future if I could add an additional 7.5% of my income to my 401(a) or 403(b) plans each year, and then collect it, with the interest, when I retire, in lieu of Social Security. . . . A lot better!

There are numerous other areas where transfers are part of the tax system, but that's a policy issue. What and whom does society wish to subsidize at any given time? But in terms of insurance, I just wanted to point out that there are both pros and cons of letting the insurance companies have all of the genetic information that will become available in the future.

CONFIDENTIALITY:

Confidentiality, I had a whole section here, but Mr. Gellman addressed many of the issues. I do, however, have a personal story to relate to you regarding the disclosure of information. I think you'll get a kick out of this, because it cracked me up. I turned forty last summer. I hit the big 4-0. All of a sudden like clockwork a new kind of "junk-mail" started arriving at my home. "Are you losing your hair?" "Are you having prostate problems?" "Are you sexually performing like you used to when you were in your twenties?" I didn't get that stuff when I was 39. Where or from whom did the marketers get that information?

Now, I wasn't thinking along the lines of disclosure from any State Motor Vehicle Department, but I cannot imagine that anyone received that information that from my subscription to *Stereophile* or the *Economist*. The *Economist* maybe, but my magazine subscriptions are really all over the place: *The New Yorker*, *Wired*, *Mondo 2000*, *Stereophile*, *Art in America*, *The Economist*, *National Geographic*, and several law reviews. It would be hard to pinpoint from my magazines that on exactly July 3rd, I turned 40, yet the junk mail comes. I also cannot imagine that one can determine that I am 40 from my buying black turtlenecks and khakis from J. Crew? Now, that's only typical age related junk-mail, and as you can see I still do have a full head of hair!

As mentioned above, the ADA does provide that any medical information be maintained as "confidential."²⁹ However, there will always be instances in which somehow the information "leaks out." Imagine what will happen when genetic information goes to and

²⁹42 U.S.C. § 12112(d)(3)(B) (West Supp. 1992).

from the medical clinics or it goes to physicians. Will there be “insider trading” in genetic information. Will there have to be a medical industry equivalent of 10(b)(5) or 14(e)? If this information can be sold to anybody, will there be a point in time when you get junk mail from the Smith and Jones Oncology Clinic, telling you, “Dial 1-800-BAD-GENE. We’ll take care of you, no fee if you die.” How will the information be controlled?

There are several legal theories that may be used. One may attempt to assert the tort of public disclosure of private facts. If a Confidentiality Agreement or Non-Disclosure Agreement was signed with the physician or the lab, then an action for breach of contract may be sustainable. Possibly breach of fiduciary duty against the physician.³⁰

An interesting issue arises with regard to company, instead of private, physicians. If your company doctor does the testing, to whom does she owe a duty — you or the corporation? To whom does information about you belong? Have you ever left a job and tried to get a complete copy of your personnel files. Good luck! This may very well be an area where medical ethics and the law clash.³¹

OTHER ISSUES:

Another issue that deeply concerns me is human error. . . plain old simple human error. I am now showing you this morning’s USA Today. Please take a look at the headline. **SCREW-UPS KILL 26.** You all know about what I’m referring to.³²

Human error happens all the time and can happen with very simple things. We all hear horror stories about lab tests and false negatives and false positives.³³ I have another a personal story, outside of the junk mail one, This one deals with human error. I was in the hospital in New York for leg surgery two summers ago. When you’re admitted for surgery in New York, they do a routine chest x-ray of almost everyone who comes in. The film is like Polaroid film; it develops in ninety seconds.

My x-ray is taken and a minute and a half later the picture comes out. I noticed something strange about the picture. The name on the film was not my name. When I told the technician of the problem, he responded “Of course, that’s you. I just took your picture a minute ago, it has to be you!” After going back and forth over this point, I showed him the name tag on my wrist. He blithely said only, “Oh,” got a piece of tape, covered the name and number on the x-ray, and hand wrote in mine. Who knows who got an x-ray with my name and number on it?

³⁰For a good discussion of physicians and confidentiality, and confidentiality, in general, see Lori B. Andrews and Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. JNL. OF LAW & MED. 75, (1991). For a discussion of the physician’s duty of confidentiality, see *id.* at 78-82.

³¹*See id.*

³²Because the printed version of this presentation is being published months after the actual speech, I am referring to the incident on April 14, 1994, in which United States fighter pilots accidentally shot down two American helicopters over Iraq, mistaking them for Iraqi ones.

³³For example, the May 19, 1994 broadcast of the ABC television show “Primetime” dealt with widespread false negatives in pap smear tests in laboratories.

Human error occurs with everything. Think of the Shuttle. It occurs in all facets of life. Human error is part of the reason that Murphy formulated his Law.³⁴

What will be the consequences of human error with respect to genetic testing, and even more scary, genetic engineering. Will the mistakes be big stupid ones, as with my x-ray, or will they be little, "hard-to catch" ones, such as typos. What will be the consequence of a false negative or positive genetic test. . .or simply misreading the "map?" What will be the consequence of human error in genetic engineering? Who knows what kind of monsters or mutants may be created by accident. All of you remember what happened in the film, *Jurassic Park*? The scientists filled in the blanks in the dinosaur DNA with frog DNA. Whoops! The dinosaurs were no longer all female! Human error? I realize that *Jurassic Park* is fiction, but what the scientific establishment is doing now sounded like science fiction twenty or thirty years ago.

What's the interrelatedness of genes? How will altering or removing one gene affect the rest of the organism? The body is a complicated machine. Drugs have side effects. The adage, "the cure was worse than the disease" is not merely a random selection of words. Now, there may be a very simple answer to the interrelatedness question. Geneticists may know. I have to admit that I am a law professor, and not a geneticist.

But if it's a situation by analogy, if GM or Chrysler or Mazda or whatever finds that a substantially large number of cars that stall at fifty miles an hour, recalled them and found out they had bad carburetors or bad fuel injection systems, you can't just remove the fuel injection system, because the car won't work. If you change it or put a new one in, it may throw off the emission system, or the idle speed.

Before I finish, I would just like to very quickly touch the surface of some other genetic technology issues. The first is with respect to patentability of genetically created animals.³⁵ As Dr. Jervis pointed out, the patent grant is a negative right. It gives the patent holder the right to *exclude* others from making, using, or selling the invention for a period of 17 years.³⁶ It does not give you the right to practice your invention.³⁷ When the PTO³⁸ came out with its 1987 ruling regarding the patentability of animals, it expressly excluded humans.³⁹ Many people think that the Thirteenth Amendment of the United States

³⁴"Murphy's Law" is "Anything that possibly can go wrong, will."

³⁵For a discussion of the patentability of animals, in general, and the cases that paved the way, see, generally, M. Landau, *Multicellular Vertebrate Mammals as "Patentable Subject Matter" Under 35 U.S.C. § 101: Promotion of Science and the Useful Arts or an Open Invitation for Abuse?*, 97 DICK L. REV. 203 (1993).

³⁶35 U.S.C. § 154 (1988).

³⁷For example, if the newly patented invention is an improvement patent, the patentee must get permission from the holder of the underlying patent to practice his or her invention.

³⁸United States Patent and Trademark Office.

³⁹On April 21, 1987, the PTO announced: "The Patent and Trademark Office now considers non-naturally occurring non-human multi-cellular living organisms, including animals, to be patentable subject matter within the scope of 35 U.S.C. § 101. A claim directed to or including within its scope a human being will not be considered to be patentable subject matter within 35 U.S.C. § 101." Published at 1077 OFF. GAZ. PAT. OFFICE 24 (April 21, 1987).

Constitution⁴⁰ would be involved. Would the Thirteenth Amendment ban the getting of a patent? It would probably prevent one from licensing or assigning rights in the patent. But, it might not prevent obtaining a patent, owing to the negative right.

The other question is one of constitutional authority. Does the PTO have the constitutional authority and power to say “non-human” or is that up to the Court or Congress? In the *Chakrabarty*⁴¹ case, which dealt with patenting bacteria, a living organism, the Supreme Court made the blanket statement, “anything under the sun that is made by man” is patentable.⁴² If the Supreme Court says “anything”, does an administrative agency have the right to restrict the scope without Congress doing so?⁴³

The last genetic engineering issue is for the future; how far into the future I do not know. The issue is: what is a “person?”⁴⁴ When scientists are actually able to create life, how will a creature with some human genetic material, and some genetic material from other animals be categorized? How will “hybrid” creatures be categorized. As farfetched as it sounds, it is a very important issue, for many rights and privileges are accorded to “persons” under the Constitution and numerous other statutes. Will there be a time when “creatures” may be engineered to perform the dangerous tasks in life? Will scientists be able to genetically create a race of non-carnivorous “Morlocks⁴⁵” to work in the mines and provide the power? What is a “person?”

CONCLUSION:

We are embarking on a voyage into a new frontier. Society, science, and technology are rapidly changing. As society, science, and technology have changed in the past, so, too, must the law. This is not a new notion. Legal evolution has in step with scientific and social evolution for years. The law has been re-interpreted or adapted with almost every change in science or society.

For example, in the late 1880s, with the science and art of photography growing, the Supreme Court was called upon to determine whether or not a photograph was a “writing of an author” and, therefore, protectible under the copyright laws and under the Copyright

⁴⁰The Thirteenth Amendment to the United States Constitution provides as follows: Neither slavery nor involuntary servitude, except as punishment for crime whereof the party shall have been duly convicted, shall exist within the United States, or any place subject to their jurisdiction. U.S. CONST. amend XIII.

⁴¹*Diamond v. Chakrabarty*, 447 U.S. 303 (1980).

⁴²*Id.* at 309.

⁴³A challenge on the PTO’s authority was mounted in *Animal Legal Defense Fund v. Quigg*, 710 F. Supp. 728 (N.D. Cal. 1989). On appeal, the Ninth Circuit did not address the merits, but transferred the case to the Federal Circuit, because it arose under the Patent Laws. 900 F.2d 195, 197 (9th Cir. 1990). The Federal Circuit did not address the challenge to the PTO on the merits, but held that the plaintiffs lacked standing. 932 F.2d 920, 938 (Fed. Cir. 1991).

⁴⁴For a thorough discussion of this issue, see, Michael D. Rivard, *Toward a General Theory of Constitutional Personhood: A Theory of Constitutional Personhood for Transgenic Humanoid Species*, 39 UCLA L. REV. 1425 (1992).

⁴⁵See generally H.G. Wells, *THE TIME MACHINE*.

and Patent Clause of the U.S. Constitution.⁴⁶ In *Burrow-Giles Lithographic Co. v. Sarony*,⁴⁷ the Court answered the question in the affirmative. In the 1970s, Congress established the Commission on New Technological Uses (“CONTU”) to decide how to protect computer software. As a result of CONTU’s recommendations, Congress amended sections 101⁴⁸ and 117⁴⁹ of the Copyright Act of 1976 to expressly provide for computer programs. In the early 1980s, the courts were called upon to decide whether object code, source code, or both were protectible. In *Apple Computer, Inc. v. Franklin Computer Corp.*⁵⁰ the Third Circuit held that both types of code deserved copyright protection. In 1991, the Supreme Court, in *Feist Publications Co. v. Rural Telephone Service Co, Inc.*⁵¹ changed copyright law by expressly repudiating the “sweat of the brow” doctrine and denying protection to one of the oldest forms of copyrightable works — white page telephone directories. The Court, in an opinion almost totally lacking case precedent, and relying mainly on law reviews and commentaries, essentially told every court in the country that they had misunderstood copyright law since the *Jeweler’s Circular*⁵² case in 1922.

Over the last few years, Congress has been active on the intellectual property front passing legislation relating everything from “Patents in Space”⁵³ to “unpublished works”⁵⁴ to “digital audio tape”⁵⁵ to “visual artists rights.”⁵⁶

The law has not only changed with technology, but with society, as well. If I had handed out leaflets protesting against World War I, I would have ended up “doing time,” for my activity was a “clear and present danger.”⁵⁷ If I had protested against the VietNam War (or “conflict”), I would have been engaging in the highest form of protected speech under the First Amendment, political speech.⁵⁸ Law that was well established law for

⁴⁶U.S. CONST., Art.I, § 8, cl. 8 provides as follows: “to promote the Progress of Science and the useful Arts, by securing for limited Times for Authors and Inventors the exclusive Right to their respective Writings and Discoveries.”

⁴⁷111 U.S. 53 (1884).

⁴⁸17 U.S.C. § 101 (1988).

⁴⁹17 U.S.C. § 117 (1988).

⁵⁰714 F.2d 1240 (3d Cir. 1983).

⁵¹499 U.S. 340 (1991).

⁵²*Jeweler’s Circular Publishing Co. v. Keystone Publishing Co.*, 281 F. 83 (2d Cir. 1922).

⁵³*See* 35 U.S.C. § 105 (1988).

⁵⁴*See* 17 U.S.C. § 107 (1988). (Fair Use statute revised in 1992 to provide for cases involving unpublished works).

⁵⁵*See* 17 U.S.C. § 1001 et seq. (West Supp. 1992) (“The Home Audio Recording Act”).

⁵⁶*See* 17 U.S.C. § 106A (1990). (The Visual Artists Rights Act of 1990).

⁵⁷*See*, e.g., *Schenck v. United States*, 249 U.S. 47 (1919); *Abrams v. United States*, 250 U.S. 616 (1919).

⁵⁸*Cohen v. California*, 403 U.S. 15 (1970).

years went by the wayside as society changed. Segregation was abolished.⁵⁹ So was school prayer.⁶⁰ Abortion was legalized.⁶¹ Living organisms were allowed to be patented!⁶²

So it's up to the Courts and the Legislators to once again deal with the new genetic technology while still respecting the rights of the people as we move into the Twenty First Century. It's also important for people to think about the ramifications of the new technologies. Do we know what we really want to know?⁶³ If you knew you were going to die in five years, would you make the same contribution to your 401(k) and SEP plan or would you go on vacation? Would you want to know that you possessed some gene that was predictive a certain disorder, and that the gene might pass to your children? Technology and society are moving quickly, and we're all in for an interesting ride.⁶⁴

I apologize for running a little long. I hope that I have given you much to think about this afternoon. I hope that I've answered some of your questions, but also raised additional ones. It's a pleasure to be back at Dickinson, and I thank you.

⁵⁹Brown v. Bd. of Education, 347 U.S. 483 (1954).

⁶⁰Engel v. Vitale, 370 U.S. 421 (1962); Lee v. Weisman, __ U.S. __, 112 S.Ct. 2649 (1992).

⁶¹Roe v. Wade, 410 U.S. 113, *reh'g denied* 410 U.S. 959 (1973).

⁶²Diamond v. Chakrabarty, 447 U.S. 303 (1980).

⁶³The results of a survey published in TIME magazine indicated that those surveyed were almost exactly split 51%/49% as to whether or not they wanted to know if they had certain genes that were indicators of disease. However, 87% of the respondents said that, they would like their developing unborn child to be tested. See TIME, Jan 17, 1994 at 50.

⁶⁴A colleague of mine summed it up quite well. "Genetic testing is a technology too promising to discontinue, yet it is too potentially harmful for unchecked development." Williams, *supra*, n.6, at 208.